Musified Togetherness

Co-Singing in Families Living With Dementia

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Preface

After working as a versatile freelance musician for over 30 years, it felt like a tremendous gift to be accepted as a paid research fellow at the PhD specialisation Arts in Context at the University of Agder in September 2019. I had spent many years working part-time with music – and especially singing – within dementia care and education, and I had also experienced some pivotal moments while singing with people with dementia and their close ones. There was limited research on singing in this context, so I was curious to explore this topic.

I embarked on my PhD journey highly motivated but with limited knowledge of how one conducts a research project. My encounter with my supervisors and the UiA research group Kunst og sosiale relasjoner (Arts and social relations) opened up a new world of scientific and methodological possibilities, which gradually transformed my planned project – and my way of thinking – under the influence of posthuman and new-materialist theory.

I owe the utmost gratitude to my supervisors at UiA, Tormod Wallem Anundsen and Tony Valberg, for making my PhD process so pleasurable and inspirational. Their friendly and supportive attitude – plus Tormod's analytical precision and thoughtful recommendations and Tony's thought-provoking questions and ideas – provided safety and inspiration, which sustained my motivation and progress. I must also thank Hege Merete Bjørnestøl Beckmann at UiA for valuable supervision at the beginning and end of the process and Lilli Mittner at UiT for insightful and stimulating questions and responses at my 90% seminar. I also thank all the members of the aforementioned research group, and especially its leaders, Helene Illeris and Tony Valberg, for the varied, experimentational and inspirational meetings, seminars, workshops and discussions.

I am deeply grateful for the way in which UiA's Faculty of Fine Arts – with the PhD programme leader, Anne Haugland Balsnes, in the vanguard – facilitated such an inclusive and inspiring PhD work environment. As part of a group of several PhD students in two (and eventually three) different specialisations as well as part of a larger group of eight people in the KiK 19 cohort, I enjoyed a stimulating social environment and many lunch conversations ranging in character from light amusement to heavy, exhilarating nerdity.

I wish to thank the PhD students in all three specialisations for many exciting discussions which have opened and broadened my mind. Following their projects also inspired my own work process. In particular, I want to thank my colleagues in the KiK 19 cohort for their discussions, cooperation, feedback and support in the lunchroom as well as the seminars. I am particularly grateful to my colleague Siri Merethe Skar, with whom I shared both an office and my leisure time. Our conversations and discussions were precious to me, not least during the Covid-19 pandemic, when we were stuck in our home offices and our Zoom morning meetings supplied such valuable structure and support.

Expanding my scope beyond the PhD period itself, I wish to thank Dr Audun Myskja for many years of inspirational education and collaboration. His comprehensive research on and implementation of music in dementia care were my points of departure when I started my research process. I am also grateful to other colleagues and course participants at Opplæringsprogrammet musikkbasert miljøbehandling, and to former colleagues and guests at the day centre at Bamble Helsehus, for the valuable cooperation and abundant learning experiences regarding music and dementia.

I also wish to thank some of the people who brought singing into my life: first, my always supportive parents, especially my mother, Grethe, with whom I have my very earliest memories while sitting in her lap and singing together from a children’s songbook. She and my late father, Svein – a jazz-loving surgeon – also initiated and supported my choir career, which started in a school choir at age eight. Eventually, it expanded into many years of advanced choir singing three times a week in NRK’s Girls’ Choir and Studio Choir under their legendary conductor, Marie Foss. I am grateful to her and all the girls for the extraordinary singing experiences we shared over the years.

An interest in music has passed down to my own three, now grown-up, children and my granddaughter. Thank you, Øystein, Ingvild, Åsmund and Liv, for the treasured musical moments, love and wisdom which enchant me always. I am also grateful to other family, friends and colleagues for their companionship and loving support. Last but not least, I wish to thank my research participants, “Lilly” and “Emma”, who let me into their lives and shared many precious moments with me. Our explorations together offered an abundance of experience and learning. Also, following my granddaughter Liv’s musical journey during her first years of life created a backdrop for, and an extra dimension to, my new experiences with Lilly and Emma. After all, I firmly believe singing should be nurtured and encouraged from the beginning of life to provide a musical and relational foundation from the cradle to the grave.

While I'm finishing this monograph for submission, the state channel NRK in Norway shows a six-part TV series called The Dementia Choir. *It leaves me shaken and immensely touched, and I am obviously not alone: The series is very popular, newspapers, social media sites, and even talk shows are following up on it, and all over the country, people are starting new dementia choirs. The TV program depicts the 15 people living with dementia and their families as the versatile, warm and resourceful people they are, but most of all it depicts singing's incredible potential for joy and togetherness. In the last episode, we see the enthusiastic audience and the tears and pride of family members while the youngest choir member sings a solo with his new mates in the choir: "You'll never walk alone . . ."*

Summary

This PhD project aims to explore some of the potentials – and related implications – of low-threshold daily-life singing in the context of people living with dementia and their close ones. A central issue is how people with dementia and their relatives might use, and experience, singing as an integrated part of communication and interaction in their daily life, outside professional or therapeutic frames, based on their experiences with singing throughout their lives.

The project's primary empirical material consists of an exploratory research intra-action inspired by participatory action research. The participants were an older woman living with dementia and her daughter. Together, we explored simple singing activities which they could integrate into their daily lives based on their preferences, interests and previous experiences. Theoretically, the PhD project is grounded in Karen Barad's agential realism and theories connected to affirmative philosophy, neuropsychology and neurophysiology. The thesis' research questions engage different aspects of relational singing as practice and experience; its underlying processes and mechanisms; and its conceptual and discursive implications. Thus, the research process unveils different aspects of singing in families living with dementia as a *material-discursive practice* (Barad, 2007).

Through theoretical and empirical exploration and diffraction, I introduce multiple perspectives to daily-life singing in families living with dementia. The thesis contributes to new knowledge by exploring and weaving together existing research and different theories and discourses with the research intra-action and autoethnographic material. In this way, it illuminates affirmative and relational aspects of everyday singing for people with dementia and their close ones. Furthermore, the thesis proposes "co-singing" and various forms of "musified togetherness" as suitable terms and concepts – and examples of everyday practices – to convey the implications of such an approach to singing and dementia. These terms highlight singing as a relational activity – that is, a form of togetherness. Through its exploration via diffractive analysis in several layers, the thesis also provides a methodological contribution to performative and post-qualitative research.

Sammendrag (Norwegian summary)

Dette ph.d.-prosjektet har som mål å utforske muligheter for og implikasjoner av lavterskel hverdagssang for mennesker med demens og deres nærmeste. En sentral problemstilling er hvordan mennesker med demens og deres pårørende kan bruke og oppleve sang som en integrert del av kommunikasjon og samhandling i dagliglivet, utenfor en profesjonell eller terapeutisk ramme, basert på deres egne erfaringer med sang gjennom livsløpet.

Prosjektets primære empiriske materiale består av en undersøkende forsknings-intraaksjon inspirert av deltakende aksjonsforskning. Deltakerne var en eldre kvinne med demens og hennes voksne datter. Sammen utforsket vi enkle sangaktiviteter som de kunne integrere i dagliglivet, basert på deres preferanser, interesser og tidligere erfaringer med sang.

Teoretisk bygger prosjektet på Karen Barads agensiale realisme samt teorier knyttet til affirmativ filosofi, nevropsykologi og nevrofysiologi. Forskningsspørsmålene dreier seg om (1) ulike aspekter ved relasjonell sang som praksis og erfaring, (2) sangens underliggende prosesser og mekanismer, og (3) begrepsmessige og diskursive implikasjoner. Forskningsprosessen har dermed undersøkt ulike aspekter av sang (i familier som lever med demens) som en *materiell-diskursiv praksis* (Barad, 2007).

Gjennom teoretisk og empirisk utforskning og diffraksjon introduserer jeg flere perspektiver på hva hverdagssang i familier som lever med demens kan være. Avhandlingen bidrar til ny kunnskap ved å utforske og veve sammen eksisterende forskning, ulike teorier og diskurser, forskningsintraaksjonen og autoetnografisk materiale. Slik belyser den affirmative og relasjonelle sider ved hverdagssang for mennesker med demens og deres nærmeste. Videre foreslår avhandlingen «sam-sang» og ulike former for «musisk samvær» som passende begreper og konsepter – og eksempler på hverdagspraksiser – for å formidle implikasjonene av en slik tilnærming til sang og demens. Disse begrepene fremhever sang som en relasjonell aktivitet – en form for samvær og samhørighet. Gjennom utforskning med diffraktiv analyse i flere lag gir avhandlingen dessuten et metodologisk bidrag til performativ og post-kvalitativ forskning.

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1 Introduction

Each moment is an infinite multiplicity. (Barad, 2014, p. 169)

1.1 Prelude

As the three of us started singing together, something happened in the room – a curious blend of excitement, joy, and relief. The somewhat challenging conversation a couple of minutes earlier – Anna and I trying to include Alf, who struggled with his words – had turned into singing one of Alf's favourite songs. Now, his voice was growing in confidence and volume, and his eyes were glowing. His wife was misty-eyed, and so was I.

I was conducting a small, informal pilot study as part of a project.[1] *I was acquainted with the couple, and we had agreed that I would visit them to try out some singing and music listening. When I started to map Alf's musical preferences, it was soon apparent that he had a history of and an enduring interest in singing, which – despite his severe dementia – was still highly accessible. Therefore, we agreed on some songs that he liked to sing, which I assembled in a binder.*

During a later visit, they told me that they had begun singing the songs every late afternoon – the time of day, Anna explained, which was often challenging for both of them because of Alf's restlessness. "But with the songs, we get such a nice ending of the day", she added. For me, this was a pivotal moment. This lifelong loving couple was struggling to cope with dementia as a new, unwelcome third partner in their spousal relationship and daily life. These songs, however, obviously had the potential to make a major difference.[2] (Waage, 2022, p. 328, with minor editorial modifications)[3]

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[1] At this time (in 2015–16), I was exploring practical and educational activities in different local institutions and settings as part of the project *Miljøbehandling i demensomsorgen basert på integrert musikk – et implementeringsprosjekt i institusjoner og kommuner* (Milieu treatment in dementia care based on integrated music: An implementation project in institutions and municipalities). The project was led by Dr Audun Myskja and funded by the Kavli Trust.

[2] The personal narrative presented in the prelude is anonymised, with fictional names. "Anna" approved the application and version of the text.

[3] Parts of Chapters 1, 4, and 6 appear in my published article: Waage, H. (2022). Co-singing in families living with dementia. In R. V. Strøm, Ø. J. Eiksund, & A. H. Balsnes (Eds.), *Samsang*

In retrospect, I see this moment as pivotal to my PhD process, which started several years later. At that time, I did not expect my singing encounters with Alf and Anna to leave such profound traces. I was exploring practical and educational activities in different local institutions and settings as part of a project developing methodical implementations of integrated music in dementia care. Our activities took their impetus from the needs and opportunities within professional dementia care, but we also explored activities and processes in the wider community.

Over the next few years, I kept coming back to that experience with Alf and Anna's co-singing. By the time I started designing my PhD proposal, I was determined to focus not only on the people living with dementia but also on the close ones living with them because they were so profoundly affected by it as well. In addition, informal everyday-life singing struck me as a potentially vital, yet largely untapped, resource. A growing number of research studies and reviews were documenting a range of beneficial outcomes linked to music and dementia both within professional dementia care and through organised community musical and singing activities. Even so, the literature showed relatively little interest in music shared by home-dwelling people living with dementia and their relatives, including low-threshold everyday-life singing. Instead, professionalised contexts for music and dementia as a part of therapy or caregiving dominated the literature. Likewise, connected concepts and terms such as *music therapy*, *music therapeutic caregiving* and *caregiver singing* situated music and singing in a professional sphere. I began to wonder: What kind of concepts and language could best convey the singing practice I shared with Alf and Anna?

> *A few weeks later, I met Anna again. She looked excited and told me that an old friend of Alf's had visited the other day. At first, it had been hard to engage and include Alf in the conversation, but then she told his pal about how they had started singing together lately. He was curious, so she showed him the song binder, and she and Alf began singing. Soon, the friend joined*

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gjennom livsløpet (pp. 327–353). Cappelen Damm Akademisk. In this article, footnote 1 (p. 327) says: "This article includes content and issues that will eventually be integrated, further explored, and developed in a PhD monograph as part of my research fellowship at the PhD programme Arts in Context at the University of Agder, Norway 2019–2023". The ability to do this was decisive for my consent to contribute to the anthology. The applicable paragraphs in my monograph include footnotes, paraphrased references and citations to avoid self-plagiarism.

> *in. It was lovely, Anna said, to see the two old friends finally be able to connect through singing.* (Waage, 2022, p. 333, with minor editorial modifications)
>
> *Shortly after our meetings, Alf moved to a dementia care department. He brought the song binder with him and continued singing with his wife and even with other relatives and staff members. Not long after, he passed away. Later, I met his widow again. At the funeral, she told me, Alf's friend recalled the experience of singing together with Alf: "I will never forget that moment".* (Waage, 2022, p. 348, with minor editorial modifications)

1.2 Purpose, issue and research questions

My PhD project aims to explore daily-life singing in the context of people living with dementia and their close ones. The central issue involves how people with dementia and their relatives might use, and experience, singing as an integrated part of communication and interaction in their everyday lives. The purpose is to explore the potential and implications of a supplemental approach to relational singing outside professional dementia care (e.g., caregiver singing) or therapeutic frames (e.g., music therapy).

As part of my research, I also need a different vocabulary to convey such an approach, so I will also explore the foundation and develop some concepts and terms to capture the low threshold and relational aspects of singing in this context while drawing on people's own experiences with singing throughout their lives.

To explore underlying mechanisms and processes of relational singing in families living with dementia, I have leaned heavily on different theoretical perspectives and existing research in my investigation and this dissertation. Theoretically, my PhD project is grounded in Karen Barad's (2007) agential realism and theories connected to affirmative philosophy, neuropsychology and neurophysiology. I have also been guided by research and approaches providing perspectives on dementia and music other than the predominant biomedical paradigm and its associated discourses.

The project's primary empirical material consists of an exploratory "research intra-action"[4] inspired by participatory action research. The participants were an older woman living with dementia and her daughter. Together, we explored simple singing activities to integrate into their daily lives based on their preferences, interests and previous experiences. In addition, I draw on autoethnographic material in some sections to provide supplemental perspectives.

The main research issue engages the potentials and implications of low-threshold daily-life singing for people with dementia and their close ones. This primary issue is operationalised in the three research questions guiding this monograph:

1. *How might people with dementia and their close ones use and experience singing as an integral part of their daily-life communication and interaction?*

2. *How can theory and research – especially that based on neuroscience and posthuman theory and philosophy – shed light on mechanisms and processes in play when people with dementia and their close ones sing together?*

3. *How might reworked singing terminology and concepts nuance understandings of and insights into daily-life singing practice and experience for people with dementia and their close ones, and what might be the reciprocal implications for concept and practice?*

The research questions touch on different aspects of what Barad (2007) terms a *material-discursive practice*. The first research question's issue is *how to* do *it* and *the experiences* – that is, the *practice*. The second question circles around explanations of the *processes and mechanisms* in play – that is, the *materiality*, broadly understood. The third question concerns the implications of *vocabulary* – that is, the discursive aspect. In all, the research questions guide the exploration of relational singing in families living with dementia as a *material-discursive*

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[4] I use the term "research intra-action" to describe my interactions with the dyad and my subsequent analytical engagements with the empirical material. The term intra-action, to which I will return, is based on Karen Barad's (2007) agential realism.

practice. The material-discursive-practical aspects of the explored phenomena – as well as the three research questions – are inevitably entangled.

The literature study is built around the research intra-action and the need to present the broader context of singing and dementia in close relations. Therefore, the theoretical and the empirical sometimes serve complementary purposes in this exploration and discussion. My own work experiences with singing in dementia care have also informed this process.

1.3 Contextual background

The incidence of dementia is increasing rapidly (World Health Organization, 2017), and a growing number of people affected by dementia live at home. Waage (2022) notes that despite decades of extensive research, there is still no cure in sight, so people living with dementia and their relatives need apt strategies to cope and maintain good communication, meaningful activities, and well-being. Substantial research has shown that singing and music, particularly when used in an individualised fashion (Leggieri et al., 2019), can benefit people affected by dementia and their close ones (Särkämö et al., 2014). Therapeutic musical approaches to dementia care can likewise enhance well-being and ease communication and interaction between people with dementia and their professional caregivers (Hammar et al., 2011a) (Waage 2022, p. 329).

Elsewhere, I have noted that music therapy, music therapeutic caregiving, care(giver) singing and music-based milieu care offer different, though partially overlapping, frameworks for utilising (therapeutic) personalised music as a part of dementia care (Waage, 2022, p. 329). Whereas most research within these fields has been carried out in the context of residential dementia care, a growing body of research addresses singing and music for people with dementia and their relatives in a homecare setting (Baker et al., 2019; Baker et al., 2012; Clair, 2002; Kulibert et al., 2019). Still, such research is generally carried out within the framework of (indirect) music therapy or professionally organised group singing. Thus, informal singing at home in the context of dementia is largely absent in the literature.

Principles from existing individualised, therapeutic musical strategies in dementia care, with regular and systematic application based on personal musical preferences, can also be relevant for home-dwelling people with dementia and their families (Waage, 2022, p. 329). Accordingly, this monograph seeks to scrutinise the potential of a simple, flexible approach for this target group, exploring singing as a low-threshold daily-life resource and integrating such an exploration with apt terminology and illuminative theory and philosophy. Subsequently, such a research approach might contribute to shedding light on and facilitating low-threshold daily life singing in families living with dementia beyond institutional and professional settings.

1.4 Personal background

In the eight to ten years before I began my PhD project, I worked part-time in dementia care as a freelance therapeutic musician and in a municipal day centre for home-dwelling older adults. For four years, I also worked on projects and teaching concerning *musikkbasert miljøbehandling* (music-based milieu care), mainly as a supervisor and teacher in a national educational programme[5] in collaboration with Norwegian physician and researcher Audun Myskja. Myskja's work, research and teaching have influenced and inspired my approaches to therapeutic music in dementia care and my work with this PhD project.

While attending a part-time study in therapeutic musicianship from 2008 to 2011,[6] I read Barbara Crowe's *Music and soulmaking* (2004) as part of the curriculum. Her approach to music therapy based on chaos theory and complex systems resonated strongly with my own experiences and attitudes. The interwovenness and complexity of practice and research within the application of therapeutic music seemed to fit better with system theory than more traditional biomedical and healthcare research approaches (Crowe, 2004, pp. 25–50).

I took another step towards a personal paradigm shift when, some years later, I became acquainted with Stephen Porges' (2011) polyvagal theory (PVT). PVT enabled a deeper understanding of the relation between the social and defensive properties of the autonomic nervous system and its implications for communication and interaction, especially under vulnerable or challenging conditions. In doing so, it suddenly shed light upon why the music-based care activities I had observed and heard of during my work within dementia care – particularly care singing – seemed so powerful. At the same time, the implications

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[5] The programme, Opplæringsprogrammet musikkbasert miljøbehandling, was initiated by the Norwegian Directorate of Health in 2015 and is run by the Norwegian Resource Centre for Arts and Health administered by Nord University. It teaches healthcare professionals and others how to apply simple but systematic and individualised music activities as a part of daily care.

[6] *International Harp Therapy Program*, led by Christina Tourin.

of PVT resonated with my personal experiences as a relative facing the severe health issues of my close relations. These experiences also increased my interest in a relative’s role: There is a great need for support and strategies for cooperation and interplay when such situations arise.

Shortly after starting my PhD process, I came upon Karen Barad’s (2007) agential realism, based on quantum field theory, which offered new resonances with the entanglements and complexities of therapeutic musical processes and personal communication and interaction elucidated by Crowe’s and Porges’ work. Barad’s theory appears to embrace the inseparability of complex musical and relational phenomena and thus serves as a particularly apt scientific platform for my project.

1.5 Introduction to the research approach and some central concepts

As I considered my PhD project, I anticipated developing a mixed-methods approach inspired by music therapy and healthcare research, but my assumptions changed upon my encounters with the open-mindedness of the Faculty of Fine Arts at UiA and the works of Barad and other posthuman and new-materialist thinkers. My research gradually moved from a qualitative and abductive strategy towards a performative research approach which some might even label “post-qualitative”, though I hesitate to use that term, as I will discuss further in Chapter 3.3.4.

Since the present dissertation has unfolded over time, its respective sections may convey different epistemological perspectives and apparently diverse ontologies. I believe that the twists and turns of the research journey itself can generate productive friction along the way, and the performative research approach, outlined in Chapter 3, holds that both knowledge and the researcher are always in flux or “becoming” in a universe where everything is interwoven and inseparable.

Some central concepts are keys to conveying both the entanglements and the inseparability. First, Barad’s (2007) notion of *intra-action* implies the mutual constitution of entangled agencies and states that the ability to act emerges from within the relationship or phenomenon, not outside of it. (Conversely, the more commonly applied notion of *interaction* implies separate, pre-existing entities.) Likewise, *intra-play* (Richards & Haukeland, 2020) highlights such co-constitutive inseparability (in contrast to interplay). Furthermore, *diffraction* – in some ways synonymous with *interference* – labels the ways in which new patterns emerge when different waves ripple into one another (and might be considered an alternative to *reflection*). The concept of *material-discursive practices* signals the entanglements of matter, discourse, and practice, all understood in a broad sense (Barad, 2007). I will return to these concepts in Chapter 3 but mention them here because they appear in the outline of the thesis' structure below.

1.6 Terms and clarifications

Since this dissertation primarily concerns singing, I sometimes use the expression "singing and music", which is common in Norwegian spoken language but might be problematic in an international research context because singing is also music. I still occasionally use this expression in order to distinguish between research specifically concerning singing and other studies concerning music more broadly (though often still including singing).

I have translated the Norwegian concept of "musikkbasert miljø-behandling" as *music-based milieu care*, although other authors use different translations.[7] This term captures the importance of the care *environment* while avoiding various irrelevant associations with the latter word in English. While "music-based environmental therapy" (Batt-Rawden et al., 2021) is a common alternative, I prefer to avoid the word *therapy* because the staff carrying out these interventions are not (music) therapists as such.

Music therapy refers to direct clinical work with clients by certified music therapists. However, much research covered in this dissertation concerns other *music activities*, including a "broad range of music-based activities and interventions that are not music therapy" (McDermott et al., 2018). Different papers use different language regarding caregivers and other support people. According to McDermott et al. (2018), employed caregivers are commonly referred to as carers, caregivers, formal caregivers or professional caregivers. Others who provide care or support due to personal relationships are usually

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[7] "Opplæringsprogrammet musikkbasert miljøbehandling" has often been translated into "the educational programme for music-based care" by the Norwegian Resource Centre for Arts and Health because the programme and its methods originated within residential dementia care. The programme has, however, later expanded beyond its initial field and now also encompasses other target groups and services, such as day centres. Existing translations do not fully capture the original Norwegian meaning, and an adequate English equivalent remains an unresolved question within the Resource Centre. Please note that though I will use "music-based milieu care" here, it is not the official English name of the programme.

described as families, family carers, caregivers, or informal caregivers (McDermott et al., 2018, p. 257). I will usually use the terms applied in the respective study or paper. When addressing issues across multiple sources, however, I will primarily use the terms formal caregiver or staff to refer to paid caregivers, and family (carers), relatives or close ones, depending on the context, for family or personal caregivers.

In my work, I often use the expression *close ones*, which encompasses a broader range of close relationships, including, for instance, friends, and does not necessarily imply a caregiver role. When I refer to *informal singing*, I think of singing practised outside a professional, therapeutic or otherwise organised setting or special event. Likewise, *low-threshold singing* includes these aspects of informal singing but also implies a minimal demand on the participants regarding education, planning, organising and equipment, among other things.

The term *intervention* is often associated with clinical interventions and the biomedical paradigm. Within social science, on the other hand, intervention is often used to describe ways to intervene and effect change. Still, to avoid any clinical connotations, I have chosen the terms *research intra-action* and *singing activities* when describing my cooperation with the participating dyad.

In headlines, I use the word “conclusion” in the sense of “ending” or “summary”. I do not seek definitive conclusions but instead remain open to new potentials and becomings, in line with a performative research approach, to which I will return in Chapter 3.3.4.

The concept of *co-singing* underpins the entire dissertation. Initially, co-singing served as a preunderstanding, filling a gap in the singing terminology by more precisely conveying a relational approach to singing in the context of dementia. Therefore, while exploring the material-discursive foundations of co-singing, I generally stick to the expression *relational singing* in my earlier chapters. In Chapter 6, I first discuss the foundations of co-singing, and in Chapter 6.4, I differentiate among ways of describing it as a broad term, a relational approach and a situated practice.

1.7 Introducing the research intra-action and experiential narratives

In this project, the exploration of co-singing as a situated practice was done in cooperation with “Lilly” and “Emma”, a woman with dementia in her 80s and her daughter in her 50s.[8] Together we explored different daily-life singing activities based on my informal mapping of their singing interests and preferences. Both of them turned out to like singing combined with physical activity, so we also tried out simple exercises, dancing and walking with singing, both indoors and outdoors. The process was gradual, and songs and activities were continuously adjusted to their wishes and needs.

My private and professional autoethnographic experiences with singing throughout my life became an important backdrop for the daily-life singing explorations with Lilly and Emma. A few of those experiences – and some other personal reflections – are presented as narratives (in italics) throughout the dissertation and are included in the diffractive engagements in Chapter 7.

1.8 Thesis structure

Chapter 2 is a thematic research review covering selected relevant research – primarily studies and reviews connected to singing for people living with dementia and their close ones. Certain adjacent research themes provide context for the main issue as well.

To establish the dissertation's scientific foundation, explain its central concepts and describe the research strategies, Chapter 3 begins with a summary of Barad's agential realism. I then discuss the overall research strategies in relation to agential realism. In particular, I consider the ways in which diffraction can be applied methodologically and coexist with a more reflexive approach. I also relate my methodological choices to a performative paradigm and address the position of the flexible, de/centred researcher and the role of affect. Further, I describe how my research strategy applies to autoethnographic material and the literature study.

The last part of Chapter 3 clarifies and discusses the approaches, strategies and considerations underpinning the research intra-action, which is inspired by participatory action research and includes semi-structured interviews. I describe considerations regarding participants and the singing activity. Further, I discuss creative and responsible ways of engaging with qualitative data and describe my four-layered diffractive analysis of the empirical material through (1) concepts, (2) agency, (3) theory and (4) experience. Finally, I discuss the project's micro-ethical concerns.

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[8] Lilly and Emma are fictional names.

Chapter 4 outlines and discusses some theoretical foundations for and implications of singing, dementia and close relations. Its central themes are the concept of well-being, embodied cognition, dementia and memory, personhood and embodiment, communicative musicality, attunement and vitality, and the polyvagal theory and its implications. The theories and models are often overlapping and entangled, so I employ a diffractive approach – reading different theories or models through each other – especially towards the chapter's end.

Chapter 5 considers macro-ethical perspectives and discourses connected to dementia. This chapter leans on Karen Barad's philosophy and Rosi Braidotti's *affirmative ethics* following a consideration of dementia, othering and stigma in light of the discourse of *dementia as tragedy*.

In Chapter 6, I discuss terminology and suggest a practical and theoretical impetus for the concept of *co-singing*. I contextualise it as a form of musicking and health-musicking in relation to care(giver) singing and the concept of co-creativity. I also draw on an entanglement of theories and models from Chapter 4 to generate co-singing's theoretical foundation as a term and a relational practice. Hence, Chapter 6 presents preliminary summaries and conclusions while establishing co-singing as a fundamental concept for the following part of the dissertation.

The explorations of the research intra-actions in Chapter 7 are based on the four modes of diffractive analysis. The concept of multifaceted *space* permeates all the layers, while new approaches are added in each new layer. Agency plays out through *intra-action* (Barad, 2007) and *intra-play* (Richards & Haukeland, 2020); theory and research inform explanations, illustrations and new conceptualisations (Barad, 2007; Dissanayake, 2017; Stern, 2004), and autoethnographic experiences add practical, hands-on perspectives and nuances.

Chapter 8 presents a theory synthesis based on Chapters 2–6, mainly in relation to the second and third research questions. This concluding chapter also follows up the explorative diffractive analysis in Chapter 7 and discusses the intra-play of co-singing as a material-discursive practice. Subsequently, I suggest some philosophical perspectives on co-singing in families living with dementia as a "minor" practice based on affirmation, potentiality and accessibility, and I offer a conceptual and practical approach to different aspects of "musified togetherness", including a multicoloured "co-singing palette". Lastly, I suggest some implications and recommendations for future education, research and care.

In the last part of Chapter 8, I summarise my project's research outcomes and outline its four main research contributions:

- explorative methodology: multifaceted diffractive analysis;
- theory development: theoretical and discursive entanglements to clarify and illuminate practice;
- new concepts: co-singing and musification as terms and practice; and
- the idea of co-singing as musified togetherness in families living with dementia.

2 Background and literature review: Singing, dementia and close ones

2.1 Introduction

2.1.1 Background

Research on one-to-one singing in the context of people affected by dementia and their families has been absent in the literature until relatively recently (Chatterton et al., 2010). Hence, my review will extend to a broader range of research on music and dementia. I have selected research that can shed light on singing and dementia in general as well as research that can contextualise some of the processes and activities explored in the research intra-action with the dyad.

The dominant aims and approaches in music and dementia research are guided by biomedical and effect-oriented perspectives (Dowson et al., 2019). The following review engages with a substantial amount of such research – and, accordingly, its effect-oriented language – to produce a thorough overview of the field. However, my project focuses on singing's potential as a form of togetherness – a way to relate and experience in the moment through singing. Therefore, this review also includes research guided by more resource-oriented, less effect-based approaches, such as resource-oriented music therapy and posthuman work on arts and dementia and the concept of co-creativity.

The overall benefits of music for people with dementia are well documented despite the variable quality of the evidence and the broad range of different interventions and protocols (Hanser, 2021). In a review of reviews about the effects of the non-pharmaceutical treatment of neuropsychiatric symptoms of dementia – what is often referred to as behavioural and psychological symptoms in dementia (BPSD) – Abraha et al. (2017) conclude, "The most promising treatments appeared to be music therapy and some behavioural management techniques, particularly those involving caregiver-oriented and staff-oriented interventions" (p. 23). In a review of possible non-pharmacological approaches to dementia which informal caregivers might try or access, Hulme et al. (2010) suggest music or music therapy, hand massage/gentle touch, and physical exercise.

A growing body of scientific research confirms the beneficial outcomes of personalised singing and music as part of dementia-care strategies (Buller et al., 2019; Ridder et al., 2013; Särkämö, 2018; Särkämö et al., 2014). Outside the residential healthcare setting, research literature concerning music as a systematic resource for people with dementia and their families has been scarce but promising (Baker et al., 2012; Clair, 2002, 2016; Kulibert et al., 2019). This research field is growing, and major studies are ongoing (Baker et al., 2019).[9] Furthermore, nascent research shows initial promising outcomes for community group singing in people with dementia and their family caregivers (e.g., Clark et al., 2018; Thompson et al., 2021; Unadkat et al., 2017).

The research field of music and dementia is growing rapidly. Dowson et al. (2019) point out that more papers were published between 2010 and 2019 than in the thirty years preceding that decade. Särkämö (2018) mentions two main strands of research on music interventions for people with dementia (and stroke survivors). The first engages music therapy implemented by a trained music therapist following a music therapy protocol. The second engages other music-based activities implemented by other professionals (such as nursing staff) or family caregivers, or by the patients themselves (Särkämö, 2018, p. 672).

2.1.2 Scope and chapter layout

This literature review is thematic and explorative in the interests of providing contextual knowledge and an overall impression of the field of singing and dementia. Further, it seeks to highlight research which adds perspective to the various issues involved in daily-life singing in families living with dementia, and will serve as a knowledge base for the discussions in the following chapters. The review is structured by the following main themes:

- Context, including
    - dementia – diagnosis and background,
    - relatives – relational issues for people living with dementia and their close ones, and
    - resource-oriented music therapy.
- Music and dementia, including
    - music, cognition, and memory; and

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[9] The three-year EU-initiated HOMESIDE study started in 2019; it is a three-armed, randomised, controlled clinical quantitative study with close to one thousand participants. In it, an intervention involving indirect music therapy (individualised music programs instructed by music therapists to be carried out by the spouses of people living with dementia) is compared to a reading activity and a control group.

    - music and movement.
- Singing, dementia and close ones, including
    - (indirect) music therapy (MT),
    - caregiver singing (CS) and music therapeutic caregiving (MTC),
    - (community) group singing (GS), and
    - studies with combined approaches.
- Examples of educational efforts
- Artful intra-actions for people with dementia – posthuman approaches to music and dementia
- Discussion and conclusion
- Summary

The ways in which singing might influence daily life and relationships in the context of dementia are at the heart of this project. Therefore, I will start by offering some glimpses into the diagnosis and prevalence of dementia and address research regarding relational issues in families living with dementia.

2.2 Context

2.2.1 Dementia

According to the World Health Organization (WHO), "Dementia is a syndrome in which there is deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing" (World Health Organization, 2023). Dementia can be caused by a variety of degenerative brain diseases or injuries, and mixed forms of it often coexist. Thus, the boundaries between different dementia forms are indistinct. Symptoms can vary considerably due to aetiology and severity and can include memory loss, reduced orientation, problems with language and daily activities, and mood and behavioural changes.

ICD-11, the 11th revision of the international classification of diseases (World Health Organization, 2022), lists eight categories and several subcategories of dementia. The most common is dementia due to Alzheimer's disease, which may contribute to 60–70% of cases, according to the WHO (2023). Other major forms include dementia due to cerebrovascular disease and Lewy-Body disease. Fronto-temporal dementia, dementia due to psychoactive substances (e.g., alcohol, drugs and medications), and dementia due to other diseases or conditions (e.g., Parkinson’s and Huntington’s diseases and Down’s syndrome) are less prevalent categories of dementia. In addition, for all dementia categories, ICD-11 adds a severity level of mild, moderate or severe and provides coded specifiers of behavioural and psychological symptoms

> that may be used when these are severe enough to represent a focus of clinical intervention. […] As many Behavioural or Psychological Disturbances specifiers may be applied as necessary to describe the current clinical picture. […] Examples of such symptoms include apathy, mood disturbances, hallucinations, delusions, irritability, agitation, aggression and sleep changes. (World Health Organization, 2022)[10]

I supply the diagnostic standard here as a backdrop to my subsequent discussions and research reviews, which often involve a biomedical paradigm of dementia. As ICD-11 shows, behavioural symptoms are attached to and described as part of disease diagnosis and coding, but, as I will return to repeatedly (especially in Chapters 4.4 and 5), such “behavioural and psychological disturbances” (BPD)[11] can have other contributing causes, such as medical (e.g., pain or inadequate medication), environmental, or relational conditions and circumstances. From the ICD-11 quotations above, it would appear that a person with dementia could end up with a diagnosis qualified by a host of additional coded BPD specifiers, regardless of what caused these “disturbances”. The impact of this upon research priorities and carers and relatives’ expectations, attitudes and approaches – and any associated stigma – will be discussed later.

It is necessary to acknowledge that such behavioural and psychological symptoms – whether caused by the disease or other factors – do seriously impact the lives of people with dementia and their professional and family carers. A systematic review by Arthur et al. (2018) found that 96% of community-dwelling people with dementia had displayed at least one behavioural and psychological

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[10] While APA 7 recommends (only) ellipses to signify omitted text in quotations, I prefer them in brackets for clarity because interviews or transcribed material sometimes include ellipses to signify hesitations or pauses. Also, throughout the thesis, I aspire to convey the quotations as the authors wrote them (including regarding italics), but I prefer not to point out typographical or grammatical errors by including [*sic*] in these instances.

[11] What ICD 11 refers to as “behavioural and psychological disturbances” (BPD) are commonly referred to as either “neuropsychiatric symptoms” or “behavioural and psychological symptoms in dementia” (BPSD) in the research literature discussed below.

symptom of dementia (BPSD) during the past month, and they also found a significant correlation between the number of PBSD symptoms and caregiver depression. According to Hammar (2011), in nursing homes 85% of the people with dementia are reported to demonstrate BPSD. Aggression, irritability, and resistance are the most frequent behaviours, and they are common in close interactions with others, such as during caring routines (Hammar, 2011, p. 12).

Still, since BPSD is already a prominent focus in much dementia care and research, I would argue that there is a great need to develop complementary attitudes toward the condition. Possible underlying contributing factors causing challenges should be acknowledged and addressed. Furthermore, more attention to resources, joy and meaningful moments might lead to the development of helpful approaches in daily life for the increasing number of people and families affected by dementia. According to WHO (2017), dementia affected 47 million people worldwide in 2015,[12] or roughly 5% of the world's older population. This figure is predicted to increase to 75 million in 2030 and 132 million by 2050. Nearly 9.9 million people are estimated to develop dementia each year around the world. Services to meet needed support and care are far from sufficient and are often fragmented or even lacking entirely (World Health Organization, 2017, pp. 1–2). Hence, most people affected by dementia live at home (Daley et al., 2017, p. 57; Kulibert et al., 2019, pp. 2971–2972) even in stages of severe disease. This situation calls for constructive and supportive strategies for people with dementia and their close ones.

2.2.2 Relatives

Much research on dementia and music or dementia and relatives reports that family members experience challenges and distress (Hanser et al., 2011, p. 3) which increase significantly over time (Svendsboe et al., 2018). The distress is often caused by neuropsychiatric symptoms (Terum et al., 2017) often referred to as BPSD (Song et al., 2018; Ulstein, 2007). Family members of people with dementia in nursing homes can also experience challenges (Clair, 2016, pp. 388–389; Ridder, 2017, pp. 272, 283). Song et al. (2018) point out that the interplay between

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[12] According to WHO's 2023 March 15 factsheet, the number at that time was more than 55 million people.

people with dementia and their family caregivers influences how BPSD unfolds, but so far there is limited research on this issue.

Ridder (2017) also refers to substantial research showing a wide range of what researchers commonly call “caregiver burden”, which implies adverse psychological and health outcomes. However, Ridder points out that this concept is unclear and that subjective versus objective burden measurements correlate only moderately. Moreover, the caregivers themselves rarely use the term burden when describing their situation (Ridder, 2017, p. 272).

Hammar et al. (2019) found that family carers often felt that they lacked sufficient support or adequate dementia-care knowledge and strategies. A particular challenge was handling the changes in the spousal relationship due to dementia (Stedje et al., 2023, p. 293–294). Several relatives described how this relationship came to resemble a parent–child dynamic which made it difficult to maintain communication and intimacy (Hammar et al., 2019). Such problems were rooted in the need for practical help and guidance and the decrease in verbal communication skills due to dementia symptoms. The relatives experienced communication as especially challenging. They realised that asking for a response when their spouse was not able to answer could induce confusion, upset, and even conflict. “When conversation was hard, they stopped talking to each other” (Hammar et al., 2019, p. 283). Spouses also described conversations as unrewarding “because they did not receive adequate answers” (p. 183), leading to less interest in making conversation and a general lack of emotion and affection described as “coming to a point where it was too exhausting to be nice” (p. 183).

Spouses also pointed to their history of a loving relationship as the glue keeping them together. Despite the challenges, they said they felt valuable and wanted to care for their partners “based on their promise to each other ‘in sickness and in health, for better and for worse’” (Hammar et al., 2019, p. 184). These findings are supported by other research in that field (Hammar et al., 2019, p. 185; Stedje et al., 2023, p. 293).

Likewise, Hernandez et al. (2019) found that the history and closeness of long-lasting relationships and doing things both together and separately were essential themes for couples when one spouse had memory loss. The authors argue that an essential task for practitioners is supporting couples in reinforcing their bonds, drawing on their past strength, and finding opportunities for meaningful joint activity. Stedje et al. (2023) similarly recognise the importance of “shared activities and sustaining common interests” (p. 292). In their systematic review, they identified 20 factors (grouped in six categories)[13] influencing relationship quality in couples living with dementia. They also suggest a need for a couple-centred focus – a sense of couplehood or dyadic perspective seemed to enhance quality of life, coping and resilience for both partners (p. 283).

Fletcher (2020) focuses on inter-related role transformation arising from the dyadic experience of dementia, or what he calls the "joint career". As this joint career progresses, the relationship hardens:

> Long-term affective relationships are reinterpreted in relation to the tasks of care, in the context of low external assistance, promoting the objectification of provider and recipient. This patterned trajectory is the dyadic career, tied up with associated role, self and relationship transformations. (Fletcher, 2020, p. 717)

Ridder (2017) refers to research indicating a correlation between psychological symptoms in the cared for and the caregivers' levels of stress and anger (p. 273). In understanding caregiving, a primary focus of the literature has been on burden and health. Ridder suggests a more constructive approach in which "caregiver burden and stress coping is described with the more positive aspects of caring within the conceptual framework of self-efficacy, resilience, attachment, and communication, in a psychosocial model of dementia care" (p. 273).

Moreover, Ridder (2017) outlines extensive research that supports her notion of music interventions as a support for those with dementia *and* their family caregivers. When communication and interaction gradually become difficult as cognitive functioning declines, music might have the ability to compensate: "When words fail, music still offers a way to communicate" (p. 276). However, she also points out the need for more insight into practical implementation and the ways in which music in daily life might influence the dyad in a broader sense: "not only cognitive functions and neuropsychiatric symptoms, but also caregiver health, wellbeing, self-efficacy, and resilience" (Ridder, 2017, p. 277). Such resource-based perspectives are also essential in *resource-oriented music therapy*.

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[13] The categories are (1) attitudes and strategies, (2) behaviour and activities, (3) emotional connectedness, (4) activities and experiences outside of the home, (5) social behaviour and roles, and (6) belonging and safety (Stedje et al., 2023).

2.2.3 Resource-oriented music therapy

Christoph Schwabe (2005) developed the concept of resource-oriented music therapy (RMT) based on his experiences as a music therapist within a clinical psychotherapeutic setting in Germany from the 1960s onwards. Starting in the 1990s, he experienced in this setting "a shift from a primarily pathogenetic to a salutogenetic approach" (Schwabe, 2005, p. 49).[14] In turn, resource-oriented thinking and acting became an increasingly important part of his work, as opposed to what he calls "effectence oriented treatments" which reduce patients to "passive consumers" (p. 52).

Schwabe (2005) also advocates for group singing therapy and highlights the use of folk songs and similar songs, especially those learned early in life. He argues that such songs' symbolic content and archetypical, emotion-laden melodic forms bring meaning to, and may reactivate, individual life experiences – even dramatic ones – in an acceptable way (p. 54). I believe Schwabe's argument could also be applied to what we often refer to as *sangskatten* (the song treasure) in Norway. However, he points out that group singing can also be connected to unpleasant experiences "burdened by traumatic assessment and evaluation experiences at school" (Schwabe, 2005, p. 54). If such experiences can be overcome, he writes, "then singing may become an experience connecting body, mind, and soul" (p. 54). Further, Schwabe holds that music therapy uses music as a medium for expression, communication and reception and as such "unites the pseudo-contrasts between conflict and easiness, tension and solution, fun and earnestness, play and realitybound obligation" (p. 55).

In the Nordic music therapy field, Randi Rolvsjord (2016) has outlined resource-oriented music therapy's background and properties. She points out that various notable music therapy scholars – including Ruud, Bruscia and Stige – have already laid the groundwork for a more resource-based and salutogenic orientation within music therapy in general (Rolvsjord, 2016, p. 558).

Still, Rolvsjord does not view RMT as merely a general trend within music therapy, but advocates for a more explicitly resource-oriented approach based upon the four characteristics of RMT: "(1) involving the nurturing of strengths,

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[14] Aaron Antonovsky proposed the conceptual neologism of *salutogenesis* – the origins of health – in 1979 as an alternative to the pathogenic orientation then dominating healthcare practice and research. In the salutogenic model, health and disease form a continuum. Its central concept, *sense of coherence*, contains three key factors: motivation and meaningfulness, comprehensibility and manageability (Antonovsky, 1996).

resources and potentials; (2) involving equal collaboration rather than intervention; (3) viewing the individual within their context; and (4) seeing music as a health resource" (Rolvsjord, 2016, p. 561). She promotes the flexible and collaborative use of music as a health resource, one highlighting the individuals' existing or potential strengths and resources, their agency, and equality and mutuality in the collaborative process (p. 561).

She also points out that the development of RMT draws on several movements and fields of discourse in an interdisciplinary landscape, including positive psychology, the concept of resilience, the recovery movement and the empowerment philosophy. In addition, community music therapy shares many perspectives with RMT (Rolvsjord, 2016, pp. 567–568). She emphasises that

> resource-oriented music therapy "implies more than adding some friendly elements to existing models" (Rolvsjord 2010, p. 11). A resource-oriented approach can indeed be regarded as in tension with, if not, conflicting with traditional approaches that aligns with the medical model. (Rolvsjord, 2016, p. 569)

The RMT approach serves as both a prompt and a backdrop during the following exploration of music and dementia research, which is often positioned within the bio-medical model.

2.3 Music and dementia

2.3.1 Overview

Many studies on music and dementia do not distinguish between singing per se and music in general, so singing is often a part of them. Some also shed light on mechanisms and processes influencing why and how music, including singing, affects people living with dementia. Still, reviewers lament the challenges and limitations regarding the standardisation of procedures, which makes it difficult to draw certain conclusions. A review study by Vink and Hanser (2018) found that many studies' protocols lacked sufficient detail for comparison and replication. Music therapy and music-based interventions were also inconsistently defined, and the professional training and preparation for music-based strategies varied among the practitioners involved in the studies (Vink & Hanser, 2018). Despite these issues, however, scientific support for music as a promising and beneficial strategy in the context of dementia is substantial and growing (Hanser, 2021).

Several systematic reviews and meta-analyses support positive outcomes regarding music therapy or other music interventions for people living with dementia, although their aims and results vary considerably. For example, Dorris et al. (2021) reported a small positive effect of music participation on cognitive functioning. Lam et al. (2020) found no effects of music therapy on cognition and daily functioning, ambiguous results for quality of life and agitation, and significant improvements in verbal fluency and a significant reduction in anxiety, depression and apathy. Moreno-Morales et al. (2020) reported short-term improvement in cognitive function and quality of life after music therapy intervention and reduced long-term (but not short-term) depression. Zhang et al. (2016) reported positive evidence in support of music therapy for disruptive behaviour and anxiety and a positive trend regarding cognitive function, depression and quality of life. A large Cochrane study by van der Steen et al. (2018) found that at least five sessions of a music-based therapeutic intervention probably reduce depression, improve behavioural problems and may improve emotional well-being and quality of life and reduce anxiety. However, they found little or no effect on aggression, agitation or cognition and were uncertain about effects on social behaviour as well as long-term effects. McDermott et al. (2013) found short-term improvements in behaviour and mood after music therapy and highlighted singing as an important medium for change. When integrating and synthesising quantitative and qualitative data, Thompson et al. (2021) suggested that singing can positively impact the lives of people with dementia and their care-partners. Other research has also shown that singing and music – particularly when used in an individualised manner (Leggieri et al., 2019) – can benefit people affected by dementia and their relatives (Lee et al., 2022; Särkämö et al., 2014).

We should, nevertheless, approach the results of systematic reviews and meta-analyses with caution. They are produced within different contexts and with different aims, designs and methods, and the included studies may lack controls and be hard to compare or synthesise. For example, Clift et al. (2018) note that while many group-singing studies show a range of beneficial outcomes (pp. 108–110), one study comparing group singing with group reading showed no difference in benefit (p. 110), indicating that the social and active component may be, at least partially, responsible for the outcome. Further, different musical interventions and circumstances can generate different results: In another study, individual music therapy and recreational group-singing activity to address depression in nursing-home residents had opposite outcomes. While music therapy was beneficial, group singing increased depression (p. 113). These examples "suggests a need for flexibility in the provision of musical, creative activities and other forms of engagement which are sensitive to the circumstances, interests and health of each individual" (Clift et al., 2018, p. 111).

Much music and dementia research has concentrated on music's ability to reduce negative symptoms and adverse behaviours and promote well-being. However, other frequent research scopes involve cognition and memory, including autobiographical memory, which is claimed to support a sense of identity.

2.3.2 Music, cognition and memory

Peck et al. (2016) review and discuss research concerning the enhancing effects of music exposure on cognitive function. They point to three main underlying neurological mechanisms to explain how music may enhance memory function in people with Alzheimer's disease (AD): the dopaminergic system, the autonomic nervous system, and the default network. In brief, their article finds that music listening influences the interaction between, on one hand, the brain's reward system and the neurotransmitters involved, particularly dopamine, and on the other hand, the autonomic nervous system and arousal regulation, as well as the brain's default network, which is active during attentive resting states. Much of the research discussed in the article indicates that familiar music has a stronger effect than unfamiliar music on memory enhancement in people with Alzheimer's disease, and that it can support a sense of identity and self-awareness.

Also along these lines, a study by Thaut et al. (2020) shows that long-known music activated a bilateral network of prefrontal, emotional, motor, auditory and subcortical regions. The authors believe that this extensive activation (relative to recently heard music) may explain why long-term musical memory appears to be relatively well preserved among older people with cognitive loss. Their study was the first to "provide evidence of the neural mechanisms underlying preservation of musical memory in a cognitively impaired population", as documented by fMRI (functional magnetic resonance imaging) scans (Thaut et al., 2020, p. 271). The authors conclude, "our study suggests that exposure to preferred long-known music activates brain regions involved in the retrieval of autobiographical memory and associated emotional responses above and beyond a short-term musical memory network formed by exposure to newly-heard music" (Thaut et al., 2020, p. 271). Thus, their study's new neurological knowledge supports and illuminates the reasons why familiar, individualised music generally shows better outcomes in music intervention studies (Leggieri et al., 2019) and can enhance autobiographical memory (Baird & Samson, 2015, pp. 224–225; El Haj et al., 2015).

My PhD project begins with people's own musical experiences, preferences and interests, so these research findings offer scientific support for my approach, which also builds on dementia-care practice. Such practice experiences also include informal "song-walks" using well-known rhythmic songs as cues to support walking, as I will outline in Chapter 7. Below, I include a few selected studies regarding music, rhythm and movement as further contextualisation.

2.3.3 Music and movement

Thaut and Rice (2014) point out that an increasing body of clinical research across different medical conditions shows a significant impact of rhythm on gait movement patterns involving better posture, more appropriate step rates and stride length, and more efficient and symmetric muscle activation patterns in the legs during walking (p. 95).

Clair and O'Konski (2006) note that the loss of psychomotor skills in late-stage dementia includes walking ability, though this is in fact essential for physical health: "While the risk of falls associated with poor walking cadence is a threat to safety, the hazards of discontinued walking is equally harmful" (p. 155). An inactive lifestyle entails increased physical frailties and a reduction in life quality, so the authors studied the effects of two different forms of rhythmic auditory stimulation (RAS) in 28 people with severe dementia with high needs for locomotion assistance. Quantitative differences in gait characteristics (cadence, velocity and stride length) were not statistically significant. However, the people with dementia required less physical support when either form of RAS (metronome beats alone or embedded in music) was used. The authors therefore conclude that RAS may be able to lessen assistance needs and physical strain on the carer during ambulation, thereby extending the possibility of walking further into the disease process. I will return to walking and rhythmic auditory cueing in the case exploration in Chapter 7. As part of that exploration, we also sang well-known songs to accompany simple physical exercises.

Mathews et al. (2001) also point out the dangers of inactivity while acknowledging the difficulty of engaging people with dementia in physical group activities. Their study found that rhythmic music accompaniment – compared to no musical accompaniment – enhanced engagement with and participation in a group physical exercise for nursing home residents with dementia.

A recent study by Ferreri et al. (2022) provides new insights into mechanisms underlying the influence of rhythm on motor behaviour. Based on previous research, the authors hold that merely listening to musical beats – without any movement – can activate regions of the motor system, and that "a regular rhythmic stimulation, by tapping on perceptual and motor processes, promotes people's body movement in space" (p. 2). The findings of their experimental study "support the idea that temporal predictions driven by a regular auditory stimulation are grounded in a perception-action system integrating temporal and spatial information" (Ferreri et al., 2022, p. 6). The authors also couple such neurologic time–space links to the embodied cognition framework, to which I will return in Chapter 4.3.1. This neurology-based integration of temporal rhythmic information and spatial body-environment information may also evoke and interact with the broader time–space perspectives applied in other parts of my dissertation.

This review chapter's first part aimed to supply a fundamental research-based awareness of dementia, relationships and music. In the following, I will focus on the role of singing in this context.

2.4 Singing, dementia and close ones

2.4.1 Background

Balsnes (2010) reviews research on singing and well-being and points out singing's positive influence in five main areas: physiological, psychological, cognitive, social, and meaning and coherence. Overall, research on singing indicates a range of its beneficial outcomes, including improved mood, especially via group singing but also via solo singing (Schladt et al., 2017). A growing body of research also concerns the benefits of singing (especially group singing) for older people in community and care settings, including those with specific long-term health conditions (Clift et al., 2017; Reagon et al., 2016).

At present, research on singing mainly concerns organised group-singing activities (Balsnes, 2010; Daykin et al., 2018). Thus, Balsnes (2010) suggests that future research should include more informal singing, including both community sing-alongs and private singing practices at home (pp. 7, 28). Research on singing in the context of dementia is also growing, but there is little work on relatives singing with close ones with dementia outside of organised group settings. Not everyone has had positive singing experiences in their lives, and some might prefer other activities. Still, based on the aforementioned research – and assuming individual adaptation of the activity in question – many families affected by dementia would likely benefit from singing more actively as part of their daily lives (Parmar & Puwar, 2019) (Waage, 2022, p. 331).

Chatterton et al. (2010) conducted a systematic review of one-to-one singing with people with dementia, scrutinising both *who* sings with people with dementia and *what* its objectives and effects are. The 17 reviewed articles showed that music therapists (10) and nurses or nurse aides (7) within residential dementia care did the singing, but only one music therapist instructed the family caregiver to use singing as well with the relative with dementia. Otherwise, family or informal caregivers were absent in the English-language research material on the topic at that time (2010). The review found that the music therapists focused on clinical goals such as addressing behaviour and enhancing cognition, whereas the caregivers focused on mutuality and quality of life, particularly by enhancing communication and cooperation during care routines such as morning ADL (activities of daily life) procedures (Chatterton et al., 2010). The review included a relatively small number of studies which varied in approach and methodology, so consistent comparisons or conclusions were elusive. Still, it was clear that singing with people with dementia has several benefits, and that the act of singing itself was the most important factor, regardless of whether the singer was a therapist or a formal or informal caregiver. Therefore, Chatterton et al. (2010) conclude that there is an untapped potential for singing individually with people with dementia, and they recommend that music therapists encourage and support caregivers and families in using singing.

A systematic review by Thompson et al. (2021) over ten years later included a considerable number of group-singing studies (to which I will return in Chapter 2.4.5) but very few studies of one-to-one singing with people with dementia, and none involving family members or informal carers. These studies were typically concerned with, and provided some support for, singing as a means of enhancing memory and cognition (e.g., Fraile et al., 2019; Moussard et al., 2014), whereas an RCT (randomised, controlled trial) by Wang et al. (2018) found significant improvement in cognitive function and behaviour after combined drug treatment and extensive individual music therapy singing sessions as opposed to drug treatment alone.

2.4.2 Research gaps and challenges

Lee et al. (2020) underline the need for more research concerning singing, dementia and relatives while pointing out the challenges regarding the existing research due to methodological limitations and the heterogeneity of the research designs. Additionally, they note the absence of a reliable definition of well-being and its synonymous association with other terms such as “quality of life” and “happiness”, which create issues around the interpretation, comparison and synthesis of research (Lee et al., 2020, p. 2). Further, they address several research gaps. While most people living with dementia are community dwellers, most studies examining the effects of music interventions for this target group have been carried out in residential care settings (Lee et al., 2020, p. 3; Tamplin et al., 2018, p. 2). In addition, Lee et al. (2020) point out that “family carers have been largely absent from studies” (p. 3), and when they are included, the studies have primarily examined their impressions of music-making’s effect on the cared-for rather than its impact on the family carers themselves.

Thus, this article advocates for research in the areas which motivated my PhD project: singing for home-dwelling people with dementia and the mutual influence of singing on people with dementia and their relatives alike.

Below, I will review some studies within three main domains of singing and dementia: (indirect) music therapy (MT), caregiver singing (CS) within the field of music therapeutic caregiving (MTC), and (community) group singing (GS).

2.4.3 Direct and indirect music therapy and dementia

Studies concerning individual and group music therapy in dementia care are extensive and growing rapidly. However, studies exploring indirect music therapy – where music therapists train caregivers or other close ones to apply music regularly with people living with dementia – are nascent though promising (Baker et al., 2012; Clair, 2002; Kulibert et al., 2019); one large study, known as HOMESIDE, began in 2019 (Baker et al., 2019). Both direct and indirect music interventions and research concerning people with dementia frequently incorporate singing, though the singing activities are not addressed separately. Therefore, the field of indirect music therapy may shed light on the potential for daily-life singing for people with dementia and their close ones.

From an ecological and systemic perspective, Stige (in McDermott et al., 2018) argues that indirect music therapy is about working with both laypeople and professionals in a practice community to share knowledge and skills “in ways that stimulate health-promoting changes in the systems involved” (p. 270). In the more specific context of dementia, McDermott et al. (2018) suggest:

> In indirect music therapy practice, a therapist typically works with carers and supporters to strengthen their relationships with people with dementia and help them further develop their self-awareness and sense of competencies. However, the ultimate goal of indirect music therapy practice in dementia care remains the wellbeing of people living with dementia. (p. 256)

The authors point out that training carers is an essential part of in-direct music therapy, and that the skill-sharing can be done in different ways: The music therapist can both serve as a role model for carers during daily activities and conduct more formal further training in a teacher role (McDermott et al., 2018, p. 261).

Ottesen and Krøier (2018) conducted an indirect music-therapy project for dementia care staff and facilitated a situated, practice-based dialogical learning process including co-reflection on tacit knowledge. In this project, learning-by-doing and reflection-in-action and reflection-on-action enhanced and developed professional practice-based reflection processes among caregiver colleagues. McDermott et al. (2018) point out that the integration of using specific music skills – “what you do” – and how to be with the person in the moment – “how you do it” – are essential to indirect music therapy skill-sharing (p. 274).

The PAMI research group (at Aalborg University) conducts research on such person-attuned musical interactions (PAMI) in dementia care. Krøier (2022) describes PAMI as “reciprocal, nonverbal interactions embedded in daily practice” (p. 7), advising that music therapists facilitate PAMI training to caregivers, and connecting PAMI to indirect music therapy (pp. 61–62). Notably, she does not regard PAMI as either music therapy or music medicine because the aim of PAMI is neither to build a therapeutic relation nor to offer an intervention (p. 7). While the use of music in dementia care is often described as an intervention or activity, Krøier and Ridder (2022) “use the term musical interaction to emphasise the relational, reciprocal aspect of the use of music” (p. 2). Throughout her thesis, Krøier (2022) highlights PAMI as a relational concept involving people with dementia, caregivers and other professionals (e.g., p. 61). In addition, I will argue that the principles of PAMI have transfer value to non-professional caregivers and (other) close ones.

Odell-Miller (2021) looks at the current position of music therapy within dementia care by discussing these interventions from a clinical, educational and research perspective. Based on previous studies and present knowledge, the author highlights the importance of expanding the music therapist’s role beyond direct music therapy to include training caregivers and others to effectively embed music in daily care. She points out that direct music therapy should be prioritised in the late stages of dementia, when it is most needed, but at earlier stages music therapists might work alongside others to support or provide a wider variety of music-based activities and indirect music-therapeutic approaches (Odell-Miller, 2021, p. 7). Likewise, Bøtker and Ridder (Ridder, 2019; Ridder & Bøtker, 2019) underline the music therapist’s role as a skill-sharer for professional and family carers: “After termination of music therapy, it is important that caregivers are advised on how to use music in positive interactions in daily life. Caregivers may also be directly included in the therapy” (Ridder, 2019, p. 313).

In an RCT feasibility study, Hsu et al. (2015) found that weekly individual music therapy sessions and carer instruction during a five-month music therapy programme in dementia residential homes led to a reduction of neuropsychiatric symptoms and an increase in well-being in the music therapy group. The authors underlined the importance of the music therapist’s role in communication and skill-sharing with the carers, who received suggestions for adapted musical approaches to be applied during daily care between the sessions.

Ray and Götell (2018) studied the effects of music therapy on depression in nursing home residents with dementia which was followed by the music therapist’s training of nurses to provide music activities as part of daily care. Music therapy for two weeks significantly reduced depression symptoms. Moreover, both forms of the subsequent music activities – singing and music-with-movement initiated and instructed by the music therapist and carried out by the nurses – were found to sustain the positive outcomes of the initial music therapy, in contrast to the non-music control condition. The music-and-movement protocol particularly enhanced well-being. The study provides examples of effective music therapy skill-sharing and training, and the authors claim that it "highlights the benefits of providing music therapy and music-based care for nursing home residents on a continuum" (Ray & Götell, 2018, p. 5).

A few studies have documented the benefits of indirect music therapy for home-dwelling people with dementia and their family carers outside the professional care setting, and the aforementioned large study, HOMESIDE, has been ongoing since 2019 (Baker et al., 2019). Clair (2002) found that family carers were able to quickly learn and use familiar music in familiar settings – such as singing or dancing, according to their preference – to enhance mutual engagement. Although it included only eight participating dyads, the study indicates that music application can increase mutual engagement between people with late-stage dementia and their family carers. Moreover, this engagement increased throughout the sessions and even carried over to non-music visits.

Similarly, Baker et al. (2012) studied five caregiving spouses who were trained to self-direct a music intervention three times a week for six weeks with their spouses living with dementia. Their findings indicate that the shared music activities were beneficial for the spousal relationship, the dyad's moods, caregiving satisfaction, and caregiver well-being:

> The qualitative analyses revealed that the music intervention enabled couples to spend quality time together. Feelings of intimacy were fostered, humour and memories were shared which led to perceived increases in reciprocity between the partners, and enabled the spouses to engage with their partners in similar ways as they had before the onset of dementia. (Baker et al., 2012, p. 15)

A study by Hanser et al. (2011) showed that a music program initially instructed by a music therapist and carried out by the family caregiver at home appeared to be effective in increasing the dyads' "perceived levels of relaxation, comfort, and happiness, on average" (p. 15). However, participant withdrawal from the study was substantial, and the intervention design might have been too demanding on some of the family carers. The authors suggest that more support from the music therapist during the intervention period might be an important adjustment in future designs.[15]

The aforementioned studies focused on shared activities, and the studies of Clair (2002) and Baker et al. (2012) included familiar singing or dancing. In a different manner, Kulibert et al. (2019) studied the Music & Memory program using iPods to accommodate individualised music listening. This programme appeared to be a less relational and less structured form of activity with somewhat unclear or mixed outcomes. Moreover, some participants reported challenges regarding the music selection and the use of the equipment. The authors suggest that this kind of intervention might be more applicable to a professional care environment. However, they also conclude that, despite some limitations, "the current study does provide one important take home message: persons with dementia and their care partners are still able to enjoy many aspects of everyday life, including listening to their favorite music" (Kulibert et al., 2019, p. 2982). From my perspective, it is interesting that familiar, relational singing and dancing (Clair, 2002) seemed accessible and beneficial, whereas music-based activities involving a need for technical equipment created challenges for some participants (Kulibert et al., 2019).[16] However, these studies included relatively few participants and were all different in their designs, which might have contributed to their various challenges and outcomes.

2.4.4 Caregiver singing and music-therapeutic caregiving (MTC)

In the context of professional caregiving, extensive research addressing the potential of integrated music (including singing) in dementia care has been conducted within the frame of music therapeutic caregiving (MTC). While the concept of indirect music therapy implies training and skill-sharing initiated by music therapists, MTC implies that nurses or other caregivers are implementing the musical care strategies after receiving training from an educational programme or other caregivers trained in the methods (Hammar, 2011, p. 27; Hammar et al.,

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[15] Accordingly, the ongoing HOMESIDE RCT (Baker et al., 2019) provides a design wherein the music therapist, after the initial instruction, returns for two additional sessions during the 12-week intervention period and calls the family carers every second week to support them.

[16] Sixsmith and Gibson (2007) studied music in daily life for people with dementia living at home and in nursing homes and likewise found considerable challenges regarding the use of the technical equipment. Hence, the person with dementia largely had to rely on others to provide them with access to music.

2010, p. 36). In that regard, MTC could be considered “music medicine”, or the therapeutic use of music as part of health care which is primarily carried out by healthcare staff (Myskja, 2005a, p. 1497). According to Myskja, the *individualised music* method (e.g., Gerdner, 2005) is a synthesis of music therapy and music medicine adapted to people in nursing homes. Individualised music integrates music-therapeutic work with other nursing and care measures (Myskja, 2005a, p. 1497). Several studies (e.g., Götell, 2003; Hammar, 2011; Myskja, 2011) show that music systematically integrated into nursing homes’ daily care routines enhances communication and satisfaction among residents and staff and has a positive influence on several behavioural symptoms in people living with dementia.

Brown, Götell and Ekman (2001) introduced the term *music therapeutic caregiving* (MTC) “to describe an active form of music-making by caregivers to and/or with patients during the course of actual caregiving activities” (p. 125). Since then, different aspects of MTC during daily care have been studied at Karolinska institutet in Sweden, such as communication (Götell et al., 2002; Hammar et al., 2011a), movement and sensory awareness (Götell et al., 2003), emotions, mood and resistance (Götell et al., 2009; Hammar et al., 2011), during mealtime (Hammar, 2012), caregiver’s experience with and without MTC (Hammar et al., 2011b; Swall et al., 2020), and residents’ reactions to caregiver singing during morning care routines (Hammar et al., 2010). This research has shed light on different aspects of caregiver singing and background music’s influence on communication and cooperation between people with dementia and their professional caregivers, primarily during morning care routines. Many of the studies focused particularly on caregiver singing (Hammar, 2011). While washing and caring routines can often be challenging – especially in later stages of dementia – background music and especially caregiver singing has been shown to lessen BPSD (behavioural and psychological symptoms in dementia) and improve mood for both residents with dementia and staff. Moreover, caregiver singing entailed mutual positive changes in communication and interplay (often beyond words) between the person with dementia and the caregiver (e.g., Brown et al., 2001, pp. 130, 131; Götell et al., 2002; Hammar, 2011, pp. 67, 74).

While the studies mentioned above were carried out before 2012, more recent studies have confirmed and nuanced the earlier findings. Swall et al. (2020) write:

> The caregiver and the PWD can connect with each other through caregiver singing, and this allows bridges to be built and an unspoken understanding of the situation. They meet at a level that only singing makes possible, and this allows for a person-centred connection. (p. 7)

The study by Swall et al. (2020) nuanced the respective roles and impacts of caregiver singing and music, which could be applied in different situations: “caregiver singing to facilitate care situations and music to increase socialization” (p. 8). Moreover, this study focused on caregivers’ perspectives on singing and music as part of caregiving, and they reported that singing made them more joyful and less stressed, which agrees with earlier studies (e.g., Hammar et al., 2011a).

In Norway, Audun Myskja (2005b, 2005c, 2006, 2009, 2011) has worked extensively with research, teaching and implementation of integrated music in dementia care. His findings and experiences are congruent with the Swedish studies. However, Myskja’s concern has largely been how to develop tools, methods and educational resources to systematically integrate music and care singing in nursing homes’ daily care routines, to which I will return in Chapter 2.5. Myskja’s practical approaches build on Linda Gerdner’s research and application of *individualised music* (e.g., Gerdner, 2005) and principles from *neurologic music therapy* (Myskja, 2014; Thaut & Hoemberg, 2014). His work with rhythmic auditory stimulation to improve gait function for people with Parkinson’s disease (Myskja, 2005c) has also been adapted into a simplified, more informal (that is, less protocol-driven) version to help staff support mobility and movement for people with dementia in nursing homes helped by rhythmic singing of well-known songs, a metronome or both.

Hämäläinen et al. (2020) studied informal and formal caregivers’ experiences with *yoik* in care for older Sami people with dementia. The caregivers experienced yoik as enlivening and empowering; it induced “good feelings” and facilitated reminiscence among the care recipients. However, the participants reported that not all the healthcare staff members were supportive of the residents’ use of yoik or the yoik motions, and that there is a need for further exploration of yoik intervention and training for staff in this context. The authors argue that using yoik in dementia care for Sami people can be understood as an embodied, person-centred, dignity-preserving, culturally safe and sensitive care alternative, one which enhances their connections to themselves, nature and the community. In short, yoik facilitates attunement.

The studies outlined in this section have mostly been carried out in nursing homes with professional caregivers. Nevertheless, such studies provide nuanced and compelling insights into the potential of singing in close relations with people with dementia.

2.4.5 Group singing for people with dementia and their relatives

Research on choir and community singing for healthy older adults has revealed a range of beneficial outcomes concerning various aspects of quality of life and the reduction of anxiety, depression and loneliness (Särkämö, 2018, pp. 672–673). Accordingly, researchers' interest in group singing for people living with dementia is growing. This section reviews several studies regarding group singing for people with dementia and their relatives or family carers. I have chosen studies published after 2015 since this research field is relatively new and the studies include reviews of previous studies. I also focus on aspects of the studies which seem particularly relevant to my project. Although the studies differ in scope and methods, their findings are generally positive, and many studies highlight similar outcomes. They do, however, apply different approaches regarding focus, methodology and the set-up of the group activity.

Tamplin et al. (2018) sums up three specific benefits of active music intervention concerning the support of dyads of people with dementia and their family caregivers living together in the community. Long-preserved musical memories can stimulate engagement and social interaction. Further, individual music preferences and associations reveal the premorbid personality of people with dementia to the family caregiver. Lastly, music interventions can assist in the management of negative symptoms of dementia (Tamplin et al., 2018, p. 2).

Several studies of group singing for people with dementia (e.g., Clark et al., 2018; Osman et al., 2016; Unadkat et al., 2017) report beneficial outcomes including enhanced well-being, social interaction, self-confidence, joy and engagement. These studies have slightly different approaches. Osman et al. (2016) found that social inclusiveness and improvements in relationships, memory and mood were especially important to the participants, and that their participation also helped them to accept and cope with dementia.

Unadkat et al. (2017) centred the couple's relationship and highlighted the accessibility and joy of singing combined with effective group facilitation as the essential premises for various individual and dyadic benefits following active and equal participation and new experiences (p. 472). Their focus on singing's *accessibility* resonates with my own project's approach and experiences outlined in Chapter 7. The authors point out that "nearly all participants reiterated that participation in these particular singing groups was not dependent on singing ability, and that being encouraged to participate equally as part of a group enabled expression: 'I can't sing, but I enjoy the singing.' (C16)" (Unadkat et al., 2017, p. 475). The authors emphasise shared creative processes while noting that previous research has often highlighted the reminiscence aspects of singing rather than creativity and learning. While the authors acknowledge that reminiscence can be enjoyable, they also refer to research which questions some forms of reminiscence therapy–focused group activities. In contrast, they note that participants in singing groups described "a sense of excitement, a desire to look forward and an appreciation of learning a new skill" (Unadkat et al., 2017, p. 476).

Clark et al. (2018) highlight the importance of group facilitation by credentialed music therapists in therapeutic community-based group-singing interventions for people with dementia and their family caregivers. Recognising the shortage of music therapists in relation to the growing dementia population, they suggest a model involving collaboration between professional musicians and music therapists (p. 11). Their study explored therapeutic group singing (TGS) sessions underpinned by Kitwood's person-centred care model. They found that the sessions led to supportive friendships among participants and supported the dyadic relationship (p. 10). The individual benefits reported in this study, such as enhanced quality of life and mood and reduced anxiety and depression, align with systematic reviews on group singing, both for people with dementia and other populations (p. 11). They also note that the "mental stimulation, enjoyment, and improved feelings of social confidence and self-esteem" (Clark et al., 2018, p. 11) identified in their study correspond with other qualitative studies.

Lee et al. (2020) suggest that

> singing groups for people at the same stage of dementia and their family carers can foster feelings of support, solidarity and belonging. Evidence of multidimensional enhancement of well-being, the absence of adverse effects, and the accessibility of this musical medium support increased provision of group singing interventions for these populations. (Lee et al., 2020, p. 14)

Harris and Caporella (2019) included undergraduate students in an inter-generational choir as part of "the process through which to begin to create a dementia friendly community" (p. 2556). They found that the students "showed an increased understanding about the lived experience of dementia, a reduction in dementia stigma, and an increase of awareness about the capabilities of people with dementia". In addition, the people with dementia and their family members had "very positive and meaningful interactions with the students" (p. 2572).

Mittelman and Papayannopoulou (2018) highlight the ability of people with dementia to acquire new skills and learn new songs. Their choir pilot study suggested that "people in the early to middle stage of dementia and their family members and friends can enjoy and learn from rehearsing and performing in concerts that also engage the wider community" (p. 779). Unlike most studies at that time, their study sought to support the caregiver in particular.

One part of a feasibility group singing study by Tamplin et al. (2018) also wanted to provide resources for a home music program designed to help family caregivers manage the behavioural and psychological symptoms of dementia with their loved ones (p. 3). However, the participants did not utilise their planned home music program; instead, the authors gave them recordings of songs they were singing in the group sessions to enable and encourage them to continue singing and learning together at home. The participants did find these recordings encouraging and helpful (p. 8).

Thompson et al. (2021) conducted a comprehensive systematic review of quantitative (26), mixed-methods (5), and qualitative (9) studies concerning singing and dementia, some of which included family carers. Most of the studies involved group singing with people with dementia (18) and their informal care partners (16), while a few studies concerned one-to-one singing (6). The authors initially reviewed the quantitative (narrative synthesis) and qualitative studies (thematic synthesis), respectively. Afterwards, they applied a meta-integration method to synthesise themes across the two approaches. Due to various limitations and challenges regarding heterogeneity in design, intervention type, dosage, and quality of reporting, they were not able to draw clear conclusions. Despite the weak evidence for specific outcomes as such, their combined analysis of qualitative and quantitative data indicates that singing, particularly in groups, can benefit people with dementia and their care-partners. Their research implies that participants may derive joy, positivity and personal well-being from group singing. The study also reinforces the significance of meaningful social interaction and activity for well-being, which are particularly valued by those living with dementia.

2.4.6 Combined approaches: The Finnish studies

Most singing and dementia research involves either group-singing, music therapeutic caregiving (MTC) or indirect or direct music therapy (MT). Such studies are usually based on short-term intervention periods; they often do not include relatives; and the MTC and MT mostly concern music more generally and not singing per se. While qualitative designs often indicate favourable outcomes, this tendency is not mirrored by quantitative assessments, which frequently fail to reach statistical significance while occasionally suggesting positive but uncertain outcomes (Lee et al., 2022; Mittelman & Papayannopoulou, 2018, pp. 780, 786; Thompson et al., 2021).

For my research, then, the much-cited RCT by Särkämö et al. (2014) is compelling because of its multifaceted and long-term approaches, which showed statistically significant positive outcomes. Two different music group interventions – one with a singing group and one with a music-listening group – were combined with the coaching of formal caregivers in residential dementia care and informal caregivers for home-dwelling or short-term resident people with dementia (Särkämö et al., 2015; Särkämö et al., 2014). The caregivers were guided to apply singing or music listening, respectively, between sessions and after the group-intervention period. Särkämö et al. (2014) found that regular engagement in musical activities such as singing and listening to familiar music provided by caregivers can benefit people with dementia cognitively, emotionally and socially. Compared to standard care, these activities can improve their mood and "maintain or enhance general cognition, orientation, attention and executive function, and remote personal episodic memory" (p. 645). Music listening improved the quality of life of people with dementia, and singing, specifically, enhanced their short-term and working memory and their family members' emotional well-being.

Särkämö et al. (2014) speculate that the singing activity was more difficult for the relatives to maintain at home than music listening, which was applied more frequently. They suggest that more intensive coaching for an extended period, possibly followed by periodic recapitulation sessions to encourage the caregivers to keep up the musical activities at home, might be needed to establish musical activity more firmly as part of everyday care routines and to see more robust long-term effects (p. 648). Nevertheless, singing was found to reduce the psychological burden experienced by the family members of those with dementia six months after the intervention. The authors suggest that their findings have promising clinical implications and encourage the use of singing and music listening as leisure activities both for people with dementia and their caregivers (p. 648).

Based on the same data material, Särkämö et al. (2015) analysed how the clinical, demographic and musical backgrounds of the people with dementia influenced the efficacy of the caregiver-implemented singing and music-listening activities previously shown to improve or maintain cognitive functioning, mood, quality of life and caregiver well-being. I will not address the detailed clinical nuances presented in the study but instead focus on some general trends relevant to my project. The authors found that the positive outcomes of the interventions transpired regardless of the musical background of the individual with dementia, indicating the broad applicability of such interventions. Other cross-analysis indicated that singing was more beneficial in earlier stages of dementia compared to music listening and care as usual, whereas music listening showed more pronounced outcomes in moderate stages and within residential care. The reasons for these differences are not obvious and may involve circumstances not fully explored in the study. Nevertheless, both modes of musical intervention were found to be beneficial throughout the course of the dementia.

Another interesting finding was that Särkämö et al. (2015) "did not observe any mediation of the clinical, demographical, or musical background variables on the positive effect of the singing intervention on caregiver burden, suggesting that singing activities could be widely used to support the emotional well-being of caregivers" (p. 779). My project has a particular interest in the relative's perspective and situation, and this finding suggests further exploration of singing as a resource for the (home-dwelling) people with dementia and their close ones. The findings from these Finnish studies also actualise the utility of educational efforts.

2.5 Examples of educational efforts

In Norway, healthcare professionals are offered courses and education in music-based milieu care. Since 2015, a national educational programme anchored in political plans and white papers has been organised by the Norwegian Resource Centre for Arts and Health (Batt-Rawden & Storlien, 2019; Batt-Rawden et al., 2021). Likewise, training in *singing* as a resource in ageing and dementia care has been provided by publicly supported organisations and programmes (Batt-Rawden & Stedje, 2020). However, comparable systematic resource-oriented music-based support or training has not been developed for the home-dwelling context.

While music-based tools and methods are promoted as important resources in ageing and dementia care, the political justifications of such programmes have often been instrumental and focused on symptom reduction, as can be seen in Norwegian healthcare white papers. These same white-paper citations also appear on websites promoting the educational programme for integrated music in dementia care (Opplæringsprogrammet musikkbasert miljøbehandling, MMB).[17] The following citation from two different healthcare white papers, also cited in the course description, illustrates my point: "Recent studies show that when employees get the opportunity to use singing and music therapeutically, it works against uneasiness/anxiety [Norwegian: *uro*] and depression in dementia or against acting out [Norwegian: *utagering*] during care and daily activities" (Meld. St. nr. 15, 2017–2018, p. 136; Meld. St. nr. 29, 2012–2013, p. 85) (my translation).[18]

The further wording is also similar across the two white papers and focuses on reducing medication and employee sick leave, preventing escalating situations, and reducing coercion and the number of staff needed to carry out care for challenging residents. However, the most recent of the two papers displays slightly more nuanced wording and also notes that singing and music can facilitate communication and new understandings and impact the quality of relations (Meld. St. nr. 15, 2017–2018, p. 136). The section describing integrated music in dementia care is placed in the chapter "Helsehjelp" (Healthcare). In contrast, the chapter "Aktivitet og fellesskap" (Activity and community) does not even mention music or singing in its main text.[19] I believe this is because the MMB programme has been strongly profiled as research-based and striving towards clinically professional goals and structured implementation. The promotion of music-based methods and tools as richer than simply music (including singing) as "cosiness" and entertainment is considered essential, though this might also raise the threshold

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[17] See https://musikkbasertmiljobehandling.no/om-musikkbasert-miljobehandling/.

[18] "Nyere studier viser at når ansatte får mulighet til å bruke sang og musikk terapeutisk, fungerer det mot uro og depresjon ved demens eller mot utagering ved stell og daglige aktiviteter."

[19] Music is only occasionally listed as one of many activities in the textbox descriptions regarding examples of several general and local activities and organisations. Only one specific musical activity/training is mentioned very briefly: Sang i eldreomsorgen (singing in ageing care).

for their implementation. A research report evaluating the MMB programme concludes that staff members experienced a range of positive outcomes from using the methods, but there were pronounced challenges regarding implementation, suggesting a greater need for management support and a focus on these processes (Batt-Rawden et al., 2020; Batt-Rawden et al., 2021).

In a pilot study, Thurn et al. (2021) evaluated a novel intervention, MusicKit, designed to provide family caregivers with flexible, low-threshold[20] music tools to help cope with challenging situations caused by BPSD. The foundations for MusicKit are developmental music therapy and Orff music therapy, and it emphasises the needs of the client and the importance of family relationships (p. 5). It is also based on situational modular musical elements applied by the family carer spontaneously and directly during daily-life activities "to alleviate challenging situations with the help of music" (p. 6). The authors describe how "combinations of musical elements in small situational songs or chanted requests can be used in a functional way to affect challenging situations in daily care of people with dementia" (Thurn et al., 2021, p. 9). The elemental and modular structure of the method resembles some of the tools within Musikkbasert miljøbehandling (music-based milieu care), which has influenced and inspired my research. I will return to the further application of such an elemental and modular way of "constructing" singing interplay in Chapter 8 with what I describe as the "singing palette". However, unlike the music-based milieu care discussed above, MusicKit does not apply familiar songs but only modular and often multisensory (that is, including touch, movements or visuals) elemental singing phrases.

Nevertheless, the study offers insights into a structured guiding model of ways to build and apply multisensory singing elements. Moreover, it focuses on the family carers' well-being (not primarily on the person with dementia) and reports that the participating carers described the music interventions as a form of self-care (p. 16) and found MusicKit to be useful and supportive in daily care. However, they also wanted more extensive instruction than that which was provided during the two sessions (p. 19).

While MusicKit aims to help the carer "alleviate challenging situations" (Thurn et al., 2021, p. 6), my approach is less goal oriented and concerns how the close ones *and* the person with dementia can integrate singing into daily-life

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[20] According to Thurn et al. (2021), "low-threshold" refers to the fact that MusicKit requires no additional preparation time, musical education or previous experience in order to be used (p. 6).

interaction and communication. That said, I fully acknowledge the challenges entailed by the progression of dementia and the need for constructive non-pharmacological methods and tools. Nevertheless, since much dementia research and caring practice already address the "problems", I aim to explore a resource-oriented approach which is neither therapy nor a "care intervention" as such but rather a way to be – or become – together. Such singing togetherness may still have therapeutic ramifications as a "side effect".

There is also nascent research regarding arts and dementia which leans towards a performative or post-qualitative research paradigm and draws on posthuman and new materialist theory and philosophy (e.g., Artful Dementia Research Lab., 2021, n.d.).[21] In the following, I will discuss some research relating to music and dementia within such a framework.

2.6 Artful intra-actions for people with dementia

> What happens if we change our ideas and approach people with dementia as who they are, not as who we remember them to be? (Quinn & Blandon, 2020, p. 85)

2.6.1 Foundations of artful intra-actions in dementia care

There is now an increasing amount of research on artful interactions with people with dementia anchored in social science and posthuman theory. Such research often aims to move beyond dementia as a deficit category and offer new perspectives and more positive ways of understanding and approaching it:

> The virtue of posthuman ideas is that they can help to understand that we are all in a relationship with the world that is not dependent on fixed boundaries, voice, identity and rationality; that questions our limited view of what a "human" is. In more clearly revealing these unfixed relationships with the world, people with dementia may be in the vanguard, potential leaders not losers. (Quinn & Blandon, 2020, p. 2)

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[21] The research platform "Artful dementia lab" at the Arctic University in Tromsø, Norway, contributes to this field.

Quinn and Blandon (2020) discuss posthuman ideas and put them to work with their arts-based research studies. They acknowledge that "the world of dementia is a harsh one, but in its rigour it can be transformative as well as traumatic" (p. 84). Accordingly, they advocate an attitude that "allows people with dementia to be as they are, rather than trying to retrieve what they were" (p. 65). They point out that rather than focusing on memories and constantly trying to steer people with dementia back to the past, their capacity for curiosity needs to be stimulated (p. 86). The authors' research therefore offers an approach to arts, music and dementia which is focused on positive experiences, "magical moments", ways of non-verbal communication, lifelong learning, and social inclusion.

The groundbreaking projects and research of Anne Basting, who promotes the notion of "creative care", build on similar premises. She points out that caregivers tend to focus on refreshing or exercising memory, which may work well for some people with dementia but alienate others: "It is asking them to speak a language they no longer have access to. It is asking them to perform their loss" (Mittner et al., 2022, p. 28). Moreover, Basting (2020) also interrogates the instrumental framings of arts-based activities and suggests a greater emphasis on the arts' community-building power (p. 140), which I will return to in Chapter 6.3.3. Her approach resulted in several large-scale creative projects in residential care facilities.

2.6.2 From non-verbal to post-verbal

In their research studies, Quinn and Blandon (2017, 2020) and Quinn et al. (2021) suggest the concept of *post-verbal* people (including people with dementia) as an alternative to the term *non-verbal* to signify that the "lost" language does not simply imply a lack of communication skills but also a potential for alternative ways of communicating (Waage, 2022, p. 345):

> Those who do not speak are commonly called "non-verbal", but this automatically positions them as deficit, as lacking. Taking a post-human position where "post" is conceptualised as "going beyond", we have adopted the term "post-verbal" for our participants. This helps to capture the sense that there are other ways of being and communicating that move past words. (Quinn & Blandon, 2017, p. 587)

Quinn et al. (2021) point out that there are limited longitudinal qualitative studies on the unspoken in music and other arts, and that the materiality of non-verbal communication is rarely addressed. Further, they hold that “unspoken aspects like body language, spatial and visual environments, culture and ethos appear to be important aspects of inclusive music practice, yet have not been widely researched or understood” (p. 75). They present a longitudinal study of a weekly community music-and-arts activity for a mixed population[22] of post-verbal people and offer a variety of case examples of the intra-actions of music and other agential factors as part of “agentic assemblages” (Bennet, 2010). Their focus-group interviews also illustrate how singing in this context represents an alternative means of communicating for post-verbal people living with dementia since even those who struggled with speech were able to sing and even use singing as part of their communication (Quinn et al., 2021, p. 82).

The communicative aspects of musical encounters are also central to Mittner’s (2022) study, which was based on a situated art intervention in a Norwegian residential care home. She aims to analyse the co-creative aesthetic potential of what she calls “socio-material connectivity”, which, she concludes, offers an entrance point for studying different ways of relating to people living with dementia. Mittner explores social connectivity beyond the individuality which underpins person-centredness by looking at whom and what connect – including group members and musical instruments – and how these connections can be understood. Her participatory research unveils how (unusual) behaviours can be reinterpreted as, and redirected into, artful and aesthetic co-creation, communication and inclusion.

2.6.3 Co-creativity: From disability to possibility

Zeilig et al. (2018) explore the concept of co-creativity in conjunction with artistic practice with people with dementia to challenge the functional and instrumental approaches to arts and dementia dominating existing research and intervention practice. As an alternative, they propose the arts as a creative and playful way of interaction and expression wherein the therapeutic effect can still be a potential but is not the goal. Similarly, Basting (Mittner et al., 2022) advocates elevating

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[22] The participants were people of different ages with diagnoses like autism, dementia, aphasia, stroke, brain injuries and learning disabilities.

creative engagements into the mainstream, identifying mechanisms across the arts and exploring different ways of engaging using them: “Creativity loses its power if you treat it like a pill and dose it for specific health outcomes” (p. 32). The ways in which Basting (2020) and Zeilig et al. (2018) anchor and argue for the concept of co-creativity will be further explored in my terminology discussion in Chapter 6 and my methodological issues discussion in Chapter 3.

Mittner et al. (2021) also adopt the co-creative approach in their situated arts-based research interventions in two Norwegian dementia care units. They use the GAP model[23] to shed light on co-creative spaces and processes for people living with dementia in residential care. Drawing on critical disability theory, including critical ableism studies, the GAP model situates “disability” in the space between individual abilities and societal requirements (Mittner et al., 2021, p. 66). Thus, the authors propose a shift in the understanding of dementia “from an experience of ‘disability’ towards an experience of ‘possibility’” (Mittner et al., 2021, p. 67). Their research reveals how the gap in abilities narrows or rather disappears in reciprocal aesthetic experiences with people living with dementia by transforming the gap “into a space of becoming” (Mittner et al., 2021, p. 69–70). Mutual, reciprocal, co-creative aesthetic experiences, that is, can transform relations and perceptions of dementia:

> Thus, within an aesthetic model of disability, dementia can be understood differently if we connect within ourselves and to each other in a larger imaginative and aesthetic universe. Understanding the gap as a possibility instead of a disability can result in fundamental new ways of relating to and being with each other. (Mittner et al., 2021, p. 71)

2.7 Discussion and conclusion

Thompson et al. (2021) and Dowson et al. (2019), point out that previous music and dementia research has often privileged outcome measures focusing on symptom reduction rather than the potential positive outcomes which music can bring. Thompson et al. (2021) found that participants and researchers observed

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[23] The Nordic Relational Model of Disability (GAP model) “conceptualises levels of functioning as a mismatch between individual abilities and requirements from the environment” (Mittner et al., 2021, p. 63).

transient or in-the-moment benefits from group singing which existing outcome measures might not capture. Furthermore, they point out that these transient benefits support the findings of Särkämö et al. (2014) that ongoing interventions can be necessary to sustain the benefits experienced by the participants (Thompson et al., 2021, p. 25).

Some other aspects of the studies of Särkämö et al. (2015; 2014), mentioned in Chapter 2.4.6, raise compelling questions. The musical background of the people with dementia was not found to influence the beneficial outcomes of the interventions. However, might the musical background of the carers who implemented the singing or music-listening activities have influenced the outcomes? As far as I know, the relative/carer's musical background was not mapped in the studies. It is reasonable to ask whether more musically experienced (family) carers would apply the music activities more often. The frequency of application was relevant in that more frequent caregiver-provided sessions correlated with better results (Särkämö et al., 2015, p. 769). In addition, might more musically confident carers have had a stronger influence on the person with dementia's activity reception and outcome? These questions are also relevant because Särkämö et al. (2014) suggest that more extensive and intensive coaching of the (family) carers could have influenced the long-term effects of the study (p. 648), especially regarding the singing activity, which was less frequently applied perhaps because it was more demanding for the carers (Särkämö et al., 2015, p. 779).

Several studies in my review also highlighted the *accessibility* of singing and noted that some participants reported positively about singing at home between the sessions (Mittelman & Papayannopoulou, 2018, pp. 784, 785; Tamplin et al., 2018; Unadkat et al., 2017) "because we can just pick it up again instantly, without needing any props or equipment or things" (Unadkat et al., 2017, p. 474). Likewise, the integrative review of singing and music interventions for family carers of people living with dementia by Lee et al. (2022) underlined the accessibility of group singing in particular; the authors note that "participants reported an innate ability and desire to sing" (p. i55). They also emphasise "the potential for family carers to continue using music beyond the intervention" (p. i57). From my point of view as a researcher, these interesting observations suggest a synergetic effect of group singing facilitation and low-threshold daily life singing at home, to which I will return in Chapter 8.

As mentioned above, much music and dementia research conveys problem-focused approaches and instrumental goals within a bio-medical paradigm. A posthuman perspective on dementia, however, urges us to embrace the fluidity and reconsider what dementia is and does, but even more, to open up and renew our conception of what it means to be human altogether:

> [People with dementia] have entered into a different form of engagement with the world and the construction of the human does not accommodate, cannot deal with, this bursting of the bounds of body, time and space. Instead of placing the person with dementia aside as "dead" or "not as they were", we must put the limited category of "the human" aside to make way for something new. (Quinn & Blandon, 2020, p. 85)

One step in this direction might be to incorporate broader perspectives on cognition, identity and communication, and to discuss the discourses and broader ethical perspectives of dementia. I will return to these issues in the literature study in Chapters 4 and 5. In this thematic literature review, I have presented studies on singing and dementia within three main frameworks:

- Music therapy: music as part of clinical therapeutic processes provided by professional music therapists
- Music in care (music medicine): music used to support caregiving and well-being within healthcare settings by staff members
- Community music: music (group) interventions organised in the community by music therapists, other professionals or volunteers

In addition, I have presented some research on artful interventions in dementia care based on critical gerontology and posthuman theory, not specifically concerning singing but often including music.

Figure 1 illustrates these different research approaches to singing (and arts) in the context of dementia. In the intersections are indirect music therapy studies or other studies with mixed approaches which include coaching (e.g., Hsu et al., 2015; Ray & Götell, 2018; Särkämö et al., 2014). "Creative care" and "artful dementia" interventions apply arts more broadly but often include music, even singing, and might imply forms of "co-creative" or relational singing, recalling community group-singing and caregiver singing.

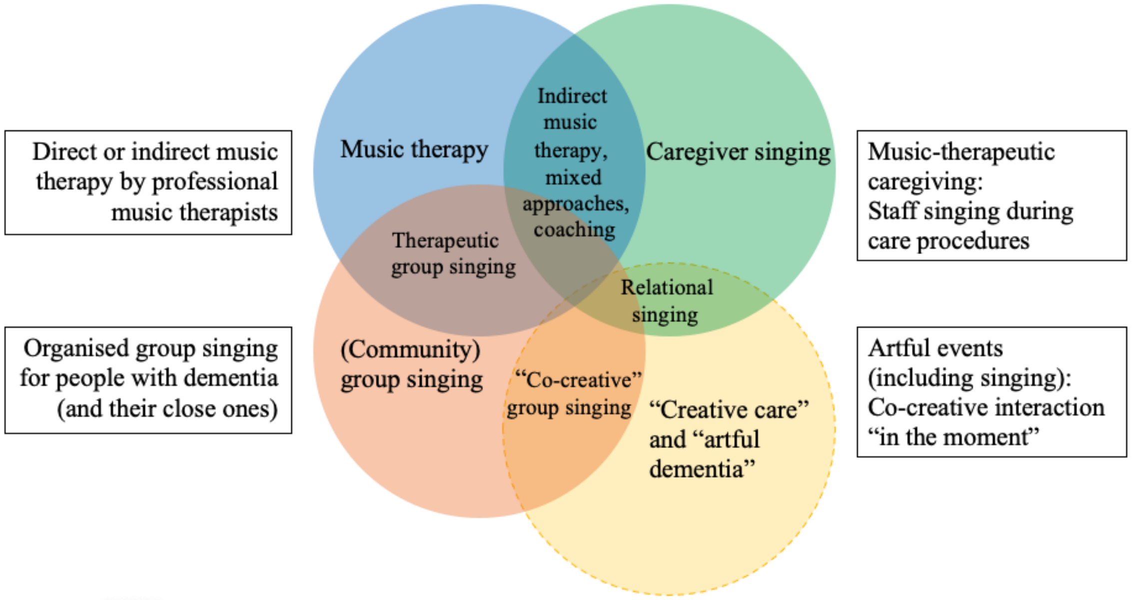

Figure 1. Research fields of singing and dementia

Much of the reviewed research conveys an instrumental approach: Music is often used to reduce negative symptoms and sometimes, more explicitly, to promote positive experiences, well-being or co-creativity. Using "posthuman theory as a navigational tool" (Quinn & Blandon, 2020, pp. 65, 66) for alternative ways of understanding and approaching dementia beyond the scope of deficit, disaster and loss can add valuable perspectives to my further exploration. Ultimately, the attitude of affirmation and entanglement found in posthuman arts and dementia research also provides a foundation for my own empirical and theoretical exploration and engagement, which I will describe, diffract and discuss in the following chapters.

2.8 Summary

This chapter provides an overview of and a thematic literature review on singing, dementia and close ones. Research on singing in the context of home-dwelling people with dementia and their close ones is sparse. Thus, the chapter draws from broader studies on music and dementia and provides contextual information about dementia and the role of relatives.

Given the increasing prevalence of dementia, the development of supportive strategies to maintain communication, interaction and well-being for people with dementia and their close ones has become essential. The dementia diagnosis, with its included list of potential "behavioural and psychological disturbances" (ICD–

11), reflects a problem-oriented perspective on dementia which is also predominant in the biomedical-oriented research literature on music and dementia. Music interventions for people with dementia are frequently designed to address these issues, although some fields, such as resource-oriented music therapy, apply more resource-based approaches.

Relatives facing dementia in loved ones experience significant distress and a shifting relationship dynamic due to neuropsychiatric symptoms, communication difficulties and increased assistance needs and often feel a lack of adequate support, knowledge and strategies. Still, the bond and history of the relationship can also foster self-efficacy and resilience. Researchers suggest a dyadic approach focusing on shared activities to maintain relationship quality. Although music interventions show promise in enhancing communication, more research is needed on their practical implementation and music's broader influence on dyads' well-being, resilience and self-efficacy.

Music and dementia research includes promising results on well-being, cognition, mood and social inclusion, and reductions in anxiety, depression and apathy. However, the diversity of study designs and outcomes complicates comparison and the drawing of specific conclusions. Narrower research on singing and dementia and relatives echoes these outcomes, particularly regarding social inclusion and well-being. Research on singing and dementia has mainly been carried out within three fields:

- *music therapy* (MT), including in-direct MT designed to extend the benefits of sessions into daily care and activities through skill sharing and collaboration between music therapists and family or professional carers;
- *music therapeutic caregiving* (MTC) – including caregiver singing – where professional staff integrate music into daily care routines to enhance communication and cooperation; and
- therapeutic or community *group singing* for people with dementia – sometimes including family members – particularly promoting social inclusion, the joy of singing together, and sometimes the learning of new skills.

A fourth field worth noting is "creative care" or "artful dementia", based on critical gerontology and posthuman perspectives where artful events (sometimes including singing) are used to explore co-creative and "in the moment" interaction.

Some studies imply a blend of the first three approaches and indicate that the combination of singing or music-listening activities with coaching relatives or staff – to support music activities between sessions – can be particularly beneficial. These studies actualise the potential benefits of organised educational efforts, which have shown promise in Norway while facing some implementation challenges. Finally, “creative care” and “artful dementia” approaches move beyond viewing dementia as a deficit and highlight the arts’ (including singing’s) co-creative and communicative potential in the gap between disability and possibility.

3 Methodological perspectives and influences

3.1 Introduction

This chapter presents my research platform and outlines my ontological and epistemological foundations, methodological influences, and research strategies and considerations. I use Karen Barad's agential realism as the overall framework, in which her notions of ethico-onto-epistemology, material-discursive practises, intra-action and diffraction are essential both to the methodological perspectives and research strategies and, later, as part of the theoretical framework for exploring relational singing. Barad's non-dualistic theory and philosophy blur the traditional research schism between methodology and theory. To be able to thoroughly convey the methodological implications, I need to explain the theoretical foundation. On the other hand, Barad's theory and philosophy also have consequences for later theoretical and discursive exploration and framing.

The chapter starts with a description of Barad's agential realism and an outline of the methodological perspectives and influences, primarily based on a performative research approach. From this foundation emerge my developing research strategies, which are inspired by literature study, discursive approaches, auto-ethnography and action research. These approaches have "crystallised", or rather been organised, into a multifaceted literature study and the research intra-action with the dyad, both of which intra-act with each other and my professional and personal (autoethnographic) experiences, as is conveyed in my multi-layered diffractive analysis. The matrix below provides an overview of these influences. Please note that the divided cells and columns are merely schematic and illustrative and do not imply actual separateness during the performative research process.

Influences	**the whole project**	**the literature studies**	**the research intra-action**
Philosophy of science	Agencial realism (Barad, 2007)		
Research methodology	Performative (Østern et al., 2023)		
Ethics	Affirmative ethics (Braidotti) General research ethics	Macro-ethical perspectives: Affirmative ethics (Braidotti) “Justice to come” (Barad) “Ethics of musicality” (Kontos & Grigorovich)	Micro-ethical perspectives: Formalities, vulnerability, power-balance, transparency
Phenomena	Dementia Relatives Singing Embodiment Researcher	Music-and-dementia research Embodied cognition Implicit memory Personhood Communicative musicality Artification (Dissanayake) Attunement and forms of vitality (Stern) Polyvagal theory (Porges) Agential realism (Barad)	Co-singing in a dyad living with dementia (Woman with dementia and daughter)
Activity			Individualised, flexible, process-oriented daily-life singing activities
Methodical inspirations Apparatuses	“Making data” (Ellingsson & Sotirin) “Thinking with theory” (Jackson & Mazzei) Intraplay (Richards & Haukeland) Autoethnography	Thematic research review Literature study Discourse	Participatory action research Semi-structured interviews
Performative research strategies	Diffraction Material-discursive-practical engagements	Diffractive and reflexive reading	Participation, observation and conversation 4-layered diffractive analyses

Figure 2. Research strategy matrix

3.2 Philosophical foundation of research: Barad’s agential realism

3.2.1 Agential realism’s overall principles

The main foundation of the philosophy of science relied upon in this PhD project is Karen Barad’s (2007) agential realism. Barad’s theory implies a relational ontology where everything is inseparable and entangled, including matter, knowledge and practice: what she calls *material-discursive practices*. What follows is a necessary inseparability of ontology, epistemology and ethics, or what she terms *ethico-onto-epistemology*.

Hence, agential realism also implies a performative, non-representational, non-dualistic approach to research wherein the knower and the known, nature and culture, subject and object are interwoven *phenomena*. Barad (2007) uses the term *intra-action* instead of *interaction* to express this inseparability. Her diffractive methodology aims to explore entanglements and new patterns, or "differences that make a difference" (p. 72). Hence, *diffraction* can be seen as an alternative to *reflection* and mirroring, on the one hand, and dialectical approaches leading to critique or dualistic opposition, on the other. Thus, Barad's theoretical position is compatible with Gilles Deleuze's affirmative philosophy of immanence (Murris & Bozalek, 2019), which also informs parts of this dissertation.

3.2.2 Agential realism's background and theoretical basis

Barad's (2007) point of departure is her interpretation of quantum field theory, which leans heavily on Niels Bohr's philosophy-physics. Barad elaborates on what she considers to be the ontological implications of Bohr's work, to develop her ethico-onto-epistemology of agential realism, where ontology, epistemology and ethics are entangled, inseparable, and equally primary (e.g., pp. 185, 381).

Agential realism challenges the Newtonian worldview and the classical binaries – in short, the heritage of the Enlightenment which remains widely influential within research as well as everyday life. Barad's (2007) theory, based on quantum field theory, which positions quantum entanglements at the heart of the matter, implies a universal connectedness and entanglement of all there is and, therefore, an immanent responsibility. Subjects and objects cannot be separated but are always part of phenomena within phenomena; hence, she always applies the word phenomenon in its plural form. In short, everything consists of entangled phenomena, and the researcher is therefore always a co-creative part of the world she seeks to explore and understand.

Still, Barad's (2007) theory does not imply a relativist view of knowledge and science, holding instead that we can obtain "objective" knowledge about the world but only within phenomena and depending on the configurations of different *apparatuses*,[24] or boundary-making phenomena (p. 148). Our knowledge will always depend on the apparatuses we apply in our research, whether the setup for a physical experiment, the theoretical and methodological approaches, the nature of our language, our own perceptive and cognitive skills, or unforeseen contexts influencing the research, to mention but a few.

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[24] Barad (2007) consistently uses the plural form *apparatuses* rather than the strictly Latin *apparati*, so I have followed her lead.

3.2.3 Critique of Barad's agential realism

According to Faye and Jaksland (2021), some proponents of agential realism (AG) – and parts of Barad's own writings – imply that quantum physics justifies AG. On the other hand, the authors point out, Barad's interpretation of quantum physics is but one of several possible interpretations. In addition, they claim that Barad is misreading Bohr (pp. 8240, 8251) and that her interpretation of quantum physics even implies some subtle but important differences from Rovelli's *relational quantum physics* (pp. 8249–8251) "which Barad accentuates as similar to her own interpretation" (Faye & Jaksland, 2021, p. 8233).[25] The authors even argue that whether AG is consistent with quantum physics is unclear and demands further scrutiny.

Space does not permit any indulgence in the specifics of quantum physics and the many interpretations of Bohr's writings. Still, it could be argued that Barad's own formulations (Barad, 2007, pp. 333, 351) do not necessarily imply that she aligns her interpretation of quantum mechanics with relational quantum mechanics (RQM) but rather simply points out important similarities with RQM and other new approaches to quantum mechanics and quantum gravity. Moreover, Barad seems well aware that the ontology of agential realism is an elaboration upon what she sees as the implications of Bohr's epistemological framework (Barad, 2007, p. 352).

Nevertheless, Faye and Jakson's (2021) main point is worth quoting:

> We conclude […] that neither Bohr nor quantum mechanics as a whole proves Barad's agential realism to be true. Barad's ideas are profound, interesting, and thought provoking, but like any other piece of social theorizing, agential realism must earn its merits, if any, by its utility and not by its quantum mechanical origin. (p. 8235)

Two central concepts in agential realism which I find both useful and fruitful as parts of my theorising and research are *intra-action* and *diffraction*.

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[25] Barad states that Rovelli's interpretation, and some others, "have important features in common with each other and the view presented here" (Barad, 2007, p. 333). On p. 351, as well, Barad outlines part of her ontological argument and notes that "this seems very much in the same spirit as", among others, the relational quantum mechanics approach.

3.2.4 Intra-action and diffraction

According to Barad (2007), we need to meet the universe “halfway”; we can never step outside the phenomena we explore, but neither can we view them totally from the inside. Something will always be hidden, not only because we do not have access to any “truth out there” but because phenomena are indeterminate before they are processed through our apparatuses.

The traditional term *interaction* implies the existence of separate beings interacting with one another, which is impossible according to Barad’s interpretation of quantum field theory. Hence, Barad (2003, 2007) introduces the term *intra-action* to embrace the inseparability not only of “material” entities but also of space, time, matter and meaning (2003, pp. 817–818; 2007, pp. 179–181).[26]

To constitute “reality” in the un/limited potentiality of the so-called quantum vacuum – which is far from empty despite the word choice – specific intra-actions perform *agential cuts*. Phenomena – and simultaneously meaning – can only become determinate by “separating” something from the virtual potentiality of the quantum field. Manifestation (matter) and meaning are inseparable: “Subject and object, wave and particle, momentum and position exist only through specific intra-actions. These enact cuts that make contingent rather than absolute separations” (Murris, 2022, p. 30).

Barad’s theory of agential realism implies a relational ontology “that holds that entities, or relata within phenomena, do not precede their relationships. They arise through relationships” (Murris, 2022, p. 30). The relations unfold through intra-actions which are enacting agential cuts within phenomena, thereby creating connections and boundaries which are simultaneously differentiated and entangled (Murris, 2022, p. 70), or what Barad (2007) calls “cutting together and apart”:

> It is through specific agential intra-actions that the boundaries and properties of the “components” of phenomena become determinate and that particular embodied concepts become meaningful. A specific intra-action […] enacts an agential cut. (Barad, 2003, p. 815)

Also central to agential realism is *diffraction*, both as a concept and as a methodology. Put simply, a diffraction pattern emerges when two or more waves –

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[26] This paragraph and most of the following one are based on my unpublished exam essay (Waage, 2020, p. 5).

water, light or sound – “ripple” into one another when encountering an obstruction, for example (Barad, 2007, p. 74). Water waves are impossible to separate, which is the case with any object or phenomenon. They will always be entangled, diffractively threaded through each other and constituting *phenomena*.

Barad (2007) argues that diffraction and interference are in fact synonymous (p. 80).[27] Within physics, the concepts of destructive and constructive interference point to how the interfering waves are cancelling each other out or enhancing each other (p. 77) “depending on the relative height and the phases of the overlapping waves” (Murris, 2022, p. 54). That is what produces the characteristic diffraction patterns, or patterns of difference.

Quantum entanglement is often termed *quantum coherence*, and, as I see it, coherence and interference are entangled rather than discrete: Entanglements of waves will interfere in more or less coherent or diffractive ways, just like music, where there are different degrees of consonance and dissonance. One important and exciting aspect of music is the tension and integration of the harmonious, more coherent consonance and the contrasting, titillating dissonance. To me, this resembles a diffractive research approach in and of itself.

Barad (2007) sees diffraction both as an “apt overarching trope” for her theory and a description of a methodological approach (p. 71). She refers to Donna Haraway’s use of the term within feminist science, but in her own work, Barad applies the meaning of the term as understood within quantum field theory,[28] which has far broader implications than the “optical” understanding of the term.[29]

Like Haraway, Barad (2007) turns to diffraction as an alternative to the long traditions of using *reflection* and *reflexivity* as metaphors for knowledge and science. While reflection points to mirroring “sameness” and is linked to a representational approach to science (pp. 86–90), diffraction points to “patterns of

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[27] Some physicists maintain the historical distinction between “diffraction” and “interference”, but Barad dismisses this as “purely a historical artefact with no physical significance” (Barad, 2007, p. 80).

[28] Within quantum physics, a diffraction pattern is also evidence of superposition: “When a particle exhibits a diffraction pattern it is in a state of superposition” (Barad, 2017, p. 65). However, quantum physics allows for the possibility of not only the superposition of space but also temporal diffraction and thereby the superposition of time: “Temporal diffraction is a manifestation of another, much less well-known, indeterminacy principle: namely, the time-energy indeterminacy principle. As a result of this indeterminacy principle, a given entity can be in (a state of) superposition of different times” (Barad, 2017, p. 65).

[29] This paragraph and most of the following one are based on my unpublished exam essay (Waage, 2020, p. 4).

differences that make a difference" (p. 72): "Diffraction patterns map the effects of difference rather than just where differences appear" (Murris, 2022, p. 54). Moreover, diffraction is associated with a non-representational and thus performative approach to knowledge, not as something given from outside but as something which is always part of creation and becoming.

By reading or engaging with different texts or phenomena diffractively – "through" one another – the meaningful differences, or patterns of coherence and interference, can offer new perspectives and insights: "By making new patterns of meaning that matter, a diffractive methodology is both constructive and deconstructive rather than destructive" (Murris, 2022, p. 54). Murris and Bozalek (2019) note the non-dialectical approach of diffractive readings:

> A diffractive reading is different from critique in that text/oeuvres/approaches are respectfully read through each other in a relational way, looking for creative and unexpected provocations, strengthening these, rather than using an atomistic binary logic to compare one with the other. (p. 2)

In addition, the authors remind us that reflection and diffraction are not binaries. As Barad (2014, p. 185 fn 2) has pointed out, reflection and diffraction are not opposites but overlapping optical intra-actions in practice (Murris & Bozalek, 2019, pp. 2–3). For my research approach, this point is central: Diffraction and reflexivity overlap and intra-act throughout the dissertation; they are often entangled and cannot be separated.

3.3 Developing a foundation for research strategies

3.3.1 Reflexivity and diffraction

My PhD project relies upon agential realism and the concept of diffraction both to comprehend the entanglements of phenomena and as a methodological entrance. Harnessing agential realism as my philosophical foundation of science, however, was much easier than forging my path in an unknown methodological landscape. Therefore, I began my journey by seeking similarities and connections rather than differences between qualitative and post-qualitative research strategies.

I found that the concept of diffraction had some striking similarities to Alvesson and Sköldberg’s (2018) concept of *reflexivity,* wherein they distinguish between *reflective* as more focused and specific and *reflexive* as more multi-dimensional and applicable across different levels of interpretation:

> The word “reflexive” has a double meaning, also indicating that the levels are reflected in one another. A dominating level, for instance, can thus contain reflections of other levels. Two or more levels may be in a state of interaction, mutually affecting one another. […] We will denote this double nature by the term “reflexive”. […] We want to contrast the focused and somewhat specialized nature of reflection with the multi-dimensional and interactive nature of what we refer to as reflexivity. (p. 329)

Qualitative approaches and reflexivity informed my research process and the development of this dissertation, even as I grew to acknowledge and respect the differences between these familiar, “safe” approaches and the unknown, “unsettling” territory of diffraction and intra-action. The co-creative nature of a research process wherein the researcher and the knowledge apparatuses are fully entangled with the phenomena being researched does imply a difference which matters in relation to qualitative approaches.

3.3.2 Reworking methodology in an agential realist framework

Research and knowledge will always be dependent on the configuration of different *apparatuses,* Barad (2007) writes:

> *Apparatuses are the material conditions of possibility and impossibility of mattering;* they enact what matters and what is excluded from mattering. Apparatuses enact agential cuts that produce determinate boundaries and properties of “entities” within phenomena, where “phenomena” are the ontological inseparability of agentially intra-acting components. […] [T]he apparatus specifies an agential cut that enacts a resolution (within the phenomenon) of the semantic, as well as ontic, indeterminacy. *Hence apparatuses are boundary-making practices*. (p. 148)

When we explore phenomena, our dependence on the apparatuses, which are themselves phenomena, also implies that there may exist different "truths" according to the configuration and nature of our apparatuses which enact different constellations of agential cuts, and thus different boundaries. Hence, it is possible to conceive of research methods and issues as apparatuses within phenomena. The non-representational, performative view of knowledge within agential realism supports an open-ended research process wherein different apparatuses may result in different, equally valuable "truths" within phenomena. For my PhD project, this invites me to explore and analyse different parts of the research material – literature, theories and practices – within several contexts and with various perspectives and methodological and analytical tools (apparatuses). Then different aspects of insight may emerge.

Schadler (2019) argues that the new materialist theories of scholars like Haraway, Braidotti and Barad "allow for a reconfiguration of analytical research tools without using the representationalist epistemological framework these tools are often embedded in" (p. 215). She describes the theoretical foundation of new materialism as based on anti-dualism, radical immanence, transversality and posthumanism (pp. 216, 228). Drawing upon Barad's concept of "exteriority within",[30] Schadler proposes a research process where new boundaries and intra-actions are made within phenomena, including the researcher and her methods: "The concept of exteriority within (Barad) does not imply that research objects are represented or constructed by the researcher, but that the process of research refers to a phenomenon that includes intra-action with methods, instruments and subjects" (Schadler, 2019, p. 218). Central to Schadler's account is the understanding of research methods as apparatuses within phenomena which allow for different boundaries, and hence different research outcomes, depending on the methodological and analytical apparatus in question. She encourages scholars to realise their own reconfigurations of their methods and research processes "in order to give more complex accounts about the world we inhabit and shape through our research" (Schadler, 2019, p. 129).

Haseman (2006), from his own point of departure in performative research, also suggests that researchers inflect qualitative methods as part of their research

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[30] The concept of *exteriority within* establishes an outside position within a phenomenon (Schadler, 2019, p. 218). Barad (2007) also refers to exteriority within phenomena as *agential separability* (see, for example, pp. 140, 184).

process: “Most commonly, performative researchers progress their studies by employing variations of: reflective practice, participant observation, performance ethnography, ethnodrama, biographical/autobiographical/narrative inquiry, and the inquiry cycle from action research” (p. 104). Further, he suggests that researchers, as well as modifying existing research methods, “are inventing their own methods to probe the phenomena of practice” (pp. 104–105).

3.3.3 Intra-play

One approach that contributed to transforming my research engagement and thinking was the notion of “intra-play”. Richards and Haukeland (2020) propose the concept of “intra-play” as the basis of a philosophical and methodological approach to sustainability research. Their explorations of the ontogenetical processes of intra-play also have obvious relevance for other fields, including my own research project.

> We set out to explore what could be rather than what is or has been, while recognising that these temporal aspects are not separate but rather connected within the research process. The focus is on the intra-play between traces of the past, the enduring potential of the future and you as a researcher in the present. (Richards & Haukeland, 2020, p. 31)

As this citation implies, the authors also focus on the concept of “becoming”, recalling the work of Deleuze and Guattari as well as Barad. However, the authors connect the concept to anthropologist Tim Ingold’s description of the shift from *ontology* to *ontogenesis* or what Andrew Pickering calls “an ontology of becoming” (Richards & Haukeland, 2020, p. 30). They also draw inspiration from the a/r/tographer Rita Irwin and play theory (p. 31). Ingold’s approach shifts the focus away from the object (in contrast to object-oriented approaches like Harman’s) and onto its pathways of becoming as part of a meshwork (as opposed to Latour’s network of actants), a myriad of interwoven lines wherein “knots” can add new threads and discard others – in short, a meshwork of lines of becoming (Richards & Haukeland, 2020, pp. 35–36). Thus, drawing on Ingold, the authors suggest that “If movement is life, […] then in order to study it, researchers must also be mobile, free to move and become along its path, free to play with what appears in the field of study” (p. 36).

The notion of the researcher as a nomadic and co-creative part of the research process resonates with Barad's position, and the term *intra-play* draws directly on her concept of *intra-action* (instead of *inter-action*). Richards and Haukeland (2020) use the same argument to go from *inter-play* to *intra-play*:

> The distinction being that with *inter* the play would be between separate things in a nodal network, whereas *intra* means play in between forms (Barad, 2003, p. 815) in which the different forms are inseparable from the play and the intentions, meanings, values and the forms themselves come into being in new ways through this process. (p. 38)

The authors argue that the term *play* suggests "a continuous, unfolding process of engaging with and responding to a plurality of forms and a plurality of imaginative aesthetic expressions, through a haptic (or full sensory) engagement with the world" (Richards & Haukeland, 2020, p. 38). Further, they point out that such a process does not seek end goals external to itself but rather implies an aesthetic freedom that enables one to create or experience something new: "As such, the word 'play' invokes an openness and freedom to new intra-relations that dissolves the notion of a singular intentionality (or hylomorphic imposing of an idea on to a passive material world) that lingers over words like action or craft" (p. 38).

Richards and Haukeland (2020) suggest four forms or aspects of intra-play: co-attending, co-responding, co-forming and co-rendering (p. 39). These aspects supply one approach to the concept and practice of co-singing, as we will see in Chapters 7.4.2 and 8.3.

3.3.4 A performative research paradigm?

My journey from qualitative to diffractive research strategies – and the necessary entanglements between them – has also created tension in my understanding of paradigms. The binaries of a representational versus a non-representational concept of knowledge, and a centred versus a decentred researcher subject, are seen by many scholars as belonging to different research paradigms: (quantitative and) qualitative methodology, on one side, and performative or post-qualitative research, on the other.

Some researchers, on the other hand, argue that these binaries are constructed and contradictory, given that posthuman and new-materialist philosophies largely oppose binaries. Gerrard et al. (2017) find some common ground with post-qualitative researchers' concerns regarding qualitative research approaches. Still, when reading the post-qualitative literature critically and through a post-colonial lens, they bring up three main issues: (1) the danger of (unintentionally) reifying binaries and producing new boundaries despite the stated openness; (2) the heralding of "new-ness", which may also create new closures; and (3) the lack of awareness of history and power dynamics and, hence, the danger of unintentionally marginalising one's research subjects.

Østern et al. (2023) propose a performative paradigm for post-qualitative inquiry "where knowledge is viewed as knowledge-in-becoming as the constant creation of difference through researcher entanglement with the research phenomenon and wider world" (p. 272). Ideas about a performative paradigm come mainly from artistic research, while ideas about post-qualitative research are based on a spectrum of "post-" approaches. However, the authors argue that both strands emerged from their friction with established qualitative methods and "positivist leftovers" exposed in academic language and pre-described methods (Østern et al., 2023, p. 274). They suggest that the performative paradigm can embrace both of these strands.

With a performative research paradigm, the authors highlight research as a non-representational creation, situated knowledge, a decentred, in-becoming researcher fully entangled with the research, and a performative approach towards languaging. They also argue that the research operates on an onto-epistemological level with "relational phenomena, not separated subjects and objects" (Østern et al., 2023, p. 273) as the smallest "unit", and being and knowing in constant joint. Moreover, they emphasise the entanglements of ethical implications throughout the entire research process. All of this resonates with Barad's theory, including her notion of ethico-onto-epistemology, and my overall research approach.

The authors focus on what research is *doing*:

> With a performative research paradigm, the research focus shifts from what a research phenomenon "is" to what it "does". This shift requires methodological innovation and experimentation, and also implies a shift from being to becoming. This is an onto-epistemological shift. (Østern et al., 2023, p. 277)

Further, they underline that “performative research does not attempt to represent reality, but instead to engage with it” (Østern et al., 2023, p. 277). This focus on doing, becoming and engagement is shared by Ellingson and Sotirin (2020a, 2020b), who, in their specific approach to *data engagement,* offer an alternative to performative and post/qualitative researchers’ approaches to data.

> Both narrative/performance scholars and postqualitative researchers express unease with the notion of data because of its [positivist] baggage. And yet at the same time, practitioners within these movements necessarily sneak data back into their projects under the guise of empirical materials. (Ellingson & Sotirin, 2020a, p. 819)

Although sympathising with scholars who point out the problematic nature of data, the authors will not – like Dunn – declare data dead. They point out that “refraining from calling the practices data collection does not stop us from collecting and curating both discursive and material artifacts from our own and others’ lives and making sense of them” (Ellingson & Sotirin, 2020a, p. 819). I will return to their model of data engagement in chapter 3.6.7.

Following Ellingson and Sotirin’s (2020a, 2020b) argument, I have been hesitant to use the term performative *paradigm*. Still, I prefer the term “performative” inquiry or research over “post-qualitative” to highlight the performativity – the *doing* aspect – and lively open-endedness of knowledge exploration and creation. As I argued in Chapter 3.3.2, qualitative methods – maybe better considered strategies – can be incorporated into a performative inquiry process as part of the research apparatus.

3.3.5 The de/centred researcher

I also embrace the notion of a decentred researcher in contrast to a traditionally centred researcher subject. I understand Barad’s notion of “subjectivity” as an always already entangled multiplicity in continuous becoming – not preceding relations and intra-actions but continuously (in)formed by and through them. Still, I sense that the nomadic, decentred researcher subject comes in different grades and shades of “centredness”.

Barad and other posthuman thinkers use slashes to convey the intra-active and multifaceted implications of phenomena and concepts. The slash embraces the term's simultaneously complementary and alternative aspects. I will likewise acknowledge the concept of subject centredness with such a Baradian slash and next discuss the implications of the de/centred researcher.

Lise Hovik (2014) describes the poststructuralist alternative to the centred, rational, human subject as a diverse, fragmented, unstable and decentred subject. Drawing on Clair Bishop, Hovik further notes that theories of the decentred subject show up in the writings of Barthes, Foucault, Lacan, Derrida and Deleuze. Hovik concentrates on Deleuze and Guattari's idea of the diverse, creative subject: a subject not defined by rational self-awareness but by continually creative becoming.

Relatedly, Rosi Braidotti (2019b) suggests the notion of "self" might be seen as "a movable assemblage within a common life-space which the subject never masters but merely inhabits [. …] For posthuman theory, the *zoe*/geo/techno-framed subject is a transversal entity, fully immersed in and immanent to a network of human and non-human relations" (p. 158). Indeed, my own experiences as a musician, therapeutic musician, teacher, relative, and researcher are impossible to distinguish among in terms of being centred "outside" or immersed "inside" my explorations of phenomena. Still, it remains possible to move through various roles and experience different degrees of subjective de/centredness depending on the circumstances of the actual work and situation and the apparatuses or methods in play. This can even enrich the research process if handled with care.

3.3.6 Affect, intuition and insight

My de/centred researcher role came about in the intersection between explicit and tacit knowledge exploration and synthesis. Massumi's (1995, 2015) discussions of (the Spinozian notion of) *affect* will help to conceptualise such de/centred knowledge development. In Massumi's (2015) notion of affect as embodied, preconscious "thinking-feeling", I see some striking correlations to research on inner experience (Walach, 2013), intuition (Sadler-Smith, 2016), insight and tacit knowledge (Brock, 2015). This is a vast field of inquiry, and I will only touch upon a few implications for the performative unfolding of my project's knowledge apparatuses.[31]

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[31] For example, I will not delve into the differences between affect, emotions and feelings discussed by various scholars but instead concentrate entirely on Massumi's notion of affect.

First, *affect* (*affectus*, not *affectio*), as outlined by de Spinoza (1677/2020) in his *Ethics*, is defined as “the power [or capacity] to affect and be affected” (Massumi 2015, e.g., p. viii). Massumi notes that this definition encompasses relation. It implies a primary openness to the world and a willingness to engage in and be engaged by it. With this basic definition, Spinoza captures both the passive and the active dimensions of affect, framing it as a change in the body’s capacity for action, which might be either aided and increased or restrained and diminished. Massumi adopts Spinoza’s position but expands beyond his rather personalised description of affect. Massumi (2015) sees affect as intensities emerging from encounters – through events – and argues that affects are transversal and polyvalent: “Although affect fundamentally concerns relations in encounter, it is at the same time positively productive of the individualities in relation” (p. ix). To help rethink the opposing categories implied in the affective encounters, Massumi develops several “fellow-travelling concepts”, including “differential affective attunement” (to which I will return in Chapter 4.8.1) and “collective individuation” and “thinking-feeling” (p. x).

I find the idea of affect as thinking-feeling particularly helpful in illuminating the role of the de/centred researcher. Massumi (2015) insists that affect cannot be reduced to feeling as opposed to thinking but “has to be understood as *involving feeling in thinking, and vice versa*” (p 91). In this sense, his understanding of affect comes quite close to the concept of intuition, which can be defined as “a tacit hunch or feeling that influences thought with little conscious effort” (Brock, 2015, p. 134). The connections between affect and intuition are also conveyed in Sadler-Smith’s (2016) phenomenologically based definition of intuition: “positively- or negatively-valenced affective states, manifesting cognitively or somatically, arising automatically, rapidly and subconsciously, informed by prior learning and experiences, affording subjective evaluations and guiding subsequent behaviours” (p. 1080).

In my research process, intuition and affect (in Massumi’s relational understanding of the concept) have played a substantial role in several ways. While searching for literature, reading and writing, affective, intuitive hunches often

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However, when occasionally referring to emotions or feelings elsewhere in this dissertation, I will lean on Antonio Damasio’s (and other scholars’) differentiation between (1) the less distinct affects experienced by most living beings, (2) emotions as (intense, fluctuating, embodied) psychological states, and (3) feelings as the complex, conscious experience or subjective awareness of affects and emotions, an experience which is also shaped by memory and learning.

guided my thoughts and choices. Moreover, in the research intra-action with the dyad, I would often abandon my initial plans due to the affective and intuitive input during the encounter, to which I will return to in Chapter 3.6.

I believe my affective and situated awareness during the research project's various processes and activities has also been nurtured by my meditation practice. A daily morning meditation routine and small meditative intersections during my work day have contributed to tu(r)ning my mind towards what might be termed inner experience (Walach, 2013) – "first-person knowledge that is received through systematically training our mind and looking inwards" (p. 10) – as opposed to the still dominant tendency in science of observing phenomena and systems from outside, as objects or "objectively" (pp. 8–9). The authors suggest that while outer experience teaches us about content and material realities, inner experience gives us access to structures (pp. 16–17), which corresponds with my experiences: Sudden insights into connections between phenomena and ways through which to structure or analyse the material sometimes appeared during or in the aftermath of meditative states. This might unfold in the form of sudden ideas, for instance, which thematically connected experiences from my research intra-action with the dyad to concepts, theories or research studies, ultimately informing the diffractive analysis. Likewise, parts of the analytical *structure* largely emerged in such (semi)meditative states.

Broch (2015) defines insight as "an explicit awareness of novel relations between concepts that arrives with apparent suddenness and little conscious awareness of processing" (p. 133). He holds that tacit knowledge (knowledge that cannot be explicitly stated) interacts with conscious thinking (the explicit) through the processes of intuition and insight. However, he distinguishes between them by pointing out an essential difference between hypothetical cognitive entities – like the hunches, feelings, and awarenesses of intuition – and the processes that make use of those entities – that is, insight (p. 128). Nevertheless, I would argue that Massumi's (2015) discussion of affect can contribute to a better understanding of the intersections or integrations of insight and intuition and tacit and explicit knowledge. Affect, in short, overlaps with and nurtures intuition and thus contributes significantly to insight and tacit knowledge. Massumi's fundamentally relational and "thinking-feeling" notion of affect also contributes to an understanding of the "bridging" of the tacit and explicit in an integrative, non-dualistic way, which is compatible with Barad's (2007) agential realism. Thus, affect is a performative agent – or apparatus – in the intra-action and diffraction of different forms of experience and knowledge development during the research process.

3.3.7 Remix, triangulation and layers

Annette Markheim (2013) proposes the concept of *remix* to reconceptualise research processes, products and goals:

> A remix conceptualization of inquiry emphasizes that any articulation of knowledge is a process of finding, borrowing, and sampling from any number of relevant sources, creatively reimagining how these elements might be put together, and then creating an assemblage that one hopes has significance, salience, and meaning for those people who experience it. (Markham, 2013, section 4.2, n.p.)

Such a remix assemblage may also unfold from different positions and evolve in multiple layers.

In my PhD project, I have triangulated among the research literature, including different discourses, models and theories, my research intra-action with the dyad, and my earlier experiences with singing and dementia and as a relative. I use the term triangulation[32] not primarily in the narrow sense of method triangulation but rather to refer to a movement between different positions and layers within the research phenomena and apparatuses, which weaves together or entangles research strategies, issues, theories and practice.

I have been inspired by qualitative research methods such as action research, auto-ethnography, and literature studies, including discursive approaches. Eventually, the assembled, co-created and remixed material has been "read" – or engaged with – diffractively, in line with a performative research approach. I engage the empirical material, literature and theory within different configurations of phenomena and apparatuses, and diffractive readings of different parts of the research material feed into an overarching explorative and reflexive process. As the set of diffractive and reflexive layers develops, new actual

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[32] Triangulation was first used in 1818 in the context of navigation: "The division of a map or plan into triangles for measurement purposes, or the calculation of positions and distances using this method" (https://dictionary.cambridge.org/dictionary/english/triangulation)

phenomena and apparatuses also emerge which form new constellations of apparatuses and phenomena and add new layers to the diffractive-reflexive web.

3.4 Autoethnographic experiences and narratives: Re-turning

My autoethnographic experiences with singing throughout my life and with individualised and group singing in dementia care became an important backdrop for the whole project, especially for the research intra-action with the mother with dementia, Lilly, and her daughter, Emma. Initially, the aim of presenting such personal experiences as narratives (written in italics) was to serve as illustrations and to include more performative and affective ways of writing. Eventually, they came to fill an additional role as intertwined empirical material which was constitutive in the project's making of data.

Thus, my previous private and professional singing experiences – and other personal experiences connected to the role of a relative – have functioned both as a background and motivation (as mentioned in Chapter 1.4) and as secondary empirical material which intra-acted with the project's explorations of literature and practice. Such experiences are also included in the diffractive analysis in Chapter 7. In addition to my often vivid memories from these former professional singing experiences, particularly within dementia care, I have, during many years of education and work projects, assembled private, anonymised notes which also provided valuable nuances and memory support when I was integrating and diffracting such work experiences with the research material "assemblage".

Barad's notion of re-turning sheds light upon the methodological aspect of diffraction which is particularly relevant to autoethnography. It is not a reflective return to past experiences but a diffractive re-turning – a turning over and over again – from a relational present which is never the same but exists in a "thick" moment (Barad, 2014; 2017; Murris, 2022, pp. 111–113). Auto-ethnographic narratives can provide a diffractive lens, adding illustrative, affective time-space multiplicities while simultaneously sharing a glimpse into my de/centred researcher mind, supplying transparency regarding the experiences which have coloured my attitudes and influenced my research process.

3.5 Literature study and discourse

Descriptions of my theory development and discursive and conceptual contexts and frames are essential to this PhD project. In the research review in Chapter 2 and the other literature studies contained in Chapters 4, 5 and 6, I explore and discuss research literature, theories and discourses in relation to dementia, and singing as communication, co-creation and co-regulation. In Chapter 4, I focus on research and discourses connected to well-being, embodiment, memory and personhood, perspectives based on communicative musicality (Malloch & Trevarthen, 2009), attunement, vitality and meaningful moments (Stern, 2004, 2010, 1985/2018) and Stephen Porges' (2011) polyvagal theory. Moreover, I include aspects of Barad's (2007) agential realism towards the end, and especially the concepts of *intra-action*, *dis/continuity*, and *diffraction*. In Chapter 5, I explore discourses around dementia and connect them to macro-ethical perspectives and even relational singing. In Chapter 6, I continue along this discursive and conceptual trail and discuss terminology for relational singing. This chapter, that is, seeks to sum up the material-discursive explorations of the previous chapters and provide a stepping-stone to the further exploration of singing as practice in the research intra-action with the dyad.

A written thesis requires a linear presentation, which makes it hard to fully convey the complex connections between the various approaches and phenomena. While the research intra-action with the dyad is only briefly introduced before the outline of the literature study, the project's different parts still intra-acted in the research process.

My singing experiences, especially my work in dementia care, informed my selection of research literature and theoretical perspectives and especially my interest in the polyvagal theory (Chapter 4.9). The initial singing encounters with the dyad also influenced such choices, particularly connected to research on music and movement (e.g., Chapter 2.3.3) and my growing interest in more embodied (Chapters 4.3 and 4.5) and affirmative (Chapter 5.5) perspectives. Further, the literature study led to the snowball effects of reference tracing. Altogether, personal experiences, the literature study and my research intra-action with the dyad mutually and performatively (in)formed each other and co-(per)formed the material-discursive-practical research project and this dissertation.

3.6 Research intra-action: Approaches, strategies and considerations

> Knowledge is *knowledge-in-becoming as the constant creation of difference through researcher entanglement with the world*. (Østern et al., 2023, p. 278)

> Sampling in music refers to incorporating bits of others' songs into one's new song, where the sampled bit both retains the legacy of its origins and adds to the meaning of the new composition. In research, participants provide us access (purposefully or unwittingly) to bits and pieces of their lives, and we sample these, hopefully with great care, leaving participants better, or at least no worse, than before. (Ellingson & Sotirin, 2020a, p. 820)

3.6.1 Attitude and inspiration

In this section, I will outline and explain how the making of data came about during the research intra-action with the dyad, Lilly and Emma, and present some of the methodological, theoretical and practical considerations which informed the process. I will describe what the participating dyad and I, the participating researcher, did in our encounters. In addition, I will draw on research connected to the circumstances of my exploration and strategies, including influences from action research, issues involved with interviews in the specific contexts of dementia, and considerations about data engagement.

My overall research approach, as outlined above, has developed over time. The qualitative methods and measures towards which I was initially oriented ultimately served only as inspirations and potentials. My final research "design", then, was emergent though somehow prepared, representing a purposeful, performative response to the needs and changing circumstances of my singing encounters with Lilly and Emma.

The research intra-action with the dyad was inspired by principles from participatory action research (PAR) (Greenwood, 2004; Hughes, 2008; Tedmanson & Banerjee, 2010). In short, action research is participatory, cooperative, practical, cyclical, change-promoting, empowering and integral to a co-learning process (Löfman et al., 2004, p. 334). Ericson-Lidman and Strandberg (2018) add:

> PAR uses the knowledge and experiences of the participants […]. PAR puts an emphasis on collaboration and strives to engage subjects and researchers as equals in the process […]. Collaboration with research participants as co-researchers is in focus. Through the process, the participants become empowered to specify their own problems and to consider solutions […], which means that they are considered experts on their own needs and desires. (p. 192)

The reasons and justifications for my PAR-inspired strategy have both ethical and scientific grounds. First, PAR shifts the research power balance by offering research participants a more active role (to which I will return in Chapter 3.7.3). Further, PAR allows for a potential richness of experience wherein the reflexive, cyclical process in itself can generate new insights. Also, it fits into performative research by recognising researchers and participants alike as active participants in and of the phenomena they create and constitute through the research process.

From the perspective of PAR methodology, the concept of co-creativity outlined by Zeilig et al. (2018) (discussed in Chapters 2.6.3) can contribute to an open-ended research attitude. The authors acknowledge that co-creativity is not a fixed concept: “We are aware that co-creativity is partly understood as a phenomenon that exists along a spectrum of possibility” (p. 142). Further, they point out that co-creativity can facilitate “communication, expression and glimpses into people’s interior worlds” (pp. 141–142). My encounters with Lilly and Emma aimed to explore such glimpses through co-creative engagements along the spectrum of possibility in different everyday-life situations.

3.6.2 Approach and strategy

My research intra-action with the dyad contained

- an introductory get-to-know-each-other meeting,
- six singing sessions, including informal singing-preference mapping and conversation; and
- three semi-structured interviews with the dyad together or the relative alone, before and after the session period and about four months after the sessions.

The encounters took place at the participants' chosen location – generally, the mother's home. Appendix F displays an overview of the sessions and interviews. The empirical material consisted of

- sound recordings of all the encounters (meeting, sessions, interviews),[33]
- my field notes and reflexive memos, and
- transcriptions of parts of the encounters and written reports on the rest.

In addition, I chose to include more embodied and "fluid" aspects in the research material and my analytical engagements with it. These included

- my (embodied) memories from the encounters,
- my former experiences as a therapeutic musician and educator,[34]
- my reflections and meditations, and
- the writing process itself.

I will describe the process and elements below and weave other researchers' experiences and reflections into mine to provide further perspective.

In close dialogue and cooperation with the dyad, I proposed individualised, flexible, low-threshold singing activities which were based on their musical preferences, experiences and interests. The dyad carried out the process-oriented daily-life singing activities, supported by regular meetings with me as the researcher. These meetings included planning and singing together, small talk, discussion and activities adjustment and guidance according to their interests and wishes.

Initially, during, and after the activity period, I carried out semi-structured interviews with the daughter, Emma, individually and the dyad together. Thus, the mother, Lilly, was included in some of the interview sessions but with the daughter's support to enhance her memory and sense of safety. Emma was also invited to contribute to the research material through written or audio-recorded journals.[35]

The semi-structured interviews and singing sessions, including the activity planning dialogues, were audio recorded. The interviews and selected parts of the singing sessions – including planning and informal conversation – were

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[33] We considered video recordings, but the daughter preferred sound recordings only.

[34] This material also encompassed my (anonymised) notes from previous sessions and seminars.

[35] The daughter was initially interested in this contribution but eventually preferred not to submit extra entries beyond our meetings and conversations.

transcribed right after the sessions; less-detailed written reports conveyed the rest. My research fieldnotes and reflection memos written just after the encounters and later alongside the analytical process were also included in the empirical material. During my analytical engagement with this material, I also read through and reflected on notes from my previous work as a therapeutic musician and educator in music-based milieu care.

3.6.3 Participants and singing activity

The participating dyad was recruited by chance after a cultural event, although I also tried to recruit participants through municipal day centres.[36] The mother with dementia initially lived at home alone, supported by home nursing and relatives. The dyad did not focus on the actual diagnosis, and what unfolded in the singing encounters could be explored regardless of a specific dementia diagnosis.

I strove to ensure that the activity design was both flexible and individualised according to the participants' situations, making it as manageable as possible for them. I instructed and adjusted the singing activities to make them easy for the dyad to carry out in daily-life situations of their choice. My planning dialogues with the dyad were crucial both to the research itself and to adjusting the activities according to their ongoing experiences, interests and wishes. Compared to the original outline, the activity period grew considerably due to the pandemic and certain practical issues connected to life events. Throughout, the schedule and activity plan were adjusted to the participants' needs.

My initial idea was to present the intervention as a "singing palette", introducing a flexible "menu" of different approaches to and ways of singing expressed along musical and situational axes. This continued to serve as an inspiration, though it became less formal and structured than initially planned. The participants could choose and mix approaches and receive basic instructions and guidance accordingly. As the activities were carried out, the participants could make their own experiences, which we discussed consecutively, followed by adjusting or reconsidering the activities. Even in the very first get-to-know-each-

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[36] The participants were introduced in Chapter 1.7 and will be presented in Chapter 7.2. The initial plan was to explore four to six cases, starting with a one-case pilot study. However, the singing exploration with Lilly and Emma offered an abundance of experiences. The Covid-19 pandemic also made it hard to recruit more participants. Therefore, rather than expand into more cases, I chose to explore the singing encounters with the first dyad in greater detail.

other meeting, we ended up singing some favourite songs together and, in this way, starting the informal mapping of the dyad's musical preferences and interests, which in turn shaped the initial exploratory singing activities.

Within music-based milieu care, music preference mapping is usually carried out as a systematic session and includes filling out a form. However, I applied a more flexible, orally based musical mapping in my informal conversations and sing-alongs when I worked part-time in a day centre for older adults from 2011 to 2019. Such a flexible and practical approach to mapping is also described by Myskja (2005b, pp. 18–19).

Thus, in my research intra-action with the dyad, the mapping was entangled with the conversations, singing activities and interviews. The goal was not to be comprehensive but to gradually map and build a small but useful repertoire of songs and activities. These were assembled in a personal binder to be used in daily life. Following PAR principles, I encouraged the dyad to play an active role in the activity design. Their experiences and considerations influenced the development of the ongoing singing practice, to which I will return in Chapter 7.

More generally, making singing a substantial part of the project sessions and conversations is vital for multiple reasons. It is an easy way to map song preferences by trying and observing, thereby modelling a low-key approach which relatives might try out on their own. Moreover, it enables different modes of communication and interaction with people living with dementia whose language abilities might be compromised due to their condition. Through the inclusion of singing and a relative in these sessions, the person living with dementia may experience an enhanced sense of safety, belonging and mastery, following the principles conveyed by Hellström et al. (2007):

> Several commentators suggest that it is important to leave the person with dementia with a sense of achievement, and to find a positive subject on which to conclude. […] It may be advisable to work with a gatekeeper, usually the family carer, to ensure that a positive perception is created. (p. 612)

As mentioned, I always carried out my semi-structured interviews with the mother and daughter together or the daughter alone, and I included singing to create variation, evoke engagement, and ensure inclusion and active participation beyond the need for spoken language.

3.6.4 The semi-structured interview

Although the informal conversations as part of the singing sessions provided much information, I also wanted the opportunity to focus more directly on the dyad's experiences and reflections concerning the co-singing process. Therefore, I also incorporated semi-structured interviews. Over time, the boundaries between sessions, conversations and interviews grew blurred, to which I will return. Semi-structured interviews are flexible and fluid, organised around themes and topics which are set in an interview guide (see Appendix E) to provide some structure but allowing for openness and flexibility in how the questions are formulated, sequenced and developed (Mason, 2004, p. 1020).

Kvale and Brinkmann (2009) argue that the qualitative interview is a coproduction of knowledge wherein the contextual and relational interaction between the interviewer and the interviewee(s) actively shapes the knowledge-production (pp. 72–73, 184). The researcher undergoes a learning process where new dimensions of the research theme may appear through the interviews, both in the conversations themselves and during transcription and analysis (pp. 127–128). This was indeed my experience – the researcher role was a learning process and interviewing a person with dementia demanded extra awareness and adaptation. During the interviews, for example, I would suggest small breaks in the conversation to include activities we had explored during the sessions such as singing a loved song or doing a couple of physical exercises or a short, simple waltz.

On the other hand, the singing sessions also included informal conversations, which were an essential part of the exploratory process and the eventual research material. Therefore, the form and role of the singing sessions and interviews became less distinct than I had anticipated, and the process came to feel somewhat messy, but I eventually embraced this quality. I became increasingly confident that my flexibility and sensitivity to the needs and potentials of the moment were not only permissible but also necessary, productive and ethical.

When leaning into the situation and using empathy and insights in an empowering way for the interviewee, it is possible to learn something new and "give something back" at the same time, even if the situation sometimes feels "muddy" (Lippke and Tanggaard, 2014).

3.6.5 Interviewing people living with dementia

Interviewing people living with dementia has distinct and serious practical and ethical implications. Since memory recognition is more accessible than memory recall (Sabat, 2008, pp. 72–73), the interviewer needs to get the person “on track” in their answer or story. Otherwise, the person may experience a lack of mastery, and the researcher will receive limited information. Thus, the questions will often appear to be potentially leading because the researcher must provide a possible starting point for the person’s answer.

Angus and Bowen-Osborne (2014) suggest methodological approaches for weaving together the apparently chaotic and nonlinear fragments of the person’s narrative by tracking, documenting and systemising them. They also propose a repetition technique called “quilting narrative” wherein the interviewer introduces a topic by employing colloquial speech used by the person in previous conversations, “which provides the speaker living with dementia the opportunity to expand on the topic rather than having to recall a particular topic” (Angus & Bowen-Osborne, 2014). Interestingly, Kvale and Brinkmann (2009) also advocate for leading questions as a means of checking the response’s reliability and verifying the interviewer’s interpretation of it. They suggest that leading questions can enhance rather than weaken the reliability of the interview and could be used more often (pp. 183–184).

Using leading questions and quilting the narrative were also important parts of my approach during my interviews and the informal conversations included in our singing sessions. I had a sense of weaving together bits of information assembled throughout the sessions and interviews. In particular, the informal conversations entangling our singing activities helped me to “get glimpses” into the dyad’s “interior worlds”, as Zeilig et al. (2018, p. 142) put it.

Interviewing a person living with dementia together with a relative or friend has, in my experience, some significant advantages and some less significant disadvantages. The safety provided by the presence of a dear one and the back-and-forth which can arise in conversation are major assets. In addition, the mother, Lilly, was sometimes hard to understand, and Emma could then “translate” or elaborate upon what she was trying to convey. On the other hand, a person living with dementia can lose initiative if the relative is very verbal and communicative. As a researcher, I tried my best to include Lilly by asking follow-up questions drawn from the responses of both her and her daughter.

Repstad (2007) points out that a general problem with qualitative methods is that the researcher acquires information more easily from articulate and cooperative informants, and the temptation is to spend most time and energy on them (pp. 59–60). When people living with dementia are included in the research, this issue is twofold; in a setting with people without cognitive loss, the person with dementia may lose initiative. Also, among people with dementia, the most articulated will more easily have their say.

People living with dementia often need more time to process a question and develop an answer. Given the potentially considerable latency time, both the interviewer and the relative can be inclined to fill the silence. However, slowing down and allowing pauses are essential to encourage participation. The inclusion of singing can provide some space in this regard and potentially nurture communication, association and reflection.

3.6.6 Making data

In her article “Interviews as intraviews”, Kit Stender Petersen (2014) describes a new approach to the interview situation in light of concepts from Barad’s agential realism such as “apparatuses”, “phenomena”, “intra-action” and “material-discursive”. Petersen emphasises that both human and non-human agencies influence the interview situation and can create unforeseen diversions and contribute to reworking power relations (pp. 38–40) and uncovering and reframing the stories (p. 40). In my case, singing activities often played an integral role in the conversations or interviews. Thus, the “materiality” and agency of songs, singing and movement contributed to the material-discursive entanglements of the research process.

Referring to Barad, Petersen (2014) argues that “materiality is discursive just as well as discursive practices always already are material, which means that materiality and discourses always already are intertwined and mutually co-constitutive” (p. 33). Further, the researcher must be seen as part of the apparatus, not external to it, and the research must be understood as produced by its scientific apparatuses. Hence, interview data is not collected but *created* and dependent on the interview apparatus. The conditions, boundaries and intra-actions are never fixed but always affected by a wide range of intra-active material-discursive forces or open-ended practices (p. 34). Petersen (2014) also discusses reframing data as *creata* or, following Barad, as *relata*. She points out that there is no reality or pre-existing data to collect separately from the phenomena. Rather, intra-actions consisting of both human and non-human agencies enact relata within the phenomena (Petersen, 2014, p. 35).

In this, Petersen aligns with Ellingson and Sotirin (2020b), who claim that despite data's inherent messiness, it should never be considered natural or raw: it is always already "cooked" (Ellingson & Sotirin, 2020b, p. 8). Ellingson and Sotirin (2020a, 2020b) acknowledge that most qualitative research textbooks address the constructed nature of data, and that critical and interpretive scholars understand data as co-constructed between researchers and participants. Yet, the authors propose a more radical rethinking of data. They urge researchers to engage with the data lively, to become with the data (2020a, p. 817), and they "invite researchers to depart from convention" (2020a, p. 820). They promote an approach where the questions of what data is and how it can be collected are substituted with what data does and "what are the possibilities for making data?" (2020b, p. 1).

This represents a new entry in the debate over qualitative versus post-qualitative approaches to data, and over some scholars' rejection of the concept of data altogether. Ellingson and Sotirin describe a process of *data engagement* "as a generative alternative to the post-qualitative abandonment of the concept of data and the social constructionist bracketing of important epistemological and ontological issues while doing (and teaching) data collection" (2020a, pp. 817–818). Further, they argue that "data are made rather than found, assembled rather than collected or gathered, and dynamic rather than complete or static" (2020a, p. 819).

In my research intra-action with Lilly and Emma, we generated data *together*. I brought with me certain preconceptions about how relational singing might be used in their daily life based on my previous experiences with singing in the context of dementia, my role as a teacher in music-based milieu care, and the initial orientation of my singing and dementia research. At the same time, I tried to be responsive to their interests, song preferences and wishes. After a short period of exploring favourite songs together, their apparent interest in movement with music suggested some activities that I had not foreseen, which also, as mentioned in Chapter 3.5, influenced my selection of literature in both the research review and the literature study. Emma's respect for her mother and their reciprocal affirming relationship also profoundly impacted me. Altogether, their interests and attitudes and our initial making of data inspired my exploration of embodied and affirmative perspectives.

3.6.7 Data engagement

As I revisited the sound recordings, transcripts and other notes from the singing sessions and interviews, I engaged in a range of intellectual, emotional, embodied and meditative engagements and their intra-actions (which I will discuss further in Chapter 7). Oftentimes, my affective embodied responses to the material would start a reflexive process connected to the theoretical part of the thesis. Other times, ideas and structural connections would arise during or immediately following meditation or walks in nature. My meditation practice[37] has played a substantial role in this process (Sikh & Spence, 2016) by releasing impulses, ideas and intuitive insights which represented an important aspect of the diffractive-reflexive process. It is worth acknowledging the ways in which researchers live, breathe, move and become with our research projects and analytical engagements over time, and I also consider the writing process in and of itself as a vital part of my analytical process: Writing is inquiry and produces thinking (St. Pierre, 2019, p. 3). Because my project also involved considerable theoretical explorations in supplying a material-discursive foundation for relational singing, the writing process – entangled with the reading – became an essential part of my thinking and processing of ideas.

Such diverse engagements also reflect the different roles, subjective positions and degrees of de/centredness I discussed in Chapter 3.3.5. Sometimes, I engage intellectually as the analytical researcher; other times, I engage from the practitioner's experiential point of view. In some circumstances, I even take a more personal and affective subjective stand or engage in a meditative and intuitive dialogue with the material. These perspectives and approaches intra-act in different configurations of cognition/analysis, affect/experience and intuition/meditation. Thus, the *moveable assemblage* of self – to use Braidotti's (2019b, p. 158) expression – intra-acts with/in the research process.

3.6.8 Diffractive analysis

During the research process, I was increasingly influenced by Barad's (2007) theory and inspired by different approaches to diffractive methodology (e.g., Bjørkøy, 2020; Juelskjær, 2019; Klungland, 2021). Hence, my approach evolved

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[37] This meditative practice (also explained in Chapter 3.3.6) includes a regular morning meditation routine, small, random meditative intermissions and meditative/reflexive walks in nature.

into diffractive engagements with the research material, which I recognised, partly along the way and partly in retrospect, as a four-layered structure from which I could develop my own analytical model by engaging with (1) concepts; (2) agency, intra-action and intra-play; (3) theory and research; and (4) experience. I will elaborate on each of these layers below.

According to the notions and terminology of agential realism, I have been making *agential cuts*[38] to derive from my empirical material certain themes, events or phenomena which could shed light on the research questions. Initially, I brought the central themes and concepts which "stuck out" of the material into dialogue with other parts of the material and the literature. Eventually, I also explored "performative agencies"[39] to see how they intra-acted within specific episodes to access deeper layers and details of the chosen phenomena in tandem with theory. My attitude to the making of agential cuts as part of the research process is affective and intuitive (as discussed in Chapter 3.3.6) as well as analytical and draws on the idea of *data engagement* (Ellingson & Sotirin, 2020a, 2020b) discussed above.

In my four-layered diffractive engagement introduced above, I first read and sensed parts of the material through the concepts which came to the fore during my initial encounters with it. I thought of this approach as "engaging with concepts", and it was influenced by *Thinking with theory in qualitative research* (Jackson & Mazzei, 2012) and *Making data in qualitative research* (Ellingson & Sotirin, 2020b). I have chosen the word *engaging* rather than *thinking* to encompass the implications of *sensing* and *making sense*, as well as *becoming with* the data, theoretically and intellectually, practically, sensorily, affectively and intuitively.

Second, I diffracted parts of the material in a rather literal sense: *Diffraction* stems from the Latin word *diffringere*, which means "to break up, break apart, shatter" (Merriam-Webster, n.d.). I broke certain selected events into performative agencies to revisit the ways in which they intra-act as part of the respective event. I call this "engaging with agency", and it also includes engaging with *intra-action* and *intra-play*.

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[38] The agential cuts "I make" are based on the intra-action of and with multiple emergent agencies connected to internal (embodied, interoceptive) and external (worldly, perceptive) phenomena.

[39] I use the term "agency" instead of "agent" to highlight the performative and relational aspect of agency because "agent" points more towards an acting object/subject.

Third, I read parts of the material through different theories, philosophies and research studies, which I call “engaging with theory and research”; this approach recall Jackson and Mazzei’s (2012) *thinking with theory*. Moreover, the conceptual diffraction had two layers: a more general layer in the first part and later, in the third part, an overarching, structural layer as I diffracted the engaging-with-theory through Barad’s concept of *material-discursive practices*, thus somehow “diffracting diffraction” (Barad, 2014).

Following this multifaceted diffractive exploration, I revisited some of my insights from the research intra-action with the dyad using aspects of my previous working experience with music, including singing, within dementia care. I call this “engaging with experience”.

My analytical process and this four-layered, intertwining structure evolved directly from my engagement with the research material – both the empirical material from the explorative co-singing intra-actions and the research literature, theory and philosophy I consulted. The process was less a preordained analytical strategy than a way to recapture, reorganise and restructure what I did during the research process.

Figure 3 illustrates my four-layered analytical engagement model. Please note that my notion of layers is not meant to imply structural separateness: The layers are entangled, and each layer brings with it elements from the previous ones.

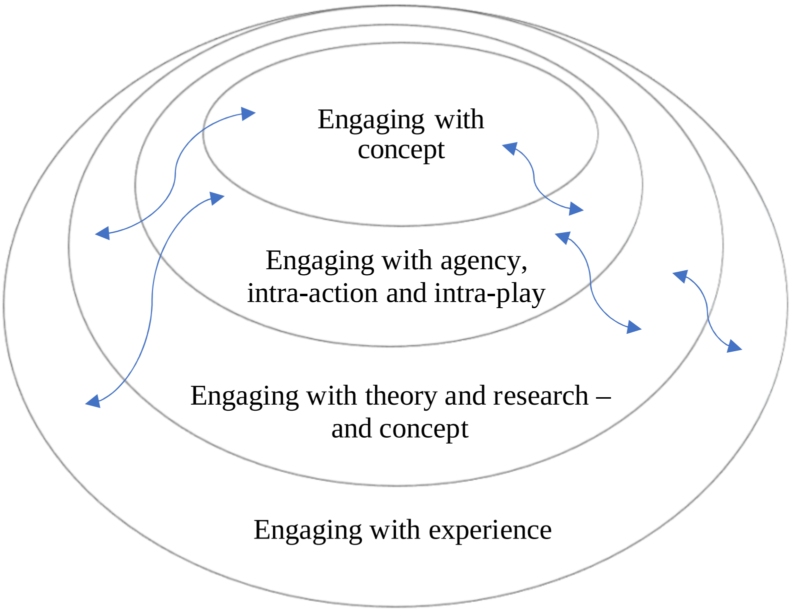

Figure 3. Four modes of diffractive engagements – a diffractive analytical model (Waage)

In my PhD project, the role of this research intra-action with the dyad is to explore how co-singing in families living with dementia might unfold – to allow for ideas and potentials and draw attention to and engage in a marginal area of music and dementia. The goal is not representation but rather experimentation and creation (St. Pierre, 2019, p. 4; Østern et al., 2023, e.g., p. 286). Thus, Alvesson and Sköldberg's (2018) description of the potential impact of empirical material resonates with my outlook:

> Empirical material resembles a picture in a hall lined with convex and concave mirrors (researchers, language, theories, reality), rather than the result of one single reflection of "reality". But data cannot prove anything. Apart from supporting various views on "how it is" or (better) fruitful ways of describing and understanding "reality", empirical material can also be used in other ways. It may be used, for example, to generate ideas, to illustrate or to encourage and guide critique and modification of theories, and to generate insightful descriptions through drawing attention to neglected dimensions. (p. 370)

Figure 4 illustrates my overall research "design", including its strategies, methodological influences, phenomena and analytical engagements. Barad's (2007) agential realism serves as my overall philosophy of science, while performative inquiry (Østern et al. 2021) is the overarching research approach. This performative inquiry consists of multiple phenomena, including the researcher and her research strategies and methodological influences – the boundary-making apparatuses like literature study and the influence of action research and autoethnography. These approaches and phenomena intra-act, and they are engaged with diffractively and conveyed in my four-layered analytical model.

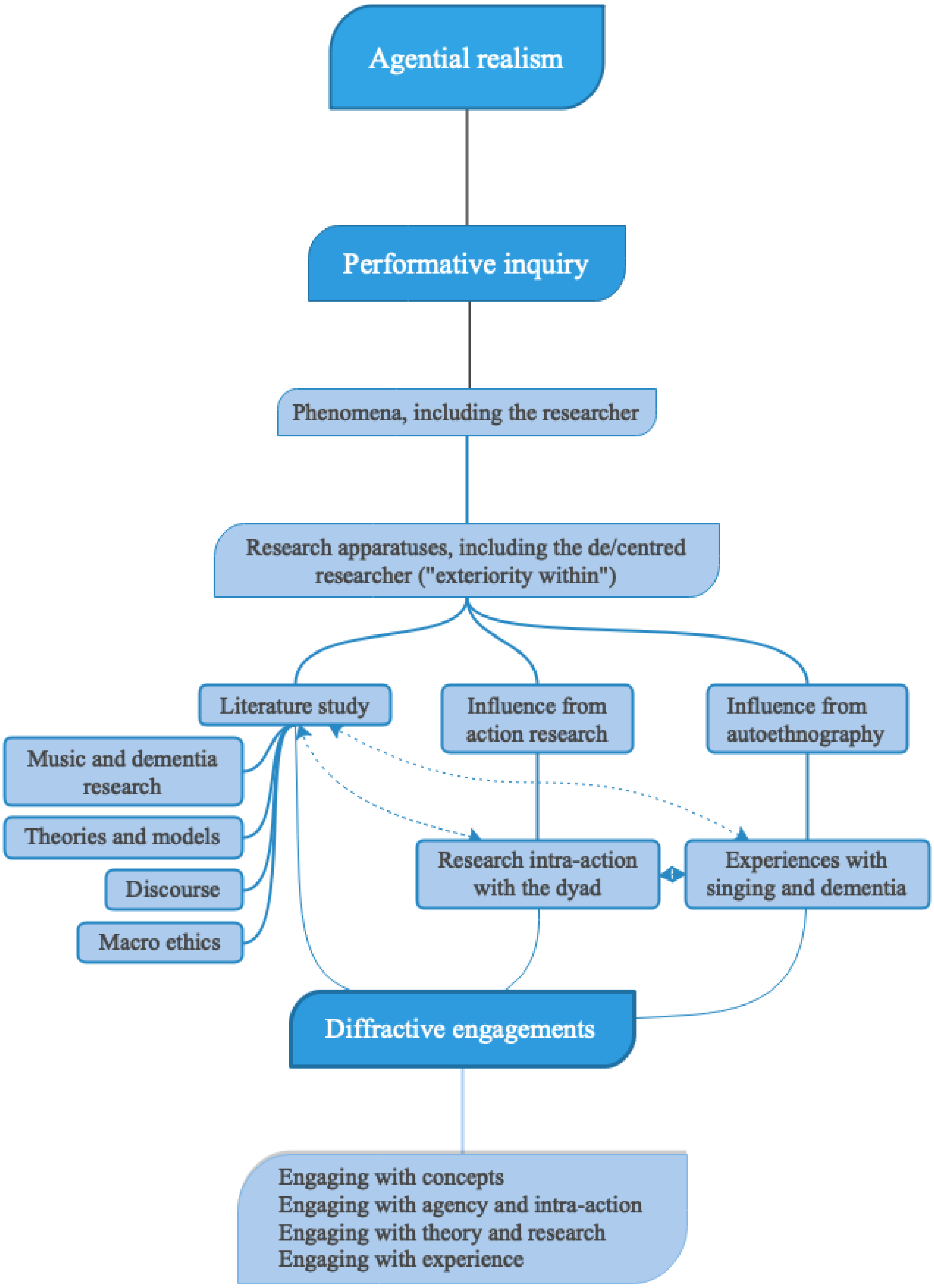

Figure 4. My research strategy apparatuses

3.7 Ethical considerations

> Ethics is not just the application of moral protocols, norms, and values, but rather the force that contributes to conditions of affirmative becoming. (Braidotti, 2019b, p. 168).

This citation points to different levels of ethics, often framed as micro-ethics and macro-ethics, which I have chosen to address in different parts of the dissertation. Various stigma-causing discourses and macro-ethical perspectives will be addressed in Chapter 5. In the present section, I explain the ethical foundations and considerations related to my research intra-action with the dyad, including its formalities.

3.7.1 Formalities and consent

At first, it was unclear whether this project would require the approval of REK: Regionale komitéer for medisinsk og helsefaglig forskningsetikk (Regional committees for medical and healthcare research ethics). I was told to apply at the start of the project period and later added requested information, but REK eventually concluded that the project was outside their domain and did not need their approval. Next, I sent an application to NSD: Norsk senter for forskningsdata (Norwegian centre for research data), which approved the project. (See letters from NSD and REK in the Appendices A and B.) I was careful to consider the principles and guidelines of research ethics in the project planning, and in the handling, processing and presentation of the material, especially regarding ethical issues concerning decision competence and personal protection.

The participating dyad received written information about the project (see Appendices C and D) and then signed the consent forms. The daughter helped inform the mother with dementia before she signed the form. Although the mother was able to consent by herself, I continually made sure that she wanted to take part and did not feel uncomfortable during the meetings and activities. Through the written participant information and during the initial meeting, I was explicit that the participant could withdraw from the project at any time, without explanation, or withdraw consent regarding the use of the research material but still continue with the planned musical sessions if they wished to.

Hellstrøm et al. (2007) discuss the challenges and dilemmas connected to informed consent and argue that consent should be considered a process dependent upon the here-and-now context and one’s ongoing experience and feelings rather than a cognitive understanding of standard information supplied at the outset only. Hence, non-verbal and behavioural cues should also be considered in the assessment of consent (pp. 611, 615). They argue that current notions of informed consent reflect a “universalistic exclusionary” approach to ethics that is, in essence, based on a “one size fits all” model. They instead advocate for a “particularistic inclusionary” model of consent which considers the capacity of people with dementia in “situation-specific contexts” and builds on their remaining strengths rather than exaggerating their weaknesses (p. 611).

Hellström et al. (2007) also point out that even though every effort was made to ensure “maximally informed consent” in their own work, they were less confident about whether it was consistently achieved. While spouses acted as spokespeople for the people with dementia and supported them in making their own decisions, some would occasionally try to convince their hesitant spouse to continue in the study, which raised potential ethical issues (p. 615).

A subtler variation upon this issue involves times when people with dementia pick up on their relatives’ strong desire for them to participate and perhaps do so mainly to please them. This could have been a risk in my project as well since the daughter was highly motivated to attend. Therefore, I paid close attention to the verbal and non-verbal responses of the mother with dementia to be sure she remained interested in participating.

3.7.2 Risks, dignity and vulnerability

As discussed in Chapter 2, existing research and practice show that singing and music represent a valuable and harmless resource in the care for and communication with people with dementia (see, for instance, McDermott et al., 2013; Ridder, 2003, 2011, 2017). Hence, there was basically minimal risk associated with my project.

However, the ongoing Covid-19 pandemic complicated the project’s risks by introducing required infection-control considerations into the research design. Initially, the participants chose physical encounters because the infection situation seemed under control, with very little contamination in Norway at that time. Nevertheless, I did my utmost to maintain safety and was careful about distancing and hand hygiene, and I disinfected the song binders and plastic pockets in advance. Later, some of the sessions did have to be postponed – and one interview with the relative was done by phone rather than in person – due to issues such as changing local contamination levels.

Hellstrøm et al. (2007) argue that people with dementia are among the most excluded groups in Western societies due to the double stigma of ageing and cognitive frailty. Academia has contributed to this exclusion by basing much of the research on proxy accounts, primarily from family caregivers, though this is changing amid the growing realisation that researchers must listen to the people who are experiencing the condition. People with dementia are often more capable of speaking for themselves than previously realised (p. 608). Hellström et al. (2007) also call attention to various related ethical and methodological discussions and challenges. First, they oppose the often-used argument that people living with dementia should be spared the possible burden and stress connected to research participation and instead claim that the silencing effect of exclusion amounts to a more significant burden over time. Moreover, they point to research showing that inclusion in project interviews can be a positive and enhancing experience for people with dementia, provided that the researchers manage to create a safe and affirmative setting (p. 610). Lastly, they argue that “the exclusion of people with dementia is itself an affront to their dignity, and that inclusion, if appropriately handled, would enhance their dignity of personal identity” (p. 609).

I intended to include the participant with dementia as much as possible during the research process, but, in practice, I tended to rely more on the relative during the interview sessions. Therefore, my subscription to Hellstrøm et al.’s points about exclusion and proxy might seem paradoxical. Still, I would suggest that the participant with dementia had a central position in my research; she participated in some of the interviews and all the singing sessions, including the related informal conversations. Also, it should be said, my project concerns the relative’s experiences and point of view as well as those of the person with dementia.

Löfman et al. (2004) point out the paradox which can emerge when one takes the participant’s vulnerability into account: In the researcher’s attempt to protect “vulnerable” participants lies the danger of underestimating both their capabilities and the researcher’s protective ability (p. 337). Moreover, the very notion of vulnerability and protection introduces the paradoxical risk of exacerbating an unbalanced power relation – a dilemma which might be particularly relevant in the context of dementia. Hence, the researcher must strive to be attentive and considerate regarding the participants’ needs – and particularly those of the person with dementia – without patronising or underestimating anyone’s abilities or self-awareness. In practice, I attempted to adjust to the participants needs by meeting the dyad at their preferred spot at times suitable to their life rhythms and schedules and by being open and aware while always considering their initiatives and concerns.

At times, I felt vulnerable in my position as a researcher. In the middle of a pandemic, it was difficult to recruit further research participants. Also, my engagement with the first dyad of participants generated far more material than I anticipated. Still, a deep dive into this material was at once tempting and intimidating – for example, what if they chose to withdraw? A vast amount of work would promptly become useless to my project. Also, my efforts to balance my behaviour and adjust to their needs in themselves put me in a position of power in that they might have felt as though they owed me something because I was nice to them. In the end, I simply had to trust the process, make accommodations to the best of my ability, and view it all as part of my learning experience as a research fellow.

3.7.3 Power balance

Ethical perspectives are part of the reason for choosing a research approach influenced by participatory action research (PAR). PAR is intended to facilitate positive change and describe/evaluate outcomes of interventions (Ellingson & Sotirin, 2020a, pp. 818–819). Hughes (2008) points out that PAR also has the capacity to challenge existing structures of knowledge and power: “Participation of key stakeholders, especially those who are usually excluded from decision-making about research (such as clients, patients and community members), leads to projects that are more relevant to the lives of ordinary people, while good PAR is itself an empowering process” (pp. 5–6).

Tedmanson and Banerjee (2010) also underscore the emancipatory quality of PAR because it enables the co-production of new knowledge and theoretical insights regarding innovation and social change based on the lived experiences and activities of the individuals affected by the issues. Thus, PAR may act to shift the power balance between the researcher and the participants, in the sense that the latter can take on a more active role and influence the research process: “Value is added in applied everyday settings, and learning by doing is facilitated through cycles of reflexivity” (Tedmanson & Banerjee, 2010, p. 2).

On the other hand, this form of cooperative relationship also brings some challenges. The relatives may feel obliged to contribute more than their time and situation allow in the long run, so that their initial enthusiasm morphs into a feeling of having promised more than they can deliver. This appeared to be an issue for the daughter in my project, who wanted to sing more with her mother between our sessions and contribute with a sound log but eventually realised that this would be too hard to manage in the way she had hoped. I underscored that our encounters in and of themselves provided me with abundant information and encouraged her to adjust their participation according to their opportunity, energy and interest.

Another essential issue was adequately incorporating the mother to avoid side-lining her in the researcher–relative relation, which can be challenging when the person with dementia has difficulties with language. As a result, I relied on singing to facilitate mutual involvement and communication during the interviews as well.

The researcher's authority – and the participant's preunderstanding of what research is or can be – can also influence the research process. I welcomed the participants' opinions and suggestions regarding both the design of the singing activities and the interview exchanges. Still, there remained a risk that what they assumed would be useful to me as the researcher would steer their contributions, so I made a concerted effort to welcome any part of their experiences and considerations, no matter how apparently mundane, into our conversation.

3.7.4 Personal motivation

As mentioned in Chapter 1.4, I have experienced different severe health issues in my own close relations. Moreover, I have found that the healthcare system's focus on relatives' situations, perspectives and needs is presently limited. I am therefore admittedly biased regarding my research topic, but the insights I have drawn from my life experiences have usefully informed my scholarly perspective.

My interest in dementia does not share this personal background but instead developed over my eight years as a part-time therapeutic musician in dementia care and three years as a part-time teacher of music-based milieu care to dementia-care staff. Through this work, I saw the difference which music made to people with dementia, their families and the relevant staff and began to develop my resource-based and joyful approach to these practices.

3.7.5 Data engagement with pragmatism, compassion and joy

Ellingson and Sotirin (2020a) underscore that “data are never neutral but are always already imbued with discourses of power” on multiple levels (p. 822). They consequently advocate for pragmatism, compassion and joy as three underlying ethical commitments to “infuse the making, assembling, and becoming of data” (p. 823).

Pragmatism is about “balancing imagination with practicality” and making data in “the confluence of opportunities, interests, availabilities, needs, and desires” (p. 823). In my case, pragmatism was essential to managing the unforeseen limitations brought about by the pandemic and other practical issues connected to the participants’ life events and logistics. Nevertheless, the initial constraints opened and reconfigured the project towards other opportunities and imaginings. Moreover, pragmatism enabled different engagements based on the participants’ changing and developing needs and desires. When I dove deep into what I could still do despite the limitations, new material-discursive-practice entanglements appeared.

Next, Ellingson and Sotirin (2020a) refer to Ellis and Patti when describing compassion as “a holistic mind-body-spirit practice of caring for self and other that involves listening deeply, giving undivided attention, and authentic caring about another person as we make data together” (p. 823). My engagement in the participants’ interests and my efforts to adapt activities and communication to their needs and abilities is one aspect of compassion. Another aspect, this time of self-compassion, encompassed my attempts to take my intuitions and more-than-cognitive, affective impulses seriously as part of my engagement with the data.

Finally, Ellingson and Sotirin (2020a) “propose joy as an ethos of data engagement” (p. 824). Joyful engagement with data can spur novel thoughts and actions and unanticipated ways of becoming, even as this work remains inherently troublesome, confusing and disorienting: “The joy of data engagement is in despair and elation, in data that resists capture and inspires thinking, and in research encounters with data that cross new thresholds” (p. 824).

My encounters with research, theory, and my sessions with the dyad have indeed been at once joyful and unsettling. Puzzlement often accompanied the project’s unfamiliar theoretical landscapes and unpredictable “fieldwork” conditions. Nevertheless, the intense joy of co-creating and digging deep into the theoretical and empirical material was never far off. Moreover, I experienced my employment as a research fellow as a privilege, which also prompted my joy as I cavorted with the data and toiled with the research process.

3.8 Concluding summary

This chapter has presented my research strategies and methodological influences and considerations. The overarching philosophy of science is Barad's (2007) agential realism, based on and developed from Niels Bohr's interpretation of quantum physics and his notion of "physics-philosophy". The inseparability of everything there is, including matter, time, space and knowledge, are conveyed in Barad's concepts of *material-discursive practices* and *ethico-onto-epistemology*, signalling a fundamental interwovenness and entanglement, and implicit in Barad's notion of intra-action and her use of diffraction as a conceptual and methodological foundation. All "entities" are relational phenomena (always plural) which are impossible to separate from their constantly ongoing relational intra-actions. Such intra-actions are also nuanced and deepened in Richards and Haukeland's (2020) notion of intra-play and their four forms: co-attending, co-responding, co-forming and co-rendering.

Barad's philosophy corresponds with the performative research paradigm, as outlined by Østern et al. (2023). These scholars argue that both performative and post-qualitative inquiry can be framed within the performative research paradigm. The entanglements of phenomena, including the decentred researcher, intimately interwoven with the research phenomena, shift the research approach away from prescribed methods, findings, representational logic and descriptions of what *is*. Instead, the focus becomes what research phenomena are *doing* and the meaningful differences and coherences – or diffraction – that can be traced and provoked during the research process. Rather than collected, data is (collaboratively) made (Ellingson & Sotirin, 2020b) – as creata or relata – and can be incorporated into a remix of assembled phenomena.

In my project, the remixed assemblage consists of autoethnographic personal and professional experiences with singing, literature studies including music and dementia research, relational and neuro-science-oriented theory, and broader ethical-discursive frames and contexts. The primary empirical material was made in my research intra-action with a dyad of an older woman living with dementia and her daughter, exploring daily-life singing activities based on their interests, preferences and ongoing material-discursive experiences. The research intra-action was inspired by participatory action research and included singing sessions, informal conversations, and semi-structured interviews which were sound-recorded. The analytical engagement with the research material resulted in a new four-layered diffractive analysis model which evolved during the research process.

Ethical implications permeate the project at the macro level and will be addressed in Chapter 5. At the micro level, ethical considerations have revolved around (the ongoing evaluation of) consent and the specific challenges and possibilities of including people with dementia in the research activities.

4 Theoretical perspectives: Literature study and material-discursive entanglements

4.1.1 First epistle – entanglements

"Gje meg handa di ven" *(Give me your hand, my friend).*[40] *One single song is linked to an infinity of life stories – entanglements of events, atmospheres and fates. This particular song followed my father and my grandmother to their final rest. Some years earlier, it unintentionally morbidly accompanied my youngest son's unrest and pain during late nights at the national hospital after his severe hand injury. Give me your hand – clearly out of the question since his crushed hand was wrapped in a huge bandage to keep it warm enough after complicated finger replant surgery. Luckily, I was just humming.*

Singing or listening to this song today – even just thinking about it – can bring forth images as diverse as the beloved faces of my father or grandmother, my son's huge bandage, or even the leeches helping his finger's blood circulation. The leeches, and the hand-specialist microsurgeons who were also my late father's former colleagues,[41] *actually rescued my then seven-year-old son's right forefinger, now a very handy body part for a passionate young jazz vibraphone player. During isolation due to the Covid-19 pandemic, he accompanied my writing of this very passage in our shared "home office" in the living room. As Karen Barad exclaimed after an introduction to a lecture in a YouTube video, in response to some meaningful coincidence: "Of course, it is entanglements all the way down!"*

Still, while these stories stick out, they have serious competition from my encounters with several people at the edges of life, from the newly born to those headed toward end-of-life, many of whom lived with dementia. I have crossed the path with many vulnerable though still strong and unique individuals in, through and with that song. My impressions of their stories, faces, and "awakenings" with glimmering or sometimes misty eyes are,

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[40] "Gje meg handa di ven" is an old Irish folk tune to which the Norwegian singer Sondre Bratland has written a new Norwegian text.

[41] They were even working on the same team before he retired. For twenty years, that is, he had contributed to building the expertise that later rescued my son's finger.

> *together with the leeches, surgeons and my father and grandmother's passing, all threaded through this song. It constitutes a universe in its own right, like a sea or a flood, with waves of diffractive memory patterns, affecting not only my mind but even my bodily senses. Give me your hand . . .*[42]

4.1.2 Introduction

In this chapter, I supplement issues from the research review in Chapter 2 and aspects of the philosophy-of-science foundation from Chapter 3 with a selection of other research and theoretical and discursive approaches which shed further light on daily-life singing in families living with dementia.[43] Thus, this chapter mainly concerns the second research question:

> *How can theory and research – especially that based on neuroscience and posthuman theory and philosophy – shed light on mechanisms and processes in play when people with dementia and their close ones sing together?*

As noted in Chapter 1.2, this question mainly engages the *material* (broadly understood) aspect of the material-discursive practice. However, the mechanisms and processes also have *discursive* implications, which are initially presented in this chapter and further elaborated on in Chapter 5.

I start with a discussion of *well-being* because much music and dementia research is directly or indirectly linked to well-being as an outcome. Then I continue with *embodied cognition* to add a theoretical basis to singing's non/post-verbal properties, discussed in Chapter 2.6.2. Next, I look at research on dementia and memory before offering a short introduction to person-centred care as a backdrop to my exploration of different perspectives on *embodiment and dementia*, which are connected to different notions of *self* and *personhood*. Next, I shift to *communicative musicality*, Dissanayake's *artification hypothesis* and

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[42] Chapter 4.1.1 is based on my unpublished exam-essay (Waage, 2020, p. 1), with minor editorial adjustments.

[43] Parts of Chapter 4 (mainly in Chapters 4.3.2, 4.6 and 4.9) are based on and developed further from my published article; see Waage (2022). The applicable sections or paragraphs are marked with footnotes, paraphrased references, and citations in the text to avoid self-plagiarism.

Stern's concepts of *affect* and *attunement*. Further, I dive into the autonomic nervous system (ANS) and Stephen Porges' *polyvagal theory* to shed light on the substrates of safety, trust, regulation and social interaction.

Lastly, I diffract and discuss aspects of this material using perspectives and concepts from Barad's agential realism and the work of other posthuman scholars. Posthuman approaches challenge both fundamental, taken-for-granted issues in general, and dominant trends within dementia care and music-and-dementia research in particular. Its thought-provoking perspectives further inform engagements with discourse and macro-ethics in Chapter 5 and my discussion of terms and concepts in Chapter 6. Subsequently, in the monograph's last section – Chapters 7 and 8 – I engage with the larger implications of the concept of co-singing in families living with dementia through the exploratory research intra-action and other theoretical and conceptual diffractions and discussions.

4.2 The concepts and contexts of well-being

The concepts of *well-being* and, accordingly, *health* and *quality of life* are often taken for granted, although their boundaries and contexts can be blurry. I will refrain from suggesting general definitions but still want to address related challenges here.

4.2.1 Well-being and health

Linton et al. (2016) did an extensive thematic review of 99 studies concerning self-reported subjective well-being and examined their measurement tools, dimensions and themes. They found that the researchers had applied a variety of methods and were rarely explicit about how theory had influenced their tools: "The striking variability between instruments supports the need to pay close attention to what is being assessed under the umbrella of 'well-being' measurement" (Linton et al., 2016, p. 1). Among the 196 dimensions identified in the studies, the authors found a clustering around six main themes: mental well-being, social well-being, physical well-being, spiritual well-being, activities and functioning, and personal circumstances (pp. 11–12).

One of the aspects the authors discussed involved the blurred boundaries between the concepts of *health* and *well-being*. Many studies used WHO's definition of "health as a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity" (World Health Organization, 1948, p. 100) which has remained unchanged since 1948. Contributing to the confusion is the fact that WHO still roots health firmly within society and culture. Acknowledging the dated nature of the abiding definition, the authors of a recent WHO report (Fancourt & Finn, 2019) point out that "complete health and well-being may not be everyone's goal" (p. 2) and that illness in many cases can be managed:

> Management is shaped in part by resilience and whether individuals can adapt with their health: whether they can restore their physiological homeostasis (balance) and feel they have the capacity to cope and fulfil their potential with a degree of independence and opportunity to participate socially […]. Health is, therefore, a dynamic process that, at its core, is about having the capacity to self-manage. (Fancourt & Finn, 2019, p. 2)

Conceptualising health as a dynamic process connected to the capacity to self-manage further blurs the boundaries between health and well-being.

4.2.2 Which "being" in well-being?

In the article "Which 'being' in wellbeing? Ontology, wellness, and the geography of happiness", Smith and Reid (2018) discuss several issues with the concept of well-being in the research. Researchers often take the term for granted, which might sometimes serve to veil socioeconomic inequality, impose an ethnocentric or paternalistic understanding of the concept, and result in ambiguous research results. The particular phrasing of a given research question, for instance, may not resonate with the notion and experience of well-being within specific cultures and contexts (Smith & Reid, 2018).

In addition, the time, place and context of the inquiry or survey make a difference – general assessments of well-being or life satisfaction are more susceptible to contextual and emotional fluctuation than assessments of real-time experiences (Kahneman & Krueger, 2006). Besides, adaptations to changes in life conditions, even severe ones, generally neutralise a preliminary change in the sense of well-being or life satisfaction within a couple of years (pp. 14–18).

Smith and Reid (2018) question the individualised nature of the conception of subjective well-being presently dominating the research field: "This assumed individualism is understandable for garnering large-scale average statistics, but conceals an underestimation of the performative impact of place, activity, age and contextual events on psychological conditions” (p. 815). They advocate for a concept of well-being inspired by Barad’s notion of intra-action because the well-being of the individual subject cannot be isolated from the subject’s relational and environmental contexts. They see well-being instead as performative and relational, situated and emergent, and call for well-being scholarship with a “renewed attention to the ‘intra-active’ space-times of wellbeing, moving from retrospective, representational approaches to more-than-representational situations of intra-action and performance” (Smith & Reid, 2018, p. 823).

To the extent that I wish my research to contribute to the well-being of families living with dementia, I understand the term in line with Smith and Reid’s performative and relational approach as situational and fluid (and therefore correspondingly amenable to the influence of relational singing).

4.2.3 Well-being and quality of life in music and dementia research

Another aspect of well-being (or the lack of it) is reflected in the behavioural and psychological symptom assessments which are described in much dementia research. In their systematic review of dementia and singing, Thompson et al. (2021, p. 10) follow other academics (Dowson et al., 2019, p. 30) and dementia advocates (Swaffer, 2018) in advocating for a change in terminology around BPSD. Several studies measured outcomes relating to different aspects of psychological well-being, including neuropsychiatric symptoms like depression, anxiety and agitation, which have historically been classified as BPSD in the dementia literature. Thompson et al. (2021) mention the risk of stigma and lack of acknowledgment of other potential causes that may trigger such “symptoms”, such as an inadequate environment or support, and reliance on imperfect pharmacological treatments. Therefore, they use the term “psychological well-being” when describing the outcomes in the reviewed studies (p. 10).

A similar issue appears in a metanarrative review by Dowson et al. (2019) examining the indicators and measure instruments which had been used to evaluate the impact of music on the health and well-being of people with dementia.[44] The

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[44] They began with Kuhn’s theory about scientific paradigms and especially his fourth domain: the instruments which are accepted as tools for measurement.

review, which covered 163 papers, highlighted not the findings of the studies but the ontological and epistemological positions underlying research within this field. Music and dementia research, after all, has evolved within different disciplines including music therapy, nursing and psychology, and its outcome measures have often focused on a reduction of neuropsychiatric symptoms like anxiety, depression or adverse behaviour and especially agitation, which was frequently measured.

Even measurements of well-being or quality of life were often linked directly to the absence of neuropsychiatric symptoms, and Dowson et al. (2019) point out that only one study even used the phrase “promoting wellness”: “This raises questions about whether quality of life is represented by the presence of a positive state of being, or whether it is simply the absence of negative symptoms which detract from wellbeing” (p. 29). The authors argue that if researchers focus predominantly on symptom reduction, they risk ignoring part of the spectrum of music’s potential benefits. They suggest that measuring an increase in positive responses might be an alternative to measuring a reduction in negative symptoms.

Dowlen et al. (2022) go beyond the dominant pre/post-intervention approaches altogether to advocate for a broader use of music for home-dwelling people living with dementia and an “in-the-moment” approach to musical experiences in the context of dementia. They argue that this position addresses the gap in most existing music and dementia research, which mostly conveys a biomedical narrative:

> Here, music is considered as an “intervention” of which success, or failure, is measured against the reduction of a range of “behavioural and psychological symptoms of dementia” (BPSDs), […] which leaves the subjective musical experiences during the period of engagement significantly undervalued and under-reported. (Dowlen et al., 2022, p. 2643)

A plausible reason why biomedical measures and approaches have dominated music and dementia research connects to professional strategies: “For music therapy to be recommended in health guidelines at a national level, there is a need for systematic reviews and meta-analyses and therefore a need for more randomised controlled trials” (Ridder, 2019, p. 315). Ridder also underscores the impact of a broader research perspective on the development of best practices and a better sense of how music works and might be applied for people with dementia in their daily lives and relations (p. 315).

Existing clinical assessment batteries – largely dedicated to BPSD – may be easier to quantify than “golden moments”, social inclusion or smiling faces, of course. A much-reported trend in mixed-methods studies is that beneficial outcomes from the qualitative part of the study are frequently not mirrored in the quantitative part of the study. As the studies by Dowson et al. (2019) and Dowlen et al. (2022) and the research within “artful dementia” and “creative care” referred to in Chapter 2.6 indicate, efforts are underway to approach music and dementia with more resource-oriented attitudes. A focus on embodiment is often part of such approaches.

4.3 Embodiment, cognition and memory

4.3.1 Embodied cognition

The field of *embodied cognition* challenges the dominant views of the mind in the traditional cognitive sciences. According to Wilson and Foglia (2017), proponents of several different directions within the field of embodied cognition agree upon a common base, formulated in what is known as the *embodiment thesis*:

> Many features of cognition are embodied in that they are deeply dependent upon characteristics of the physical body of an agent, such that the agent’s beyond-the-brain body plays a significant causal role, or a physically constitutive role, in that agent’s cognitive processing. (Wilson & Foglia, 2017, p. 14)

Wilson and Foglia hold that embodied cognitive science can ascribe three distinct functions or roles to the body: (1) as a constraint on cognition, (2) as a distributor for cognitive processing, and (3) as a real-time regulator of cognitive activity (Wilson & Foglia, 2017, p. 18). Further, they see no general rupture between cognition, bodily experience and real-life contexts. Within embodied cognitive science, that is, cognition is viewed as a result of the dynamic interplay of both neural and non-neural processes. Understanding how the body constrains, distributes or regulates cognitive processing in particular environments “raises the prospect that cognition itself is neither bounded by the brain, nor perhaps even by the body itself" (Wilson & Foglia, 2017, p. 19).

This has profound implications for how we understand and perceive cognition, embodiment and the environment in the context of dementia outside of the biomedical perspective. Accordingly, people with this cognitive deterioration could be offered more holistic and constructive approaches and facilitation to support these bodily and environmental contributions to their cognitive capacity.

Wilson and Foglia (2017) refer to several examples of experimental research that challenge traditional cognitive science in favour of embodied cognitive science (pp. 20–23). Such research points toward cognition's profound reliance on "processes evolved to allow organisms to interact effectively with the environment" (p. 23). Furthermore, they point out that while it is not always clear *how* the dynamic interplay between innateness and learning proceeds, most researchers today recognise that cognition develops because of it (p. 27). They note that empiricists generally view the world as an objective entity presented to an individual, which leads to the formation of a fixed representation that guides the individual's actions. Contrarily, embodied cognitive science addresses how the interactive relationship between an embodied agent and the world produces cognition: "It is this focus on dynamic, worldly interplay that provides one link from embodied to embedded cognition within situated cognitive science". (Wilson & Foglia, 2017, p. 28).

At the end of their extensive review and discussion of the foundations of embodied cognitive science, Wilson and Foglia (2017) state that they "think there is broad empirical support for the idea that sensorimotor activity and central cognitive processing are more deeply dependent on one another than previously thought" (p. 47). If cognition, then, is embodied and embedded, this has important implications for how we regard the condition and symptoms of dementia, as well as singing and music and a host of related issues. Memory is one such issue closely connected to our perception of dementia.

4.3.2 Implicit versus explicit memory in dementia

Memory loss, or more precisely, the loss of *explicit memory*,[45] is often an initial sign of the most common forms of dementia, like Alzheimer's disease and vascular

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[45] Explicit memory is also often referred to as "declarative memory".

dementia. Other forms of dementia, such as frontotemporal dementia, however, may have more striking behavioural indications. There are two forms of explicit memory: *semantic memory*, which refers to general knowledge, and *episodic memory*, which is connected to specific personal experiences. *Autobiographical memory* is based on a combination of semantic and episodic memory. The categorisation of dementia into mild, moderate and severe stages is also connected to the perceived degree of explicit memory loss (Harrison et al., 2007, p. 287) (Waage, 2022, p.335).

Explicit memory is a conscious, often intentional effort to recollect prior experiences and facts, whereas implicit memory[46] involves the influence of prior episodes on current behaviour without intentional retrieval or even, at times, the conscious remembering of those prior episodes (Schott et al., 2005, p. 1257; Son et al., 2002, p. 264) (Waage, 2022, p. 335). Fuchs (2020) highlights four forms of implicit memory:

1. *Procedural memory* implies the sensorimotor capabilities of the body, such as well-practised habits and skills, and familiarity with repeated or practised patterns of perception. Such skills enable us to perform many types of tasks without conscious awareness of the previous experiences.
2. *Situational body memory* enables us to recognise and skilfully cope with familiar spatial situations, such as habits and movement patterns adapted to well-known environments – like the childhood home – where the body connects and interacts with environmental affordances.
3. Intuitive non-verbal communication with others, based on *inter-corporeal memory* – including the *implicit relational memory* referred to in infant research – goes back to earliest childhood and implies embodied patterns of social interaction imprinted in the body long before the development of autobiographical memory.
4. Individual habits, attitudes and roles inform what Fuchs has termed *incorporative memory* because it is often taken over from others and incorporated as an embodied personality structure (Fuchs [2020] connects this to the *habitus* in sociology).

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[46] Implicit memory is sometimes referred to as unconscious memory or automatic memory.

Koch, Caldwell and Fuchs (2013) also include (5) *pain memory* and (6) *traumatic memory* in their classification of embodied memory.

Fuchs (2020) holds that implicit, embodied memory is a constitutive part of personal history and individuality:

> We see how the continuous embodiment of existence produces a form of memory which from birth on integrates a person's past into her present bodily constitution. Far from ensuring solely an anonymous, pre-reflective existence, the habitual body always forms an excerpt of personal history. It is the expression of our individuality at all levels, not just in the sophisticated ways of self-reflective thought, autobiographical memory or verbal interaction. (p. 669)

Koch et al. (2013) point out that explicit memory recollection is directed from the present back to the past and describes the "knowing what", while implicit memory conveys a tacit "knowing how" and does not represent the past but rather "re-enacts it through the body's present performance. Hence, body memory is our lived past" (p. 84). *Priming* is a smaller subset of implicit memory which involves using stimuli or cues to induce recognition of information or experience.

Due to the different forms of memory, there are also different ways of retrieving information. *Recalling* information involves explicit memory and is often much harder for people with dementia than *recognising* information, which draws on implicit memory (Sabat, 2008, pp. 72–73):

> Thus, although the ability of a person with AD [Alzheimer's disease] to recall information may be compromised, the ability to recognize the same information may be less compromised, and the ability to learn new information can be intact, even if the person does not recall having learned that information. (Sabat, 2008, p. 73)

Explicit and implicit memory are claimed to be separate neurological systems, processing and storing memories in different brain regions and depending on different neural pathways (Harrison et al., 2007, p. 287; Schott et al., 2005). While explicit memory gradually deteriorates due to the progression of dementia, implicit memory persists and may, therefore, play a more important role than previously, also in dementia-care strategies (Harrison et al., 2007; Son et al., 2002) (Waage, 2022, p. 336).

Son et al. (2002) point out that infants are born with the ability to acquire habits and skills, whereas explicit memory matures slowly. Thus, patients with dementia or amnesia can maintain previously developed habits and skills for two reasons. First, there are two distinct neural systems in the brain from infancy in humans. Second, these habit and skill systems are formed before the damage or disease (e.g., dementia) affects the brain and are generally not harmed by disease. Once the brain has formed a neural representation of a stimulus or experience, this stored representation "can be retrieved by stimulus cues through a process of associative recall and stimulus-response mechanisms" (Son et al., 2002, p. 265).

In other words, much of our early experiencing and learning of habits and skills depend on implicit memory, and these neural networks are less affected by dementia. The hippocampus is essential for explicit memory and is one of the first areas affected by Alzheimer's disease whereas, according to Fuchs (2020), implicit memory largely remains unimpaired even in the late stages of dementia. Thus, people with dementia can retain abilities within all the forms of body memory described above. However, Fuchs also points out that the realisation of such abilities is linked to "appropriate, complementary conditions of the surroundings" (Fuchs, 2020, p. 670).

In 1979, James J. Gibson introduced the concept of *affordances* to describe the relationships between organisms and their environments: "The affordances of the environment are what it offers the animal, what it provides or furnishes, either for good or ill" (Gibson, 1979, p. 127, as cited in Chong & Proctor, 2020, p. 118). The concept was originally developed in the context of ecological psychology but has since been transformed – and, some would say, misused – beyond its original context and intention (Chong & Proctor, 2020; Dotov et al., 2012). Affordances are part of the "complementary conditions" referred to by Fuchs. However, the physical environments, and the surrounding people's behaviours, may also be actively shaped and adapted to enable or support another person's implicit, embodied memories and skills. Moreover, through cues or "triggering" experiences (priming), those memories and skills can be recognised and activated.

Singing and music provide such cues with the potential to connect the person with previous life events and autobiographical memories (Baird & Samson, 2015, pp. 224–225; El Haj et al., 2015). Musical memories and their autobiographical implications do not unfold exclusively at the explicit memory level but also manifest as implicit or procedural, embodied memories providing (or reviving) atmospheres, associative stories, images, feelings, movements or skills, thus offering a sense of familiarity and safety (Fuchs, 2020, p. 671; Tomaino, 2013, pp. 238–240). Hence, singing might create a "bridge over the troubled water" of disorientation and confusion following symptoms of dementia and guide the person into a "safe harbour" of familiarity and sense of identity and embodied connection.

On the other hand, there may also be a small risk that music can invoke less pleasant memories or even trauma. In the vulnerable state of dementia, a variety of different stimuli may trigger unpleasant as well as pleasant memories or associations, and music is no exception (Waage, 2022, p. 337). Silverman et al. (2020) have addressed the need for an awareness of the complexity of potential music-induced harm, for instance due to overstimulation or the triggering of adverse memories.

Still, the literature on music and dementia generally promotes music interventions as safe, with "little capacity to do harm" (Nair et al., 2013, p. 50). Moreover, as Anne Basting points out (Mittner et al., 2022), the possible "harm" of music or other artful engagements must be put into context and proportion: "Some of the drugs that elders take have side effects that are incredibly harmful, or even deadly. As far as I know, no one has ever died of poetry. Or shaping sounds or gentle movements into a story" (p. 31). Furthermore, several studies and reviews point out that, regardless of the music intervention approach, individualised music regimens provide the best outcome for the patient (Leggieri et al., 2019; Nair et al., 2013, p. 50). Making individual adjustments and carefully choosing the songs or pieces presumably also minimises the risk of harmful or unpleasant experiences.

As such, individualised approaches to music and dementia fit well with dominant trends in present dementia care and research founded on the principles of person-centred dementia care.

4.4 Personhood and person-centred care

4.4.1 Person-centred dementia care

Dementia researcher Tom Kitwood's *person-centred care* model (Kitwood & Brooker, 2019) is widely recognised within dementia care. Person-centred care acknowledges each person's intrinsic value and uniqueness and focuses on inclusion, individuality and dignity while respecting and responding to the person's perspectives, preferences and needs. Person-centred dementia care involves the provision of an overlapping cluster of five primary psychosocial needs: *comfort, attachment, inclusion, occupation* and *identity*, coming together in the all-encompassing need for *love* (Kitwood & Brooker, 2019, p. 92).

Kitwood (1997) describes identity as knowing who one is, with some sense of continuity to the past and consistency across the course of present life. He also links identity to a personal "narrative" about oneself and one's life. Further, he holds that identity, to some extent, is conferred by others because their responses convey subtle messages about how the person is perceived. As dementia progresses, he notes, others may therefore play a central role in maintaining the person's identity:

> Many of the sources of identity are taken away in dementia, the causes being both neurological and social-psychological; narrative identity may survive for a considerable time, but even that is likely to be taken away as cognitive impairment advances […]. If identity is to be maintained, then, it will be very largely on the basis of what others provide. (Kitwood, 1997, p. 20)

Kitwood brings the philosophically well-established and much debated notion of personhood to life in the context of dementia care, defining it as "a standing of status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood & Brooker, 2019, p. 19). Moreover, he argues that the prime task of dementia care is to maintain personhood "in the face of the failing of mental powers" (Kitwood, 1997, p. 20). He suggests that this can be done through a sensitive, and individually adapted, meeting of the mentioned cluster of psychosocial needs and adds that providing these needs may entail several virtuous circles, enhancing the overall sense of self-worth and enabling the person to move "out of fear, grief, and anger, into the domain of positive experience" (Kitwood, 1997, p. 20).

In contrast to this person-centred provision of needs, Kitwood points to what he terms "malignant psychosociology". This draws attention to the ways in which the environment may also negatively influence the behaviour and well-being of the person with dementia. Hence, person-centred dementia care shifts the emphasis from pathology to understanding the meaningfulness of behaviours.

On the other hand, Fletcher (2020) points out a potential pitfall in contemporary iterations of person-centredness which place too much emphasis on individualism without sufficient consideration of relational issues. From the dyadic perspective – and based on current research – he addresses the risk of turning from one dichotomy of “bad versus good” to another:

> Whereas the “carer as victim” concept positioned people with dementia as causes of burden […], person-centredness has cast people with dementia as victims of carers’ “malignant social psychology” […]. Victim and perpetrator have swapped roles. […] It reifies people’s complex experiences into narrow good or bad categories; and in venerating one party, it ascribes negativity to the other, cleaving dyads into two individuals. (Fletcher, 2020, p. 710)

Nevertheless, Kitwood’s model offers an essential alternative to biomedical explanations: “According to a person-centred approach to dementia care, challenging behaviours are regarded as communicative behaviour and an attempt to express unmet psychosocial needs” (Ridder, 2019, p. 312). This is contrary to the biomedical paradigm, which generally entails an understanding of adverse behaviour as the result of the degenerative disease[47] rather than acknowledging relational and environmental – or discursive – factors.

4.4.2 From challenging to responsive behaviours

In an interview study, Dupuis et al. (2012) explore the influence of the biomedical paradigm upon the ways in which caregivers in long-term residential care attach meaning to behaviours. While other scholars have also addressed the relational impact on behaviour in dementia care – for example, through the lenses of person-centred or relationship-centred care – they extend the approach beyond individual relationality at the microlevel to include broader social and discursive impacts. The caregivers they studied perceived the behaviours of people with dementia through a pathologizing lens due to their education and training. While some also saw the behaviour as conveying and communicating meaning, they made little effort to

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[47] As pointed out in Chapter 2.2.1, the ICD-11 even codes different “psychological and behavioural disturbances” as additional diagnoses entailing the primary dementia diagnosis.

understand or address it. One example of how even people with dementia anticipate possible misunderstandings is the “warm-blooded” man with early-stage dementia recalling how he joked with his children that he might find his future long-term care facility too warm: “I’m going to remove my clothing because I’m hot. And I will be labelled as sexually inappropriate, but it will be the heat” (Dupuis et al., 2012, p. 163).

The authors conclude that the biomedical and pathologising discourse not only influences how caregivers interpret the behaviour but also how they respond to it via crisis management. Based on input from the dementia community, they propose the term “responsive behaviour” as an alternative to the pathologising lens of “challenging behaviour” and call for a discourse that emphasises multidimensional lenses for the perception of actions and behaviours. Paradoxically, a biomedical lens may not even capture the biomedical conditions as such because its focus on cognitive impairment and supposed BPSD[48] may mask other physical issues. For instance, pain is highly prevalent among nursing home residents with dementia (Helvik et al., 2021): “Undiagnosed and untreated pain may trigger neuropsychiatric symptoms such as aggression, psychosis, affective and apathy symptoms” (p. 2). More mundane issues or needs can also be interpreted as adverse behaviour, which I have also experienced in my work as a therapeutic musician:

> *I am singing and playing my harp during a music and sing-along session in the living room of an assisted living dementia department. One of the residents who is usually attentive to my sessions is uneasy and frequently tries to get up from her chair. A nurse aide repeatedly hushes her and silently but insistently – even physically – guides her to sit down. I feel awkward but cannot interfere in my role. Luckily, the session is coming to an end anyway. As soon as the session is finished, the resident tries to get up and insistently asks for help. It turns out that she desperately needs to go to the bathroom.*

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[48] behavioural and psychological symptoms in dementia

4.4.3 The psychosocial model for music in dementia

Biomedical approaches have influenced much research on music and dementia; still, resource-based approaches to music therapeutic interventions and care often – explicitly or implicitly – draw on the principles of person-centred care mentioned above. McDermott et al. (2014), for example, conducted a qualitative study involving people with dementia, family members, care staff and music therapists and developed a psychosocial model for music in dementia care. The study's findings and model resonate with Kitwood's concept of person-centred dementia care. "The accessibility of music for people at all stages of dementia, close links between music, personal identity and life events, the importance of relationship-building through music making were particularly highlighted as valuable" (McDermott et al., 2014, p. 706). Based on the study, the authors developed the psychosocial model of music in dementia, which demonstrated the importance of music in supporting the care home's psychosocial environment as well as the residents' personal psychology.

Kitwood's influential contributions to dementia research are highly valued in the academic and healthcare communities, even as discussions concerning selfhood and embodiment continue to address the limitations of person-centred care.

4.5 Personhood reconsidered

Several scholars within sociology and posthuman theory have criticised the concept of selfhood in person-centred dementia care. There are two main directions of critique: one involving the *form* of selfhood described (Fuchs, 2020; Jenkins, 2014; Kontos, 2004, 2005) and the other involving the adequacy of the notion of selfhood altogether (Quinn & Blandon, 2020, pp. 4, 23–38).

One point of departure when discussing personhood and dementia concerns the research on dementia, memory and embodiment discussed earlier in Chapter 4.3.2. While Fuchs (2020) acknowledges that reflectivity and autobiographical memory are crucial to our sense of identity, he also underlines the importance of intercorporeality and interaffectivity as foundations of the self which remain viable despite severe dementia:

> In body memory, the past continues […] as organically accumulated and sedimented history, and it becomes effective in our personal forms of

> perception, behavior and interaction, without our being conscious of their particular origins. It is on this continuity and memory of the lived body that the identity of the patient [with dementia] is still founded. (Fuchs, 2020, p. 674)

4.5.1 Embodied selfhood

In line with Fuchs, Pia C. Kontos (2004) challenges the mind/body dualism, which she argues underlies the assumed loss of selfhood in the current fear-provoking construction of Alzheimer's disease and other forms of dementia. While linking selfhood primarily to cognition and memory is deeply rooted in Western philosophy, she advocates instead for a theoretical framework of embodiment drawing on perspectives from Merleau-Ponty and Bourdieu. Her central claim is that "selfhood is embodied and characterised by an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body" (Kontos, 2004, p. 831). Her ethnographic study of residents in a dementia-care facility demonstrates the embodied properties of selfhood through its rich sampling of behavioural observations and analyses (Kontos, 2004). Kontos' notion of *embodied selfhood* "captures the idea that fundamental aspects of selfhood are manifested in the way the body moves and behaves" (Kontos, 2005, p. 556).

Kontos (2005) then develops her concept of embodied selfhood in the context of person-centred care. She acknowledges Kitwood's much-needed focus on the importance of psychosocial factors. However, she argues that the embodied aspect of personhood is still largely missing in this context since the selfhood of the person with dementia is supposed to progressively fragment and dissolve due to cognitive deterioration and must be sustained by caregivers. Although person-centred approaches to dementia care increasingly use and value multi-sensory stimuli and activities, Kontos (2005) argues that agency and selfhood in this context are still mainly linked to cognitive capacity, while the body is treated as a substituting instrument for expression and communication to compensate for the cognitive deterioration. Kontos advocates for directing person-centred care toward both acknowledging and addressing embodied selfhood and especially the body's agency.

Kontos and Martin (2013) argue that this attention to embodiment in dementia care "offers a more comprehensive understanding of the body by illuminating the complex interrelationship between the body, the interactional, environmental, socio-cultural, and broader socio-political landscapes that influence care practices and the experiences of persons with dementia" (Kontos & Martin, 2013, p. 294). Further, it shifts the focus from dysfunction and control to the support of intentional, meaningful and creative means of expression and the embrace of a broader range of behaviours and relational opportunities. Lastly, they argue that arts-based approaches to person-centred dementia care "draw significantly on the body's potentiality for innovation and creative action and significantly support non-verbal communication and affect" (Kontos & Martin, 2013, p. 294).

4.5.2 Relational citizenship

Kontos' earlier articles (2004, 2005) give the impression of embodied selfhood as anchored within a concept of selfhood as *individual*. In her later articles, however, she increasingly underscores the broader relational aspects of embodied selfhood. Kontos et al. (2017) describe developments in dementia care and the newer paradigms intended to address limitations in person-centred care: especially relationship-centred care addressing "the decontextualising of the individual from relationships with others and the ways in which issues of agency and power differentials are profoundly ignored" (p. 183). However, the authors point out that

> even within relationship-centred care, the focus remains on care relationships, thus overlooking other relationships that individuals might have, such as those with the state and its institutions. Consequently, the person with dementia continues to be solely conceptualised within the in need-of-care context. (Kontos et al., 2017, p. 183)

To redress some of the limitations of both person-centred and relationship-centred care, then, Kontos et al. (2017) develop and integrate a *relational citizenship model* as a framework which also encompasses human rights and socio-political implications. The model is an extension of social citizenship, which in the context of dementia is defined as follows:

> A relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to

> grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (Bartlett et al., 2010, p. 37, as cited in Kontos et al., 2017, p. 184)

Kontos and various colleagues (Kontos & Grigorovich, 2018a; Kontos et al., 2017) argue that the model of relational citizenship extends the model of social citizenship and expands beyond the limits of person-centred and relationship-centred care "by drawing on insights from critical and cultural gerontology's theoretical subfield of embodiment and dementia" (Kontos & Grigorovich, 2018b, p. 41). Kontos and Grigorovich (2018b) also hold that the relational citizenship model recognises that corporeality is a fundamental source of self-expression, interdependence and reciprocal engagement. Engagement with music holds significant potential for such embodied, relational creativity.

4.5.3 Embodied and relational musicality

Kontos and Grigorovich (2018b) introduce important aspects to the discourse on music, ageing and the body through relational citizenship by analysing the musicality of two residents in long-term dementia care, Abe and Betty, as it forms a creative and relational part of their daily life. They draw on Merleau-Ponty to argue that the resilience of the residents' musical expressions could be understood as embodied know-how and practical sense – that is, "a perspectival grasp of the world from 'the point of view' of the body" (Kontos & Grigorovich, 2018b, p. 45). This musical engagement is not fostered by pre-planning and a cognitive form of consciousness but is instead a bodily form of consciousness or a manifestation of the body's pre-reflective ability to direct itself towards the world:

> Their creative and spontaneous acts render visible how musicality emanates from the body as a generative spontaneity which asserts itself in an improvised engagement with the world. The idea emphasized here is that musicality entails an intrinsic intercorporeality of being-in-the-world, a positioning and directionality that is inherently primordial and relational. (Kontos & Grigorovich, 2018b, p. 45)

This has profound implications for the potential of relational singing for people living with dementia and their close ones. Another important contribution to the discussion of personhood, identity and relationality is the framework of *dividuality* from cultural anthropology.

4.5.4 Dividuality

Hoppe (2020) discusses the concept of *dividuality* based on the case of a family committing to long-term care for their husband and father with early-onset dementia. She uses the framework of dividuality to explore the family dynamics which an individual framework tends to overlook:

> The individual is seen as indivisible; it has an essential core which defines it. The individual is atomistic, an autonomous social actor, a free agent, and the author of his or her own actions. The dividual is seen as divisible, containing interrelated dimensions. The dividual is fractal, socially embedded, performs a culturally written script, and is defined by cultural structures. (Hoppe, 2020, p. 233)

Hoppe points out that research on person-centred care, even as it acknowledges the relational aspects of personhood, views the maintenance of personhood for the person with dementia as a compensating and unidirectional act originating with the healthy carer. Hoppe, on the other hand, demonstrates that the relational, dividual aspects of personhood are reciprocal, multifaceted and changing. Most relational dementia research has been subjected to dyads, but Hoppe advocates a systemic approach encompassing the broader family dynamics as well. She notes that the different family members, including the person with dementia, contain each other's values, wishes, and needs in a way that continually shapes and reconfigures their identities.

Hoppe uses dividuality as a conceptual tool even though she admits that anthropologists nowadays find that the division between individual and dividual cultures is not straightforward and that the self is characterised by both.

4.5.5 The dividual, inter-embodied self

Jenkins (2014) also challenges the humanist concept of individual selfhood promoted and operationalised through "person-centred" approaches to health and social care. He points out that the individuality of selfhood is a peculiarly Western construction, whereas other cultures more readily acknowledge dividual aspects of personhood. The dividual is widely covered in the anthropological literature but, according to Jenkins, "has received surprisingly little attention in relation to dementia" (Jenkins, 2014, p. 129).

Referring to Geertz (1975), Jenkins (2014) holds that dividuality is based on the belief that people are created through processes of transaction and sharing (p. 129). Jenkins, therefore, proposes an alternative approach to the humanist notion of the individual self which he labels the *inter-embodied self.*[49] He argues that the process of "becoming-self" is achieved through dialogical (self–other) interaction at the reflexive (discursive) and pre-reflexive (embodied) levels (p. 126): "Embracing this intercorporeal aspect of the self, therefore, is to recognise the ways in which selfhood is transacted, pre-reflexively, through embodied interaction" (p. 130). Jenkins argues that our inter-embodied selves can be conceptualised as montages in which polyphonic repertoires of voices and experiences coexist in dialogical relationships which are constantly updating and changing (p. 133). One implication of this for dementia care is that "the primary goal of practitioners should not be the fixing, reviving or re-unifying of a pre-morbid self but, instead, enabling a rich and polyphonic montage of selves to emerge" (p. 125).

Jenkins (2014) suggests three core principles for promoting a montage of selves: the respect for dividuality, the encouragement of dialogicality and the embrace of intercorporeality (p. 128). Further, he holds that aspects of the embodied self, such as gestures, movements and mannerisms, are not solely individual but may be transmitted and enfolded through embodied interaction: "Embracing interco[r]poreality in dementia therefore involves promoting and celebrating the sharing of embodied selfhood" (Jenkins, 2014, p. 131). Such sharing of different aspects of the embodied self can be conveyed visually and audibly.

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[49] Daniel J. Siegel's (2022) book *IntraConnected: MWe (me + we) as the integration of self, identity, and belonging* adds interesting perspectives and nuances to the discussion of the dividual inter-embodied self, but its argument is too extensive to dive into here.

4.5.6 The audible body and "voice shame"

Different forms of vocal sounding, including singing, represent one means of sharing (inter-)embodied selfhood, and Schei et al. (2019) introduce the related concept of the *audible body*. They note that body language, relational behaviour and the display of emotion are "subtly interwoven with characteristics and qualities of the voice" (p. 200):

> By talking about "the audible body", not "the voice", we want to highlight that when people hear each other, or know they are being heard, they inevitably produce complex, tacit, normative interpretations not only of the sound, but of the person whose sound it is […], and of the person's presentation of self […]. (Schei et al., 2019, p. 198)

Schei and various colleagues (Schei & Schei, 2017; Schei et al., 2019) underscore the voice as an intrinsic part of one's self-expression and acknowledge the vulnerability and shame connected to the rejection or disapproval of that voice. Schei and Schei (2017) describe the term *voice shame* – coined by Tiri Schei in 1998 – as "the uncomfortable feeling of being heard as ridiculous, worthless or 'not good enough'. Voice shame arises when a subject becomes aware of an observer's attention and believes the evaluation to be negative" (p. 1). If one is ridiculed or rejected based on voice performance, the consequences can be severe, even lifelong, as we will see in Chapter 7.8.3.

However, at best, sharing and entangling audible bodies – for instance, when singing together – can unfold as an intercorporeality "promoting and celebrating the sharing of embodied selfhood", as Jenkins (2014, p. 131) puts it. The relationality and unfolding of audible bodies can also encompass post-verbal expression (Quinn & Blandon, 2017, 2020), as mentioned in Chapter 2.6.2.

4.5.7 Post-verbal communication and agentic assemblages

Quinn and Blandon (2020) rely on several posthuman thinkers to focus on acts and bodies (Braidotti, 2013), intra-activity (Barad, 2007) and the agency of things (Bennet, 2010) and begin to transcend the idea that being is intrinsically linked to memory and vice versa. In turn, they argue that a posthuman approach "validates people living with dementia and recognises other forms of being and learning that are not about speech and memory. It also seeks to challenge old certitudes regarding identity and subjectivity" (Quinn & Blandon, 2020, p. 65). They draw further upon the research of Zeilig et al. (2018), Kontos (2004) and Jenkins (2014) to contest the loss narrative of dementia and discuss and claim other forms of selfhood. While articulating similar positions regarding memory and experience, Quinn and Blandon (2020) also argue that these scholars "still speak in terms of 'self', albeit a self that is differently constituted" (p. 4). Ultimately, they prefer to move beyond notions of the self altogether and see people with dementia in terms of Bennet's "agentic assemblages" and Barad's "intra-activity".

> Rather than constantly seeking to restore people with dementia to their former state and to the anchoring of memory, we seek to validate their ways of being and explore them. As such, we focus not on them as individual selves but as parts of "agentic assemblages". (Quinn & Blandon, 2020, p. 12)

In an interview with Juelskjær and Schwennesen (2012), Barad touches on the notions of self and individuality:

> It's crucial to raise the question of how "the individual" […] is iteratively (re)constituted. […] Derrida might remind us that an autobiography is not a telling of a past that is present, but the ongoing openness of the narrative to future retellings […] it is a question of inheriting the future as well as the past. (Juelskjær & Schwennesen, 2012, p. 11)

The openness to future narratives and "inheriting the future as well as the past" recalls what the research discussed to this point has stressed in different ways: There is considerable potential for other ways of living and relating if we abandon the notion of a fixed selfhood suffering from fragmentation due to dementia.

4.5.8 Towards a "polyphonic personhood"

There is a considerable gap between the person-centred humanist notion of self closely connected to individuality, autobiography and identity and the posthuman approach to the person as part of an agentic assemblage (Quinn et al., 2021). Presumably, there is much to gain by avoiding a restricted, conforming, cognitively based sense of selfhood which implicitly – though not intentionally –

side-lines people with dementia as less than human.[50] Taking inspiration from the research outlined above, I will continue to explore the potential for a less intrinsic notion of self – one that uses the inter-subjective and inter-embodied notions of selfhood to move towards a greater sense of openness and multiplicity.

Still, I will not abandon the notion of self altogether, as Quinn and Blandon (2020, pp. 4, 23–38) seem to do. In Chapter 3.3.5, with regard to the researcher self, I argued that the de/centred researcher subject exists along a continuum, and the same could apply to selfhood more generally. Sometimes one may grasp the present moment with a strong sense of individual identity; other times, one may simply float along with various senses of time, space and immersive dividuality. Even along such a continuum, however, some underlying structural characteristics can still be identified.

One of Jenkins' inspirations for the inter-embodied self is the *dialogical selfhood theory* developed by Herman, and especially its notion of the *polyphonic self* (Jenkins, 2014, pp. 129–130): "Within our polyphonic selves […] exists a plurality of consciousnesses and worlds that develop in dialogical relationship with each other" (p. 130). According to Jenkins, enabling and sharing these polyphonic consciousnesses and worlds – either discursively or pre-reflexively through embodiment – is central to creating conditions for developing dialogicality in dementia care. Jenkins defines dialogicality "as the ability of the human mind to conceive and communicate in relation to otherness" (p. 29).

Chaudhary and Sriram (2001) discuss Herman's dialogical selfhood theory in terms of Indian culture. While they appreciate the "idea of a dialogically created and socially sustained dynamic self, which supposedly transcends cultures" (p. 379), they wonder about the way in which Herman operationalises his theory in psychotherapy. Their perspective on Herman's theory resonates with central aspects of the discussions of the self above and highlights the polyphony of voices, stories, roles and interactions:

> For most Indians, there are always a multiplicity of voices that shape the self. The stories of the past merge with those of the present to give shape to the stories that will outline the future. […] The "self" would be expressed

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[50] I will address the ethical implications of othering and stigma in Chapter 5.

> variously given the role it plays, and the interactions encountered. (Chaudhary & Sriram, 2001, p. 381)

The authors also comment on Herman's intertwining of self and culture: "Here is the departure from the dualistic notion of self and other. Rather, the social interactions involved in relationships emerge as predominant, shaping the self through dialogue with individuals in different zones and voices" (Chaudhary & Sriram, 2001, p. 381). They remark that the musical metaphor of polyphony initially used by Bakhtin is apt as a descriptor of the multi-voiced construction of the self theorised by Herman. They then link Herman's theory to Shore's *The culture of mind* (1996), which also refers to polyphony. Shore begins by describing the mind as a relationship between the nervous system and a large set of external and internal models on which it feeds (p. 7). To encompass the complexity of experience, he suggests that "human consciousness might be referred to, using a musical metaphor, as 'polyphonic'. A thick and complex texture of conscious experience is made possible by the simultaneous interaction of several 'layers' of different sorts of knowledge" (Shore, 1996, p. 93).

Chaudhary and Sriram's perspectives add depth to the ways in which a multiplicity of interpersonal and intrapersonal processes shapes the polyphony of voices in the dialogical self. Although they do not discuss embodiment as such, their reference to Bakhtin suggests their awareness of the body's role in this polyphony:

> Life by its very nature is dialogic. To live means to participate in dialogue: to ask questions, to heed, to respond, to agree, and so forth. In this dialogue a person participates wholly and throughout his whole life: with his eyes, lips, hands, soul, spirit, with his whole body and deeds. (Bakhtin, 1929/1984, p. 293, as cited in Chaudhary & Sriram, 2001, p. 381)

In a different field of study, Moe and Sidorkin (2019) argue that there is a need to rethink the understanding of the self within educational theory and propose the *polyphonic embodied self* – based on Bakhtin's theory of polyphony and the carnival – as a means of interrogating educational organisations:

> "The grotesque body, as we have often stressed, is the body in the act of becoming […] The body swallows the world and is itself swallowed by the

> world" (Bakhtin, 1984, p. 317). To be in dialogue, we need a certain way of physical being, a playful relation to our own and to the collective body. (Moe & Sidorkin, 2019, p. 32)

In the following, I will adopt and adapt a notion of "polyphonic inter-embodied personhood" – shortened to "polyphonic personhood" – as a conceptual tool with which to encompass the aspects of inter-corporeality highlighted in Kontos and various colleagues' research discussed above as well as the montage proposed by Jenkins (2014) without explicitly speaking of the *self*. Polyphonic personhood acknowledges the multiplicity of inter-corporeal "voices" playing out through, within and between people who can still be part of the broader agentic assemblage of Quinn et al. (2021). I would even suggest that the broader assemblage might be regarded as an overarching polyphony.

I find the musical metaphor of polyphony appealing for several reasons. The concept of diffraction is already deeply connected to soundwaves, coherence and interference – and thus to music – as described in Chapter 3.2.4. As people, we are fluent and contingent, both inhabiting and inhabited by the wider world. Still, within this indeterminate fluency, there are various ways and degrees in which we as be(com)ings experience our sense of self and subjectivity. Polyphony implies a melodic structure of multiple layers, within which each tone is itself a multiplicity of overtones (harmonic and inharmonic partials).[51] Each tone is intra-acting with and diffracting the multiplicity of frequencies of other melodies and their tones and overtones, thus creating multidimensional melodic structures and timbres.

As mentioned in Chapter 3.3.5, some posthuman thinkers use slashes to convey a term's simultaneously complementary and alternative aspects. Following this, I regard – and experience – the internal and external in/dividual personhood as a continuous process of de/composition and de/fragmentation. Internal and external life, thoughts and voices are part of who we are as in/dividuals but are still fluctuating fragments combining with other fragments – or melodies – of different

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[51] Most acoustic instruments emit complex tones containing many individual partials (component tones). However, the untrained human ear typically perceives a musical note as one sound. The quality or timbre of that sound results from the relative strengths of its individual partials. Partials which are near matches to integer multiples of the fundamental frequency (e.g., from string or wind instruments) are called "harmonic partials", while partials whose frequencies are not integer multiples of the fundamental (e.g., from drums and cymbals) are referred to as inharmonic partials. Many sound sources emit a mix of harmonic and inharmonic partials (e.g., piano, marimba, singing bowls) (https://en.wikipedia.org/wiki/Harmonic).

times and spaces and merging within different configurations of the polyphonic personhood and the broader, overarching polyphony.

Experiencing symptoms of dementia may add to this process of fragmentation and thereby foster confusion and even anxiety or fear. However, the surrounding people could refrain from re-iterating the notion of a “lost” identity which needs to be restored – which might merely add to the person’s sense of loss that often already follows dementia. Instead, they might embrace the polyphonic in/dividuality and approach fragmentation as natural and inherently human. Then, the enhanced polyphonic aspects which follow upon symptoms of dementia could even become resources for communication and interaction. In the context of dementia research, as well, polyphonic personhood enables a less restrictive and more inclusive sense of self, one which is adaptable and applicable to different contexts and conditions. For example, it may allow us to reframe some of the aspects and symptoms of dementia often problematised and inscribed in the discourse of “dementia as tragedy”,[52] including time slips and the following dis/orientation regarding memories, sites and people. The complementing and contrasting “melodies” or “dances” of inter-embodied polyphonic personhood can play out with both consonance and dissonance in different time spans and resonate in different physical and imaginative “locations” or spaces inhabited by the sensing, affective body. As such, it both comprises and displays diffraction and intra-action. Singing can activate some of the voices of the polyphonic personhood while giving voice to – and adding voices (lines/parts) to – both the personal *and* the overarching polyphony.

In the aforementioned research by Kontos (et al.), Jenkins, and Quinn (et al.), they primarily draw on observational studies and social or posthuman theory and philosophy in their arguments and models related to dementia, embodiment and selfhood. However, the foundational processes of non-verbal communication and creative embodied expression can also be seen in light of *communicative musicality* (Malloch & Trevarthen, 2009) or *proto-musicality* (Stige, 2012).

4.6 Communicative musicality or proto-musicality

Embodied and communicative aspects of singing connect to the *communicative musicality* model (Malloch & Trevarthen, 2014, 2018; Trevarthen & Malloch,

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[52] This will be discussed in Chapter 7.3.4, “Stigmatising discourses – dementia as tragedy”.

2000), which was developed out of extensive research on mother–infant communication and interaction. Acoustic and video analysis of non-verbal communication between mothers and infants uncovered fine-tuned, musical and gestural interactions which the authors position as precursors of language, rituals, and artistic expression. They define this innate communicative musicality according to three main elements: *pulse*, which implies rhythmic patterns and turn-taking; *quality*, which describes the fine-tuned modulation of voice as well as imitation or mimicking and gestures; and *narrative* (pulse and quality coming together), which captures the meaningful communication in these non-verbal vocalisations and gestures. Referring to Dissanayake (2000), to whom I will return, Malloch and Trevarthen (e.g., 2014) argue that this form of communication is an evolutionary adaptation intended to allow immature, highly dependent infants to communicate and bond with their caregivers. The model of communicative musicality resonates with Bjørkvold's (1992) notion of *the Muse within*, which refers to ancient Greek mythology:

> The Muses – the divine muse-ical [*sic*] beings – were created precisely to give the world the voice that had been lacking. They were a manifestation of life, just as the primal cry of the newborn infant is a manifestation of life. Seen in this light, all playing and singing children are the legitimate heirs of the Muses. The Muses, then, according to the ancient myth, gave the universe an audible voice – a voice that could create new universes of pictures and concepts of the mind. […] New worlds can be created through something as direct and simple as song. (Bjørkvold, 1992, p. 55)

Bjørkvold's studies and descriptions of children's spontaneous musicality as it unfolds in play, learning and living are referred to in the work on communicative musicality. Bjørkvold, for his part, cites Trevarthen's mother-infant research.

Music therapists turn to communicative musicality to shed light on the therapeutic effect of music and the music therapist–client relation. However, they also emphasise that the musical interplay in music therapy implies a very different relationship from that of mother–infant communication. Rolvsjord (2002) notes that since both the client and the music therapist generally draw upon substantial musical experiences and memories, the musical meaning will also be connected to narrative and symbolic content. She considers this an additional resource, however, on top of musical communication’s more direct or immediate meaning (pp. 29, 30).[53]

In the context of dementia, the principles of communicative musicality point to the utility of singing and/or paying extra attention to prosody (voice modulation), timing and gestures in spoken communication. In this way, one may draw upon (innate) non-verbal – or post-verbal – communication skills: “Rooted in the infant’s implicit, preverbal, embodied memory, singing and communicative musicality can enable communication and ‘narrative’ even when the loss of explicit memory and language makes verbal communication challenging. Thus, the communicative potential of singing […] is actualised by the way in which memory mechanisms and embodiment operate during the progradation of dementia” (Waage, 2022, p. 337).

An example of this arises in an interview in the music intervention study by Quinn et al. (2021) mentioned in Chapter 2.6.2, where participating music leaders commented that the care home residents with dementia who otherwise struggled to communicate retained their ability to sing. After increased music stimulation, they were even able to “have some sort of conversation and might even communicate using a line of the song” (p.82), socially engaging while singing to each other.

While the communicative musicality model is clearly able to shed light on musical and embodied aspects of non/pre/post-verbal communication, some scholars note its limitations and even suggest alternatives. Stige (2012) observes that Dissanayake, to a greater degree than Trevarthen and Malloch, draws important distinctions between the connection and continuity of mother–infant interaction and cultivated forms of music. He therefore prefers the term proto-musicality rather than communicative musicality because “the term ‘music’ is not defined, so that the distinction between mother–infant communication and the elaborated patterns cultivated in musics [*sic*] becomes too blurred” (Stige, 2012, p. 152). For support, Stige refers to Dissanayake’s ethological definition of music as behaviour: “the capacity to ‘artify’ and/or respond to the artification by others of various protomusical components, including concurrent vocal, visual, and kinesic elements, whose effects encourage participation and positively affect the participant’s sense of well-being” (Dissanayake, 2001, pp. 164–165).

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[53] Chapter 4.6, up to this point, is based on my article’s (Waage, 2022) section about communicative musicality, pp. 333–334, with some editorial modifications.

4.7 The artification hypothesis

As mentioned, Dissanayake (2015, 2017) argues that early parent–infant communication – termed *communicative musicality* by Malloch and Trevarthen – allows immature, highly dependent infants to communicate and bond with their caregivers. Dissanayake then argues that the arts themselves are rooted in a similar evolutionary adaptation, in that their function is not mainly diversionary but essential to regulating social relations within the group, and therefore to survival. She then suggests an ethological approach to the arts which emphasises artistic behaviour, or what people do, over what art *is* (2017, p. 144). In her earlier work, she proposes several descriptions of this playful practice of the arts, including "make special", "making the ordinary extra-ordinary", and "elaborating". Later on, she subsumes these descriptions within the terms *artifying* and *artification* (2017, p. 148): "Unlike most other concepts of art, artification considers art as an activity and does not require that the results be skilled or beautiful" (Dissanayake, 2017, p. 161).

Dissanayake then proposes what she calls the *artification hypothesis*: "in my quest to understand how art began, I discovered a plausible evolutionary explanation for how and why interpersonal neurobiology in humans itself began in the common, ordinary playful interactions between ancestral hominin mothers and infants" (2017, p. 144). She identifies five operations which contribute to the extraordinariness of artification: formalisation (including shaping, composing, patterning, organising, schematising and simplifying), repetition, exaggeration, elaboration and (sometimes) manipulation of the perceiver's expectation. She argues that artifying emerged out of mother–infant bonding in tandem with two early adaptations in hominin evolution: bipedality (walking upright) and brain enlargement. These two conflicting adaptive trends – bipedality leading to a narrower pelvis and brain enlargement requiring a wider birth channel – resulted in increasingly premature newborns in great need of attentive caregivers to ensure their survival (2017, pp. 149–150).

> I propose that mother–infant interaction became part of this care. The usual labels for the interaction – "baby talk," "infant-directed speech," or "motherese" – do not sufficiently emphasize two of its most important features: its dyadic nature, where both partners influence each other, or its multimodality. (Dissanayake, 2017, p. 150)

Dissanayake (2017) suggests that the simplified, stereotyped, repeated, exaggerated and elaborated affinitive signals of parent–infant communication are related to the operations used by artists in the artification process. Both processes imply making their signals more distinct and noteworthy (p. 151). She also stresses the role of playfulness, originating in parent–infant communication and persisting throughout childhood and – in more stereotyped forms – into adulthood.

She then notes that biologically important artefacts or occasions around the world are made special and extraordinary through the inclusion of complex physical and mental constructions and actions which are not obviously related to the original thing or event. Such ceremonial rituals are an essential part of social life in small-scale groups, and she argues that they were the primary occasions for the arts in premodern societies. Rituals and their cultural contexts may differ considerably around the world, of course, but Dissanayake (2017) argues:

> Yet if examined closely, their individual components can be regarded as extensions and elaborations of the innate – aesthetic – operations that originated in ancestral mother–infant playful interaction. That is to say, ordinary faces, bodies, body movements, vocalizations, utterances, surroundings, and materials are transformed and thereby also attract attention, sustain interest, and create or mold others' emotions. (p. 155)

Countryman et al. (2016) draw on Dissanayake's artification hypothesis in their research on three- to twelve-year-old children's spontaneous vocalisations and musicking during self-directed play. They found that such musical utterances – which, they hold, are likewise rooted in mother–infant communication – are almost always "part of multimodal expressions involving movement, gesture and speech as well as vocables, and are used to express emotions, to make meaning, to communicate and to initiate or extend social connection" (p. 1). Further, their analyses revealed that these spontaneous musical interactions utilised the five key components of what Dissanayake termed the "protoaesthetic" – patterning, repeating, exaggerating, elaborating and manipulating expectations – which are also used by artists "to attract, sustain and shape the attention and responses of their audiences" (Countryman et al., 2016, p. 2).

In communication and interaction with people with dementia, proto-musicality (or communicative musicality) and "artified" interactions offer a particularly interesting perspective on some of the condition's central traits (e.g., regarding memory, embodiment and personhood, as discussed above). Moreover, such communicative and artified interactions may also influence and be influenced by the capability of what Stern calls *affect attunement*.

4.8 Attunement, vitality and moment

The seminal research and writing of Daniel Stern have had a massive influence on music therapy research and practice and the broader field of psychology. There are also connections and mutual influence among Stern's work and the works of Malloch, Trevarthen and Dissanayake discussed above. Stern's concepts of attunement, vitality forms and meaningful moments are particularly relevant to my project.

4.8.1 Attunement

In *The interpersonal life of the infant*, Stern (1985/2018) introduces the concept of *affect attunement* (pp. 138–161). Unlike imitation or matching, affect attunement is often cross-modal or intra-modal and responds to the affect underlying the infant's expressed behaviour: "Affect attunement […] is the performance of behaviours that express the quality of feeling of a shared affect state without imitating the exact behavioural expression of the inner state" (p. 142). In contrast to imitation, attunement behaviours shift the focus from the form of behaviour to the quality of feeling behind it. Stern argues that the term attunement describes this process more accurately than terms such as (affect) *imitation, matching* or *echoing* (pp. 142–144).

Massumi (2015), briefly discussed in Chapter 3.3.6, refers to Stern's (1985) concept of attunement as "a crucial piece in the affective puzzle" (p.56). Like Stern, he regards attunement as more precise than other notions like imitation or contagion: "it [attunement] finds difference in unison, and concertation in difference" (p.56) and, therefore, can better convey collective situations' complexity and the various reactions of what might be considered the same affect (p. 56). Thus, Massumi also sometimes use the expression "differential attunement" (e.g., p. 94, 115) as one of several polyvalent "fellow-travelling concepts" (p. x).

Ridder (2019) suggests that *validation*, as part of our psychosocial needs, has parallels with Stern's notion of attunement. She argues that interactional attempts at validation are not directed towards the specific behaviour but rather towards the underlying emotional state. “An unmet need may be behind the action” (p. 303). Validation, then, is the attempt to identify and facilitate the meeting of that underlying need: “Both validation and affect attunement are not just imitations of the person, but an empathic attunement of emotional states. It is the attempt to share the person’s subjective experience, not only the actions” (Ridder, 2019, p. 303).

Krøier (2022) offers broad explorations and analyses of attunement in dementia care from the various angles of research literature, music therapists and professional caregivers. In a meta-ethnographic review of six studies, she and her colleagues found three partly overlapping themes regarding approaches to attunement in dementia care. These themes emphasise person-centredness, an empathic approach, and the use of musical parameters – both in musical interactions and through awareness and adjustments of tempo and timing in other interactions (Krøier et al., 2022). Music therapists’ experiences of non-verbal interactions with people with severe dementia displayed vitality, disciplined subjectivity, attunement, therapeutic presence and validation as their central themes (Krøier et al., 2021). Krøier and Ridder (2022) found that caregivers exploring musical interactions in dementia care highlighted how such interactions could create vitality and communication; connectedness through attunement; serve as a personal life story soundtrack; and “transform anxiety into reassurance” (p. 15). The authors underline that musical interactions are bodily, social and intersubjective experiences and can enhance the non-verbal interaction between caregivers and people with dementia.

Stern (1985/2018) acknowledges that attunement is part of what Trevarthen describes as *intersubjectivity*, in that it concerns the mutual sharing of psychic states. Still, he points out that the intersubjectivity in Trevarthen’s account mainly concerns intentions and motives (or *interintentionality*) rather than the qualities of affect and feeling (or *interaffectivity*) (p. 144). He adds: “[Intersubjectivity is] an entirely adequate term and concept, but it is too inclusive for our purposes. Affect attunement is a particular form of intersubjectivity that requires some processes that are unique to it” (p. 144). Stern also refers to “embedded attunement” – namely, affect attunement as an integral part of more general or complex behavioural patterns. Embedded attunements are very common and often subtle and might therefore be difficult to uncover or recognise, but they still convey much of the overall impression of the relationship quality (p. 141).

A voluntary or involuntary mismatch of attunement can have different causes and even serve different purposes. If the other person misinterprets the underlying affect, the resulting affective and behavioural response may be inadequate. Stern (1985/2018) terms these kinds of unintentional misattunements *true misattunements*. However, sometimes purposeful misattunements can be utilised to regulate the other person's affect – for example, one might partly match the affect but alter the intensity to upregulate or downregulate the other person's affective state. In such cases, Stern uses the term *tuning* (p. 149).

4.8.2 Affect and forms of vitality

Stern (1985/2018) distinguishes between two different forms of affect: categorical (sadness, anger, fear and joy, for example) and vitality (explosions, rushes and fading, for example) (pp. 53–60, 156–157). Vitality affects can occur with or without categorical affects.

> For example, a "rush" of anger or of joy, a perceived flooding of light, an accelerating sequence of thoughts, an unmeasurable wave of feeling evoked by music, and a shot of narcotics can all feel like "rushes." They all share similar envelopes of neural firings, although in different parts of the nervous system. (Stern, 1985/2018, p. 55)

Stern points out that all mental acts (perception, feeling, cognition, remembering) are accompanied by input from the body – also sensing of the internal state, commonly referred to as *interoception*: "The internal input includes the momentary states of arousal, activation, tonicity, levels of motivational or satiety (in various systems), and well-being" (Stern, 1985/2018, p. xvii). Stern notes that this internal, bodily input recalls what Antonio Damasio calls "background feelings", which are similar to Stern's vitality affects (p. xvii).

In a later book titled *Forms of vitality*, Stern (2010) elaborates upon the theoretical background and implications of what he calls *dynamic forms of vitality* and locates some differences between vitality dynamics and Damasio's "background feelings". While background feelings are clearly connected to the overall functioning and changes of inner states, vitality dynamics "focus more on the dynamic quality of the experience, in particular the profile of the fluctuations in excitement, interest, and aliveness" (Stern, 2010, p. 45). Stern then introduces the “fundamental dynamic pentad” of movement, time, force, space and intention/directionality which gives rise to the experience of vitality (pp. 4–5) and “applies to the inanimate world as we observe it, to interpersonal relationships as we live them, and to the products of culture as we experience them” (pp. 6–7).

Like the concepts of proto-musicality and communicative musicality, Stern’s notion of vitality is also closely linked to mother–infant communication. He writes that his preoccupation with dynamic forms of vitality started while he was observing mother–infant interactions, and he first coined the term “vitality affects” in this context. He was particularly inspired by how the mothers would respond to their babies’ feelings and express their understanding by doing a selective imitation, shifting to a different modality but keeping the dynamic features and matching the vitality form: “The match thus becomes a match of internal feeling states, not overt behaviors. Some sense of mutual understanding has been established. ‘Affect attunement’ is based on matching and sharing dynamic forms of vitality, but across different modalities” (Stern, 2010, p. 42). The dynamism of vitality forms and affect attunement is also closely related to being in “the present moment” and the experience of “now” (p. 42).

4.8.3 Meaningful moments

In the article “The present moment as a critical moment”, Stern (2004) describes the present moment, like critical moments which effectuate change, as a contradiction: It has a duration in which something happens and, at the same time, takes place during a subjective “now” (p. 366). He exemplifies this contradiction with a musical phrase which he describes as “a continuous, enduring, single, flowing whole, occurring during the ‘now’ […] as a global entity that cannot be divided up without losing its gestalt” (p. 367). To understand the present moment, Stern advocates for a different sense of the flow of time – in effect, a subjective stretch of time – especially in moments where events demand action or are propitious for action. The ancient Greeks called this “kairos”:

> Kairos is a moment in which events come together and meet, and the meeting comes into awareness as a coherent aggregate such that intentional action must be taken […]. It is a small window of opportunity for action or inaction relative to a situation. (Stern, 2004, p. 367)

Further, Stern writes: "*A moment of meeting* is a particular case of doing something together. […] The participants' minds must be partly permeable to each other to enhance intersubjectivity in the sense of affectively participating in another's experience" (Stern, 2004, p. 372). According to Stern, affect attunement is therefore a requisite for *moments of meeting* (as moments of kairos) to even appear.

Scholars within resource-oriented areas of music therapy or music-and-dementia research have underlined the value of "being in the moment" and "magical moments" (e.g., Dowlen et al., 2022; Trondalen, 2007). As mentioned in Chapter 4.2.3, Dowlen et al. (2022) underscore the need to redirect music-and-dementia research towards a greater emphasis on musical experiences "in the moment" rather than on pre/post-evaluations (of biomedical and behavioural outcomes). Dowlen et al. refer to Keady et al. (2022), which, based on several studies, outlined a definition of "being in the moment" in the context of people living with dementia:

> Being in the moment is a relational, embodied and multi-sensory human experience. It is both situational and autobiographical and can exist in a fleeting moment or for longer periods of time. All moments are considered to have personal significance, meaning and worth. (Keady et al., 2022, p. 687)

Anne Basting (2020) describes moments of *awe* and argues that there is a fourth portal to awe in addition to nature, spiritual belief and art or creativity: "one can access awe by connecting to the vastness of another human soul" (p. 125). Her goal in her work with creative care is thus "to identify concrete ways we can experience awe in our daily lives and to facilitate the experience of awe for others" (p. 125).

Singing together can capture the relational, embodied, multisensory, situational and autobiographical properties which are key to the "in-the-moment" experiences described by Keady et al. above. Moreover, relational singing can provide a concrete means of facilitating and experiencing awe in our daily lives, in line with Basting's account.

In research into meaningful moments, scholars have used various terms to capture these micro events, including *micro-moments* (Mittner & Gjærum, 2022) or *resonating moments* (Mittner, 2022). Tia deNora and Gary Ansdell and their colleagues in the *Care for music*[54] project have explored such micro-moments in musical interventions in dementia care (deNora et al., 2022; Schmid et al., 2021) in terms of both how music might help (Ansdell, 2014) and what might help music (to help). By studying "split-second 'nano-ethnographic' moments that produce patterns over time" (deNora et al., 2022, p. 240), they unveil how tiny relational events like gestures, mimics and micro-interactions contribute to facilitating or supporting the agency of music. Moreover, these micro-events are able to unveil the agency and learning abilities of people in late-stage dementia (deNora et al., 2022).

In my research intra-action with the dyad, such relational micro-moments and events are captured through the concepts and operationalisation of intra-action and intra-play, to which I will return in Chapter 7. The autobiographical epistles throughout the thesis are often based on micro-moments as well.

This chapter's previous sections have outlined how different research issues and theoretical approaches can contribute to an understanding of why and how singing communicates with people living with dementia – and their close ones. This content has so far included research on well-being, embodied cognition and memory, discussions of dementia, personhood and embodiment, and insights drawn from communicative musicality, artification, and the concepts of attunement, vitality forms, and meaningful moments. Next, I will add Stephen Porges' polyvagal theory (PVT) to singing's neurophysiological and psychological foundation in order to elaborate on subtle, in the moment, communicative, affective and embodied features.

4.9 The autonomic nervous system and the polyvagal theory

> My life changed when I read Stephen Porges' book *The Polyvagal Theory*. Suddenly, the world made sense to me in a new way. (Dana, 2018a, p. xiv)

At the heart of Porges' (2011) polyvagal theory (PVT) is its focus on safety and trust as a basis for social engagement and non-defensive behaviour. In Chapter 4.4.2, I considered how the biomedical approach to dementia entails a narrative of adverse and challenging behaviours due to the disease. Several researchers have pointed out the need to acknowledge other possible reasons and explanations for

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[54] See https://careformusic.org.

such behaviours as well – that is, to consider them responsive or relational in a broad sense.

Barad's notion of material-discursive practices is premised on the inseparability and interconnectedness of all there is, which again is rooted in her interpretation of quantum field theory. At the heart of her agential realism, therefore, lies a fundamental relationality. Accordingly, I will argue that an understanding of the autonomic nervous system (ANS) and how it intra-acts internally in the person, with other (human) beings, and with the wider world supplies a material-discursive substrate for the comprehension of behaviours and social relations. Moreover, PVT can shed light on how some of the basic properties of singing may facilitate or support ANS regulation and social engagement.

PVT is widely cited in academic journals, where it is acclaimed but also disputed (Flater, 2020, p. 21). In any case, leading clinicians, therapists and researchers – especially in the trauma field – have described PVT's ability to make sense of extensive clinical experiences which did not otherwise fit with existing theories and explanatory models about the ANS (Porges & Dana, 2018). For example, Levine (2018) writes:

> This unifying theory would forever change the landscape of clinical and theoretical work in trauma. […] It would also contribute to a number of medical, social, and educational fields. Most importantly, for me, it provided the remaining piece of the puzzle. (p. 14)

4.9.1 The relevance of polyvagal theory for my project

Like Dana and Levine, I found that the world made a new kind of sense upon my acquaintance with Porges' thinking. Experiences and observations from my work within dementia care and my personal life and relations, especially during challenging times, were more understandable through the PVT lens, and I agree with Badenoch (2018): "It was as though my body felt the truth of its functioning being reflected and was saying yes to this new way of seeing our autonomic nervous system" (p. 74). Further, as my knowledge of PVT increased, my access to regulating affects and reactions – and affirmatively co-regulating them with others – also increased. Among other things, the relational perspectives of PVT shed light upon my own and other healthcare workers' observations about the surprisingly strong effects of individualised music in dementia care, and especially care singing.

Porges' (2018b) motivation for his polyvagal theory was

> to generate testable hypotheses and to stimulate research expanding our understanding of how the autonomic nervous system influenced mental, behavioral, and psychological processes. Polyvagal Theory was generated as an expansive brain–body model that emphasized the bidirectional communication between the brain and the body. The theory, with its strong evolutionary and developmental perspectives, was proposed as a framework to explore links among observable behaviors, psychological processes, and autonomic state. (Porges, 2018b, pp. xix–xx)

When Porges first came up with the theory, he did not anticipate how clinicians would embrace it, especially within trauma care (Porges, 2018b).[55] It brings equally valuable perspectives to dementia care. PVT can enable a broader understanding of relational issues which are relevant regardless of the presence of illness or trauma but often actualised in challenging life conditions. Moreover, the polyvagal lens can expose the underlying mechanisms of singing as a relational activity, especially in vulnerable conditions like dementia in the family.

Ridder (2007, 2011) has noted the relevance of PVT to a better understanding of the music therapy process, especially with regard to dementia (2007, pp. 434–437; 2011). Its impact on the use of relational singing may also have implications outside the professional therapeutic context.

4.9.2 Introduction to the polyvagal theory

The polyvagal theory developed by Porges (1995, 1998, 2001, 2007, 2011, 2021a) traces the phylogenetic, neurophysiological substrates of the ANS and its implications for human social behaviour, communication and interaction. The term "polyvagal" refers to the fact that the vagus nerve (the tenth cranial nerve) has two branches: the unmyelinated dorsal branch, also found in reptiles, and the phylogenetically more recent, myelinated ventral branch, which is found in

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[55] Ever since Porges presented PVT at the Boston Trauma Conference in 1999, more and more therapists worldwide have found its heuristic implications to be of great clinical value.

mammals, including humans (Porges, 2011, pp. 284–285). PVT sheds light on the roots and mechanisms behind, and balance between, our defensive and social strategies of behaviour and communication (Dana, 2018a; Porges, 2011; Porges & Dana, 2018). It also clarifies how these strategies are affected and modulated by interactions within our bodies, our relations, and our past and present life conditions.

The commonly applied notion of “fight, flight or freeze” describes different innate defensive strategies for experienced threats. In addition, Porges introduces the “social engagement system” (Porges, 1998, 2011, p. 56) to describe our phylogenetically more advanced social survival system, which can downregulate these defensive strategies, provided that subtle signals of safety have been picked up on, through an unconscious process which Porges describes as “neuroception” (Porges, 2011, pp. 11–19). He also brings more attention to the oldest defence system – collapse and “feign death” – connected to the dorsal vagal pathway.

PVT also explains how tiny nuances in facial expression and tone of voice (prosody) are monitored via neuroception. Such micro-expressions are crucial to inducing a sense of safety and trust which is sufficient to enable social cooperation and interplay instead of defensive activation or shutdown (Eide-Midtsand & Nordanger, 2017; Porges, 2015). The neuroceptive feedback loop of subtle cues of safety or danger is constantly and unconsciously monitored, resulting in accordingly adjusted behaviours based on adaptive social or defensive strategies (Porges, 2011, pp. 11–12) (Waage, 2022, p. 339).

4.9.3 Critique of the polyvagal theory

According to Porges, PVT is based on established literature on neurophysiology, neuroanatomy and psychophysiology (Porges, 2011, p. 20). Porges admits that PVT is based on several premises: Some are firmly grounded in scientific data, while others are more speculative (Porges, 1995). Since introducing PVT to the scientific community in 1994 (Porges, 2018b, p. xix), its theoretical substrates have evolved and become more nuanced (Porges, 2011, 2021b). Related research is ongoing, especially concerning its therapeutic implications.

Grossman and Taylor (2007; Taylor et al., 2014) have contested certain of PVT’s premises, noting, “polyvagal theory can be falsified by observations of respiratory–heart rate interactions and myelinated vagal fibers in vertebrates that evolved before mammals" (Porges, 2021b).[56] Porges (2021b) revisits the premises of PVT in order to dismiss this critique, partly by pointing out its misconceptions and partly by undercutting their argument using substantial multidisciplinary research which aligns with the premises of PVT and uncovers flawed assumptions in the measurements (Lewis et al., 2012) used to verify the criticism. More importantly, Porges (2021a) points out: "The theory was not proposed to be either 'proven' or 'falsified,' but rather to be informed by research and modified" (p. 6).

Porges' main point when addressing the criticism is that "although the ventral vagus […] may have an origin in reptiles (Taylor et al., 2014), it appears that it is only in mammals that this pathway has been repurposed as cardioinhibitory and to respond to social cues, via neuroception, as a potent mediator of autonomic state" (2021a). In other words, Porges holds that whether there are (neural) similarities in ancestral vertebrates or not is irrelevant; instead, the question should be how these circuits have "been adapted to provide a unique mammalian autonomic nervous system that is intimately intertwined with co-regulatory social behaviour. There are many examples of the unique type of sociality expressed in mammals, which differentiates mammals from their reptilian ancestors" (Porges, 2021a, p. 6).

Flater (2020) also discusses the criticism of PVT.[57] She finds that other established, uncontroversial models of the ANS (Kozlowska et al., 2015; Roelofs, 2017) is in accordance with central premises of PVT. While Taylor et al. express doubts about the mechanism Porges proposes, "his concept that we turn to progressively older defense responses is in line with the view held by the scientific community at large" (Flater, 2020, p. 22).

Furthermore, whether experts disagree about the details of phylogeny and neurophysiology or not, PVT's practical and clinical implications have already demonstrated their considerable utility. For this PhD project, as well, the heuristic

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[56] In fact, Porges does not claim that the differentiation between the dorsal and ventral branches of the vagus are unique mammalian, as Grossman and Taylor imply (2007, pp. 273–275). On the contrary, he admits that "some reptiles (turtles) still have a connection between the two nuclei (dorsal motor nucleus and nucleus ambiguus), while others (lizards and crocodiles) have a separation as complete as in mammals" (Porges, 2011, p. 30). Taylor et al. (2014) likewise acknowledge the complexity of the phylogeny of vertebrate species (p. 692).

[57] Flater (2020) did a Medline search on PVT by authors other than Porges and found that 61 out of 64 articles embraced the theory. Many of them also presented studies in support of PVT: "One article was neutral to it […] Two articles (with one common co-author [Taylor]) were directly critical of the theory and raised important arguments against its validity (Grossman & Taylor, 2007; Sanches et al., 2019)" (Flater 2020, p. 21).

value of PVT represents an important way to include and better understand the social and relational implications of the ANS. Thus, PVT adds valuable perspectives to the context of relational singing in families affected by dementia.

4.9.4 The three branches of the autonomic nervous system (ANS)

Porges (1998, 2018a) sees three distinct evolutionary stages in the features of the ANS. The first stage is connected to the dorsal, unmyelinated vagal pathway shared by virtually all vertebrates. In mammals, this pathway primarily regulates the organs below the diaphragm and functions to support health, growth and restoration. However, when it is recruited for defence, this pathway may induce an energy-conserving state involving withdrawal, shutdown or feign death. Since mammals are far more oxygen-demanding than vertebrates (Porges, 1995, pp. 306, 308), this defence system can be lethal to mammals (pp. 307, 308–309) and thus functions as the last option.

In the second stage, the arousal-driving sympathetic nervous system developed and complemented the downregulation functionality of the ancient vagal pathway. The sympathetic nervous system mobilises to facilitate high-demanding tasks and, when recruited for defence, supports fight or flight behaviours.

During the third stage, while mammals developed, an additional ventral myelinated vagal pathway evolved. This ventral vagus regulates the organs above the diaphragm and is connected in the brain stem with motor pathways that control the striated muscles of the face and head. According to PVT, these connections result in a functional social engagement system which enables the eyes, ears, voice and head to work in concert with the heart and bronchi. Thus, facial expressions, voice prosody and gaze are connected to the regulation of heart and breathing rate, sending and receiving subtle cues of safety or danger to signal whether or not others are safe to approach and connect with (Dana, 2018a, pp. 27–28; Porges & Lewis, 2010, pp. 257–258). The newer (ventral) vagal pathway slows the heart rate and thus functions as a “vagal brake”, supporting the calmness required for social interaction. This brake can be released to allow a heart rate increase and sympathetic mobilisation.

When the outputs of the three branches of the ANS are well-regulated in safe settings, their interplay allows for mobilised social play (sympathetic and ventral vagal) and immobilised intimacy (dorsal and ventral vagal) (Porges, 1998;

2021a, p. 4).[58] In addition, these three branches can be coordinated for one's defence. If a situation cannot be solved via the social engagement system (through negotiation or co-regulation, for example), the older defence systems of sympathetic mobilisation (fight or flight) or dorsal vagal immobilisation (withdrawal, collapse, shutdown) are recruited: "The three circuits can be conceptualised as dynamic, providing adaptive responses to safe, dangerous, or life-threatening events and contexts" (Porges, 2007, p. 120). Elsewhere, Porges adds: "In this hierarchy of adaptive responses, the newest social engagement circuit is used first; if that circuit fails to provide safety, the older circuits are recruited sequentially" (Porges, 2022, p. 3). In a state of homeostasis, or "dynamic equilibrium", the three branches of the ANS work together to support health, growth and restoration under the overall regulation of the myelinated ventral vagus (Dana, 2018a, p. 31; Porges, 2011, pp. 103–105).[59]

4.9.5 Neuroception and connection

The process of neuroception (Dana, 2018a, pp. 35–39; Porges, 2011, pp. 11–19) is beyond consciousness and cognition and is always running in the background of – or rather prior to – perception: "although we are often unaware of the stimuli that trigger different neuroception responses, we are generally aware of our body's reactions […] embodied in autonomic signatures that support adaptive behaviors" (Porges, 2022, p. 7). Reminiscent of neuroception are Massumi's (2015) concepts of *micro shock* and *microperception*: "It's a perception of a qualitatively different kind. It's something that is felt without registering consciously. It registers only in its effects" (Massumi, 2015, p. 53).

According to PVT, neuroception influences the autonomic bodily state, which influences behaviours and the conception of what is going on as the mind tries to make sense of what the bodily state is saying (Waage, 2022, p. 339). The triggering cues of danger or supportive cues of safety will determine the autonomic state and the "story" to be made of it – that is, the story follows the state (Dana, 2018a, p. 35), not the other way around. Consequently, insight into these

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[58] The neuropeptides oxytocin and vasopressin also play a role in this co-option of different autonomic strategies and outputs (Porges, 1998).

[59] Also safe states with external demands such as play, work or physical activity require a tradeoff between internal, visceral homeostasis and external mobilisation. However, in a safe state, the homeostasis will be regained as soon as the exterior demand is finished.

mechanisms can suggest a retelling of the story: “If people are aware that their body is reacting and colouring their perception of the world, that knowledge helps them revise their narrative” (Buczynski & Porges, 2013, p. 7).

Humans are wired to connect because being included in the herd is part of our evolutionary survival. Thus, central issues for the ANS are to avoid danger and to connect socially when safe. This depends on not only the absence of cues of danger but also the presence of cues of safety in social relations and the environment (Porges, 2015), but the “innate alarm system”[60] (Lanius et al., 2017) connected to ANS cannot always differentiate between real and conceived or imagined danger and instead can overreact (Dana, 2018a, p. 38; Porges, 2011, pp. 12–13, 17–18). How individuals respond to distress or critical situations will differ significantly based upon earlier experiences and present health conditions affecting both how and how readily the defence mechanisms get triggered and what defence strategy is recruited (Dana, 2018a, p. 33; Porges, 2022, p. 4) (Waage, 2022, p. 340).

Moreover, when we are triggered, our perception is inherently biased – according to Porges, our middle ear regulation shifts away from listening for the human voice and towards listening for the low-frequency sounds of predators or the high-frequency sounds of distress. Dana (2018a) adds: “The system is now tuned to the sounds of danger and not to the sounds of connection” (p. 25). Likewise, our ability to read facial cues can become compromised, so that neutral faces might appear angry and be experienced as dangerous (Dana, 2018a, p. 25; Porges, 2011, p. 15 e.g.) (Waage, 2022, p. 340–41).

Thus, due to a variety of internal and external challenges to our ANS regulation, we are in constant need of self-regulation and co-regulation (Dana, 2018a, pp. 44–47). Dana (2018b) holds that ANS is a relational system entering into feedback loops with other nervous systems, conveying cues of safety or danger which serve “to either co-regulate or increase reactivity” (Dana, 2018b, p. 384).

To help someone out of a collapsed or mobilised defensive autonomic state, someone else – whether a therapist, relative, colleague or friend – must stay regulated in, or must self-regulate into, a safe and sociable state. Otherwise,

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[60] “The innate alarm system” (IAS) encompasses regions of the brain including the brainstem, amygdala, pulvinar and frontotemporal cortex which together facilitate a “fast-track” response to threatening stimuli.

through neuroception, the two individuals will feed each other's autonomic nervous systems new cues of threat or danger, trapping them both in a vicious circle of defensive, dysregulated states (Porges, 2011, p. 15). On the other hand, neuroceptive cues can also impel a more positive spiral, enhancing memories or impressions of safety, comfort, or joy. Deb Dana (2018a) calls such positive triggers "glimmers" (pp. 66–71) (Waage, 20221, p. 341).

4.9.6 Glimpses as glimmers – a personal perspective as a relative

My experiences as a relative have prompted my interest in the relatives' situation and PVT. One incident still touches me emotionally because it subtly illustrates the heart of my concern as a relative: the wish to be seen, acknowledged, and counted on. It also demonstrates how tiny nuances in behaviour and communication can determine the sense of inclusion or exclusion.

> *My father was seriously ill from cancer and was to undergo surgery. At his wish, I followed him to the hospital. The day before the surgery, he was lodged at the hospital hotel. He was signed up for a row of appointments with different professionals to prepare him for the operation and the following convalescence. I was struck by the professionals' variety of attitudes towards me, from total ignorance to friendly hellos, but all with what seemed like somewhat excluding approaches.*
>
> *Finally, the surgeon turned up. My father – himself a retired doctor – and the surgeon spoke in professional terms of the upcoming surgery. There was every imaginable potential that this meeting might leave me entirely side-lined, but strikingly, that did not happen. Now and then, the surgeon gave me little glances. I was stunned – both then and when thinking back on the situation – what a huge difference those little glimpses made for me. Their message appeared to be: "I see you, I acknowledge your presence, and I include you."*

In retrospect, now knowing PVT, I expect there were also other neuroceptive cues involved. Probably, the glimpses were only the more obvious of several subtle nuances in the surgeon's facial expressions, prosody and body language, offering me – and my father – the subtle signs of safety and a willingness to connect. The surgeon's inclusive glimpses induced co-regulation and helped me reorient after hours of slight dysregulation due to the other professionals' apparently dismissive attitudes. The glimpses acted as glimmers.

4.9.7 Triggers and glimmers

A friendly smile, a caring gesture or a pleasant memory are other examples of glimmers, and singing and music have great potential for incorporating glimmers in addition to their other potential beneficial neurophysiological influences (Waage, 2022, p. 341), to which I will return in Chapter 4.9.9. Dana (2018a) introduces the concept of glimmers in contrast to negative triggers. While triggers induce the neuroceptive cues of danger and threat, compromise the sense of safety and trust, and activate one's defences, glimmers induce the neuroceptive cues of safety, supporting the safe and social autonomic state (pp. 66–71). Dana insists that drawing attention to glimmers should not imply underestimating the suffering induced by triggers. Still, she points to the benefits of a more strength-based perspective, reminding us that well-being is not merely the absence of problems and disease but also the presence of strengths and positive social and emotional functioning (Dana, 2018a, p. 71).

Stern's account of forms of vitality discussed earlier includes describing their dynamics also on the micro level, recalling the subtle expressions connected to neuroceptive cues within PVT. He describes the "dynamic" of the very small events

> that make up the interpersonal, psychological moments of our lives: the force, speed, and flow of a gesture; the timing and stress of a spoken phrase or even a word; the way one breaks into a smile or the time course of decomposing the smile; the manner of shifting position in a chair; the time course of lifting the eyebrows when interested and the duration of their lift; the shift and flight of a gaze [. …] [I]t makes up the matrix of experiencing other people and feeling their vitality. (Stern, 2010, p. 6)

Thus, the promotion of glimmers may be linked to the experience of affirmative forms of vitality, possibly inducing a sense of safety, satisfaction or even joy. I will argue that for people in a vulnerable state like dementia, a resource-based enhancement of glimmers might compensate for the susceptibility to triggers which can accompany cognitive loss.

4.9.8 PVT and dementia: An introduction

Interpreting and understanding sensory stimuli can be challenging for people with dementia. Therefore, their defensive systems may more readily be activated, in either the mobilising mode (fight or flight) or the immobilising mode (freeze or feign death) (Ridder, 2011, p. 131), as noted by Waage (2022, p. 338). Because of the cognitive impairment, people living with dementia are often also more easily overstimulated and less capable of reorienting and self-soothing; thus, they tend to need regulatory support from caregivers, therapists or family members (Ridder, 2019, p. 311). PVT's focus on safety, trust and coregulation as a basis for social engagement is therefore particularly relevant in the case of dementia.

Different autonomic states can manifest in different ways and levels of intensity. In my experience with dementia care, the states of withdrawal, apathy and dissociation are particularly easy to overlook or misunderstand. Treusch et al. (2015) note that while apathy is considered the most common behavioural symptom in dementia, there is little information or guidance available for dealing with it. A lack of understanding and assessing apathy may lead caregivers to misinterpret apathetic behaviour (p. 1).

In the same way, the subtle initial signs of mobilisation into flight or fight can also be underestimated and left unregulated until they build up and eventually erupt into various adverse behaviours. When it comes to dementia, then, understanding the features of ANS regulation is critical to better understanding the illness' vulnerabilities and the potential of regulating interactions and measures, including music and singing.

4.9.9 PVT and sound, music and singing

> Music moves us, not only putting bodies in motion but also stirring autonomic state shifts. (Dana, 2018a, p. 88)
>
> People have always known that – with chanting, with mother's lullabies, with motherese, (speaking), and even with normal engagement behaviors amongst friends – voice is important. (Buczynski & Porges, 2013, p. 5)

According to Porges (2010, 2011), the polyvagal theory also explains how music and music therapy can recruit the neural mechanisms that integrate facial muscles and the visceral condition to promote restorative affective states and prosocial behaviour. He holds that music listening, singing and music therapy represent ways to engage and exercise the social engagement system (2011, pp. 246–254). Melodic music contains acoustic properties which are reminiscent of vocal prosody and may, therefore, activate the social engagement system by challenging and modulating the neural regulation of the middle ear muscles (Porges, 2011, pp. 209–210; Porges & Lewis, 2010, p. 260) (Waage, 2022, p. 341).

Porges and Rossetti (2018) describe *prosody* as "the emotional tone embedded in speech through the modulation of vocal intonations" (p. 117). They conceptualise vocal prosody along a continuum of intonation modulation – from speech to vocal music – wherein infant-directed speech ("motherese") could be described as exaggerated prosody and lullabies and vocal music as hyper-prosodic vocalisations. This prosodic continuum, they note, "helps explain the efficiency of music as a treatment modality in conveying cues of safety and trust to a 'prewired' neurological portal" (p. 118). Due to the way in which different wavelengths travel over distances (Porges & Lewis, 2010, p. 261), however, low-frequency sounds or noises are more audible than prosodic, social human vocalisations, especially for those with hearing loss (including many older adults both with and without dementia). The degree and prevalence of hearing loss are strongly related to age (Contrera et al., 2016)[61] and are most distinct at higher frequencies (Homans et al., 2017).

Porges and Dana also focus on the regulating potentials of breathing and singing because the phrasing of music produces short inhalations and long exhalations, thus decreasing the heart rate and inducing a calmer state (Porges, 2011, pp. 246–254): "Slow exhalation, the respiratory process associated with expressive social vocalizations, enhances the impact of the myelinated vagus on the heart, promoting calm states" (Porges & Lewis, 2010, p. 262). A long out-breath during singing, that is, can induce a downregulation of defence and make the social engagement system more accessible. Besides, via breath, articulation and intonation, singing activates several muscles connected to the social engagement system, including facial muscles and muscles in the middle ear (Dana, 2018a, pp. 149–150; Porges, 2011, pp. 253–254). Lastly, when people sing in unison, the song's structure can act to synchronise the respiratory impact on the singers' hearts and induce an "inner entrainment" which can affect perception and

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[61] The prevalence of hearing loss doubles with every decade of life, and by the age of 70, two-thirds of adults are hearing impaired (Contrera et al., 2016).

behaviour (Vickhoff et al., 2013) (Waage, 2022, p. 341). Flater (2020) also cites research which links singing and hearing to autonomic states and the social engagement system (p. 26).[62]

Referring to Porges' PVT, Ridder (2011) describes how people living with dementia can be engaged in social communication via integrated therapeutic singing as part of a music therapy process. She points out that the person's adapted behavioural response to the experience of unsafety is often misinterpreted and considered a result of the degenerative brain disease (p. 141). The therapist's task, on the other hand, is specifically to recognise, address and regulate such behaviour, and she outlines a threefold process towards this end wherein adapted and individualised singing (1) creates a safe setting, (2) regulates arousal and (3) creates possibilities for social engagement (p. 134). This perspective may also be relevant to care singing and music therapeutic caregiving (MTC) as well as other contexts of relational singing activities.

Krøier and Ridder (2022) found one important aspect of attunement through musical interactions to be the transformation from anxiety to reassurance, for instance when people with dementia experience fear or confusion: "When the music is used for reassurance, the caregivers often combine singing and humming with touch and movement to help the person move through the anxiety and feel safe" (p. 11). The authors also note that sometimes singing and listening to music can help even the caregiver feel safer in the situation. However, caregivers remain aware of "the fact that they must regulate their own arousal level to be able to calm and reassure the person with dementia" (p. 11).

For some people, especially those with a history of trauma, direct eye contact and face-to-face interaction in and of themselves can be threatening. Porges (2011) observes that using voice and music can stimulate the social engagement system without requiring face-to-face interaction (p. 253).

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[62] Flater writes, "It is recognized that singing affects the autonomic nervous system, and that prolonging exhalation increases vagal activity (Shaffer et al, 2014; Russo, Santarelli & O'Rourke, 2017; Gick, 2011). It is also well documented that a benefit of group singing is social bonding (Irons, Sheffield, Ballington & Stewart, 2019; Gick 2011)" (Flater, 2020, p. 26).

4.9.10 PVT, trauma and dementia

Eide-Midtsand and Nordanger (2017) point out that both PVT and the concept of "the window of tolerance"[63] shed light on the underlying mechanisms of developmentally traumatised children's regulation problems and often confusing behaviour. I would argue that the same applies to people living with dementia. As their cognitive capacity diminishes, their regulatory capacity may also suffer, narrowing their window of tolerance and making their social engagement system less robust and accessible. Thus, their defence systems are more easily triggered, and they may need more regulatory support.

Porges and Rossetti (2018) point out that the physical and mental consequences of trauma and chronic stress "'retune' the nervous system from being spontaneously trusting with a capacity to co-regulate to being hypervigilant and defensive" (p. 118). They also point out the potential of reversing such disruptive effects "by conveying cues of safety and trust" (p. 118). Our fight-or-flight reactions are more commonly known and understood, whereas our oldest defence system, parasympathetic collapse, had been overlooked by trauma researchers previous to Porges' work (Eide-Midtsand & Nordanger, 2017, p. 922). There is also, as mentioned above, only limited acknowledgment of apathy within dementia care (Treusch et al., 2015). If a person with dementia is approached too abruptly while being in a collapsed state of withdrawal or apathy, she might be triggered back into a fight or flight mode, a reaction which might seem incomprehensible or even violent. From the perspective of ANS dysregulation, on the other hand, this behaviour might be more understandable and could be met with gentle awareness: "Ann seems frozen and out of herself. Maybe I can gently mobilise her by soft speech, humming or singing?"

Even without a history of trauma, the experiences of loss and confusion following the progradation of dementia can be traumatic in themselves. Schwarts (2018) uses the terms *big-T* and *small-t trauma* to distinguish between events which everybody agrees are traumatic – such as rape or war – and events that overwhelm people's coping strategies but are not at that level (p. 271). Facing

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[63] *The window of tolerance*, originally developed by Daniel Siegel, describes the optimal zone of arousal within which people can function and manage their emotions. Outside of this zone, people can experience dysregulated states of hyper-arousal (over-activation, fight and flight) or hypo-arousal (under-activation, shutdown or collapse). If the window of tolerance is very narrow – for example, due to trauma or disease – it is harder for people to remain regulated and manage their emotions (Eide-Midtsand & Nordanger, 2017).

dementia in the family brings with it the potential for small-t trauma both for the person and the close ones.

Moreover, some people living with dementia have prior big-T traumatic experiences. Russell (2013) refers to an episode where a woman with advanced dementia, who was generally withdrawn and uncommunicative, suddenly acted inappropriately and violently when local children visited during a Christmas carol arrangement. It turned out that she had suffered traumatic war experiences, including witnessing several schoolchildren killed by a bomb. This led Russell to more research into the residents' trauma history. She concludes: "much of their repetitive, often violent behavior was the result of previously experienced traumatic events. […] This woman, I believe, was still desperately trying to keep the children safe" (Russell, 2013, p. 899).

Health care procedures may sometimes, by themselves, trigger cues related to abuse or other traumatic events, even in otherwise healthy people. In addition, people with dementia may also be unable to make sense of what is happening in the medical or healthcare procedural situation. Craftman et al. (2020) did a qualitative study on nurse aides' experiences caring for Holocaust survivors with dementia. The nurse aides emphasised the importance of person-centred care, and especially of knowing the residents' life stories, to be able to both avoid triggers and interpret their experiences and (subsequent) behaviours adequately and adjust their care accordingly.

One would think that this kind of adjustment would be easier for relatives, but it is not uncommon for trauma survivors to keep their experiences to themselves because they are too painful or shameful to share, even with their loved ones. Often, then, relatives can be equally unaware of their family member's traumatic history and potential triggers (Craftman et al., 2020, p. 626).

Other scholars have researched the possibility of a connection between trauma and dementia. Greenberg et al. (2014) review studies and literature regarding the link between stress/PTSD and dementia. They conclude that there is indeed a heightened risk of dementia associated with these conditions, but that more research is needed to understand why. In any case, there is clearly an enhanced *statistical* risk that people with PTSD will also develop dementia (Greenberg et al., 2014, p. S163). These findings should remind us that trauma survivors may be slightly overrepresented among people living with dementia, and that we need to consider potential trauma when approaching and interpreting the behaviour and communication of people with dementia. Singing and music may contribute affirmatively to addressing the regulative and communicative potential of the social engagement system through the implicit modulative features of breathing, facial expression, voice prosody and listening.

Could we in fact meet “adverse behaviour” with a beloved song to turn down the defence and turn on social engagement, as opposed to resorting to coercion and thereby triggering potentially escalating defensive reactions? As a teacher of practical courses in music-based milieu care, I have heard several stories from experienced nurses and nurse aides about the seemingly magical effects of singing in dementia care, especially concerning the most “difficult” residents and the most challenging issues, such as personal hygiene.[64] In some cases, the institution could even repeal coercive decisions after starting music and singing interventions as part of daily care procedures (Meld. St. nr. 15, 2017–2018, p. 137).[65] Whether or not previous trauma adds to the sense of vulnerability inherent to dementia, PVT offers ways to understand some of the underlying mechanisms of singing and music’s beneficial, resource-oriented contributions to dementia care.

Daily-life singing activities may offer affirmative and potentially regulative forms of communication and interaction for people with dementia and their relatives. Regarding former trauma, the development of new, non-intrusive ways of interacting is particularly useful. Singing might also simply offer new opportunities to enhance already positive communication in harmonic relationships by adding and sustaining “glimmers” – cues of safety and joy – when language or long-time favourite activities have become less accessible due to cognitive decline. Maintaining and supporting a safe and sociable state is the basis for experiencing presence and proximity, which, in turn, feeds a sense of safety and trust, thus creating a positive feedback loop.

4.10 Diffracting and discussing theories and approaches

> They may be considered “not there” but the somewhere else they inhabit is not an empty world and can offer new opportunities for kinship. (Quinn & Blandon, 2020, p. 57)

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[64] Such case stories from practice are also supported by research on caregiver singing and music therapeutic caregiving discussed in Chapter 2.4.4.

[65] This was the case in Feviktun omsorgssenter in Grimstad municipality. Their experiences are even referred to in a governmental white paper, Meld. St. nr. 15 (2017–2018).

4.10.1 Enfolded materialisations and memories

The disorientation and confusion connected to symptoms of dementia may place the affected person in a situation where the senses of time, environment and identity are challenged and, at times, even broken into fragmentation and fractured reconfigurations (Johnson et al., 2017; Kitwood & Brooker, 2019).[66] Singing and songs, on the other hand, carry rich implicit, associative information and a great potential for connection (Hammar, 2011; Ridder, 2011) (Waage, 2020, p. 3). Posthuman theory can complement the neurological and psychological explanations of dis/orientation in dementia, and Barad's concept of *dis/continuity* is particularly apt. Before exploring it, however, I will briefly consider Barad's writings on time and memory.

In her discussion of the two-path-eraser experiments,[67] Barad (2007, 2010) concludes: "Space and time are phenomenal, that is, they are intra-actively produced in the making of phenomena; neither space nor time exist as determinate givens, as universals, outside of phenomena" (2007, p. 315). Then, after arguing that the past was not "erased" in the experiment, as some physicists suggested, and by showing that the experiment itself contained evidence of traces of the erased pattern, Barad (2010) postulates: "*Memory – the pattern of sedimented enfoldings of iterative intra-activity – is written into the fabric of the world*. The world 'holds' the memory of all traces; or rather, the world *is* its memory (enfolded materialisation)" (p. 261) (Waage, 2020, p. 6–7).

> What might memories as enfolded materialisations mean for people living with dementia? When the *explicit (declarative) memory* deteriorates due to cognitive decline, the *implicit* and *procedural memories* move to the

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[66] Parts of Chapter 4.10 are based on and developed further from my unpublished exam essay (Waage, 2020). The applicable sections or paragraphs include footnotes, paraphrased references, and citations to avoid self-plagiarism.

[67] The "two-path-eraser experiment", also referred to as the "quantum eraser experiment", is a variation of the classic double-slit experiment which expresses the central features (and "mysteries") of quantum mechanics. In short, it demonstrates that light and matter can display both wave and particle characteristics, or what is also referred to as wave–particle duality. Scully and colleagues performed the two-path-eraser experiment in "delayed-choice mode" in 1999. They found that "Bohr's prediction holds: If the which-path information is erased an interference pattern results, even if the experiment is performed in delayed-choice mode" (Barad, 2007, p. 312). These experiments confirm Bohr's central point that the set-up of the entire experiment can never be separated from the results and "that the objects and agencies of observation are inseparable parts of a single phenomenon" (Barad, 2007, p. 315).

foreground (Harrison et al., 2007; Son et al., 2002). Barad's insight represents a beautifully extended perspective in this regard by adding to neurological explanations of the documented effects of reminiscence in dementia care. From a "Baradian" viewpoint, the "enfolded memories" of material as well as non-material "matter" – whether an old tool or a song, for example – are offered directly in all their materiality and sensibility (sense-ability) via enfolded intra-actions diffractively threaded through time and space. Further, the enfolded memories of the "objects" intra-act with the embodied, implicit and procedural memories of the person with dementia. The inherent agency of these objects – including their affordances – invite the person to re-member, and re-act to, the intra-active potential iteratively and diffractively threaded through the "object". (Waage, 2020, p. 7, with minor editorial adjustments)

4.10.2 Second epistle – memories as enfolded materialisations

A couple of years ago, I offered weekly music sessions in a nursing-home dementia unit.[68] *Sometimes I also did short individual sessions after the group activity. One of the residents – let's call him "Tom" – used to play the harmonica back in the day. He was, however, facing severe dementia which seriously limited his abilities regarding speech and practical skills, and he had not played in a long time. Nevertheless, one of the staff members thought it might be worth trying and fetched his harmonica from his room, gave it to him and asked him to play. At first, Tom looked utterly bewildered; hesitantly and shakily he turned the harmonica around in his hands, looking at it like it was some kind of alien.*

I pointed at the side of the harmonica where the air is supposed to go in and gently asked him: "Is this where you blow?" I made a blowing sound. "It's a beautiful instrument. I am really curious about how it sounds. Could you blow it for me, just once, so I can hear what it sounds like?" I demonstrated with my imaginary harmonica and carefully guided his hand with the harmonica towards his mouth. He put it to his lips. I made small, supportive comments, and eventually he started blowing into the instrument. At first, only a shaky random tone whistled out of the

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[68] Chapter 4.10.2 are based on Waage (2020, pp. 7–8), with minor editorial adjustments.

> *harmonica, but slowly he started moving the instrument sideways, blowing it now and again, and after a little while, a melody appeared, unsteady and uncertain at first but soon increasingly confident. I picked up my small harp and accompanied him.*

The enfolded memory and agency of the harmonica were, with but a little facilitation, able to eventually activate and intra-act with Tom's implicit memory of his iterative harmonica-playing skills, which were still accessible despite his severe dementia. Through his tactile, embodied intra-action with the harmonica, he was able to venture from total confusion via disruptive, random tones to the continuity of a once-well-known melody and finally to mutual music-making and co-creation.

4.10.3 Dis/continuity

In one essay, Barad (2010) discusses the disruption of continuity, or what she also calls "quantum dis/continuity": "a way of thinking with and through dis/continuity – a dis/orienting experience of the dis/jointedness of time and space, entanglements of here and there, now and then" (p. 240). Her narrative, based on quantum field theory, seeks to offer the reader "an imaginative journey that is akin to how electrons experience the world" (p. 244). She cautions, however, that it "is not in order to inspire contemplation of flat-footed analogies between 'macro' and 'micro' worlds, concepts that already presume a given spatial scale" (p. 240). In other words, her narrative is literal and expresses an onto-epistemological point of departure (Waage, 2020, p. 8).[69]

I believe that Barad's concepts of *dis/continuity* and *intra-action* can inform our understanding of vital aspects of dementia symptoms as well as the "polyphonic personhood" proposed in Chapter 4.5.8. The embodied yet ephemeral in/dividuality of personhood arises as a fluctuating composition which scatters into a puzzle of fragments which reorganise in a past and present intra-action of perception, interoception and neuroception upheld by our human and non-human surroundings and relations as well as our embodiment, inner life and internal

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[69] She states this elsewhere as well: "I am not interested in drawing analogies between particles and people, the micro and the macro, the scientific and the social, nature and culture; rather, I am interested in understanding the epistemological and ontological issues that quantum physics forces us to confront" (Barad, 2007, p. 24).

voices. This polyphonic process, I will argue, is part of being human. The "fragmented" self of a person living with dementia could, thus, be viewed as a gradation of the polyphonic fluctuations of in/dividuality and de/centredness which are common to every human being. In this light, the urge to "bring the person back" could be supplanted by an embrace of in/dividuality and an acknowledgment of the present person as (s)he is, and may become, beyond any past identity.

Time displacement – the experience of being somewhere in the past – is a characteristic symptom of dementia. This apparent breakdown of Newtonian linear time is not regarded as a hallucination by professionals. Instead, they recommend that "time travel" be met and handled as a natural extension of cognitive deterioration (Johnson et al., 2017) (Waage, 2020, p. 9). A way to conceptualise such time offset might be that the current timeline occasionally collapses, and other timelines come to intertwine the past and the present – and possibly also certain expectations, fears or desires regarding the future. The merging timelines might be confusing, messy or even scary, but they might also spark a sense of sheer abundance: "Going beyond the rational and three dimensional is a posthuman aspiration; but people with dementia are already there. Finding a way to value this and possibly work with it is an important challenge" (Quinn & Blandon, 2020, p. 50).

If a meaningful present moment runs alongside the offset timeline and perhaps suggests new potentials within it, the consequently entangled timelines need not be scary for either the person with dementia or the close ones. In fact, the entangled timelines might even add the dynamic vitality of a beautiful polyphony, shifting musically among the provocative dissonances of diffracting chronologies and consonances of attunement, glimmers, safety and meaningful moments: "Quantum superpositions and, relatedly, quantum entanglements open up possibilities for understanding how the 'new' and the 'old' – indeed, multiple temporalities – are diffractively threaded through and are inseparable from one another" (Barad, 2017, p. 69). Perhaps the person with dementia could even be said to be closer to the reality of time–space superposition and capable of somehow teaching others how to relate to the diffractive aspects of time: "Dementia crashes into humanist time, breaks it, reveals its fantasy. A posthuman sense of time is a spiral moving backwards and forwards. Dementia makes observers more conscious and reflective of living within this spiralling time" (Quinn & Blandon, 2020, p. 56).

Our cognitive capacity for the structural organisation of time and space makes us capable of performing agential cuts in order to perceive time-space-matter without being (too) overwhelmed. During cognitive loss, however, these structures can sometimes and somehow break down. From the agential-realist point of view, I would suggest that, at these times, the diffractive, entangled space–time dis/continuity then comes to the foreground, putting people with dementia at risk of experiencing overwhelming chaos. We might then offer them the opportunity to regain their capacity to reorganise their perception of the world. Attunement – in several senses of the term – could serve such a purpose. Via careful intra-actions involving the modelling of our voice prosody, mimicking and gestures, we might supply attunement as a neurophysiological cue of safety and trust, in line with the principles of PVT. Further, through mutual listening and co-creation in the moment, song and singing can foster attunement. The singing and the song itself may open the moment to diffractive but still potentially reorganising, embodied and embedded stories of life history, relations and safety (Waage, 2020, pp. 9–10).

There are countless stories about how people with advanced dementia who are otherwise unable to speak suddenly sing from memory several verses of a beloved song if the song is presented to them. I have often experienced this myself. Moreover, research and practice show that singing well-known songs during care can improve the communication and cooperation between people with dementia and their caregivers (Götell et al., 2009; Hammar, 2011; Myskja, 2011). When songs and singing are part of the interaction, the enfolded, diffractive "materialisations" of the song – as well as the subtle cues of safety which the singing is activating in the facial expressions, gestures and tone of voice in the carer, in line with PVT – offer affirmative intra-actions, widening the potential in people with dementia to realise more vibrant ways of "becoming" (Waage, 2020, p. 10).

4.10.4 Material-discursive entanglements

Other humans, as well as material and immaterial "matter", touch us via intra-actions and thereby influence our behaviour in both obvious and subtle ways.[70]

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[70] Chapters 4.10.4 and 4.10.5 are based on Waage (2020, pp. 10–11), with minor editorial modifications.

Evolution plays out through our embodiment and the autonomic nervous system, re/acting upon our vital and material surroundings, strangers and acquaintances. The stories we tell ourselves and others continually intra-act with myriad phenomena implicated in our physiology, neurology and psychology, among other things. Consciously and unconsciously, our narratives are fostered by and impactful upon our past, present and future relations and events.

The polyvagal theory adds ontology as well as epistemology to our understanding of dementia. Insights from PVT reveal possible underlying reasons for what we might otherwise interpret as "adverse" behaviour, which is often, at least partly, due to others' inadequate interpretations of and responses to an experience of unmet needs or unsafety. Equally crucially, PVT reveals the intra-active potential of "glimmers", and thus social engagement and co-creation, through singing, among other things.

Based on the diffractions and discussions in this section, I argue that Barad's ethico-onto-epistemological foundation and concepts add fruitful perspectives to our conceptualisations of dementia, embodiment, co-regulation, and singing and co-creation. *Dis/continuity*, *diffraction* and *intra-action* extend the possibilities of our approaches to the confusing, fragmented yet rich life-story-containing experiences and resources of people living with dementia. It is also possible to elaborate upon our interpretation of dementia-related time confusion or "time travelling" in light of Barad's concept of *dis/continuity*.

Lastly, the concepts of *intra-action* and *diffraction* shed light on the co-regulating and co-creating potentials of songs and singing, including the relational, dys/regulative implications of PVT, especially with regard to the impact of cues of safety and trust upon social engagement and connection. As PVT deepens our understanding of the interpersonal neurological foundations of behaviour, and thus the co-regulative potential in our embodied intra-actions, there might follow a shift in the narratives linked to dementia and behaviour. How and who we are – and the narratives connected to those things – are inseparably entangled and diffracted, threaded through the past, present and future and in that way part of the co-creation of becoming.

4.10.5 Third epistle – intra-actions of senses, strings and tones

In my music sessions within ageing and dementia care units, I usually brought my little walnut "County Kerry" Celtic harp. Sometimes I played

> *in conventional keys, accompanying my own and the residents' singing. Other times, I tuned my harp in "angel mode" (the pentatonic scale) and extended it to them, one by one, allowing their fingers to hesitantly or firmly touch the strings. Their faces – sometimes uncertain, at first – opened up into a smile or look of surprise when they suddenly found themselves accompanying our co-singing with graceful arpeggios. Give me your hand.*[71]

4.11 Concluding summary

In this chapter, I have provided a material-discursive context for singing and dementia in close relations by discussing and diffracting several central themes, models and theories connected to well-being, cognition, memory, embodiment, personhood, communication and relation, from various angles and within different discursive frames.

The initial discussion of well-being refers to the cultural and paradigmatic prerequisites often taken for granted when people assess well-being in research or practice. A more relational and situated understanding of well-being invites new understandings of how a multiplicity of factors modulates well-being. This fluidity also brings benefits to the assessment of "effects" in research studies – for instance, by encompassing the micro-moments of fluctuating joy and meaningful connection in this context.

Research on embodied cognition and studies of different forms of memory, in the context of dementia and in general, highlight the need to move beyond language and explicit memory in our relationships with people living with dementia and start to draw on implicit and embodied resources and potentials including music. These embodied resources are also central to an advanced understanding of personhood not as something fixed and in-dividual which can be lost along with language and explicit memory but as something dividual, dialogic and polyphonic which resides both in and between our bodies.

The embodied, non-verbal, music-like, rhythmic communication and interaction between infants and parents – what scholars call communicative musicality or proto-musicality – creates a communicative, relational and musical

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[71] The song "Gje meg handa di, ven" (Give me your hand, my friend) goes very well with the pentatonic scale as its accompaniment.

foundation which is accessible throughout our lives and anchored in our implicit, embodied memory. Such proto-musicality and social bonding rituals also contributed, according to Dissanayake (e.g., 2017), to the development of the arts through a process of “artification”– that is, ways to “make the ordinary extraordinary”.

The affective attunement and vitality of proto-musical communication can also “tune” the social engagement system (Porges, 2011) to train or maintain the regulative capacity of the autonomic nervous system (ANS), in this way balancing responsive prosocial and reactive defensive impulses while modulating and regulating the defence mechanisms of fight, flight, freeze or collapse. Especially in the context of dementia, autonomic self-regulation and co-regulation are essential to maintaining safety, trust and social engagement and keeping the individual from being overwhelmed and shutting down or being anxious and mobilising into fight or flight reactions. The properties of gentle communication, singing or music can activate neural and muscular pathways and thereby contribute to autonomic regulation and prosocial capacity.

Barad’s (2007) concepts of intra-action, diffraction and dis/continuity offer yet other perspectives upon the aforementioned discursive and theoretical insights contextualising singing, dementia and relations. The inseparable human and non-human materialities of the relational bodies, nervous systems, voices and songs intra-act and diffract in multiple ways and dimensions as well as across linear time. Barad’s concept of dis/continuity in particular embraces the fluctuations and disjoints of time perception in dementia and offers new horizons regarding what it means to be human and what potential becoming remains in a person with dementia within this matrix of inseparability and possibility.

5 Macro-ethical perspectives and implications: A discursive approach

5.1 Introduction

In this chapter, I outline and discuss some macro-ethical perspectives, particularly connected to dementia and, to some extent, music. They are linked to posthuman theory and philosophy, outlined in Chapter 3, and research and theories connected to music and dementia, and embodiment and selfhood, outlined and discussed in Chapters 2 and 4.

Traditional research ethics provide essential guidelines and signal researchers' responsibility to base their work on a fundamental respect for human dignity in terms of their research topics, research subjects, and reporting and publishing efforts (NESH, 2016, p. 12). Relatedly, traditional ethics insist that researchers should be cautious in their design and presentation to prevent "unreasonable generalisation […] which in practice result[s] in the stigmatisation of particular social groups" (NESH, 2016, p. 24).

The tensions between biomedical and more embodied and affirmative approaches to music and dementia have arisen earlier in the monograph, but their links to particular discursive elements remain unplumbed. In this chapter, I will explore some of the implications of such discursive, perhaps paradigmatic, tensions in the context of singing and dementia. An overly biomedical disease focus and the related discourses of lack, loss and tragedy can also inform stigma, othering and ableism. It is possible, however, to highlight affirmative approaches instead. The discursive framework we create for music and dementia will eventually guide us to the potentials we seek to explore and develop in practice. In addition to Barad's philosophy, I believe that Rosi Braidotti's *affirmative ethics* can serve as an apt overarching ethical framework for my project and even for music and dementia in general.

A vital implication of Barad's theory is the necessity of always taking one's intra-active, co-constitutive role and entangled ethical responsibility into account, including in the research process itself:

> Intra-acting responsibly as part of the world means taking account of the entangled phenomena that are intrinsic to the world's vitality and being responsive to the possibilities that might help us flourish. Meeting each

> moment, being alive to the possibilities of becoming, is an ethical call, an invitation that is written into the very matter of all being and becoming. We need to meet the universe halfway, to take responsibility for the role that we play in the world's differential becoming. (Barad, 2007, p. 396)

In later articles, with reference to Derrida, Barad (2010, 2019) points out: "Justice in the form of justice-to-come is an infinite pursuit, an ongoing ethical practice" (2019, p. 236), and elsewhere: "Only in this ongoing responsibility to the entangled other, without dismissal […], is there the possibility of justice-to-come. Entanglements are not intertwinings of separate entities, but rather irreducible relations of responsibility" (2010, pp. 264–265). These Barad citations convey her ethico-onto-epistemology, which also has implications for music and dementia. Following Barad, the field must take responsibility for how discourses of dementia frame, restrict or facilitate the possibilities of flourishing for people living with dementia. These discourses affect the ways we relate to people with dementia but also influence how music, including singing, can unfold in their lives.

In his book *Hjertet mitt har ikke demens* (My heart does not have dementia), Audun Myskja (2013) describes his encounter with a woman who previously had dementia for some years due to the virus encephalitis before she ultimately recovered. She told him that the worst part of the experience was her sense of always making mistakes, being at the wrong place or at the wrong time – simply being wrong – which made her increasingly confused. As she failed to secure any confirmation of the reality around her, it came to feel as though she did not even exist. She felt guilt and shame and feared that she was a constant burden. To support and provide comfort and security to people with dementia, she stressed the importance of being patient, taking time, and explaining (pp. 74–76). She told Myskja that if he were to take one sentence from her experience, it had to be: "*You and I, we will manage this*"[72] (Myskja, 2013, p. 77).

In this light, Rosi Braidotti's (2008, 2017b) concept of affirmative ethics seems strikingly appropriate, as she also suggests a whole new kind of human subject: "the collaborative and interconnected 'we-are-in-this-together' kind of subject" (2017b, p. 23). I will argue that the focus on affirmation, flourishing, inclusion and responsibility conveyed by Braidotti's affirmative ethics resonates

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[72] My translation. Original: "*Du og jeg, vi skal få til dette her*".

with Barad’s view on ethics and responsibility and with relational and resource-based approaches to singing and dementia.

Before returning to this affirmative ethics, I will discuss some partially overlapping issues and discourses which are essential to the ethics of dementia: models of disability; othering and stigma; and dementia as tragedy and “living death”.

5.2 Dis/ability and dis/ease

Dementia is a syndrome rather than a disease, and its progress is highly variable. Different personalities with diverse kinds and stages of dementia thus have various resources, challenges and needs. Moreover, these individual configurations of strengths and challenges are unstable and fluctuate according to internal and external conditions and demands. In the end, disability and disease are themselves unstable concepts, dependent on multiple factors, including their narrative framework.

Mittner et al. (2021) refer to three different models of disability. The first is based on impairments and functional limitations and is referred to as the medical model. The second, the social model, regards disability as something produced by the environment, rendering people disabled in certain contexts. The third, the relational model, is proposed by Shakespeare et al. (2019) as a way to conceptualise dementia. They point out that the social model of disability distinguishes between impairment (medical) and disability (social) and focus on social barriers and oppression. The social model has been accused of environmental determinism, oversimplification, and the dismissal of the personal experiences of the people affected. Moreover, it is not particularly useful for conceptualising cognitive impairments and mental health issues (p. 1080).

The authors acknowledge that both the health condition itself and the social responses to it generate a disability, pointing out that “various scholars have proposed a critical realist approach to disability […] entailing a laminated model. This refers to the different levels – the biological, the psychological, the environmental, the social, the legal – which interact to produce the experience of disability” (Shakespeare et al., 2019, p. 1082). The authors believe that a relational model such as this better conveys the complexity of dementia. Further, according to Mittner et al. (2021), the relational model

> understands disability as the result of the individual–environment interaction […]. This model builds on a visual figure of "the gap" between social requirements on the one side and individual abilities on the other. The gap or the space in between these two factors represents what we can call "the disability constructing room". (p. 66)

As outlined in Chapter 2.6.3 in reference to Mittner et al. (2021), this gap can also be a space of opportunity for co-creativity and reciprocal aesthetic experiences, meaning that it can be reduced or even eliminated altogether, at least temporarily. The gap or space of the "disability constructing room" (Mittner et al., 2021, p. 66) is ambiguous and brings with it opportunities for disability and possibility alike. Thus, it may be best conveyed by "the posthuman slash" (referred to in Chapter 3.3.5) to signal the phenomenon's simultaneously complementary and alternative aspects. I, therefore, suggest rendering the relational disability model's gap or space as dis/ability, a flexible understanding also explored by Kolarova (2015), who suggests the term "debility". Referring to Fritsch, she defines debility as "the flexible gradation of dis/ability and in/capacity" (p. 78).

Concerning dementia, I suggest treating the terms disorder and disease similarly. Whether symptoms of dementia should be framed as a syndrome, a disorder, a disease or a natural progression of old age is a complex and situation-dependent issue. Thus, the dis/order or dis/ease of dementia could also be regarded as a gap – a space between condition or state and diagnosis – and a continuum between chaos and harmony, uneasiness and ease. The conceptual and discursive gaps inhabiting dis/ability, dis/order and dis/ease are also potential spaces for ethical consideration and discourse, and particularly the discourse of disability, which is also linked to othering and stigma.

5.3 Othering

Braidotti (2017b) acknowledges what she calls "the missing people", the marginalised, unprivileged and overlooked: "Who qualifies as a human […]? The experience of the marginal and the dispossessed teaches us that 'the human,' far from being a universal or neutral category, is a term that indexes access to entitlement and privileges" (p. 17). Quinn et al. (2021) – whose work was reviewed in Chapter 2.6.2 – also refer to Braidotti's interrogation of "the human" with their concept of *post-verbal* people, which contributes to a new understanding of lives which are not normative: “Ranciere typifies common assumptions about humanity and language: ‘the human is that which possesses the ability to articulate language’ […], thus placing non-verbal people outside the human category” (Quinn et al., 2021, p. 75). Drawing upon posthuman theory and Braidotti (2013, p. 26), Quinn et al. (2021) propose a more complex relational subject framed by embodiment, sexuality, affectivity, empathy and desire. Moreover, they contend that rather than positioning post-verbal people as less-than-human, their different capacities can be released and celebrated, particularly through music and art activities.

Gerrard et al. (2017) also discuss the literature’s tendency to “other” and marginalise research subjects. In line with a critical view of representational logics, they state that research is performative, with its concepts, categories, descriptions and languages having effects. “We think the challenge this poses is how to conduct research that broadens and shifts the view from the Other, to the wider cultural processes, historical practices, and socio-spatial dynamics that create the experiences and categories of ‘Otherness’” (Gerrard et al., 2017, p. 24). While they then advocate for more research on the underlying processes and dynamics which create otherness, they acknowledge the possibility and even the political need to represent the lives of “Others”. However, they ask that researchers do so “with a view on the often hidden, banal, or unspoken social relations of power” (p. 24).

5.4 Stigmatising discourses – dementia as tragedy

Mitchell et al. (2020) point out that two dominant and interrelated discourses of dementia – namely, the biomedical approach and dementia as tragedy – fuel the stigmatisation, judgment and social exclusion of people living with dementia. They argue that the biomedical discourse reduces people with dementia to their neurodegenerative diagnosis and restricts care practices to attending to their bodily needs. Accordingly, within a therapy culture, various professionals assess needs and functional deficits and assign interventions, therapies and modifications to meet them, primarily focusing on managing “challenging behaviours”.[73] Even leisure activities are used and valued primarily as non-pharmacological “treatments” to achieve medicalised outcomes. Mitchell et al. argue that such an approach to care limits meaningful participation and “normal” ways of living (p.

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[73] The medical paradigm’s influence on caregivers’ interpretation of behaviours is discussed in Chapter 4.4.2, “From challenging to responsive behaviour”.

3). Likewise, they point out that the biomedical model also operationalises a language which reflects the broader discourse of dementia as tragedy. They see this discourse as based on the assumption that the neuropathology associated with dementia eradicates the essence of the person:[74] "This is evident in the metaphors and images in policy and popular culture that represent dementia as 'the funeral without end', 'the loss of self', 'the zombie', and 'a living death'" (p. 4).

Presenting dementia as a "living death" is also discussed by Behuniak (2011), who identifies seven ways in which people with Alzheimer's disease (AD) are constructed as "zombies". She finds that such dehumanisation, based on disgust and terror, is an essential aspect of the AD stigma, even though AD researchers have often placed the blame for the stigma on the biomedical understanding of dementia.

Mitchell et al. (2020) also interrogate modern society's patterns of healthism, ageism and consumerism, which have led to an increasing emphasis on individual responsibility, control and autonomy. Consequently, health-promoting activities are considered a moral obligation and an individual responsibility. Hence, the fear-provoking discourses of dementia as tragedy or living death which fuel its related stigma may also fuel health consumerism.

According to O'Sullivan et al. (2014), their study participants with dementia were very aware of the stigma associated with dementia and consequently wanted to hide their health problems (p. 88). In addition to other people's attitudes, that is, personal attitudes were also significant: "This is important because a positive attitude from the person with dementia, as well as their carer, can help to maintain a sense of life satisfaction, self respect and confidence" (O'Sullivan et al., 2014, p. 489). The authors then advocate for the need to move away from the biomedical focus on disease and disability, which fosters prejudices, stigma and patronising approaches: "The pursuit of positive attitudes will do much to change social perceptions and enable people with dementia to live with a sense of well-being" (O'Sullivan et al., 2014, p. 483).

Clearly, then, there is a need to include more positive renderings of dementia in the discourse about it. James Fletcher (2021), however, points out that the *overly* positive portrayal of the condition risks obscuring the experiences of the many people who do suffer from it: "Worse still, it promotes an ethic of wellness in which dementia is shown to be potentially unproblematic, implicitly ascribing a

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[74] Dementia and selfhood are discussed in Chapter 4.5.

type of failure to those who do not live well" (Fletcher, 2021, p. 421). He goes on to discuss the complexity and paradoxes regarding dementia and destigmatisation. Further, he deconstructs the concept of stigma and considers its use in dementia research and advocacy. He suggests a distinction between felt stigma and enacted stigma and asks if a limited, simplified concept of stigma might be informing misguided anti-stigma campaigns and unwittingly exacerbating stigma itself:

> Some commentators argue that the medicalisation of dementia has destigmatised cognitive impairment in older people by attributing behaviours to illness rather than personal shortcomings and hence removing blame […]. However, others claim that medicalisation has exacerbated stigmatisation because a once natural process of later life has been reimagined as an incurable disease of epidemic proportions. (Fletcher, 2021, p. 422)

Fletcher (2021) also points out that ageism is often part of the stigma. Still, age is often removed from the anti-stigma campaigns: "Despite being strongly age-associated, high-profile representatives of dementia are often unusually young" (p. 421).

Despite the field's putative embrace of Kitwood's person-centred care (Kitwood & Brooker, 2019), dementia care, research and media coverage are all still largely characterised by a deficit-oriented and instrumental approach to the condition. Consequently, people living with dementia may directly or indirectly be rendered as "less than human" because of the field's tendency to be overly focused on their reduced cognitive capacity and the "challenging behaviour" which supposedly derives from it. To counter this tendency toward *pathologising behaviour*, however, Dupuis et al. (2012) advocate for the term *responsive behaviour*, as discussed in Chapter 4.4.2.

> A responsive behavior discourse views all actions as meaningful and moves us away from judging behaviors to understanding meaning in actions and responses. It means moving from a focus on dysfunction, deficit and decline, to recognizing, valuing and believing in the continued abilities of persons with dementia to express their experiences and act in purposeful, meaningful and even intentional ways. (Dupuis et al., 2012, p. 170)

Note that the responsive-behaviour discourse resonates with the relational citizenship model (Kontos et al., 2017) discussed in Chapter 4.5.2. To further disrupt stigmatising biomedical and tragedy discourses, Mitchell et al. (2020) turn to the model of relational citizenship to advance an alternative care ethics based on relational practices including the arts, to which I will return below.

5.5 Towards an affirmative ethic of musicality

When Braidotti (2008, 2017b, 2019a) proposes an affirmative ethics from a critical posthuman, new-material perspective, it resonates with Barad's (2007) theory. Also, affirmative ethics hold implications for the dementia discourses and our intra-actions with people living with dementia. Braidotti (2017b) insists, "Posthuman ethics is about interacting affirmatively in the world, together with a multitude of human and nonhuman others" (p. 20). She continues:

> For Spinoza, the ethical life consists of understanding ourselves as integral parts of the totality of being. It is the case, therefore, that not only are our bodies dynamically embedded in the interconnected whole that is the material world, but also so are our minds […]. The immanent ethical subject apprehends itself – with ever increasing adequacy – as part of that interconnected totality of both matter and thought. […] The ethical ideal is to aspire to the joyful affirmation of virtual possibilities, of what "we" are capable of becoming. (Braidotti, 2017b, p. 21)

Braidotti (2019b) does not deny negativity but wants us to rework it outside the dialectical oppositions because "negative passions diminish our relational competence" (p. 167). She claims that ethical relations create possible worlds by mobilising resources which have been left untapped in the present, including our desires and imaginations (p. 166).

The tragedy discourse of dementia as a "living death" or as relatives "losing" their dear ones can restrict the lives and possibilities of people impacted by the condition. Instead, it is possible to approach living with dementia as a *different* way to live, learn, experience and communicate for both people with dementia and their loved ones. Such an approach informs the dementia research of Kontos and colleagues (Kontos, 2004; Kontos et al., 2021; Kontos & Grigorovich, 2018a; Kontos & Martin, 2013; see also Chapter 4.5) which focuses on embodiment, relations and creativity. The proposed relational citizenship model elevates relational and embodied aspects above traditional person-centred or relationship-centred care to encompass human rights, policymaking, and power structures (Kontos et al., 2020).

Based on their research, Kontos and Grigorovich (2018b) hold that the body's pre-reflective capacity and sociocultural disposition toward musical self-expression, interdependence and reciprocal engagement persist despite severe cognitive impairment. Hence, they argue that music in dementia care should not be restricted to an instrumental tool to improve "behaviours" and cognitive functioning. Instead, they propose an *ethic of musicality*, which asks that musicality be more broadly supported in and through policies, structures and practices.

> It is a new kind of ethic that goes well beyond custodianship and remediation. It is characterized by a pre-reflective intercorporeal sensibility that shifts the goals of care to a moral responsibility to promote human flourishing […]. Flourishing in this context occurs when embodied selfhood is supported in and through the creation of enabling environments and relational practices – or corporeal-ethical spaces – that support embodied forms of communication and meaningful engagement. (Kontos & Grigorovich, 2018b, p. 46)

Likewise, posthuman and new-materialist approaches to research on arts and dementia (e.g., Mittner, 2022; Quinn & Blandon, 2017, 2020; Quinn et al., 2021; Zeilig et al., 2018) – as discussed in Chapter 2.6 – can contribute to more resource-oriented and less instrumental approaches to arts and dementia while challenging the humanist notion of what it means to be human altogether. I believe Barad's ethico-onto-epistemology and Braidotti's affirmative ethics supply the foundation for such approaches.

The arts-based research of Jerry Rosiek (2018) also underlines the importance of macro-ethical perspectives – namely, that the need to contribute to human well-being on a personal and global scale should be part of the design and, broadly speaking, "politics" of research (p. 632). He advocates for the relevance of agential realism and the "conception of ethics as a form of ontological permeability, as opposed to cognitive certainty" (p. 639) and cites an interview with Karen Barad in which she states:

> Ethics is about mattering, of taking account of the entangled materializations, of which we are part, including new configurations, new subjectivities, new possibilities. […] Responsibility then is the matter of the ability to respond. Listening for the response of the other and an obligation to be responsive to the other, who is not entirely separate from what we call the self. This way of thinking ontology, epistemology and ethics together makes for a world that is always already an ethical matter. (Dolphijn & van der Tuin, 2012, p. 69)

Based on ideas from Bakhtin, Karette Stensæth (2017) has articulated a theory about responsiveness in music therapy she calls "musical answerability" (p. 115). She points out that it also has ethical implications: "Musical answerability is a theory of ethics, too. Here, responsiveness becomes a deed, as an ethical obligation to engage lovingly and artistically in answerable acts with people around us, perhaps especially with people who are in need" (p. 117).

Singing may be a loving, post-verbal, pre-reflective, intercorporeal language with the potential to cut-together-and-apart the boundaries and spaces of dis/ease and dis/ability – and dis/connection. Singing can create response-ability and, hence, might be a responsibility. Such musical answerability resonates with Kontos and Grigorovich's (2018b) ethic of musicality and Barad's (2007) call to "being responsive to the possibilities that might help us flourish" (p. 396). In all, these perspectives reverberate with Braidotti's (2017b) ethical ideal "to aspire to the joyful affirmation of virtual possibilities, of what 'we' are capable of becoming" (p. 21).

5.6 Concluding summary

In this chapter, I further develop the discursive connotations and implications introduced in previous chapters and expand my discursive focus into macro-ethical perspectives. Braidotti's affirmative ethics and Barad's notion of "justice to come", borrowed from Derrida, supply a foundation and frame for scrutinising attitudes and discourses connected to dementia.

Dementia can also be understood in light of different models of disability ranging from the medical model (focused on physical disease and degeneration), to the social model (focused on the gap between societal demands and personal ability), to the relational model (focused on the interaction among all these factors). The GAP model of relational disability draws further attention to the gaps between various demands and abilities: "the disability constructing room" (Mittner et al., 2021, p. 66). In line with posthuman scholars, I suggest that this gap can also be seen as a space of potential in the dis/ability, dis/ease and dis/order of dementia. As Mittner et al. (2021) point out, it can be reconceptualised as a space of co-creative and reciprocal aesthetic opportunity, and when one is co-creatively engaging in the arts (including singing), that gap can shrink or disappear altogether.

The overall discourse of "dementia as tragedy" is fuelled by the biomedical paradigm and the discourse of dementia as "living death" promoted by the media and popular culture. Even health consumerism and ageism contribute to these discourses, which can lead to othering and stigma. Braidotti's (2017b) notion of "the missing people" – the marginalised, unprivileged and overlooked – puts this trend into perspective. The challenging experience of dementia instead calls for inclusion and support. Braidotti's (2017b) suggestion of a new kind of people: "the collaborative and interconnected 'we-are-in-this-together' kind of subject" (p. 23) answers this call. She argues that "posthuman ethics is about interacting affirmatively in the world" (p. 20), less by denying negativity than by transforming it and mobilising untapped resources.

Braidotti's account is in line with Barad's (2007) call to be responsible and "responsive to the possibilities that might help us flourish" (p. 396). Kontos and Grigorovich (2018b) introduce this sense of responsibility into the musical sphere through their *ethic of musicality*, wherein musicality is supported in and through policies, structures and practices which recognise embodied selfhood and forms of communication and meaningful engagement in enabling environments and relational practices, not unlike Stensæth's (2017) notion of "musical answerability" (p. 115).

6 Conceptual perspectives and implications: Co-singing

6.1 Introduction

This chapter builds upon the dissertation's philosophy-of-science foundation (Chapter 3) as well as research on and theory and discourse related to singing, dementia and relatives (Chapters 2, 4 and 5). Its goal is to develop and anchor the concept of *co-singing* as a supplement to other approaches to singing and dementia.[75]

As I indicated in Chapter 2, there are several different though partially overlapping approaches to music in dementia research and care:

- music as therapy
- music to promote health and well-being in the community
- music as part of caregiving
- music as a creative and resource-oriented intervention or event

My exploration of singing and dementia offers a supplement to the above by emphasising singing as communication and togetherness interwoven into daily life activities, events and interactions outside of a professionally organised context.

The main issues in this chapter are (1) the way in which low-threshold singing activities for people with dementia and their close ones might be communicated via terminology which is more apt than that currently used within the field of music and dementia, and (2) the way in which that terminology might be grounded in research, based on the material-discursive perspectives explored in the literature thus far in this dissertation. Thus, this chapter primarily engages with the monograph's third research question:

> *How might reworked singing terminology and concepts nuance understandings of and insights into daily-life singing practice and experience for people with dementia and their close ones, and what might be the reciprocal implications for concept and practice?*

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[75] Parts of Chapter 6 are based on – and developed further from – my published article; see Waage (2022). The applicable paragraphs include footnotes, paraphrased references and citations to avoid self-plagiarism.

While the previous chapter engaged with broader discursive implications, the present chapter dives deeper into specific concepts and applicable terminology based on the theoretical and discursive explorations so far in the dissertation.

This chapter connects singing in the context of dementia in close relations to the various, partially overlapping and interwoven theoretical perspectives outlined in previous chapters, particularly the model of communicative musicality, the polyvagal theory (PVT), research on dementia and embodiment and memory, and aspects of posthuman theory and philosophy. Further, I will propose the concept of *co-singing* and reconcile it to existing concepts and terms such as *health musicking*, *caregiver singing*, *care-singing* and *co-creation*. In short, this chapter explores and discusses co-singing as a term and practice in the context of dementia and relations, read through different, entangled theoretical perspectives and concepts (Waage, 2022, pp. 329–330). By developing and anchoring the terminology, this chapter also provides a material-discursive foundation for the further exploration of relational singing as a (material-discursive) *practice* in Chapters 7 and 8.

Not all people with dementia or their close ones have had positive singing experiences during their lives, and some might prefer other activities altogether. Still, based on the reviewed research – and provided individualised adaptation – it is reasonable to believe that many families affected by dementia might benefit from singing more actively as a part of their daily life (Parmar & Puwar, 2019) (Waage, 2022, p. 331). Therefore, my exploration of singing as a resource for families living with dementia builds on their own competencies and experiences but still enables broad and regular use. Such an approach to daily-life singing connects to research literature addressing relations, co-regulation, embodiment and memory in the context of singing and dementia.

6.2 Entanglements of theory

In this dissertation, a relational approach to singing integrated into daily life is anchored in Barad’s (relational) ethico-onto-epistemology (Chapter 2) and further explored via different aspects of research and theory connected to singing, dementia and relationships (Chapters 3 and 4) and subsequent related discourses and ethical perspectives (Chapter 5). All these factors are relational and entangled; they are inseparable, intra-acting and diffracting in multiple ways.

The early infant–parent communication and regulation described in the communicative musicality model (Malloch & Trevarthen, 2009) offer a means of exercising the social engagement system and autonomic-nervous-system regulation outlined in PVT (Porges, 2011). Such early infant–parent interplay offers the infant an "education" in modulating aspects of the social engagement system, including its neuroceptive underpinnings. Even the less attuned sequences of companionship – those which may lead to disruption – are integral to this education: "It is the *repair* of the disruption – its timing, its sensitivity, its fits, its lack of intrusiveness – that will determine how well the dyad functions over time" (Sanders, 2018, p. 361) (Waage, 2022, p. 342).

> The highly melodic and rhythmic features of the preverbal "language" described in communicative musicality activate the neural and muscular pathways of the social engagement system outlined in PVT. Thus, the basic components of communicative musicality – pulse, quality and narrative – performed through turn-taking, gestures, mimics and prosodic voicing are also key components of downregulating defence and activating the social engagement system. Singing together draws on these same basic elements, in addition to more refined creative, melodic and verbal content. When individualised adapted singing is part of communication and interaction, it can activate neural and muscular pathways supporting social engagement. In a sense, singing may offer a shortcut to social connection and the downregulation of defence at times when language alone falls short. (Waage, 2022, p. 342, with minor editorial adjustments)

People with dementia and their close ones may benefit from supplemental ways of communicating and interacting beyond words. The gestures, voice modulations and narratives of communicative musicality, and the contexts of singing together, may offer the person with dementia the well-known and still accessible expressive aspects of prosody, rhythm, music and meaning. Also, the role and skills of the *singer* may remain intact in that individual, due to implicit and procedural memories connected to the act of singing as well as the songs themselves (Waage, 2022, p. 343).

Knowledge, will and the ability to affirmatively address and draw upon implicit, embodied resources through relational singing (and, more broadly, music) are also linked to our attitudes towards dementia. These attitudes, and the discourses that shape them, have ethical implications, as discussed in Chapter 5. Such material-discursive entanglements and relational multiplicities are central in the context of singing and dementia. I believe it is also essential to consider this when exploring concepts and terminology in this area. Concepts from different music-therapeutic practices represent a relevant starting point for this discussion.

6.3 Discussion of concepts and terminology

6.3.1 Singing as health musicking

In my article (Waage, 2022, p. 332), I note that the relational and cooperative aspects of singing interactions evoke *musicking*, a term introduced by Christopher Small (1998) in the 1990s. Small's novel notion highlighted music as a relational activity instead of an independent object. Dissanayake's focus on *doing* art, discussed in Chapter 4.7, likewise recalls musicking (Countryman et al., 2016, pp. 1–2). Small writes: "The act of musicking establishes in the place where it is happening a set of relationships, and it is in those relationships that the meaning of the act lies" (Small, 1998, p. 13). The concept, process and practice of musicking are central to the music therapy field. Stige (2012) observes that aside from pointing to music-as-doing, the concept of musicking also points to music-in-context. Music therapists often focus on the musical, personal and interpersonal processes of music involvement and "typically have advocated the view that music is activity and relationships" (p. 164).

In acknowledging that the therapeutic effects of music and musicking can also arise outside the client–therapist relation, Stige (2012) puts forth the notion of *health musicking*, which in modern societies "may include any variant of nonexpert everyday uses of music-making or listening with positive health outcomes, whether these outcomes are intended or not" (p. 211). Ansdell (2013) adds that people often use music as an everyday self-care tool in a wide variety of areas, including "energy and motivation, emotion and emotional regulation, identity, relationship, socialization, restorative 'asylum', and self-reflective work in relation to everyday problems and challenges" (p. 7).

Such aspects of musical empowerment are highly relevant to families living with dementia and could also be connected to Antonovsky's salutogenic model (Antonovsky, 1996). Overall, singing together in families affected by dementia shares the features of health musicking described by Stige and Ansdell and fits readily into the broader concept of musicking proposed by Small (Waage, 2022, pp. 332–333).

Dowlen et al. (2018) reviewed 18 qualitative studies surrounding musicking for people with dementia and found a number of emotional, psychological and social benefits presented under four themes: taking part, being connected, affirming identity, and immersion “in the moment”. Their study emphasises the way in which musicking enables equal participation and allows a multisensory experience without having to rely on cognition or language. It also reveals certain barriers to musicking, especially with regard to when and how people with dementia can engage with music. The authors therefore suggest:

> Perhaps [by] thinking beyond music as a scheduled activity, and beginning to explore how musicking can become an integral part of people with dementia’s day-to-day lives and linked to the person’s biography, the barriers to taking part in musicking can be reduced. (Dowlen et al., 2018, p. 208)

6.3.2 Singing as care

Individualised approaches to music and dementia have been advocated by Gerdner (2005) and – as outlined in Chapter 2 – applied within music-therapeutic caregiving (Götell et al., 2002, 2009; Hammar et al., 2011a) and music-based milieu care (Batt-Rawden & Storlien, 2019; Batt-Rawden et al., 2021; Myskja, 2011), as well as professional music therapy sessions (Leggieri et al., 2019). It is possible to reach and enhance implicit memories by adjusting music and song selection to individual musical preferences and experiences. As discussed in Chapter 4.3.2, well-known and well-loved songs can invoke autobiographical memories (El Haj et al., 2015, p. 1720) both explicitly and on an implicit, embodied level (Fuchs, 2020) and may thus supply a sense of familiarity, safety and connection (Tomaino, 2013) (Waage, 2022, p. 343). Within dementia care, these aspects of music, including singing, have often been promoted as particularly important.

Care(giver) singing is a research-based approach utilised by nurses and nurse aides, with or without former musical experience, in nursing homes and other dementia care settings. Staff members sing familiar songs with residents with dementia during daily care procedures such as morning washing and dressing to enhance the communication and interaction and prevent adverse behaviour (Hammar et al., 2010; Hammar et al., 2011a). Terms describing such practices include the aforementioned *caregiver singing* within the larger practice of *music-therapeutic caregiving* (MTC) (Brown et al., 2001; Götell et al., 2009) and *care-singing* within the frame of integrated music in nursing homes (Myskja, 2011). While they represent a relevant point of departure here, these terms do not necessarily cover the various ways in which singing can be a resource in the daily lives of families affected by dementia. After all, they originated within professional dementia care and signal music and singing's potential as an agent of or support for this care (Waage, 2022, pp. 343–344).

The connotations and narrative of care – including comfort, "holding", safety, concern, and even love – add new dimensions to the notion of *singing* for people with dementia and their relatives or spouses. However, these connotations may also imply an uneven power balance if the cared-for individual is in an inferior or dependent situation. This can be true both within residential care and in families affected by dementia because people with dementia often require help and support (Waage, 2022, p. 344). As discussed in Chapter 4.5, some scholars (e.g., Kontos and various colleagues; Jenkins, Quinn and colleagues) have criticised the focus on identity and personhood informing Kitwood's person-centred care model. They hold that such an approach does not adequately account for the interconnectedness between the person and the environment where the person – according to posthuman theory – is intra-acting as part of a broader "agentic assemblage" (Quinn et al., 2021, pp. 76–77, 81).

One aspect of social relations which challenges the power balance of caregiving is related to Bourdieu's theory of the gift, Saur and Sidorkin (2018) point out: "The gift is ambivalent: it appears as an act of grace, but implicitly contains a demand and challenge to reciprocate. The failure to reciprocate creates a relationship of dependency, of patronage" (p. 571). They therefore argue that caregivers should learn the essential skill of how to receive something back from the cared-for, "to bend the objective situation of one-way giving into something resembling two-way mutual giving" (p. 573).

Singing might be one form of a more mutual and equivalent relation between people with dementia and their caregivers. For instance, the person with dementia – despite other challenges due to the disease – might be a more confident singer than the caregiver or even actively contribute to the caregiver's well-being through the act of singing. Moreover, singing together within families affected by dementia may also imply a sense of "self-care" and health-musicking for the person with dementia and the relative alike. Therefore, I prefer the term *care-singing* over *caregiver singing* because the "care-singers" may give to and care for themselves and one another on equal terms (Waage, 2022, p. 344).

The term care-singing can, thus, indicate both equality and relationality. However, the *institutional* context of care(giver) singing practice may, in some settings, bring with it both an uneven power balance and an overly instrumental approach to singing itself. As discussed in Chapter 4.2.3, Dowson et al. (2019) point out that outcome measures (and assessments of well-being) in most research on music and dementia focus predominantly on the reduction of negative symptoms. They argue that researchers therefore risk ignoring part of the spectrum of music's potential benefits (Waage, 2022, pp. 344–345). Further along such resource-oriented lines, there is also a growing body of research on "artful interactions" with people living with dementia, to which I will turn next.

6.3.3 Singing as co-creativity

Ann Basting (2020) established the term *creative care* and has run several projects to develop and promote artful interactions with people with dementia, both in residential care and for those living at home. Initially, these projects were framed as "therapy", but she soon began to question what was missing when one framed arts-based activities exclusively as "interventions", "therapy", and "medicine" to improve "patients": "Was there a unique power in *not* being medicine? Were we missing out on the community-building power of the arts?" (p. 140). These thoughts led her to shape several large-scale creative projects in nursing homes which engaged the entire community of care, including staff, residents, and volunteers. Basting's drive to activate the community-building power of arts and creativity likewise applies to a wide range of "communities", from large-scale to very small-scale, like a family or even a dyad. In all of these contexts, the arts can provide new ways of being together.

The concept of *post-verbal* people (Quinn et al., 2021), framed in Chapter 2.6.2 as an alternative to the term *non-verbal*, captures the potential of ways of communicating and interacting beyond words. Moreover, as discussed in Chapter 4.5.7, Quinn and colleagues focus on people with dementia as part of an "agentic assemblage" in contrast to traditional dementia-care music interventions focused on identity and autobiographical memory to support and "restore" the supposedly fragmenting selfhood which follows the onset of dementia. Thus, their artful interventions – including music and singing – aim instead at positive here-and-now experiences, means of post-verbal communication, expression, creativity and social inclusion.

Dowlen et al. (2021) also highlight "in-the-moment" experiences with music and singing for people with dementia in which creativity plays an essential role. They point out that creativity is often associated with giftedness and genius – the "big-C" creativity – but should also be understood to encompass the "little-c", everyday creativity which can arise across various "gifts" and abilities. They argue that

> by taking an embodied and sensory approach to understanding creativity in the context of music-making it will be possible to move beyond the cognitive narratives of "Big-C" creativity and towards a system that values "little-c" creativity and the benefits it engenders for people living with dementia. (Dowlen et al., 2021, p. 19)

Such approaches to dementia, arts and music are in line with Zeilig et al.'s (2018) concept of *co-creativity* as an alternative to the dominant focus on the beneficial and instrumental role of arts-based therapies and interventions in dementia care (p. 136). They advocate for co-creativity as an artful means of communication and interaction with implications beyond its potential therapeutic effect: "Co-creativity using the arts extends an invitation to participate in a shared and playful pursuit that allows unique opportunities for communication, expression and glimpses into people's interior worlds. These may have therapeutic potential but this is not the goal" (Zeilig et al., 2018, pp. 141–142). In addition, other posthuman-oriented research on arts and dementia referred to in Chapter 2.6 (e.g., Mittner, 2022; Mittner et al., 2021; Quinn et al., 2021) directly or indirectly embraces such an approach to co-creativity as the main goal of artful intervention.

Nevertheless, most studies on singing and dementia are still anchored within institutional or otherwise professionally organised settings. Furthermore, the musical interventions are primarily directed towards the person with dementia, although relatives and staff are sometimes included. Such contexts may yet be a salient part of the broader picture of resource-oriented relational singing and dementia (Waage, 2022, p. 345). However, singing activities outside of a professional or organised context which include people with dementia and their close ones alike may add nuance to the picture.

6.3.4 Singing as relation and togetherness

The aforementioned perspectives position singing in families living with dementia within the possible frameworks of health musicking, care and co-creativity. Such perspectives often contribute valuable insights regarding singing's potential in the context of dementia and close relations. However, this monograph primarily explores singing as togetherness – not as an intervention or happening but as something interwoven into daily life. As such, the singing is rooted in the competencies, experiences, embodiment and affects of the people with dementia *and* their close ones (Waage, 2022, p. 345). As I will further explore in Chapter 7, the accessibility of daily-life singing allows it to apply to a broad spectrum of relational activities, incidents and events.

The limitations of the terms caregiver singing and care-singing might tempt us to revert to the term singing alone, which is simple, open and inclusive. Yet, it is almost too inclusive, embracing vastly different singing practices and contexts ranging from pop and rock superstars performing for thousands to opera divas excelling in elaborate coloratura to the local children's gospel choir or the contemplative chant of Tibetan monks. Singing in families affected by dementia is an addition to the many settings which benefit from the inherent accessibility and versatility of the art of singing. Still, its terminology must acknowledge its unique components and implications. Based on the preceding discussion, the term should clearly reflect and highlight the togetherness of singing and capture its relational and communicative aspects and co-regulative potential (Waage, 2022, pp. 345–346). Within the field of early childhood education and care, Bjørkøy (2020) uses the Norwegian expression *sangsamspill* (singing interplay) to convey these aspects of relational singing in her research (Bjørkøy, 2022, p. 166).

In its combination of social interaction and little-c co-creativity, singing interplay is more than singing alone – it is, in fact, co-singing, in that its relational aspect is foregrounded and it derives from an encounter. Therefore, I propose the term *co-singing* to narrow the scope of *singing* and supplement the notions of *caregiver singing* and *care-singing* in professional caregiving. The term co-singing is open enough to embrace a range of contexts where singing has a clear relational and communicative aspect – including outside of a therapeutic or institutional setting – but specific enough to imply singing as an act of togetherness within a wide range of daily-life circumstances including the context of families living with dementia (Waage, 2022, p. 346).

Figure 2 illustrates how co-singing as term and concept relates to the terms and concepts discussed above. The boundaries between them will often be blurred, and in the intersections, we find, for example, care-singing with a dominant relational aspect or co-singing during daily activity. Singing in a health-musicking context can often include relational and creative aspects (as co-creativity), while co-singing can often include creative or caring aspects. Ultimately, all these approaches to singing might even be grouped under the umbrella of co-singing, depending on the context, circumstances and breadth of definition of this term.

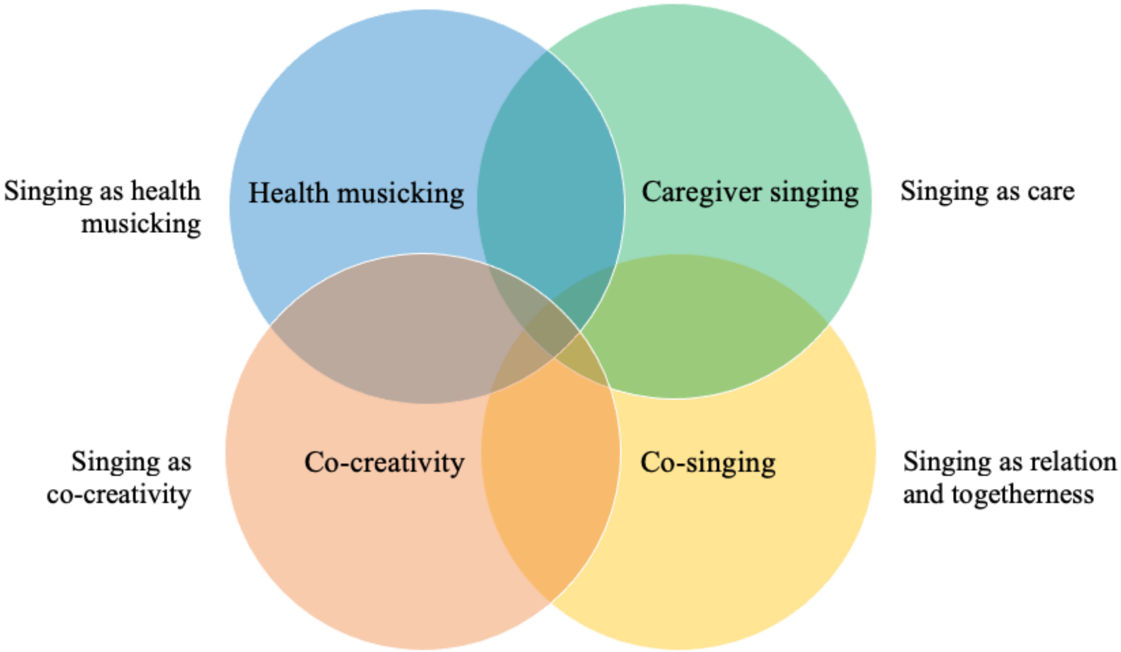

Figure 5. The concept of co-singing in the context of related concepts

6.4 Three approaches to defining co-singing

When I started to explore the potential of low-threshold relational singing in the context of dementia in close relations, I soon realised that existing singing terminology like *caregiver singing* could only partly convey the relational qualities. In this project, I wish to explore potentials and open up the singing field, so I will refrain from a conclusive definition of co-singing, which would only constrain my performative research approach (Østern et al., 2023, p. 286). Still, some description is needed. As mentioned in Chapter 1.6, I see the concept of co-singing as unfolding at three levels: a broad term, a relational approach, and situated practice.

To begin with, the broadest understanding of co-singing would be what most people intuitively assume – that is, two or more people singing together. In the introduction to the anthology *Samsang gjennom livsløpet*, Strøm et al. (2022) define *samsang* (the Norwegian equivalent of co-singing) as "all forms of activity where people meet and sing together" (p. 9, my translation).[76]

Next, I move from the broad *term* to a slightly narrower *approach* where singing plays a more distinct communicative and relational role. Although all singing is communicative and relational to some degree, co-singing as a relational approach implies that relational communication – affective togetherness – is central to the singing event. At this level, I suggest that co-singing may also exist in a "muted" form if two people sing together and one cannot sing (or sings inwardly, as in Chapter 7.8.1) but is otherwise participating in the relational singing situation. Thus, when a parent sings lullabies or play-songs with their infant, they are practicing co-singing as well.

The third level of co-singing – and the one directly connected to the present project – is when the relational approach to singing is applied within a specific context, such as families living with dementia. Then the relational *practice* of co-singing is *situated*. Overall, I follow the broad definition of the term co-singing suggested by Strøm et al. (2022, p. 9). Still, when exploring co-singing in families living with dementia, I consider co-singing a situated relational practice.

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[76] Original: "alle former for aktivitet der mennesker møtes og synger sammen".

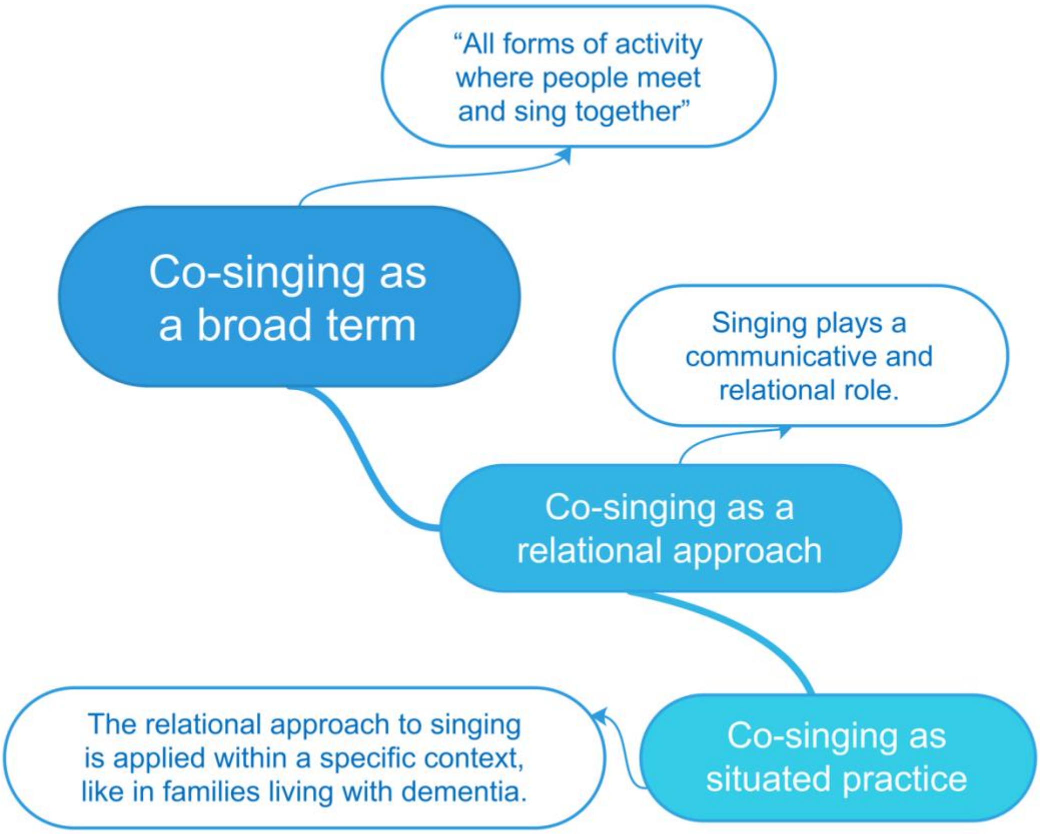

Figure 6. Three levels of co-singing

6.5 The intra-action and agency of co-singing

Regardless of these different levels of definition and description, co-singing implies intra-action and inseparability along various dimensions. The sound/waves of the separate voices merge, blend and occupy the same space, creating multiple (audible) diffractive (interference) patterns spanning different levels of harmony and dissonance. Further, the melodic, harmonic, rhythmic, textual and associative apparatuses of the song, the resonance of the room, the bodily production of the sound, and the contextual framing of the co-singing event are inseparable intra-acting phenomena/apparatuses creating a dynamic flow of different constellations of boundaries and inseparability which constitutes the agency of co-singing.

The actual song and the act of singing play in concert with the co-singers' mutual effects on each other. The ways in which music and songs are delivered – not only the quality of the singing as such but also aspects such as facial and bodily gestures, tone of voice, and eye contact – can contribute to the co-regulation of autonomic states and communication. Within this complex intra-action, the performed song is but one of multiple influences, entangled with our neurology and relational, embodied and autobiographical aspects of time and being (Waage, 2022, p. 346).

Following Bjørkvold (1992), it is tempting to view co-singing as an agent to mobilise the "muse within", both independently and reciprocally. This muse is rooted in the early, pre-verbal proto-communication described by the communicative musicality model. It "inhabits" the social engagement system described by PVT and can foster and boost co-regulative attunement, communication and interaction. Further, the muse within evolves through the experience of life and arts, including song, music and musicking, which at the same time express (embodied) autobiography, identity, and emotion. Even in conditions of severe dementia, these dynamic and vital pre- and post-verbal qualities are at least somewhat accessible through implicit memory (Waage, 2022, pp. 346–347).

These intertwined theoretical approaches can help us understand the potential of co-singing. When families affected by dementia practice co-singing as part of their communication and interaction, a multiplicity of material-discursive phenomena such as neurological substrates, implicit and embodied memories and skills, life stories of singing, and autobiographical events connected to song and music "bleed" into the co-singing moment. Thus, the multidimensional moment of tone and attunement may – at least temporarily – override the fragmentation and confusion of dementia. The "thick moment" of co-singing bears within it the meanings and embodied memories of the polyphony of one's life stories and may, thus, supply a bridge over broken timelines and impairments of memory and language (Waage, 2022, p. 347). Moreover, co-singing may even guide people towards a safe and social co-regulated state. In short, co-singing as a relational approach (and situated practice) is grounded in entangled phenomena and "factors founding and tailoring co-regulation and musical togetherness" (Waage, 2022, p. 348).

Still, the multidimensionality of co-singing brings with it both possibilities and challenges. Co-singing can, at its best, facilitate or enhance intuitive, relational connectivity between the co-singers based on an existing and shared repertoire of well-known songs. However, it can be hard for close ones to stay self-regulated and tap into co-singing's relational and co-regulative potential while also dealing with their own affects and emotions. In addition, finding, knowing and choosing appropriate songs for different situations and states of mind in tandem with their close one living with dementia likewise involves knowledge and insight. Even when they are able to draw on earlier experiences with singing, people with dementia (in the early stages) and their close ones alike would benefit from educational support or coaching, to which I will return in Chapter 8.7.1.

6.6 Concluding summary

In this chapter, I argue that singing in the context of dementia in close relations calls for a term distinguishing it from the general notion of singing while offering more flexibility and inclusivity than caregiver singing or care-singing. I propose the term co-singing and connect it to the following theoretical perspectives: the polyvagal theory, communicative musicality, health musicking and aspects of posthuman theory, all of whose principles and implications are entangled to some extent. Framing these theories and concepts in relation to embodiment and the potential inherent in implicit and procedural memories and skills can shed light on the communicative and behavioural consequences and options of dementia – and the potential of daily-life co-singing (Waage, 2022, p. 347).

To explore and anchor the concept of co-singing in relation to other singing contexts and terms, I discuss its connections to health-musicking, care(giver) singing and co-creativity. Though all these approaches may inform and be relevant to relational singing, I find that the term co-singing better conveys the relational, intra-active aspects of singing as togetherness. In the end, I refrain from presenting a conclusive definition of co-singing but instead describe the concept of co-singing at three levels:

- A broad term: Activities where people meet and sing together.
- A relational approach: Singing plays a communicative and relational role.
- A situated practice: The relational singing takes place within a specific context (e.g., people with dementia and their close ones).

Finally, I discuss the intra-action and agency of co-singing, based on the entangled theoretical perspectives discussed in previous chapters. Co-singing’s musical, autobiographical, embodied and relational multidimensionality creates great potential but also poses challenges which call for supportive measures such as education and coaching.

7 Research intra-action and diffractive engagements

7.1 Introduction: Research questions and diffractive layers

Before diving into the exploration of my co-singing intra-actions with the dyad, I will recap the research questions underpinning this PhD project. The three questions will be answered to different degrees – separately or together – by the respective sections of this chapter.

1. *How might people with dementia and their close ones use and experience singing as an integral part of their daily-life communication and interaction?*

2. *How can theory and research – especially that based on neuroscience and posthuman theory and philosophy – shed light on mechanisms and processes in play when people with dementia and their close ones sing together?*

3. *How might reworked singing terminology and concepts nuance understandings of and insights into daily-life singing practice and experience for people with dementia and their close ones, and what might be the reciprocal implications for concept and practice?*

The first research question concerns both *how to do it* and the participants' *experiences.* The second question circles around *explanation* of processes and mechanisms in play. Finally, the third question addresses how to *understand* the practice conceptually.

As I explained in Chapter 3.6.8, I developed four main approaches, or layers, of diffractive analysis as I revisited sound recordings and transcripts of the singing sessions and interviews: (1) engaging with concepts; (2) engaging with agency, intra-action and intra-play; (3) engaging with theory and research (including theory *and* concept); and (4) engaging with experience.

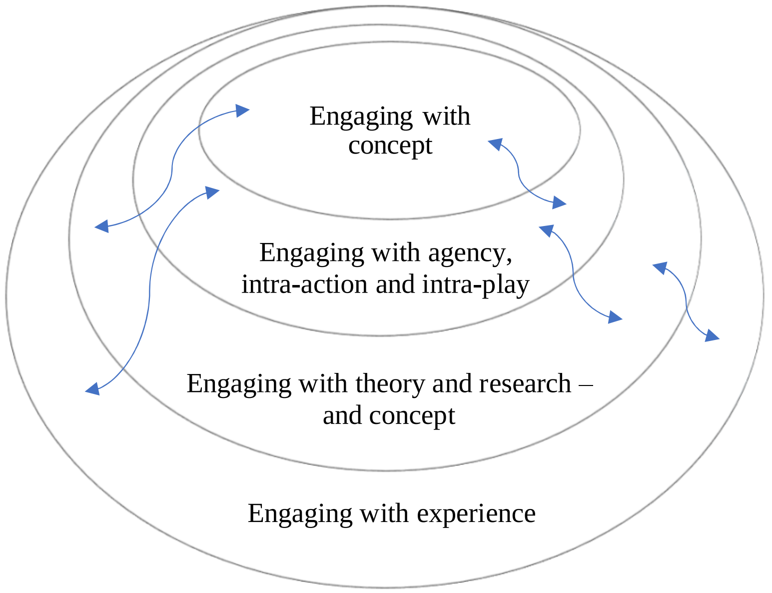

Figure 7. The four modes of diffractive engagements

First and foremost, this chapter sheds light on research question 1, concerning the doing and experiential aspect of relational everyday-life singing. However, my four modes of diffractive engagement also address different configurations of all three research questions (RQ): The first layer (concept) particularly addresses RQs 1 and 3, while the second layer (agency, intra-action and intra-play) concerns RQs 1 and 2. The third layer (research and theory) addresses mainly RQ 2, concerning the mechanisms and processes, and eventually RQ 3, concerning the conceptual. Lastly, the fourth layer (experience) primarily engages RQ 1 but from another angle. As I underscored in Chapter 3.6.8, the different layers – as well as the three research questions – should be seen not as separate but rather as entangled and always drawing on and including aspects of the other layers' and RQs' various material-discursive-practical configurations.

7.2 The singing encounters with Lilly and Emma

Serendipity brought Emma and me together after a cultural event.[77] Emma approached me out of curiosity because she heard that I was doing a research project on singing and dementia. While we were talking, I realised that Emma and her mother, Lilly, would consider being part of the project. I gave them more

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[77] "Lilly" and "Emma" are fictionalised names to ensure participant anonymity.

information and some time to consider their participation, and eventually we started the process. (The research strategy is described in Chapter 3.6.)

Lilly was in her eighties and had lived an active life. When we started the project, she was still living at home, with help from the municipal home nurse service and her children, especially Emma. She was positive about being part of my research project and participated actively in our singing activities, though frequently claiming that her singing voice was no good, in contrast to other family members. Her daughter Emma was around fifty and also active in her life, including a challenging job situation. Emma appreciated singing and wanted to be singing more, but at the time neither she nor her mother did much singing. However, according to Emma, Lilly often asked for singalongs on special occasions and wanted to sing herself.

During our six singing sessions over the course of almost four months, we tried different songs and singing activities which I tailored to their interests and wishes. The mapping process was flexible and intuitive; I based it on my experience with musical work within dementia care and as a teacher in Opplæringsprogrammet musikkbasert miljøbehandling[78] (Music-based milieu care educational programme). I started with a couple of songs that Emma told me were Lilly's favourites and then supplemented them with other songs in the same genre. After the introductory conversation and initial interview, I had more ideas of loved songs which I later brought to our sessions in printed texts or songbooks. Over time, we extended the repertoire by trying out related songs and gradually built a song binder based on observations and the sessions' conversations regarding their preferred songs and contexts for singing.[79]

Emma as well as Lilly liked singing combined with physical activity, so we included some simple dancing and exercises with singing, such as *move and troll* (Norwegian: *trim og trall*).[80] We also tried out *stroll and troll* (Norwegian: *trav og trall*): walking outdoor while singing or trolling simple march-like songs, adapting

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[78] I was engaged as a part-time supervisor and lecturer in the programme from 2016 to 2019 and from 2023 onwards.

[79] I adapted this method from the mapping of musical preferences which was developed through an extensive engagement with Norwegian healthcare institutions between 2000 and 2011 by Audun Myskja under the umbrella of individualised music (Myskja, 2005b, pp. 103–115; 2006, pp. 103–115; 2011, pp. 159–180), itself influenced by the work of Linda Gerdner (2005). Such mapping is also taught in the Norwegian educational programme for music-based milieu care.

[80] The Norwegian word "trall", which I have translated into "troll", means singing (or a song) without words.

the tempo to Lilly's gait and pace. We also brought move and troll outdoors. The process was gradual, and songs and activities were adjusted to their wishes and needs – and our ideas – along the way.

7.3 Engaging with concept: The lens of "space"

> Space and time are phenomenal, that is, they are intra-actively produced in the making of phenomena; neither space nor time exist as determinate givens outside of phenomena. (Barad, 2007, p. 315)

In this section, I read parts of the empirical material through the broad thematic lens of *space*, different aspects of which became clearer through my transcription of and attentive listening to the recordings; my embodied experience of the lack of space at some points; my reflections concerning the moments, incidents and situations; and my periods of walking, rest and meditation, when my own mind had more space.

7.3.1 Giving and getting (time)space

When I started analysing my recordings and transcripts and listened to the first meetings with the participants, I had the sense that I should have taken more time on several occasions. In short, I should have created more *space* for the mother with dementia to respond, even when I did manage to wait in silence. During the conversations and interviews, the gaps were too readily filled with more words, and the benefit of hindsight made the need for time more obvious.

My inexperience as a research fellow might have contributed to the heightening of my pulse and pace, and maybe it is just hard in general to adjust to a much slower pace without (unwittingly) somehow pushing it. Basting (2020) argues that recognising and calibrating the *temporal dissonance* between the "the world of the clock" and the world of the person with dementia "are crucial to connecting fully with another person but, with the imperialism of institutional time, often nearly impossible" (p. 173).

During the singing activities, taking time and creating space came more naturally, likely because I did have relevant experience as a therapeutic musician singing with people at different stages of dementia. In my memos and transcripts, I found several notes about how I paused after a given song verse, both to give some of the initiative to Lilly and to see how eager she was to sing more of the actual song. Despite her recurring comments about her supposedly limited singing skills, she repeatedly took the initiative and moved to the next verse when the previous verse faded into silence, and she did so both within and across sessions. My not-singing moments of silence worked as an invitation to her to take the lead. In addition, Emma, who appeared to be more confident in her singing ability, joined me in this provision of space for her mother.

Providing time-space for people with dementia seems obvious, given the latency time due to their cognitive condition. Still, my experience within dementia care is that time is often rushed in these interactions, for several reasons. First, our society's pace is already rushed, and most of us fill every waking moment with activities and impressions. Staying busy is a badge of courage in Western society, as opposed to taking one's time or even doing "nothing". Second, healthcare workers generally have very tight schedules which seem not to permit them to take the extra time to tune into the expressed or unexpressed needs of people with dementia. These healthcare workers might even feel guilty or face the impatience of their colleagues if they are not being "productive" enough. In turn, their assistance can be limited, shifting the responsibility to relatives to provide for various – often time-consuming – practical as well as relational needs.

During our meetings, Emma occasionally utilised small openings just after an interruption or my arrival, for example, to quickly address practical issues such as shifting bedclothes or tidying in the kitchen. Even so, she was able to pay attention to her mother and me simultaneously and would blend back into the singing activity after a short while. Her short "disappearances" might also have been a way of giving her mother *space* to interact and communicate with me with more initiative and independence while offering her the indirect support of being in the immediate vicinity. Thus, space also appears to imply several aspects of ambiguity, not only according to time and site but also as an intra-action of closeness and distance. In the following, space is simultaneously occupied and created by a singing voice.

7.3.2 Vocal space: Father and daughter singing at the service

> Emma:[81] *When I was little and going to church services with my family, my father always sang the hymns in a loud and sonorous voice while many of the others were shyer and sang in a more modest and subdued way. It was like my father was somehow taking responsibility for the singing because he thought that proper singing was an essential part of the service. Moreover, when my father was singing in such a powerful way, I, as a little girl, also dared to sing loudly; I was not afraid or too shy to let my voice be heard.*

Unlike Emma, Lilly repeatedly brought up her own supposedly limited singing skills in relation to her family: “I don’t sing very well, but the others were clever at singing, so then I mostly kept silent and just listened.” However, Lilly also explained and later confirmed that she appreciated listening to the others’ singing.

When Emma’s father was sharing his loud singing voice in public, in a sense occupying space with it, he was simultaneously creating space for little Emma’s voice – a safe, sonorous haven where she could blend in with her father’s confident singing. He was also signalling that it is not only okay but also necessary to share in the mutual co-singing in the church service. Thus, the sound of his voice and the power of his role as a “singer in charge” intra-actively created a space for Emma’s singing.

On Lilly, however, her in-laws’ extroversion of singing capabilities had a different effect, leaving limited space for her more modest voice to blend in and – though surely unintended – practically muted her. Still, she enjoyed listening to their songs, acquired a considerable repertoire of songs, and recurrently told her daughter that she would like to sing. As an adult, Emma now wishes to sing more actively, also with her mother. Emma takes responsibility for creating space to use her voice and aspires to create space for Lilly to co-sing, and Lilly no longer merely listens to the others’ singing but even sings along.

Emma also came to experience yet another aspect of space in the context of our work – that is, the gap between her hopes and the realistic possibilities for singing with her mother. Emma was highly motivated to sing more with Lilly, also

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[81] This narrative is based on a conversation and interview with Emma during the project period.

between our sessions, but it turned out that daily life and unexpected events made it more difficult than she imagined to find space for their co-singing.

7.3.3 A car drive as a site and space for co-singing

Taking extra time and sitting down with her mother to sing together was quite hard to fit in. However, in one of the interviews, Emma talked about how she would start singing with Lilly during daily-life activities such as a car drive:

Emma, in her first solo interview:

> I see that the things we have done lately are simply . . . like singing a little while we are cooking or in the car and things like that, and this we have never done before.[82] Also, I have never experienced that I start singing and that Mum joins in; that has never happened in my life, maybe because I have never done it, and because I took in what she kept saying about being no good at singing. But in this project [our singing encounters], this was the thing that was supposed to happen and then she has been singing along as well.
>
> So, now on Sunday, when we had been out there [at the cottage], then we sang in the car on our way home [smiling]. And it was surely not many [songs] from the binder – although I took some of those too – but like "Hvem kan segla forutan vind" [Who can sail without wind] and […] it was very easy because if we didn't remember the words, we could just go on to another song […] or quit after a verse [or troll a bit].[83] […] So, I think they are just such surprisingly fine moments, then, to be able to sing in a car.
>
> Dad sang in the car when we were small and on long travels […] and then we [kids] sang along, but I have no memory of Mum ever singing along. And now she and I sit in the car singing […] and she sings along by herself and doesn't apologise. […] I have never, I believe, just started to sing with Mum [like that] before. […]
>
> She sang on her own initiative in the car with me [laughter] when I started. It was not like: "Now we are going to sit down and sing", which

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[82] Please note: "…" signifies silence – a pause or hesitation in the flow of speech – while "[…]" signifies the omission of words contained in the recording/transcript.

[83] The bracketed part was uttered in another section of the interview when Emma returned to the same theme.

> was kind of nice . . . that we did not have to . . . she should have the energy [Norwegian: *orke*], and I should have the energy at the same time.

Helene:

> Does that mean that this happened rather spontaneously?

Emma:

> Yes, yes. After shutting the gate, I just felt like singing a bit, yes. […] And maybe in the slightly stressed-out life situation I am in […] what we did in the car […] did not need any mobilising or organising. […] Because she is tired, and I am tired . . . […] because I have been there a long time and must do all the other [practical] stuff first. But the thing in the car was entirely . . . [it was] super natural and did not take any planning or effort or being in good shape, for . . . it is getting into that mode that is challenging, not singing: That is never difficult. […] But it would never have happened if we had not started with some structure around our meetings and [the fact] that I experienced that Mum joined in with the singing. Because we were singing, right? So, then I also believe that she could do it.

This sense of situational naturalness and effortlessness, as opposed to the rigour and structure of daily-life activities, was something Emma returned to during our meetings. She also kept emphasising that singing was never difficult in itself, though creating the space and finding the energy to put her mother and herself in a singing situation was more challenging. Thanks to the catalyst and incitement of our sessions, she knew that her mother could and would sing, despite her repeated comments about her lack of singing skills. Hence, Emma was able to utilise the unexpected space for co-singing, meaning that a dull drive could become a pleasant way of being *together* and *doing* something together.

To further explore how the car drive created space for co-singing for Lilly and Emma, I will move to the second mode of analytical engagement and focus on performative agencies, intra-action and, eventually, intra-play.

7.4 Engaging with agency, intra-action and intra-play

7.4.1 Singing in the car as intra-action

The car/drive offered *space* – in several senses of the word – for co-singing. In the following, I will revisit the car-singing incident via Barad's concept of *intra-action* and the related notion of *intra-play* (Richards & Haukeland, 2020).

The space of the car intra-acted with the un/voluntary time of the drive and the autobiography of Emma and Lilly and their late father/husband's past singing. However, the space of the car drive also intra-acted with the spaces (that is, opportunities) for co-singing created during our exploratory co-singing sessions. Moreover, the multifaceted space of the car drive intra-acted with the songs and singing itself. In the end, Emma and Lilly's co-singing – integrated with the car drive – created and was created by a multifaceted space with different performative agencies, including

1) the limited *physical* space of the car,
2) the overarching *timespan*/space between the *now* of the drive and the *then* of their autobiographical memories, and
3) the limited *timespan*/space of the necessary drive.

During the car drive, these different aspects of abstract and concrete physical space (site/place) and time-space (timespan, intermission) intra-acted with the experiences from our joint singing sessions and the music, song and singing itself.[84]

Entering the limited space of a car for a limited time can activate several agencies. If the incident is read as purely transportation, the car offers literal mobility but otherwise introduces limitations including a sense of stuck-ness within its limited physical dimensions for the limited duration of the drive. There persists the possibility that Emma and Lilly could have other meaningful experiences during their drive – a nice chat, for example – thus adding a sense of meaning and togetherness to the purpose of transportation. When Emma starts singing, however, this act plus the song and the memories connected to both

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[84] Schmid et al. (2021) also outline what they describe as a complex ecology of space (place) (p. 320) and time/timing (p. 322) – one with manifold dimensions and configurations of different forms of space and time. The latter, for example, includes "clock time", physiological timings, relational/social coordination, and the experiential time of "being in the music", which may even transport people *out* of physical time (p. 322).

singing and the songs – even memories specifically connected to singing in a car – promptly become performative agencies intra-acting with the agencies of the car drive itself:

(1) The limited *physical space* of the car turns into proximity and potential togetherness not only between Emma and Lilly but also between the two of them and their late father/husband. The car also turns into a new stage for Lilly's singing – a safe space where only her daughter can hear her, and the act of singing is detached from any kind of pretentiousness or performance anxiety. Even in these conditions, Lilly's singing surprises her daughter and reveals to her a new potential for co-singing with her mother, both in general and with regard to what settings and spaces can enable it.

(2) The overarching *timespan/space* between the actual drive and the time gone by with their late father/husband turns both the car and the singing into a "time machine", offering Emma and Lilly conscious and unconscious (embodied) memories of different times, including times together with their father/husband, times travelling between different places and locations by car, and times of singing and togetherness.

(3) The car drive's limited but necessary *timespan* creates a *space* of free time in the midst of other activities. This opening intra-acts with Emma's impulsive singing and Lilly's responsiveness and creates a space for communion and co-creativity during a busy day.

To further explore the performative agencies in play during the car-singing-incident, I turn to the notion of *intra-play* (Richards & Haukeland, 2020), which is also relevant for other forms of co-singing episodes.

7.4.2 Singing in the car as intra-play

Richards and Haukeland (2020) introduce the concept and methodology of *intra-play* (described in Chapter 3.3.3) by drawing on Barad's (2007) concept of intra-action, Ingold's philosophy and Irwin's work on a/r/tography. They outline four forms of intra-play: co-attending, co-responding, co-forming and co-rendering. While these aspects originated in the field of sustainability research within heritage landscapes, they also resonate with the processes of co-singing, including that which took place in Lilly and Emma's car drive.

Overall, the term intra-play signals a more playful and possibly impulsive or even random approach than does the term intra-action. While Barad's use of intra-action also covers such associations, intra-play contributes an enhanced sense of "liveliness". *Co-attending* is about tuning into the situation and offering your attention in an inclusive way, recalling Susan Borg's *inclusive attention*, which, in Bacon's words, "involves establishing one's sense of self and then including the other person in one's attention. Out of this intentional attending/listening/feeling the communication which Borg understands as resonance can grow" (Bacon, 1992, p. 24). Emma consciously or unconsciously tunes into the emergent opportunity and proximity of the car drive in relation to the togetherness with her mother and starts singing, an impulsive response to the implicit or emergent potential of the situation. Put another way, Emma *co-responds* to the performative agencies of the car, her mother and her own wish to sing more, among others. Lilly then *co-attends* to Emma's singing and co-responds to the intention of singing by singing along, even without apologies.

Together, they *co-form* – or rather *co-perform* – a small impulsive singing session but also a new *opportunity* for singing as togetherness, in the present moment and as a future possibility. The co-singing car-drive incident forms a story which is entangled with the renderings of their late father/husband's singing as well as the renderings of their respective experiences and expectations regarding singing. The *co-rendering* of Emma and Lilly's singing intra-play in the car is thus multi-layered and embraces relational singing in the past, present and future. Their renderings may range from long-distant memories of their husband/father's singing in the church and the car via our shared singing sessions and their present exploration of daily-life co-singing activities to their notions and imaginings of future co-singing opportunities.

Likewise, these multifaceted renderings may add to the sense of embellishment co-singing brings to the otherwise ordinary car drive. To explore different aspects of such potential embellishment, I will now move to the next mode of diffractive analysis: *engaging with theory and research*.

7.5 Engaging with theory and research

7.5.1 The lens of artification and "musification"

The co-singing "embellishment" of the car drive evokes Dissanayake's (2017) notion of *artification* or *artifying* discussed in Chapter 4.7, particularly with regard to transforming the ordinary drive into an extraordinary event. Dissanayake's artification hypothesis pivots around the origins and evolutionary substrates of art, focuses on early mother–infant communication and rituals, and emphasises art as practice without any requirement concerning skilled or beautiful outcomes (Dissanayake, 2017). Emma and Lilly's car drive begins as an everyday practical necessity, but their spontaneous co-singing changes its character and nature. The ordinary car-drive is made special: extraordinary. It is elaborated with the co-singing, the actual songs, the autobiographical memories, and the implicit presence of their late father/husband's car-singing "rituals" from a distant past. In short, the car drive is artified through the multifaceted act and implications of their co-singing.

There are further links between Dissanayake's concept of artification and social bonding, PVT, and Dana's concept of glimmers (Dana, 2018a) (Chapter 4.9.7). By transforming the car drive from dull to delight through artification, Emma and Lilly also create their own glimmers, fostering enhanced access to their social engagement systems and building, at least temporarily, a buffer towards negative stress. Furthermore, the surprise co-singing moment turns into a joyful *moment of meeting*, evoking the aforementioned Greek concept of *kairos* (Stern, 2004; Trondalen, 2007, 2013) to which I will return later.

7.5.2 Discussion of musification

More favoured singing activities of Lilly and Emma could be diffracted through the lens of artification, but the phenomenon of co-singing itself needs a term of its own because artification might be hard to translate, at least into Norwegian, without the distraction of irrelevant associations. As I have already commented on the relationship between communicative musicality and Bjørkvold's (1992) references to the Greek Muses (in Chapter 4.6), I would propose *musification* or *musifying*[85] to evoke the ways in which daily-life activities transform into co-singing or musicking moments.

While Dissanayake's artification hypothesis is intended to shed light on how the arts came into being as part of human evolution, I would note that its links to musification within my project's framework derive from kinship and

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[85] My application of musification is associated specifically with the Greek Muses and the multimodality of artistic expression they represent. It is distinct from the way musification is sometimes used to describe "sonification" – based on, for example, biological data input – as part of a music composition process.

associations, not causal relations. In that sense, drawing upon the artification hypothesis to propose the notion of musification is an example of what Moe and Sidorkin (2019) term the "metaphorization" of theory, which allows for the expansion of the meaning of a concept beyond what was initially intended by it (p. 28). The point of the concept of musification is not evolutionary explanation but functional illumination: How can music and singing transform daily episodes or tasks in a manner resembling the evolutionary elaborative developments suggested by Dissanayake's hypothesis and theorising? If humans have an urge anchored in their evolution to decorate and embellish tools and objects and ritualise behaviours and communication, could this also be an incitement or inspiration in the context of daily-life co-singing?

The notion of musification and musifying could be one way to balance the more instrumental aspects of co-singing. Preventing adverse behaviour or making daily care routines easier to accomplish are common arguments or justifications for care(giver)-singing or music therapy in dementia care. To embellish and bring more joy into everyday communication and activities through musification processes may entail similar outcomes. Still, the notion of musification is anchored in a resource-oriented approach where instrumental outcomes are not the primary goal. Moreover, a focus on the joyful potential of musifying could enrich the lives of people in general, beyond the context of disease.

7.5.3 Four areas of musification

In Lilly and Emma's case, at least four different areas of musification arise in the context of four different singing activities. Co-singing in the car, as we saw above, is a musified form of *daily-life activity*. Sitting together and singing from a personalised song binder is a musified form of *communication and reminiscence*. Doing the "move and troll" activities and the simplified waltz-dancing are musified forms of *physical activity*. Lastly, the singing-and-walking activity labelled "stroll and troll", inspired by rhythmic auditory stimulation (RAS)[86] (de Dreu et al., 2014; Thaut & Rice, 2014), is a musified form of *locomotion*. I will

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[86] Rhythmic auditory stimulation (RAS) is a research-based rehabilitation technique in neurologic music therapy. By applying rhythmic cues with or without music during gait training – based on a strict protocol – RAS displays effectiveness in enhancing or recovering gait function. My application of stroll and troll takes inspiration from the basic neurological principles underpinning RAS but is nothing like the precise, protocol-based original technique.

illustrate and discuss these four forms of musification below using more examples from the sessions and interviews with Lilly and Emma, sometimes supplemented by examples from other research. Some of the group-singing studies referred to in Chapter 2.4.5 also included examples of the dyads' singing during their daily lives at home between the group sessions.

7.5.4 Musified daily-life activity

Mittelman and Papayannopoulou (2018), who studied choir singing for people with dementia and their relatives or friends, reported that many participants experienced an extended effect on the person with dementia: "He wakes up singing! He sings during the day" (p. 785), one relative exclaimed. The authors mention various examples of daily life singing between sessions:

> A participant with dementia said, "Put the music on; my mouth opens up to sing." A spouse caregiver spoke about the calm that came over her frequently agitated husband when they sang together at home. Another spouse caregiver said it gave her pleasure to hear her husband singing the songs in the shower. One caregiver commented, "Rather than reaching for a pill, we sing!" Another said, "This is as good as a patch or pill, if not better. No side effects!" (Mittelman & Papayannopoulou, 2018, p. 784)

There are countless possibilities for musifying daily life activities like waking up, taking a shower, or – as with Lilly and Emma – driving the car. When we started our sessions together, we sang songs which Lilly and Emma knew and liked, and we gradually built up a personalised song binder. Singing songs from the binder – as part of a flexible mapping, prioritising and practising process – often sparked vivid conversations based on the associations brought about by the songs and singing.

7.5.5 Musified communication and (embodied) reminiscence

> *We are trying out the song "Hovedøen", and Lilly sings along actively and takes the initiative to sing more verses. After finishing the song, Emma asks her: "Mum, have you ever been to Hovedøya?" Lilly answers immediately: "Where have I not been?" It turns into a conversation about all the places*

> *Lilly has travelled while working, since she used to travel a lot as part of her job.*

In this situation, the song reminds Lilly and Emma of a more general question that triggers memories and a conversation. At other times, it can be reversed. I remember countless breakfasts at the day centre for people with dementia where I used to work. While talking about a specific subject or memory, some of us would introduce a song connected to that subject. The song would add colour and atmosphere to the conversation and potentially spark new memories, associations or embodied sensations linked to the song, thus feeding a further conversation.

Again, the instrumental and embellishing properties of singing merge: The songs can trigger autobiographical memories (El Haj et al., 2015), thus enabling ready communication and conversation. However, Dowlen et al. (2018) found that the meaningful connections made through singing well-known songs outweighed the specific memories:

> The singing of biographically significant music acted as a catalyst for memories for the person with dementia, allowing them to remember key life events that were interwoven with different pieces, or genres, of music. However, it was the sense of strengthening a sense of identity and creating a meaningful connection with others that appeared more important than the remembrance of particular life events. (Dowlen et al., 2018, p. 209)

Further, the authors point out that if too much focus is placed on music for reminiscence purposes, “the importance of embodied, ‘in the moment’ responses, can be overlooked” (p. 209).

Songs and co-singing can also merge into the communication, thus elaborating the conversation and adding new atmospheres, moods and associations as independent elements entangled with the conversation. In later stages of dementia, when language is less accessible, co-singing can even become the conversation itself by facilitating a form of post-verbal, musified communication and togetherness. An example from the group-singing study of Unadkat et al. (2017) (see Chapter 2.4.5) may illustrate this:

> In a poignant example of togetherness, one caregiver began singing a familiar tune from the group setting to their partner, a person with advanced

> dementia who had mostly lost the capacity for speech. While the person with dementia had not spoken throughout the interview, she audibly attempted to join in with the final words of sentences in the singing. The caregiver expressed a sense of feeling togetherness during this interaction, stating ". . . see, it's obviously gone in . . . I know that she is still in there, we do everything together anyway but this is a way I get answered back, she is still there inside, I believe in that". (Unadkat et al., 2017, p. 476)

7.5.6 Musified physical activity: *Move and troll* and *simple waltz*

The rhythmic elements of co-singing allow it to serve not only as a communicative activity but also as a means of adding embodiment and movement to the interaction. Already in my second meeting with the dyad, I realised that Emma was focused on movement and was concerned that Lilly had little opportunity for physical activity since her regular training group had been cancelled due to the ongoing Covid-19 pandemic. Therefore, I introduced some very simple exercises with well-known songs through an activity known as *Trim & trall* (move and troll), based on my working experience in dementia care. I would adjust exercises and songs for the people in the group but also improvise them based on the actual situation and atmosphere. For Lilly and Emma, I tried certain basic movements and well-known songs, then adapted the selection in subsequent meetings according to their wishes, preferences, and ideas. For example, Lilly spontaneously started doing her own kind of neck exercise during one of the sessions, after which we found a fitting song to go with it and included it in the overview.

At our second meeting, Emma gave me different reasons why she liked the move and troll exercises. Adding movement brought a sense of playfulness to the process which made the singing more informal. It was also a fun way to engage in physical activity:

> I really liked the exercises because then it was a bit more fun – just that one moves – because then one can play a bit more. Then we did not get so self-conscious about how we sang. [*Directed to her mother*] Because we have talked about that you missed so much physical exercise and start feeling a bit . . . muscle stiffness, and you did like a lot to go to the training group with music and such. So, it was really nice [with move and troll], and I noticed that it was much more fun to *endure* when one had singing than just,

> like, “Now we’ll take ten repetitions”. It was […] easy to continue when we sang, instead of just counting. So, I really liked that.

I asked Lilly if it worked well for her when we sang and moved together, and she confirmed that it did. This agreed with what Emma and I saw as Lilly actively took part in both singing and moving. She mastered the activity well and appeared satisfied. This activity reminded Emma of dancing:

> Emma: It was a bit like dancing. Because you always said . . . Mum always said she wanted to dance . . . but was not allowed to dance.
> Lilly: It was so Christian where I grew up. It [dancing] was so . . . a sin.
> Helene: Would you like to . . . have you danced waltz?
> Emma: I am really fond of dancing, but Mum is cautious. [directed to her mother] You have sometimes told me that you have wanted to dance, but is it because you have had so little chance of it?
> Lilly: Yes.
> Emma: And then you have wanted it?
> Lilly [almost inaudible]: Yes.
> Emma: So, I have not experienced . . . I have not seen Mum dance.
> Helene: But do you want me to just show you a super-simple way to dance the waltz?
> Lilly: Do we have room for that?
> Helene: Yes, yes! It’s plenty of room!
>
> *I instruct the waltz while we are trolling “Skomværvalsen” together. Emma and Lilly face each other, sitting on chairs in the living room. We first do the dance-like movements sitting – swinging the arms – then standing, and eventually we add gentle foot movements. Finally, I say it is also allowed to move around, and I start dancing around a bit more while Lilly and Emma are dancing together a bit more carefully. The whole waltz “speed course” is over in three to four minutes.*
>
> Emma: This was fun! Mum, you can dance the waltz; you have a really good sense of rhythm, Mum – so much fun!
> Lilly: Not bad. [chuckles a little]
> Helene: So, this was like a waltz crash course.

We repeated the simple waltz at later meetings. The second time we did so, trolling "Rosa på bal", Lilly said: "We should have this at [name of the country house] as well." Emma replied: "Yes! Maybe there will be jetty-dancing this summer?" After some positive comments about the country house, Emma said:

> Now we have danced the waltz for the second time, Mum! Why haven't we started with that before?
> Lilly: Now you tell me. [Norwegian: *Kan så si*]
> Emma: But it is never too late.
> Lilly: No, it is not.

In later conversations and interviews, Emma returned to move and troll and the simplified waltz dancing, noting that her experience in the past was that Lilly would be reluctant when Emma tried to encourage physical activity like exercises or stair walking. However, when they could combine the movements with co-singing, the activity became more effortless and joyful. She also told me that it helped just to *know* that singing would make the movement more fun. That is, Emma's image or expectation of physical activity with her mother was also, somehow, musified, which extended even to walking, as we will see.

7.5.7 Musified locomotion: *Stroll and troll*

In a semi-structured interview with Emma during the project, she reiterated how valuable and fun the activities with singing and physical activity were. Therefore, I briefly mentioned the *stroll and troll* concept, which she said she would like to try, so in our last singing session we decided to go for a walk outdoors.

> *We are walking outside Lilly's home, singing well-known march-like songs. From our work with move and troll, I already know several marching songs which they know and like to sing. Both Lilly and Emma participate actively. Between the songs, I briefly explain the basic principles of stroll and troll, and I encourage Emma to pay attention to Lilly's gait pace and adjust the rhythm of the song accordingly. Both Emma and I observe how Lilly's gait becomes more fluent and effortless when we start singing. Later, Emma*

> *says that they also get into a different mode when singing while walking. She feels that they are together in a different way.*

The musified locomotion works in parallel at the concrete, instrumental, synchronising and entraining levels, easing Lilly's gait while embellishing the stroll by influencing their mood during the singing and enhancing their sense of togetherness, as we will see. In the following description and analysis of stroll and troll, I will shift my perspective even as I continue reading the case material through theory. I will include an additional layer or lens – diffracting diffraction – and introduce Barad's (2007) concept of *material-discursive practices* as an overarching diffractive and intra-active apparatus.

7.6 Diffracting diffraction: Engaging with theory and concept

7.6.1 Foundation and approach

This section uses parts of the empirical material connected to the stroll and troll activity as its starting point. I read them through different theoretical lenses, including the basic neurological principles of rhythmic auditory stimulation (RAS) (Thaut & Rice, 2014) and Deleuze's philosophy (Deleuze, 1968/2001; May, 2005), especially the relation between *the virtual* and *the actual* and the focus on *becoming*.[87] Barad's (2007) concept of *material-discursive practices* will serve as an apparatus through which the different aspects of the stroll and troll practice and the aforementioned theories can be diffracted.

7.6.2 Material-discursive practices

Barad's concept of material-discursive practices points to how matter, discourse and practice, all in a broad sense, are mutually entangled and interdependent. Barad (2007) writes:

> Discourse is not what is said; it is that which constrains and enables what can be said. Discursive practices define what counts as meaningful statements. Statements are not the mere utterances of the originating

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[87] According to Murris and Bozalek (2019), Barad's ontological position is compatible with Gilles Deleuze's affirmative philosophy of immanence.

> consciousness of a unified subject; rather, statements and subjects emerge from a field of possibilities. This field of possibilities is not static or singular but rather is a dynamic and contingent multiplicity. (pp. 146–147)

In the following, I will begin with Emma's narration of her and Lilly's stroll and troll experiences – that is, their practice. Then I will read these experiences through the aforementioned theories and the concept of material-discursive practices.

7.6.3 Practice: Emma's narration of stroll and troll

In the follow-up interview four months after our singing sessions, Emma says that finding room and energy for singing has not been easy. However, singing and trolling while moving, and especially walking, turned out to be easier to fit in. Thus, stroll and troll became the activity that she and Lilly actually did together in the months following our sessions. Emma says:

> Where it was easy and was fun to see was going for walks. To see how the rhythm and singing make her go on – because that is something we have *really* seen, that she walks slower and slower the past two years – and then [with the singing] she speeds up, with small steps, but walking on the rhythm and then it becomes fun for her and me; I don't go waiting for her, and I am also put in another mode then because I do sing.

Since Emma's dog always wants to sniff around, her mother's slow tempo does not matter much at first, but eventually Emma starts to become a bit impatient. She also says that she feels sorry for her mother, who cannot move faster on her own. She adds:

> Then we just start singing a bit, and then it sort of goes completely by itself. Don't have to say anything, can just start to sing and then she trolls along a bit, and this we can do for quite a while. […] And this is so much more fun than being kind of a "coach". In the past, I would say, "Can't you go a bit faster?" Then it only lasts a few . . . I am not supposed to be like that with my mum: to rush on . . . But with the singing it always . . . I also think it is really nice that she has such a sense of rhythm.

> We are walking there in a shared rhythm […]. Because when I sing, then *I* also go in a rhythm […] and then I am in a completely different . . . mode myself, yes. So, it also gets me out of this “exercise-mom project”. I just say it with those words because, underneath, it is a bit like that, right? It [the singing] makes me happy then, on the walks. It is not just Mum who speeds up – *I* also become happier. […] And I think she experiences it as something very nice. […] She walks there, and this just happens in her body – and with the whole of her.

Emma’s observation of what happens in her mother’s body – “and with the whole of her” – during the stroll and troll activity can be approached through the lens of neuroscience, so I will next shift to the perspective of neurologic music therapy, and especially the principles of rhythmic auditory stimulation, as a further diffraction of Emma and Lilly’s experiences.

7.6.4 Materiality: Diffracting rhythmic auditory stimulation (RAS) and stroll and troll

As mentioned in Chapter 2.3.3, Thaut and Rice (2014) refer to a rapidly growing body of clinical research on the impact of adapted, regular rhythm on gait movement patterns and quality of walking (p. 95). They also explain the four neurological principles of RAS. The first, *rhythmic entrainment*, is the ability of the motor system to couple with the auditory system and drive movement patterns. The second, *priming,* “is the ability of an external auditory cue to stimulate recruitment of motor neurons at the spinal cord level, therefore resulting in entrainment of the muscle activation patterns in the legs during walking” (p. 96). The third principle, *cueing of the movement period,* means that “time stability is enhanced by rhythmic synchronization throughout the whole duration and trajectory of the movement, and not just at the endpoints of the movement coincidental with the rhythmic beat” (p. 96). Put simply, the rhythmic coordination works during the whole movement and not only on the main rhythmic “beats” when the heels hit the ground.

These three neurological principles are at work when a steady rhythm, music or song accompanies walking. However, the fourth principle, *stepwise limit cycle entrainment*, implies a process whereby the person’s current optimal step cadence or frequency – the *limit cycle* – is gradually modulated through a stepwise progression to approximate premorbid movement frequencies (Thaut & Rice, 2014, p. 96). This fourth principle is at the heart of the clinical RAS protocol and depends on precise, systematic exercise, which is very different from the informal stroll and troll activity. While RAS is a protocol-driven, systematic gait rehabilitation technique, stroll and troll is a flexible, informal daily-life singing activity. However, the first three RAS principles are at work there if the song's rhythm is steady and somewhat adjusted to the gait pace. The fourth principle is not as relevant, as Emma notes here: "and then [with the singing] she [Lilly] speeds up, with small steps, but walking on the rhythm". Lilly's small steps indicate that the song's pace is not perfectly adjusted to Lilly's gait but perhaps instead to Emma's. If the pace had been adjusted to Lilly – and modulated according to her gait's progress – then her steps would look more natural rather than "small". Despite this lack of optimisation, however, the stroll and troll activity does manage to make a significant difference to both Lilly's gait in the moment and the dyad's experience of walking together, indicating that the other three underlying principles of RAS still apply.

It would be possible to train relatives and nursing home staff to apply RAS in a more customised, structured and systematic way which might entail the potential for gait rehabilitation. In dementia care, however, such an approach might raise the threshold for doing the activity altogether – "perfect is the enemy of good", as they say. Norwegian doctor Audun Myskja has worked extensively with RAS and likewise emphasises the connection between time and space in the underlying neurological mechanisms. He points out that rhythm can help organise movement in several dimensions: When movements become more stable along the *time* axis, this rhythmic coordination also induces a more optimal axis of movement in the *spatial* dimension. In practice, this means that the movement becomes more harmonious, efficient, beautiful and apt (Myskja, 2005c, p. 17), again suggesting stroll and troll as a form of artified or musified locomotion.

After describing her experiences with stroll and troll, Emma suddenly says, with a sense of surprise: "So, yes, we are walking in the same rhythm, Mum and me." Then, recalling Lilly's way of walking without their song, she concludes: "*Completely* different pace – and *normal* walking". Here, that is, Emma suddenly realises that stroll and troll has synchronised the two of them, both literally and figuratively, in the sense of enhanced togetherness. Emma's experience of such profound "double" synchrony with Lilly evokes what Schmid et al., (2021) calls "'intercorporeal musical dialogue' when both people enter a dyadic bodily state, incorporating the perceived body of the other" (p. 318).[88]

Such an intercorporeal musical dialogue can also unfold in a group setting, as in the study by Dowlen et al. (2022):

> The group members' bodies were seen to synchronise both with the musical beat and the bodies of others. This was most obviously observed when individuals swayed in time with each other, their bodies almost taking on the role of a metronome. This subconscious bodily entrainment could have enabled the people living with dementia to feel more connected to other group members because of this synchronous experience. This sense of synchrony was also enhanced through the use of mimicry both of gesture and facial expressions, as well as musical or rhythmic phrases. (p. 16)

In Lilly and Emma's case, the neurological entrainment, priming and cueing not only eased Lilly's gait. Their rhythmic co-singing while walking – and the entailing synchronization – brought about a dyadic bodily state, which also affected their mood and sense of togetherness. Emma added:

> It has been a way for me and Mum where we have real contact, then . . . Which is sometimes difficult for me to find when I shall fix a lot for her – things she does not manage . . . So, then it was something we suddenly were in *together*.

Experiencing real togetherness can be crucial and powerful during challenging times and tasks for both the one fixing things and the one who can no longer manage.

7.6.5 Transition: Loss and potentiality

Lilly often spoke positively about Emma's singing skills, and once even added: "She is so clever, you know – at everything". Emma laughed and replied: "You are the one who has been clever at everything!"

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[88] Schmid et al. (2021) are here describing a music therapeutic relation and the synchrony of musical improvisation and breathing.

> *When I transcribed this part, I had a strong emotional reaction. Although the atmosphere at the time was cheerful, I picked up on a sense of underlying soreness. "You are the one who has been clever at everything!" Emma says, and from what they had told me about Lilly's life story, this appeared to be a genuine sentiment.*
>
> *However, Lilly talks about Emma's cleverness at the present time, while Emma talks about Lilly's cleverness in the past. Despite the good-humoured and mutually supportive atmosphere, I experience a sense of veiled sorrow which was only accessible to me in retrospect. Suddenly, the agency of grammar unveiled a new layer of meaning: an ambiguity wherein the sense of loss is lurking under the surface, though Emma is still acknowledging Lilly's strengths and integrity. Even while writing the note of reflection – and re-reading this very text – my emotion takes over and makes me cry. I start wondering why my reactions are so strong. Am I only projecting my own feelings as a relative who has experienced serious health issues in my family? Or maybe my sorrow resonates and intra-acts with the sense of loss disease brings – with the sense of what has been and what could have been?*

The lurking sense of loss and *what could have been* cannot be written out of the story of serious illness, no matter how resource-oriented and affirming the involved people mean to be – which indeed seemed to be Lilly and Emma's respective approaches. Still, there may be room for the creative impulse to transform underlying sorrow or stress into positive surprise, relief and even joy when the people involved discover new opportunities and master and enjoy new activities or develop new skills. Both the new opportunities themselves and their potential can have profound value: The sense of *what might be* plays a role in and of itself in such situations, which may also apply to co-singing.

7.6.6 Concept and discourse: Diffracting Deleuze's philosophy and stroll and troll

Tod May has framed Deleuze's philosophy with this overall question: "How might one live?" (May, 2005). In *Difference and repetition* (1968/2001), Deleuze works out a central aspect of his philosophy: the virtual field of primary difference –

difference in itself – and its continuous actualisation. This constant movement from potential to actuality also entails the reconfiguration of the virtual field in a never-ending "dance" between the virtual and the actual. Nothing is fixed; Everything is always in creation, flux and becoming. Rather than "What is?", the implicit questions in Deleuze's philosophy would be "What might be?" or "How might we?"

7.6.7 How might co-singing unfold?

When I diffract Deleuze's philosophy and Lilly and Emma's co-singing, this "dance" between potential and actuality comes to the fore. Through their exploration of stroll and troll and other co-singing activities, new ways emerge of singing, walking, and being together. "This was fun!" "We can do this when we are out walking, especially at the cottage". "We could dance at the cottage". "Maybe the rest of the family could also join us singing at the cottage?" Emma made these kinds of remarks when she was excited about or surprised by our singing activities, especially if Lilly had mastered and enjoyed something new. She was imagining how she and Lilly could integrate these activities into their daily lives in specific ways, some involving the cottage – a place of which both Emma and Lilly were very fond. Lilly even joined in on occasion: "Shall we do this at the cottage?" And specifically to me: "Will you also come to the cottage and sing?"

The co-singing activities seemed to open up a new set of imaginative circumstances for co-singing, adding a kind of anticipation and expectation via the projection of the activities into the future. Perhaps the cottage's association with simplicity and freedom from everyday responsibilities made singing there appear to be more likely? Or maybe the joyful singing moments were associated with joyful moments at the cottage? In any case, Emma's spontaneous remarks demonstrate her sense of their co-singing's *potential* as a form of mutual *becoming*. Emma especially talks vividly about her and Lilly's co-singing walks. She also notes that her new knowledge of co-singing potentials plays a role in and of itself and gives her a sense of confidence:

> What has happened to me is that I don't have any reservations. It is like it is accessible, then . . . for me, because I know it works to start singing with her [Lilly] when we go for a walk. So, then I can just do that, even if it is

> just a tiny little bit [chuckles]. [...] And I know that if I should do some physical activity with her . . . then I know that this [move and troll] would be the way I would do it. Because now I know that this is what works. Not saying: "Now we will raise our arms ten times", you know, like I would try in the past . . . And this gives me a kind of confidence [Norwegian: *trygghet*] – that I know that she likes it and I know what to do. It is like I have got a small competence [chuckles] . . . And that it will be nice . . . Some of my confidence is about [the fact] that I have seen that Mum has *wanted* to sing. With you, and with me.

Despite Lilly's recurring comments about her own lack of singing skills, Emma now knows that her mother wants to sing – and *does* sing – in certain contexts such as while walking. What has changed for Emma is her respective notions of *what singing might be*; *what physical activity or walking might be*; and *what singing and physical activity might be with her mother*. The previously discussed co-singing incident in the car (see Chapters 7.3.3 and 7.4) also opened up new potentials for co-singing. Lilly and Emma were exploring and conquering new spaces of co-singing possibility in their daily life. They were *becoming co-singers*.

During the follow-up interview, Emma noted that she used to see singing as a formal activity exclusive to certain contexts or special occasions such as family gatherings and celebrations. However, lately, she had experienced that singing could be accessible and *non*formal:

> It [singing] is something small that I – we – can just pull out without having planned it [...]. Especially with walking, it's like that. Then I think that it just *is* there for me, and then it's easy – then that walk becomes something easy and something completely different than if I just have to take my mum out because she needs to get exercise, and "do I have time for this?" and . . . right?

Singing while walking as an unexpected and easy opportunity for co-singing might have been undermined if Lilly or Emma had felt shy or self-conscious about outdoor singing, but this was not the case. During our initial singing walk, I asked Lilly how she felt about singing, outside, and she said it was all right and not embarrassing when we met other people. We talked about this again when we came back in, and Lilly said: “I am not a singer, but I am not afraid of making a fool of myself either”. In the interview just after the sixth singing session, Emma recalled:

> I think it is nice that we are not embarrassed […]. If I had been walking alone singing, I might have been a bit self-conscious […] but when I am with Mum, I am just proud of having a mother who is taking part in it […]. And maybe people can interpret this situation and think it is nice – that someone is outdoors with their mum, singing and going for a walk. Yes, I think I was in a way prouder of it than that I should be embarrassed. Also, I’m so glad Mum is not [embarrassed].

Emma’s conception of what singing is or might be – and her idea of in what circumstances singing could unfold – had changed. Lilly had less opportunity than Emma to express herself verbally because of her difficulties with language and the limitations upon our meetings necessitated by the pandemic. Still, Emma’s descriptions, along with my observations during our singing encounters and talking intersections, indicated that Lilly’s sense of singing was also changing. While describing the first incident of spontaneous singing in the car mentioned earlier, Emma said:

> She [Lilly] always said about singing before: “No, I can’t sing” – the things you have heard her say. But now she can sing, and she sings *along* and if she forgets […] then she doesn’t apologise. And both that [not apologising] and that she is singing are very surprising. And it is not so serious [Norwegian: *farlig*] then, to sing – it is not so formal anymore.

Another indication of Lilly’s developing sense of singing was apparent in our fourth singing encounter. Lilly’s comments, and our conversation between the songs, circled her family’s singing skills and how their skilfulness had made her cautious about singing herself. After trying out a song that Emma said she did not know very well (“Det som skjer, det skjer” / “Que sera, sera”) but in which Lilly seemed and sounded quite confident, Lilly uttered: “[I] get more and more self-confidence. Suddenly I’m singing anything [Norwegian: *alt mulig*].” Lilly rarely sang along with her family in the past, and she frequently commented on her lack of singing skills. Now, she sang along with her daughter and me and eventually, according to Emma, with others as well. There could be several reasons for this, but regardless of *why*, Lilly was also exploring *what singing might be*. For both Lilly and Emma, an enmeshment of material, discursive and practical conditions and circumstances gradually shaped a new sense of singing out of their co-singing activities.

7.6.8 Becoming co-singers

In this section, I explored examples of entanglements and intra-actions of the materiality of neurology, rhythm and singing. The agency of such intra-actions creates potentials which were transformed into actual possibilities through the agency of Emma and Lilly's stroll and troll and other co-singing experiences. Emma's new sense of singing as something informal, accessible and easy had been *formed by* and also *formed* in turn their explorative daily-life co-singing practice. While forming and being formed through the intra-actions of materiality, practice, and concept, Lilly and Emma's experiences illustrate the process of *becoming* co-singers; as an open-ended material-discursive practice of singing – or musified – togetherness.

7.7 Musified togetherness

At this point, I will momentarily pivot back towards the previous discussions to wrap up the concept of musification. The examples of musification explored so far involved musified daily life activity, musified communication and reminiscence, musified physical activity and musified locomotion. Taken together, they reflect aspects of co-singing as *musified togetherness*, as a way to make the ordinary extraordinary, and as a way to embellish daily life through singing together not only in planned and organised activities but also by utilising the *spaces* in everyday life. In this way, ordinary activities can become significant moments – moments that create a sense of awe and add new dimensions to otherwise ordinary events, recalling Stern's (2004) *moments of meeting*, which he links to the Greek term *kairos* (mentioned in Chapter 4.8.3).

7.7.1 Moments of meeting

In my first separate interview with Emma, she commented on co-singing with her mother as a form of core togetherness – a way for them to have real contact outside of the help Lilly required with many practical tasks. She added:

> On Sunday, when we were eating by the sea […] where it is just totally calm and both of us share that experience completely, so it is like the song/singing [Norwegian: *sangen*] in a way is a thing that has happened where we just do something together, where the two of us are just as . . . I am at least as happy about it . . . and I am grateful that it is happening because I have wished to do it [sing with my mother] and I do like to sing and hardly ever sing . . . so . . . it could not have happened at any better place than together with Mum who also wished to sing.

Initially, Emma hoped that other family members might also sing with Lilly, but she eventually put that ambition aside: "Because it is a larger project when everyone is tired [Norwegian: *slitne*] to make someone sing with Mum [just] because I have started with it":

> Maybe I need to recline in [the realisation] that it is good enough. Yes, that it is not – put somewhat extremely [Norwegian: *satt på spissen*] – I am not going to reverse Mum's disease by singing [laughs]. It shall be what it is, then, which is a very fine meeting between me, Mum, and the song/singing [Norwegian: *sangen*] and with what it brings along of joy in our meeting.

Stern (2004) describes how the present moment can turn into a critical moment and effect a change in the therapeutic relationship. However, such *moments of meeting* can also resonate with a broader field of relational encounters:

> The participants have created a shared private world. And having entered that world, they find that when they leave it, their relationship is changed. There has been a discontinuous leap. The border between order and chaos has been redrawn. Coherence and complexity have been enlarged. They have created an expanded intersubjective field that opens up new possibilities of ways of being with one another. They are changed and they

> are linked differently from having changed one another. (Stern, 2004, p. 371)

At best, the musified togetherness of co-singing might become such a *moment of meeting*, which “opens up new possibilities of ways of being with one another”. Or, in the spirit of Deleuze and Barad, we might say that such moments of meeting actualise virtual encounters – performing agential cuts through our intra-actions – thus allowing for new ways of *becoming* with one another.

Dowlen et al. (2022) observe that embodiment and gesture can also be an essential part of such co-singing moments of meeting:

> The group was singing Phillip’s favourite melody (*Abide with Me*) and Scott reached his hand out to connect physically with Phillip […]. The two men, who both had challenges relating to verbal communication, connected physically in a way that did not need words. This simple gesture of reaching out during a song that had special meaning for Phillip was a visible gesture of friendship and support from Scott. (p. 15)

The authors add that this interaction happened after Phillip returned from a two-week break and thus might have signified that Scott had sensed his absence and was somehow welcoming him back (pp. 15–16).

Although such moments of meeting can include audible and visible communication and interaction, they do not depend on evident and outgoing activity. Instead, I will argue that the primary prerequisite for co-singing encounters is the ability to *listen*, shifting my perspective yet again to the last mode of diffractive reading: *engaging with experience*.

7.8 Engaging with experience: Diffracting the research intra-action and previous experience

Some of my singing encounters and conversations with Lilly and Emma recall earlier experiences from my work with music as a daily-life and educational resource within dementia care. Those earlier experiences also convey other angles and aspects of these issues not yet touched upon here.

7.8.1 The active act of listening

The aspects of co-singing as encounter and togetherness may be more obvious when both parties actively and confidently sing together, which was often, but not always, the case with Lilly and Emma. Moreover, Lilly's repeated comments about her supposed lack of singing skills might suggest that her relationship with singing was somewhat strained. However, on several occasions during our sessions and interviews, either Lilly or Emma talked about incidents which clearly indicated otherwise.

In singalongs for people with dementia, singing could be considered an active response, and not-singing, a lack of response. In my experience, though, this is not always the case. While Lilly readily sang along in our sessions and privately with her daughter, she could still be one of the participants *not* singing in a group setting. Lilly admitted that when she was young, she did not sing along when her family sang together, but she thought it was "cosy" (Norwegian: *koselig*) and enjoyed listening.

Even the lack of other responses such as bodily movements or facial expressions can be misleading, as I have experienced while working as a therapeutic musician. For two years, I had weekly music sessions customised as singalongs in some dementia departments' living rooms, singing well-known songs accompanied mostly by my Celtic harp and some cello. Most residents were in advanced stages of dementia.

> *One morning, there was a new lady. She was leaning backwards in her wheelchair with closed eyes, showing no facial expression during the whole session. I wondered if she was asleep, and my impression was that she did not get anything out of the session. While packing up my instruments afterwards, I suddenly heard a thin voice from behind: "You, you! The new lady was calling for me: "You . . . singing?" I confirmed. "More . . . beautiful", she replied.*

This incident is one of the more obvious examples of how difficult it can be sometimes to interpret participants' responses. Another example was from a department with people with dementia at less severe stages. Many of them usually sang along, but one woman was always silent. Still, I could see the subtle movement of her lips while the group sang. When I talked to her afterwards, I said that she appeared to know the songs very well. She nodded eagerly and said: “I am singing inwardly”. Participation and response, then, can take many forms and be even more elusive if the person is unfamiliar to you. In addition, listening is not the same as passively consuming – it can also be an activity in its own right, especially when disease or disability makes other forms of activity challenging. Therefore, as indicated in Chapter 6.4, I propose that co-singing can also exist in a “mute” form and still offer the togetherness which is at the heart of the matter. In their study, Schmid et al. (2021) also observed a wide range of musical embodied expressions which were “evidence of explicit or micro-participation” (p. 319).

The notion of listening as an activity contributes to a rounder impression of co-singing as a material-discursive practice. What is generally considered a “practice” is often determined by habits and expectations themselves coloured by society’s focus on *doing* and being productive and “active”. However, the practice of listening – with or without explicit or micro embodied participation – sheds new light both on the broader concept of co-singing and on co-singing within the specific context of families living with dementia. The co-attending, co-responding, co-forming and co-rendering of co-singing intra-play would be unthinkable without active (embodied) listening. It is also essential to pay attention to and not underestimate related (micro) responses to the musical activity to appreciate the full range of “small-c” co-creativity and to avoid overlooking subtle signs of dissatisfaction or discomfort.

7.8.2 “They just want her to shut up”

While some people with dementia participate in music or singing activities mutely via attentive listening and micro-responses, others may co-form more extroverted expressions, fully exposing their “audible body” (Schei et al., 2019) and even coming across as *too* loud. During my participation as a teacher in music-based milieu care training (Musikkbasert miljøbehandling, or MMB), I observed several assessment presentations concerning the implementation of the music-based tools and activities which the course attendees had learned. Bringing the activities back to their workplaces and working actively and systematically with one or a group of residents was an essential part of this training. Subsequently presenting their experiences and receiving feedback from the group was an equally essential means of sharing insights and skills among both participants and teachers. Several of these cases made a profound impression on me, as the following excerpts will demonstrate.

> *Course participants from one nursing home had tried out individualised music with a resident with dementia who had outbursts and shouted a lot. Wearing headphones, he was seated close to the window with a view of the garden. He enjoyed the music and could relax while listening, although he would still shout at times and even occasionally respond to the music with loud musical outbursts. I remember the participants' ambivalence: They were thrilled that their musical efforts made a difference for the resident, but they also experienced a frustrating lack of broader understanding from some of their caregiver colleagues and the department management concerning motivation and priorities regarding implementing the musical measures. A loaded comment from one of the participants struck me: "They just want him to shut up [Norwegian:* tie still*], but we want him to have a better everyday life".*

This may illustrate the tension – or diffraction – between different attitudes and approaches influenced by instrumental and biomedical goals, on one side, and the caring or co-creative engagement with and understanding of the person and context, on the other. If the goal is to make him "shut up", sedatives may be the first choice in a busy department with many urgent needs in order to restore the ward's peace in the short term.[89] Even a joyful response to music can sometimes be overly loud, and staff and residents may not be particularly accustomed to these outbursts.

Moreover, despite the pleasure offered to the resident, mapping his favourite songs and facilitating small music-listening sessions take more effort from the staff. While this work might even entail better "behavioural outcomes" in the long run, it may be abandoned if the behavioural response is not considered adequate or timely.

Another complicating factor when one is facilitating music for people with dementia is that their responses to singing and music may not always be easy to interpret or comprehend. For some, previous life events heighten the threshold for

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[89] Over-medication and polypharmacy can, however, have serious side effects and other challenges in the long run.

participation and may even make singing appear to be a bad fit. On several occasions, though, I have found that when offered a gentle introduction at a customised pace, some of these people come to benefit immensely from the formerly avoided activity.

7.8.3 "I think it is gruesome"

Over several months, I regularly visited a dementia department with my Celtic harp to offer weekly singing sessions. One of the residents initially seemed somewhat reluctant to attend them.

> *On one occasion, the staff member placed this lady in the group and then went away.*[90] *She eventually started hustling one of the other residents to help her get out to smoke. "No", answered the other resident, "I want to sing and listen to the beautiful music. Don't you want to listen to the music?" "No, I think it is gruesome", the lady replied forthrightly. I was perplexed but had to keep on playing and singing with the others.*
>
> *After the session, I consulted the staff to understand the lady's needs. I learned about her severe hearing impairment and bad experiences with singing at school, where she was told she could not and should not sing along with her peers. No wonder she was reluctant to attend the singing sessions! Nevertheless, the staff also told me she had two favourite songs. So, at the next session, she was seated in the back of the group, at a considerable distance from my instruments and me, since her hearing distortion could make instrumental music challenging. I was also cautious about my volume, keeping her in the corner of my eye and softening and simplifying my playing if she looked uneasy, which seemed to work.*
>
> *Towards the session's end, I approached her without my instrument, sat close to her, and softly sang her two favourite songs a cappella. She responded with eye contact and even little smiles, and towards the end of the second song she even started singing along in her way. It felt like a profound moment, and the staff members were misty eyed. From then on, she willingly attended and seemed to enjoy the singing sessions. She even*

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[90] At least one staff member was supposed to be present during the session, but on rare occasions this person would disappear to tend to other urgent needs.

> *occasionally joined in singing. I must add to the story that, at every session, I underlined that singing along was voluntary and that the quality of singing was not an issue: "Every bird sings with its own voice" was my favourite saying.*

In their childhoods, some older people experienced harsh feedback from a schoolteacher or other adult telling them their singing voice was no good. While teachers today avoid such insensitive messages, many younger people also suffer from a lack of confidence in their singing voice. The professionalisation of singing artists, fewer opportunities for daily life singing, and less focus on singing in education (to which I will return in Chapter 8.7.3) are some of the factors contributing to "voice shame" (Schei & Schei, 2017), as discussed in Chapter 4.5.6.

As mentioned, Lilly clearly showed signs of voice shame. She repeatedly referred to the gap between her family members' singing skills and her own. I once asked if anyone had ever actually told her she did not sing well. She replied that they were too polite to do so but she knew that they thought so – "so then I listened instead".

Favourite songs were a familiar entrance to co-singing, based on my former experiences in dementia care and my training in individualised music (Gerdner, 2005; Myskja, 2011). Initially, this strategy also worked well with Lilly and Emma. Nevertheless, my co-singing explorations with them could also put that "default mode" into question.

7.8.4 The missing binders

As mentioned previously, Lilly, Emma and I tried out different songs and singing activities based on their preferences and interests. I assembled these songs and activities in a binder and tried to design it with some pleasant illustrations and an easy-to-read layout with big letters. I also made a second, identical binder at Emma's request so they could have one in Lilly's home and one at the cottage.

> *At our last meeting, I realised that the binders had somehow got lost, probably when Lilly moved to another residence. So, I gave them my own copy of the binder. Emma said she felt ashamed because of the lost binders and was very happy to get a new one. She found name tags and, together*

> *with Lilly, tagged the binder carefully. Their diligent care in tagging the binder made me feel emotional. I wondered why.*
>
> *Maybe, without really wanting to admit it to myself, I had hoped that Lilly and Emma would keep singing more regularly together after our sessions, but that seemed not to be the case. Lilly had moved to an assisted-living residence, and for several reasons, including the Covid-19 pandemic, Emma's visits were at times limited. However, singing was part of the activities at the residence, and Emma told me that Lilly was then actively singing along with the others.*

In hindsight, I wondered whether the missing binders might have contributed to Lilly and Emma's experiences with stroll and troll. Previously, Emma had confessed that singing favourite songs together was hard to fit into otherwise busy days. With the binder missing, it was probably even harder. It may be that this sparked their desire to sing on other occasions, such as driving in the car or walking or exercising. That is, the intra-action of the missing binder afforded more informal singing (and moving) activities. And perhaps, in turn, the new, carefully tagged binder might afford new becomings of co-singing in Lilly's assisted-living residence.

The agency of song lyrics in co-singing with people with dementia is a double-edged sword. My experiences from my singing sessions in dementia care units have made me very cautious about handing out songbooks or texts, and I always indicate that not using a book is perfectly fine. Sometimes I abandon the songbooks altogether in departments with residents in a severe stage of dementia. In one sheltered dementia department, there was a lady who loved singing but was completely mute if she did not have the songbook. With the book and a little facilitation from a caregiver or me to help her keep track of the lines, however, she could sing an enormous repertoire of well-known songs. On other occasions – when I did not know the residents, for example, or when well-meaning staff handed out the books a bit too eagerly – the book could actively hinder the singing of some residents. Even when the staff and I helped the participants find the right page and song, some soon became disoriented, flipping aimlessly through the pages and thereby losing contact with the singing activity.

Ridder (2005) discusses the pros and cons of using songbooks with people with dementia. A songbook with well-known songs can remind people of earlier experiences of unity and companionship within a specific group wherein certain songs were part of being together. On the other hand, people might “hide” behind the books and thus avoid being carried away with the music. Moreover, people with dementia can become upset if they are not able to read the words or find the right page. In such circumstances, Ridder suggests skipping the songbook (pp. 20–21) and taking advantage of the enhanced opportunity for interpersonal connection and interaction while singing, including eye contact and facial and other embodied expressions.

Thus, the songbook, whether present or absent, has profound agency and acts like an apparatus, performing a range of agential cuts and intra-acting with the participating co-singers’ attention, skills and senses. Moreover, the present songbook also somehow regulates the space between co-singers, like a hub creating an anchor for joint co-creativity or a barrier leaving them somewhat visually isolated. In general, the performative, material-discursive role of the songbook can be co-formed and co-rendered by attentive participants to facilitate manifold co-singing options. Omitting the text and just singing one or two verses or trolling may add playfulness and afford livelier sharing of both active body language and the subtle neuroceptive cues of an online social engagement system, in the language of polyvagal theory. Such *impulses of togetherness* afford *presence* and *sensory anchoring* (Valberg, 2012).[91]

A further step along such a line of playful communication might be to (sometimes) abandon not only the texts but even the songs themselves.

7.8.5 Spontaneous singing

The following vignette based on one of the MMB education assessment presentations exemplifies how spontaneous singing can serve as a form of post-verbal expression:

> *An older resident with dementia frequently complained about pain. The staff regarded his suffering as an expression of emotional as well as physical pain. After trying out some music activities, they discovered that he enjoyed singing spontaneous little “self-*composed*” songs or phrases.*

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[91] Valberg (2012) proposes the Norwegian terms *samværsimpulser* (impulses of togetherness), *nærvær* (presence) and *sanseforankring* (sensory anchoring) as part of his outline of a relational music aesthetics.

> *The staff started encouraging him to do so regularly, often before or after meals or activities.*
>
> *They found that this form of spontaneous singing allowed him to express experiences, thoughts and feelings that he was not able to convey through words alone. This way of processing his experiences through spontaneous singing, thus, appeared to influence his well-being along multiple dimensions, facilitating expression, outpacing the pain, and boosting his self-esteem, since the staff and other residents expressed their enjoyment of his singing and sometimes even participated in a singing "conversation".*

This spontaneous singing is yet another form of "musified communication and embodied reminiscence" (see the examples described in Chapter 7.5.5).

Basting (2020) describes a somewhat similar approach. She intended to sing a well-known, thematically relevant song with a male with dementia interested in rocks but quickly abandoned her guitar, scores, and lyrics as they started gathering words and themes from former conversations, first spontaneously but later as part of their collaborative creation of song lyrics (p. 183). This revisiting of well-known melodies, melodic themes or fragments need not end with actual lyrics but instead can produce a kind of conversation from the random, spontaneous words which emerge. Relatedly, the MusicKit method (Thurn et al., 2021) described in Chapter 2.5 can facilitate this form of musified communication. The person with dementia and family or professional caregivers can be guided in the application of modular musical elements in small situational songs or chanted requests during daily-life activities.

Training and educational resources can support co-singing strategies and competencies. Below, however, I will suggest that the initial "education" and co-forming of listening attentiveness, confidence in one's singing voice, and spontaneous unfolding of singing can be fostered from the very beginning of one's life.

7.9 Becoming co-singers: A personal diffraction of stroll and troll and lullaby

The same day
as the second follow-up interview with Emma –
and her vivid description of her singing walks with Lilly –
I am sitting by my three-year-old granddaughter's bed,
singing lullabies:
the same ones I sang to her as an infant,
and to her mum and uncles decades ago,
also, while carrying a younger one
under my chest.

While watching her drowsing with narrowing eyes
a sudden wish overwhelms me:
"I really hope she will sing with me
if I ever get dementia –
or even if I don't."
I feel a blend of getting touched and a subtle joy,
knowing that she is growing up
becoming
a naturally competent co-singer.
From the very beginning of her being,
she has experienced singing
as core togetherness;
with grandparents, parents, and kindergarten staff
entangling singing into daily life and play.

I can visualise her in the future,
visiting me at the nursing home
or sitting close by my sickbed.
I know she will be able *to sing – and I hope she will* do *so.*

And I think – as I have thought time and again –
that the co-singing "education"
of future healthcare workers, teachers, relatives and friends

should start in kindergarten –
no – at birth, or in the womb.

My granddaughter was singing before she could talk,
she was dancing before she could walk.
Even non-musical rhythmic sounds
could make her dance –
like when she was seven months old,
and the neighbours above
were redecorating their home:
She was standing on her knees,
dancing vigorously to the nagging rhythms of the floor grinder!

These memories and thoughts are flowing through my mind,
before my inner sight returns to Emma and her Mum:
I see them with my inner eye, walking outdoors, side by side.
Their co-singing gives rise
to Lilly's inner rhythm,
entrains her slow, unsteady gait into a more fluid pace
while shaping Emma's inner state towards a sense of joyful peace.

My granddaughter is now asleep.

7.10 Concluding summary

This chapter has presented a diffractive exploration of Lilly and Emma's daily-life co-singing. The diffractive engagement began with multifaceted concepts of *space* and moved through four layers by engaging with concept, agency, theory and research (including concept) and experience. Each layer incorporates the previous layers to some degree, adding conceptual and theoretical multiplicity and entanglements along the way.

Engaging with concept brought to the fore how the multifaceted concept of *space* – regarding both time and place – encompassed the potential of space to be an invitation to develop enhanced initiative and integrity during co-singing in terms of both Lilly's singing in old age and Emma's singing as a child. While *engaging with agency*, an ordinary car drive unveiled the potential of different aspects of space to be intra-acting *agencies* – the car turned into a "time machine", connecting singing memories and ideas from the past to the present and suggesting them for the future as well. Moreover, the car offered a protected stage for unpretentious and informal singing opportunities. The incorporation of the notion of intra-action and later the four forms of intra-play – co-attending, co-responding, co-forming and co-rendering – further expanded our awareness of the dynamics and entanglements of co-singing during the car drive.

Engaging with theory and research brought to the fore the idea of co-singing as *musified togetherness*, inspired by Dissanayake's (2017) notion of *artification* and evoking Stern's (2004) concept of *moments of meeting.* Furthermore, Lilly and Emma's musified togetherness was located in four main areas: musified communication and reminiscence, musified daily life activity, musified physical activity and musified locomotion.

Engaging with theory and concept highlighted co-singing – especially as exemplified by Lilly and Emma's rhythmic co-singing walks: their "stroll and troll" activity – as a material-discursive practice. My diffractive analysis traced the intra-actions of materiality, concept and practice not as distinct and different aspects of phenomena but as complementary and interwoven modes of becoming. The mode of materiality was illustrated by neurological mechanisms, rhythm and body movement. Practice was illustrated by Emma and Lilly's experiences with stroll and troll and other daily-life singing activities. The entanglements of materiality and practice intra-acted with past, present and future ideas or concepts of what singing has been, is or might become.

Through this process, another research "discovery" involved how the participants' – most notably Emma's – concept of what singing *is* gradually changed. My own concept of singing was transformed as well. The idea of singing, according to Emma, as something "small", accessible, and easy – something that just *is* there for us and can be pulled out without planning or preparing – changed their practice as well as their sense of what co-singing might be as part of their daily life.

While *engaging with experience*, I read the insights from Lilly and Emma's co-singing explorations through my other experiences as a therapeutic musician and educator to demonstrate the range of factors and approaches influencing how co-singing can unfold. *Listening* was actualised as a full-fledged activity in its own right. Further, experiences from the MMB[92] training illustrated the entanglements of and tension between instrumental and biomedical approaches, on one side, and caring, co-creative and spontaneous musical engagement on the resident's premises, on the other. Revisiting such experiences also highlighted the need to consider each person's background, relationship with singing and their voice, and physiological prerequisites including hearing impairment.

Moreover, the story of the lost binders and the discussion of songbooks illustrated how the "materiality" of the presence or absence of song texts contributes to the affordance of different modes of co-singing and adds new possibilities for singing spontaneity, expression, improvisation and communication.

In all, the analytical layer of engagement with (former) experience provided colour and nuance to the previously sketched modes of co-singing as musified togetherness and material-discursive practice. The range and mode of participation in co-singing practice can include silent, attentive listening and mute inward singing with or without embodied (micro)expressions, as well as semi-mute participation with any quality of voice sparsely and occasionally sounding along. Thus, co-singing also offers an opportunity to the formerly dismissed voice, de-territorialised by (voice) shame – whether induced by self-judgment or other's insensitive comments – and re-territorialised in a sound landscape of loved songs and the acceptance of every bird's im/perfect voice, celebrating the "audible body". Co-singing unfolds in the span between biomedical instrumentalism and aimless moments of joyful togetherness. It varies in form and circumstance, anchored in books and songs or in free and fragmented spontaneous melodic outbursts.

The "smallness" and accessibility of co-singing highlighted by Lilly and Emma's experiences, can also be valuable to other people with dementia and their families or even beyond. The co-forming of materiality, concept, and practice within the field of co-singing opens up further theoretical and philosophical questions and issues to be discussed in the next chapter.

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[92] Musikkbasert miljøbehandling (music-based milieu care).

8 Discussion, summary and implications

8.1 Introduction: Research questions and chapter outline

Before discussing my engagement with theory and practice throughout the dissertation, I will again return to the research questions. The project's aim, and its main research issue, is to explore the potential and implications of low-threshold daily-life singing for people with dementia and their close ones. This primary issue generated the following three research questions:

1. *How might people with dementia and their close ones use and experience singing as an integral part of their daily-life communication and interaction?*

2. *How can theory and research – especially that based on neuroscience and posthuman theory and philosophy – shed light on mechanisms and processes in play when people with dementia and their close ones sing together?*

3. *How might reworked singing terminology and concepts nuance understandings of and insights into daily-life singing practice and experience for people with dementia and their close ones, and what might be the reciprocal implications for concept and practice?*

The diffractive explorative process outlined in Chapter 7 engaged all research questions (RQ), particularly RQs 1 and 2. Lilly and Emma's daily-life co-singing experiences shed light on RQ 1 and the *practice* of co-singing. I explored RQ 2 partly through my research review in Chapter 2 and mainly by way of the outline of different theoretical perspectives in Chapters 4 and 5. It was also part of my diffractive engagements with theory in Chapter 7. Chapter 4 particularly engaged the material (broadly speaking) aspects of co-singing and partly the discursive aspects, while Chapter 5 fully engaged in the discursive and ethical aspects. I further conceptualised those discursive aspects in Chapter 6 through the terminology discussion (RQ 3) connected to co-singing and in Chapter 7 through my diffractive engagements with concepts and theory, including the concept of musification and how Emma and Lilly's singing practice changed along with their notions of what singing might be.

My research relies upon Barad's (2007) agential realism outlined in Chapter 3, wherein the concepts of *intra-action* and *diffraction* are essential. Therefore, there is no way to strictly separate the three research questions and the ways they actualise co-singing as a material-discursive practice. They are already entangled in and threaded through one another and the diffractive fields (Toxværd, 2023) of this dissertation and co-singing itself.[93] In this final chapter, I will elaborate upon these diffractions and discussions while reconnecting previous sections of the dissertation to summarise, further entangle, and actualise the theoretical and practical implications of my PhD project. The further discussion will, thus, sometimes address specific research questions and, at other times, engage in interwoven implications of the general research issue.

I summarised various parts of my theory exploration in the chapters' end sections and, to some degree, in Chapter 6. Below, I will offer a brief overall synthesis of the different theoretical aspects, their entanglements, and their connections to the second research question in particular. Further, I will bring together the notions of material-discursive practices (Barad, 2007) and intra-play (Richards & Haukeland, 2020) to move from the theoretical underpinnings to conceptual and discursive entanglements, which I develop further in Chapter 8.4 to dive more deeply into the philosophical perspectives connected to co-singing.

Then, primarily in terms of research questions 1 and 3, I will connect the conceptual framework of musification arrived at in Chapter 7.5 to actual practice, look at how such a practice might be framed, structured and formed, and suggest some implications for future research and education. Further, I will offer a concluding summary, suggesting my project's main research outcomes. Lastly, I will review my dissertation's four main contributions to the field, including the way in which its entanglements of different theoretical aspects shed light on co-singing and dementia in close relations.

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[93] The notion of "diffractive field" is introduced by Toxværd (2023) in a recently published PhD dissertation and could be a useful concept for future investigation.

8.2 Theoretical summary and synthesis

The literature study includes

- a research review of dementia, singing and relatives (Chapter 2)
- the philosophy of science foundation of Karen Barad’s agential realism (Chapter 3)
- different theoretical perspectives from critical gerontology, neuropsychology, neurophysiology and posthumanism (Chapter 4)
- the project’s discursive and macro-ethical implications (Chapter 5)
- the anchoring and discussion of the term co-singing (Chapter 6)

Taken together, these outlines, discussions and diffractions entangle different aspects of posthumanism, music and dementia research, and neuroscience and psychology in novel ways to shed light on the foundations for and implications of daily-life co-singing in families living with dementia.

Barad’s agential realism provides a platform for grasping the ever-changing entanglements of all phenomena, including the fleeting, becoming properties of subjects and objects (among which is the researcher). Barad’s concept of material-discursive practices, to which I will return, provides a framework and an apparatus for describing the unfolding of such entanglements also with regard to co-singing in close relations.

The research review in Chapter 2 uncovered only limited academic work on daily-life singing in families living with dementia. Adjacent research, however, did examine the untapped potential for singing in the context of dementia as well as a range of positive outcomes of it, especially regarding enhanced well-being and social inclusion. Moreover, several studies displayed the synergetic effects of organised singing, coaching, and everyday-life singing between sessions – in a home-dwelling setting or as caregiver singing in institutions.

The theoretical outlines, discussions, and diffractions in Chapter 4 unveiled the potential inherent in opening up the concepts of identity and self within dementia care and research to encompass a more embodied and dividual sense of “polyphonic” personhood. Research explorations within the frame of critical gerontology (e.g., the work of Pia Kontos and colleagues) share much with post-human approaches to the arts and dementia, though the latter’s concept of self is even more volatile. In any case, when put into practice, both of these approaches highlight singing and music – or the arts more generally – as inclusive, small-c creative ways of being together. Such interactions can also induce autobiographical memories, which are highlighted in much research and therapy as a way to restore or support identity. While that is not the point of the activity according to the approaches of critical gerontology and posthuman studies, it can be considered a “side effect”. Alternatively, these activities can be seen to support people with dementia and allow them to unfold in embodied ways which are not dependent on language or explicit memory. Research on music and memory acknowledges that implicit, embodied memory can still be active even in the late stages of dementia when language is compromised or absent. Music, including singing, offer a gateway to such implicit, embodied, post-verbal memories or sensations.

Moreover, research on proto-musicality (Stige, 2012) and communicative musicality (Malloch & Trevarthen, 2009) sheds light on embodied, music-like communicative properties which are at play from the beginning of life. This proto-musicality unfolds before explicit memory matures and is, thus, anchored in implicit, procedural memory and accessible beyond explicit memory and words (Fuchs, 2020; Son et al., 2002). This form of communication is also closely connected to interpersonal attunement (Stern, 1985/2018) and forms of vitality (Stern, 2010). There are also strong scientific arguments for anchoring proto-musicality in evolution since the bonding it makes possible would have supported the survival of vulnerable human new-borns (Dissanayake, 2017). Dissanayake argues that proto-musicality was also the foundation and precursor of the emergence of the arts through the process of artification, or “making the ordinary extraordinary” via the embellishment of tools and the development of artified social-bonding rituals.

In addition, proto-musicality exercises and educates the infant’s “social engagement system” (Porges, 2011) and helps develop the healthy regulation of the balance between the social and defensive mechanisms of the autonomic nervous system. Beyond parent–infant communication, musical influence on the autonomic nervous system – especially through singing – is available throughout one’s life. Through the neural and muscular pathways connected to the inner ear and the face, and through the breath’s influence on the vagus nerve and the heart, singing (and other prosodic vocalising) can support pro-social engagement and contribute to downregulating the defensive mechanisms of fight, flight and withdrawal (Porges & Lewis, 2010). Music and singing can override triggering signs and the sense of threat or insecurity but also support and enhance cues of safety, or glimmers (Dana, 2018a), thus supporting the basis of resilience and joy.

Discourses of dementia have been coloured by the notion of a "lost self" and "dementia as tragedy" fuelled by the biomedical paradigm within research and healthcare and conveyed by media and popular culture. Such discourses foster "othering" and stigma, resulting in a prejudiced and even mistaken understanding of the behaviours, communications and potentials of people living with dementia. Singing, music and other artful activities can offer and facilitate resource-oriented, non-intrusive ways of being together which transcend mere words and the limited notion of self based entirely on cognitive properties and abilities. Artful small-c creativity and togetherness like co-singing may thus offer more affirmative – and ethical – forms of in-the-moment activities and social inclusion.

To convey such an affirmative, inclusive, here-and-now approach to singing, I find that co-singing is more apt than terms such as caregiver singing or care singing because co-singing better conveys the equal and relational implications while still connecting to existing singing practices and the notion of (health) musicking.

Co-singing can also be interwoven into daily-life activity. In Chapter 7.4, I engaged with the four forms of *intra-play* to shed light on some of Lilly and Emma's daily-life singing occasions. In Chapter 7.6, I discussed the entanglements of materiality (broadly speaking), concepts and practice using Barad's concept of *material-discursive practices*. Below, I will bring these two notions – intra-play and material-discursive practices – together to explore how co-singing might unfold as *material-discursive intra-play*.

8.3 Co-singing as material-discursive intra-play

In this section, I suggest that material-discursive practices can be viewed through the lens of the four forms of intra-play outlined by Richards and Haukeland (2020) – that is, the aspects of co-attending, co-responding, co-forming and co-rendering can shed light on the processes of co-singing as a material-discursive practice.

At first, Emma was influenced by her existing idea of singing as something quite formal and done within specific frames and conditions, which made the threshold for singing actively with her mother relatively high despite her wish to do so. I do not think Emma's concept of singing was unique – society's focus on singing competitions as entertainment, massive distribution of musical recordings of singing artists, and a general tendency to formally organise leisure-time singing activities, such as choirs or cultural school lessons, leave little room for more spontaneous singing.

During my work at the municipal day centre, several older adults told me about how they used to sing together as a family at dusk while waiting to light the paraffin lamps because they had to conserve fuel. Absent today's digital entertainment (and even TV and radio), family singing was a relatively common form of togetherness and "entertainment". As such informal co-singing contexts have disappeared, the general notion of what singing might be has also become more limited.

Emma's notion of what singing might be *co-responded* to her experiences of the spontaneous, unplanned singing incidents while in the car or walking outdoors with Lilly. Emma and Lilly's singing practice and concept *co-formed* while they tried out new ways of using singing in daily life. The "materiality" of neurology, spaces, sites, and the songs and music itself participated in this co-responding and co-forming. Eventually, the notion of singing as something "small", accessible and easy was co-formed and co-rendered through the material-discursive practice of their co-singing. The changed notion and rendering of singing might thus foster further co-forming of new singing intra-play potentials.

8.4 Philosophical perspectives on co-singing in families living with dementia

The concept and approach of *co-singing* with people living with dementia discussed in this dissertation implies looking beyond singing and music as a means of symptom reduction and care provision. The exploration of research question 2 begins with Karen Barad's *ethico-onto-epistemology* (Barad, 2007) (outlined in Chapter 3), Rosi Braidotti's *affirmative ethics* (Braidotti, 2019a, 2019b) (described in Chapter 5), and Deleuze's concepts of *becoming* and *difference in itself* (Deleuze, 1968/2001; May, 2005) (mentioned in Chapter 7.6.6). The neurological, theoretical and conceptual underpinnings of co-singing outlined in Chapter 4 and discussed in Chapter 6 entangle with the abovementioned philosophical outlooks.

Emma ultimately came to view singing as accessible – as something "small" and "easy" (Chapter 7.6.7), which recalls Deleuze and Guattari's concept of "minor(itarian)" (Massumi, 1992, e.g., p. 193). In a way, daily life co-singing could be seen as a "missing practice" – one de-territorialised by music professionals, therapists and education and potentially re-territorialised through a material-discursive re-forming and re-rendering of daily-life singing practice. This would redress it as something “small” and accessible that we “can just pull out” and “that just *is* there for us”, as Emma puts it (in Chapter 7.6.7). Such a position resonates with the notions of informal and low-threshold singing explained in Chapter 1.6 and revisited throughout this dissertation.

To celebrate the accessibility and small-ness of little-c co-creative singing when integrated into multiple situations and activities in daily life, and to release the potential of everyday singing competence acquired throughout life, one can internalise the Spinoza citation already embraced by Braidotti (2017a, p. 303) and Deleuze (May, 2005, p. 3): “Yet, no one has hitherto determined what the body is capable of […] [T]he body itself, from the laws of its nature alone, can do many things at which the mind is astonished” (de Spinoza, 1677/2020, p. 165). Likewise, we do not yet know what people with dementia are capable of when we change our lens from non-verbal to post-verbal (Quinn et al., 2021), disability to dis/ability – among other things, their lack of remembering can become re-membering through co-singing and other attuned and embodied forms of pre/post-verbal togetherness. The communicative musicality model (Malloch & Trevarthen, 2009), resource-oriented music therapy (Rolvsjord, 2016), and posthuman research on music and dementia (Mittner, 2022; Quinn et al., 2021) point toward this potential. The singing, audible body (Schei et al., 2019) – “from the laws of its nature” – can do astonishing things.

Taylor (2016) suggests: “Posthumanism invites us (humans) to undo the current ways of doing – and then *imagine, invent and do the doing differently*” (p. 8). The various aspects of co-singing practice may invite families living with dementia to imagine what singing might be to *them* and then invent the spaces and en/act/ment/s of singing together, based on their preferences and experiences, while still trying to “do the doing differently” by opening up to the “minority” and accessibility of co-singing as a dynamic part of daily life. Quinn et al. (2021) point out that “everyone and everything is engaged in what Karen Barad calls ‘the ongoing dynamism of becoming’ (2007, p. 142). Engagement with music illuminates this process” (Quinn et al., 2021, p. 77). Accordingly, co-singing may illuminate and be illuminated by the ongoing dynamism of becoming a family living with dementia.

8.5 The conceptual framework of co-singing as musified togetherness

The different forms of musification arrived at during the exploration of Lilly and Emma’s co-singing incidents are not exhaustive but rather serve as a point of departure for a conceptual framework and entailed practice. The details of such a practice may differ according to previous and current singing interests and present life conditions. Still, I will propose a few suggestions to establish a conceptual and structural framework for co-singing as musified togetherness in families living with dementia – and possibly for others as well.

8.5.1 Co-singing as musified daily-life activity

Musified daily-life activity could range from singing in the car, as discussed in Chapter 7, to care-singing during morning routines like dressing or washing, whether in a nursing home or in a home-dwelling setting. What would make the latter co-singing rather than care-singing? Co-singing may suggest more equal initiative and a focus on the communicative and fun part of singing rather than an instrumental, task-oriented approach. However, whatever term one chooses in these situations, the following question is essential: Is the singing primarily an opportunity to get a practical task completed as efficiently and manageably as possible, or is the daily-life incident a valuable opportunity to connect and communicate and have some fun? The way care-singing is applied and legitimised within professional health care – something to which I will return in Chapter 8.7.2 – privileges a task-oriented, instrumental underpinning even though the caregiver and cared-for can still enjoy the singing and experience reciprocity in doing it.

Co-singing as a musified daily-life activity, on the other hand, offers an opportunity to “make special” or “make the ordinary extraordinary” (Dissanayake, 2015, pp. 12–13). Rather than primarily being an agent for task-solving, co-singing as part of daily life activities may offer a subtle kind of “little-c” co-creativity and embellishment. Co-singing’s entangled aesthetic and communicative aspects can add colour and companionship to otherwise dull, tiresome or even challenging incidents. At its best, it might bring about a transformation “from dull to delight”, but it can also simply enhance joy and inspiration in already positive relational activities, adding strength to what Deb Dana calls glimmers (Dana, 2018a, pp. 66–71), or the sparking of positive neuroceptive triggers to foster social engagement and down-regulate defence.

8.5.2 Co-singing as musified communication and post/verbal reminiscence

Co-singing as *musified communication and reminiscence* can range from leisure-time singing of well-known songs – integrated with small conversations brought up by associations – to singing little song phrases as (part of) post-verbal communication (Quinn et al., 2021, p. 82) or even spontaneous, improvised singing in the moment. The post-verbal (Quinn et al., 2021) potential of co-singing mirrors this range of possibilities. Humanistic approaches have often emphasised singing and music's potential to connect the person with dementia with a "lost" identity and retrieve autobiographical memories. Posthuman approaches to music and dementia, however, have primarily focused on the person here and now as an intra-acting (Barad, 2007) part of an "agentic assemblage" (Bennet, 2010, pp. 23–24; Quinn et al., 2021, p. 76). Thus, musical interaction and co-creation in this setting occupy common ground with Stern's (2004) notion of "meaningful moments" or even *kairos*, as discussed in Chapter 7.7.

While the retrieval of memories is not the focus of posthuman approaches, memories can still be vital parts of musical co-creation and post-verbal communication. However, the memories are by-products or even parts of the agentic assemblage rather than a goal, which means they can also be more diffuse – not primarily explicitly autobiographical but also associative, implicit and embodied. Such memories foster affective and post-verbal rather than cognitive and verbal transmission and communication. Co-singing enables a range of such embodied renderings, thus intra-acting with the participants' "polyphonic personhoods" (discussed in Chapter 4.5.8) at various non/verbal and un/conscious levels. Thus, co-singing may be regarded as a post/verbal mode of musified reminiscence, co-rendering and communication.

Singing together implies a form of company wherein the "dialogue" can be maintained without needing an "answer" as such. This reduces the pressure on both parts: People with dementia need not comprehend the verbal content, and others can keep this "dialogue" going without the strain of seeking any specific response (Ridder, 2005, p. 110). Moreover, silence and subtle post-verbal embodied signs and signals in communication and interaction can be as important in this case as audible sounds or words (as discussed in Chapter 7.8.1). It is therefore crucial to allow sufficient time and space for such silent post-verbal qualities or micro-events to unfold as part of co-singing as musified communication and reminiscence.

8.5.3 Co-singing as musified physical activity

While the embodiment of co-singing thus encompasses space and stillness, there is also a salient potential for movement and vigour. Lilly and Emma's joy and interest in movement and singing steered our collaboration in a direction I had not foreseen. In retrospect, however, the entanglement of singing and moving seems obvious, even in this context. Likewise, during my former experiences with singing in dementia care and caregiver education, several participants were enthusiastic about the easy and flexible move-and-troll[94] instructions. The multimodality of the activities provided the inclusion: If the physical activities were challenging for certain individuals, they could still participate in singing, trolling, humming or simply moving freely along with the rhythm. Furthermore, as Emma pointed out (in Chapter 7.5.6), singing together made physical activity more fun and easier to accomplish, and the singing became less "serious" since it was not the main goal of the activity. Thus, pretentiousness, voice shame (Schei & Schei, 2017), and a focus on remembering or reading the song text were all reduced, also because "trolling" (singing without words) was the primary mode of singing in this setting. Likewise, the simple waltz implies a very low-threshold and inclusive means of singing and moving because it can be simplified and adjusted according to participants' mobility, balance and preferences, and the singing can also be without words.

8.5.4 Co-singing as musified locomotion

As indicated, Lilly and Emma responded well to singing and moving activities. Therefore, I showed them some basic principles drawn from rhythmic auditory stimulation (RAS) and we explored a simplified stroll-and-troll activity while walking outdoors. I had shared this musified walking with many of the guests at a municipal day centre, where it encouraged more fluid and harmonious walking patterns during regular outdoor walks – individually or in small groups – and in efforts to support slow, unstable walkers during short, individual indoor sessions using well-known, rhythmic songs, a metronome, or both.

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[94] "Troll" means singing (or a song) without words.

During my work in the music-based milieu care educational programme,[95] I heard from several attendees who reported their positive experiences with rhythmic singing or using a metronome to enhance nursing home residents' mobility even while simply moving around the facility. Caregivers would also sometimes use rhythmic singing to hearten and support anxious residents during required relocations, thus avoiding the use of force or a wheelchair. Some found that applying singing or rhythm while walking outdoors was both useful and fun. Likewise, stroll and troll offers a low-threshold and straightforward mode of rhythmically cued walking inspired by RAS.

Emma also expressed her enthusiasm about our outdoor co-singing walks with her mother, and they continued to do this after our sessions ended. The singing not only helped Lilly's walking but also added a sense of togetherness that affected them on an emotional level as well (see Chapters 7.5.7 and 7.6).

8.5.5 Co-singing as musified togetherness

The different forms of co-singing as daily-life musification come together in the notion of co-singing as *musified togetherness*, which encompasses the aspects of musified activity, communication, movement and *moment*. The notion subsumes and transcends these different forms and highlights the essence of Muse-ic (Bjørkvold, 1992) intra-action (Barad, 2007) or intra-play (Richards & Haukeland, 2020). Based on the reviews, explorations and diffractions in which I have engaged throughout this dissertation, I propose that my idea of "the material-discursive intra-play of co-singing as musified togetherness" rests on three primary principles or properties: inherence, accessibility and affirmation.

These basic properties move along different axes. Co-singing as musified togetherness is *inherent* because it tracks along a range of embodied and neurophysiological substrates such as entrainment and priming (Thaut & Hoemberg, 2014), implicit knowledge and skills (Fuchs 2020), and the social engagement system (Porges, 2011). It is anchored in our natural proto-musicality (Stige, 2012), or what Malloch and Trevarthen (2009) have termed communicative musicality. Moreover, songs and singing have been involved in human rituals and

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[95] From 2016 to 2019 and from May 2023 onwards, I have worked part-time as a consultant and lecturer at Opplæringsprogrammet Musikkbasert miljøbehandling.

bonding since the dawn of time and are part of broad cultural and musical heritages.

Co-singing as musified togetherness is *accessible* because people always have their voices with them, it does not require either tools or expertise, and its potential always already resides in any little incident of daily life. In short, it can be something quite "small": a "minor" practice, a melodic, sounding out-breath, a spark from "dull to delight", a neuroceptive "glimmer" (Dana, 2018a).

Co-singing as musified togetherness is *affirmative* because it is based on the co-singers' existing experiences, interests and competencies, and non-instrumental, resource-oriented, and joyful approaches to music, both utilising and fostering "little-c" co-creativity. Likewise, it is an inherently generous gesture, offering a (post/verbal) sounding, embodied companionship without the need of any response and creating "an expanded intersubjective field that opens up new possibilities of ways of being with one another" (Stern, 2004, p. 371). It therefore resonates with affirmative ethics (Braidotti, 2019b, pp. 353–373) and points toward actualising new potentials of becoming (Barad, 2007; Deleuze, 1968/2001; May, 2005).

In all, the power and potential of co-singing as musified togetherness incorporates the intra-action of past, present and future – the inherent past of neurology and (embodied) autobiography bleeds into the accessibility of present daily-life incidents and points affirmatively towards future becomings, or "ways of being with one another". Yet, musified togetherness as material-discursive intra-play is not merely abstract but also utterly practical because it extends its invitation to literally anyone to incorporate and utilise the musical potential inherent in daily interpersonal life. It is particularly relevant to togetherness with pre- or post-verbal people (Quinn et al., 2021) – including small children or people with severe dementia – in close relations on the "micro" level. It may also be relevant in a broader context, across generations and various aspects of life at the "macro" level.

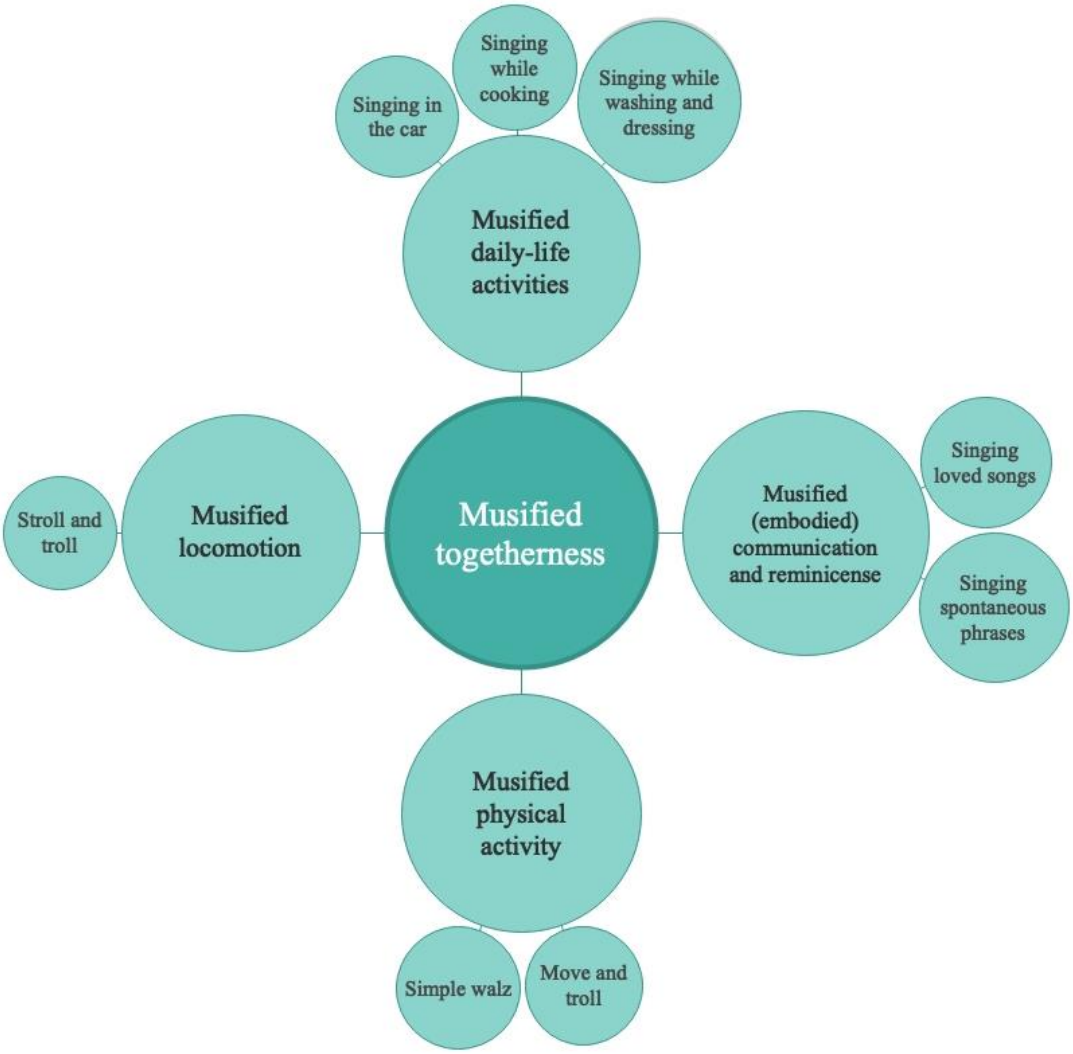

Figure 8. Examples of forms of musified togetherness

8.5.6 Musified togetherness as cross-generational inclusive ritual

I am sitting in a packed local church, looking for my four-year-old granddaughter in the children's choir in the front. It is a family service including baptisms, and the three local children's choirs of different ages from three years onwards are included with concert sections and as lead singers of the hymns. The hymn repertoire is novel, adjusted to the younger generation, and the texts and sometimes melodies are projected on white screens on either side in the front, where they are easy to see for everyone. When the first hymn starts, it overwhelms me. The multigenerational co-singing, led by the children with their conductor in the front, touches me deeply. I try to join in on the songs, some of which I know. Others I do not know at first, but by the last verse, I am already getting the hang of them.

The togetherness of co-singing is here raised to the macro level. The service ritual and baptising event are musified in multiple dimensions. The priest and choir are singing the religious texts, answered by the audience; the choirs are singing their own repertoire; everyone joins in on the hymns. Even the creed is musified, adapted to the multigenerational audience as a simple, rhythmic rap performed by the oldest members of the children's choir, with catchy refrains sung by everyone, all accompanied by a small band.

I am not a regular church attendee, and I was not prepared to experience such a novel musical framing at a traditional countryside protestant service. Still, it makes me hopeful: to see rituals and musification taking new, inclusive forms and expanding beyond expectation. However, I believe we would benefit from such musified togetherness at the macro and micro level in every aspect of life, also outside the religious sphere: in homes, kindergartens, schools, workplaces, and social gatherings for celebration and mourning alike. If co-singing could be entangled in different aspects of our lives, it would be easier to apply it to daily-life togetherness beyond words among close relations when apt or needed.

8.6 The practice of co-singing in families living with dementia

8.6.1 "The co-singing palette" for musified togetherness

To acknowledge and visualise the accessibility and flexibility of daily-life co-singing, I propose the process of musified togetherness visualised as a "palette" containing co-singing modes or "colour-tones" and associated brushes and tools. The palette may illustrate how different co-singing modes and incidents may be generated, formed, and rendered. The symbolic palette allows for mixing and nuancing different colours. Different forms of co-singing, then, may be rendered as "primary colours" moving along six dimensions: physical (embodied), situational, vocal, improvisational, temporal and dynamic. These dimensions – which are not all-encompassing but may visualise some structural properties and potentials – are inspired by my practical co-singing experiences and explorations with Lilly and Emma (Chapter 7) and during my previous work as a therapeutic musician.

In addition, they are informed by the theoretical engagements throughout this dissertation, including the main features of Stern's (2010) forms of vitality (discussed in Chapter 4.8.2) and his "fundamental dynamic pentad" of movement, time, force, space and intention/directionality, which I will put in parentheses to clarify the kinship. The situational dimension (space) ranges from different everyday incidents to organised activities or events such as singing in the car or while dressing, leisure-time singing from a songbook, or singing along with physical activity. The physical dimension (movement) ranges from motionless positions to various movement patterns such as sitting in a chair, dancing on the floor, or walking outdoors. The vocal dimension (intention/ directionality) ranges from different non-verbal tones and techniques to melodic verbal singing such as toning, humming or trolling motives and melodies or singing phrases or songs with a text. The improvisational/structural dimension (intention/directionality) ranges from spontaneous expressions to predefined songs or activities such as spontaneous phrases of singing "conversation" or singing actual songs in a planned setting. The temporal dimension (time) ranges from still and slow to fast – for example, a lullaby, a steady march, or a dance tune. Finally, the dynamic dimension (force) encompasses different and contrasting intensities in volume and energy level.

As the examples indicate, different dimensions can intra-act in multiple ways, meaning that a two-dimensional palette has clear limitations as a model here. Hopefully, the enormous potential of mixed colours and multiple tools and brushes, canvases or surfaces, might capture the multiplicity and multi-dimensionality of co-singing. To envision some central aspects of different co-singing activity elements, I will summarise brief examples in each dimension:

- Situation: driving, dressing, washing, relaxing, socialising, mealtime, entertainment, promenade, training
- Movement: sit, stand, sway, walk, dance, clap
- Vocal: sing inwardly (in one's imagination), breathe, tone, hum, troll, sing, rap
- Improvisation/structure: random, spontaneous, improvised, semi-structured, motivic, fragmented, thematic, melodic
- Temporal: still, slow, rubato, steady, rapid
- Dynamic: silent, muted, flowing, majestic, vigorous, loud, ecstatic

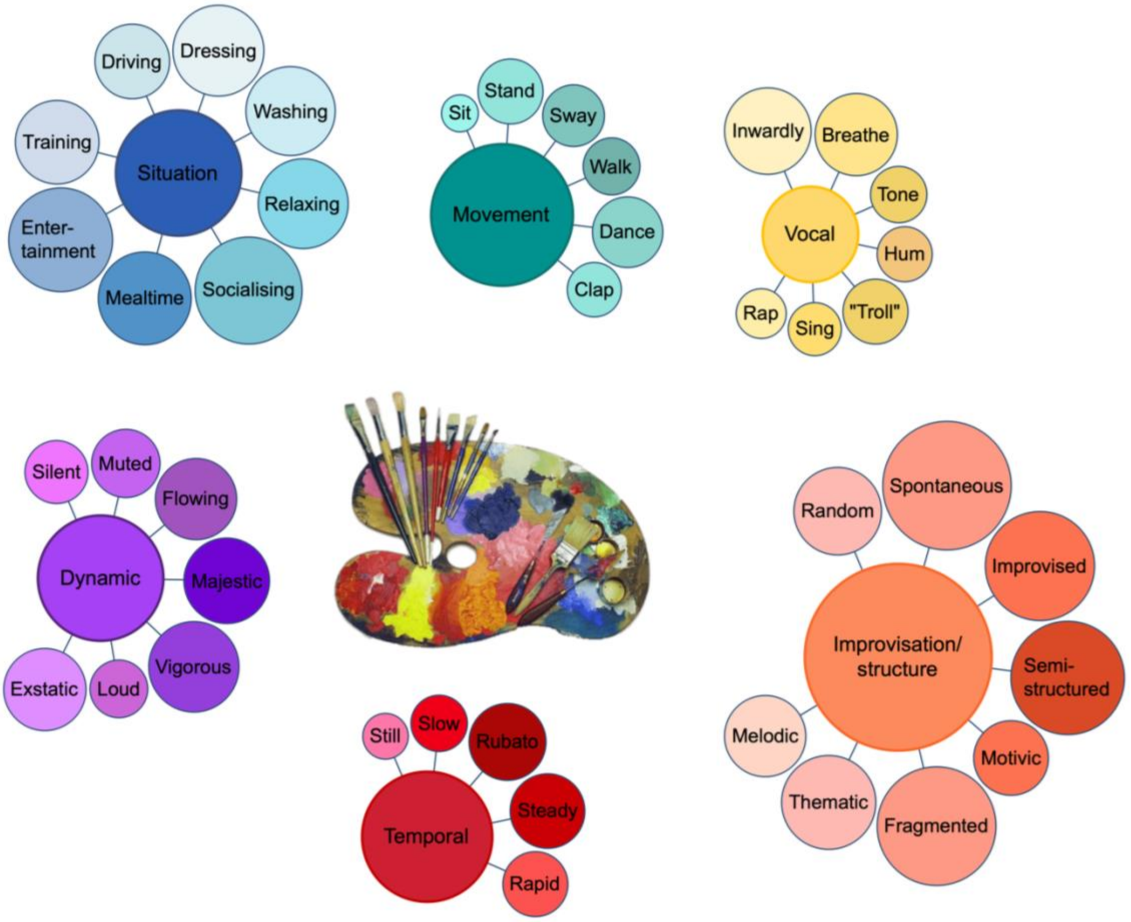

Figure 9. Illustration of the co-singing palette[96]

To further concretise these dimensions, the co-singing activities I explored with Lilly and Emma were

- spontaneous singing or trolling by heart during daily life incidents (e.g., in the car),
- singing favourite songs from a binder or songbook,
- move and troll: trolling well-known songs while doing simple, physical exercises;
- “simple waltz”: singing or trolling well-known waltzes while (progressively) doing simplified waltz movements (sitting, standing, or moving around), and
- stroll and troll: walking outdoors (or indoors) while singing well-known rhythmic songs, adjusting the tempo to the pace of the unsteadiest walker.

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[96] The palette photo in the middle of the illustration is from the public domain.

Based on the colours and dimensions of the co-singing palette, many co-singing modes and activities can be generated according to the co-singers' interests, wishes, needs and circumstances. The musified daily-life activities I explored with Lilly and Emma (in Chapter 7) could be developed further and supplemented with a range of other possible co-singing becomings. Co-singing might even be envisioned as musifying brush strokes with co-singing colour tones on a virtual canvas: actualising embodied and situated meaningful moments into abstract, post-verbal images or more figurative musical motives and landscapes.

8.7 Implications for education and future research

As discussed in Chapter 2.5, courses and education in singing (Batt-Rawden & Stedje, 2020) and music-based milieu care have been available for healthcare professionals in Norway for some time, especially since 2015 (Batt-Rawden & Storlien, 2019; Batt-Rawden et al., 2021). While they highlight the resources of music in these settings, political justifications of such programmes are often instrumental and focused on the reduction of negative symptoms. Moreover, for families living with dementia – whether in a home-dwelling or residential setting – there is no comparable resource-oriented music-based support or education.

Based on this dissertation, I will suggest three different educational aspirations:

- to offer low-threshold singing and music-training programmes for family members *and* people with dementia,
- to promote a greater awareness of resource-oriented and embodied attitudes towards music-based tools and methods in dementia care, and
- to anchor the singing competencies of the population in general lifelong education and social life.

8.7.1 Low-threshold singing support programs

The provision of singing and music training programmes for family members *and* people with dementia could support daily-life singing and music, based on their experiences and competencies. Such programmes could combine group singing, seminars, and coaching and comply with Särkämö et al.'s (2015; 2014) findings discussed in Chapters 2.4.6 and 2.7. Other group-singing research studies (referred to in Chapter 2.4.5) regarding people with dementia and family caregivers likewise discerned the synergetic effects of group or choir singing and singing at home (Mittelman & Papayannopoulou, 2018, pp. 784–785; Tamplin et al., 2018, p. 8; Unadkat et al., 2017, p. 474).

Such training could be offered within already existing programmes and structures. First, for example, the municipal day centres for people with dementia often offer singing and music as part of their activities. By incorporating relatives into some of these activities, participants might be encouraged to continue singing or other musical activities at home.

Second, most Norwegian municipalities offer so-called Demensskole (Dementia school) to people recently diagnosed with dementia and their next of kin. After the basic training, the municipality could design additional sessions including singing and music as a daily-life resource, taking advantage of the fact that the group members have gotten to know each other and developed an understanding of what life with dementia is. This approach, that is, builds on existing recruitment and facilitation infrastructures.

Third, some municipalities have professional music therapists as employees, and they could offer group sessions for people with dementia and relatives including singing, reflection and coaching. Music professionals working in the municipal leisure-time cultural school (*kulturskolen*) could also undertake such activities. Some cultural schools are already involved in music-based activities and training connected to implementing integrated music in municipal psychiatric, ageing and dementia care (Rangul et al., 2022). Community music organisations and initiatives could also provide educational co-singing activities.

Fourth, the publicly initiated or supported initiatives already offering music-based training and education for professional caregivers could extend their target group to include relatives – and possibly also people with early-stage dementia – and offer adjusted, low-threshold training sessions to support the daily use of singing and music. In Norway, this might begin with Opplærings-programmet musikkbasert miljøbehandling (Music-based milieu care educational programme) and extend to the nationwide organisation Krafttak for sang, which already runs educational programmes involving singing in many institutional and educational contexts, including ageing care (Sang i eldreomsorgen). Again, it is possible to draw on existing competencies and infrastructure to do this.

8.7.2 Enhancing affirmative attitudes to music-based care

I believe that there is a need to highlight resource-oriented perspectives in music-based educational initiatives addressing people with dementia and their caregivers to enhance their focus on the "glimmer" (Dana, 2018a, pp. 66–71) properties of music and mitigate negative bias and stigma.[97] While music-based interventions are often described in positive and resource-oriented terms, there persists a predominant focus on singing and music activities as agents to prevent negative symptoms and adverse behaviours. This position is also reflected in the way in which research and educational programmes are justified in healthcare white papers (e.g., Meld. St. nr. 15, 2017–2018, p. 136; Meld. St. nr. 29, 2012–2013, p. 85), as I pointed out in Chapter 2.5.

Consequently, providers of music-based tools often promote their methods as meeting professionally and clinically valid standards and as more than mere entertainment and diversion. Raising the awareness of the proficiency and scientific foundations of music in dementia care is necessary but may yet be a double-edged sword, exaggerating the biomedical, instrumental approach while even potentially raising the threshold for implementation. While studies reveal that music-based tools and training receive very positive responses, healthcare workers report challenges regarding implementation (Batt-Rawden et al., 2020; Batt-Rawden et al., 2021; Egset & Salhus, 2018). Thus, there is a need to strengthen the focus on implementation strategies.

In addition, I suggest a supplemental approach offering a less clinically and structurally rigorous but still supportive low-threshold approach to music, and especially singing, in dementia care, akin to the principles for co-singing explored in this thesis. For such an approach to have a sustainable foundation, society would benefit from a change in the general approach to singing within education.

8.7.3 Singing in education

Singing is still part of the teaching of music in Norwegian primary schools. In recent curricular revisions, however, singing's position has gradually been weakened (Beckmann & Christensen, 2022; Krafttak for sang, 2019).[98] Its

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[97] Stigma is discussed in Chapter 5.4.

[98] This has resulted in concern about the possible marginalisation of singing in schools, and 35 organisations came together on a joint petition opposing it (Krafttak for sang, 2019).

presence in the classroom is therefore largely dependent upon local principals' and teachers' singing interests and competencies. Beckmann and Christensen's (2022) research also found less singing activity at higher grade levels. Moreover, several of their interviewees claimed that singing in primary school was generally less prevalent than before and that many teachers lacked confidence in their singing skills. This may be because singing is no longer part of general teacher education in Norway: Aesthetic subjects are only available as electives (p. 158).

I believe that people could benefit from a thorough anchoring in singing as a natural competence from the very start of life – one which is systematically supported throughout the entire educational system, from kindergarten throughout primary school and into higher education. Nurturing and supporting "the audible body" (Schei et al., 2019) has broad general benefits for one's presence and ability to communicate. Moreover, confidence in one's singing voice and ability is an essential asset in the preparation of future caregivers, relatives and friends for joyful and meaningful communication and companionship with pre- and post-verbal people. I do not, however, propose the co-singing approach to undermine the importance of the effective clinical implementation of music-based tools and methods in professional dementia care. The two are complementary, and structures and education to promote systematic implementation are crucial. Otherwise, positive initiatives can fade away when encountering challenges like staff turnover, reorganisations or resource limitations (Batt-Rawden et al., 2020).

8.7.4 Implications for future research

The studies by Batt-Rawden et al. (2020; 2021), mentioned above, argue for a focus on implementation strategies in educational oeuvres regarding music-based approaches to dementia care. However, research remains limited in this regard. Amano et al. (2022) identify some crucial gaps regarding implementation of music interventions – namely, music therapy and individualised music – in long-term care facilities. They found research gaps regarding understanding the effectiveness of different implementation strategies. Further, they also uncovered a lack of focus on structural and policy contexts and asked future studies to "identify implementation strategies that address systemic barriers" (Amano et al., 2022, p. 11).

Research on informal home-singing activities in general, and for people with dementia and their relatives in particular, is equally minimal, also within the developing field of posthuman-anchored research on arts and dementia. Lastly, Quinn et al. (2021) point out that the materiality of non-verbal communication is rarely addressed in research on inclusive music practices (p. 75) (see Chapter 2.6.2), and that introducing posthuman theory and concepts to the study of arts and health might generate theoretical contributions going both ways:

> These [post-human] concepts allow difference to be perceived positively and generatively and open up new understandings of what it is to be human and well. Similarly, the arts are an ideal tool for doing post-human thinking, as they provide ways to avoid the binaries of body and mind. This fusion of arts, health and post-humanism thus has immense potential. (Quinn et al., 2021, p. 84)

8.8 Concluding

8.8.1 "Mind the gap"

The research field of music and dementia is expanding rapidly, but little research has been done on daily-life singing in families living with dementia. Moreover, as mentioned, approaches to music – including singing – and dementia have often been directly or indirectly coloured by the "dementia as tragedy" discourse and a biomedical orientation. In short, these approaches tend to link singing and music to the functional goals of "restoring" memory and identity or preventing adverse behaviours. Lately, resource-oriented music therapy and social- and posthuman-oriented dementia research have begun to challenge – and propose extensions and alternatives to – such attitudes. Nevertheless, little research has engaged with the potential of singing outside an institutional or professionally organised setting. Scrutiny of the theoretical foundations and conceptual and practical implications of low-threshold relational singing in families living with dementia has considerable untapped potential.

8.8.2 Limitations

This dissertation has some profound limitations which I will acknowledge before I present its main research contributions. First, its overview and discussions of research and theory are not intended to be systematic but rather to present certain chosen angles and approaches. Furthermore, its empirical research intra-action includes only one dyad and does not provide any evidence or basis for drawing broader conclusions. It does, however, provide a contextual knowledge base and diffractions and explorations to generate ideas and suggestions for potential approaches to singing as a relational activity in families living with dementia.

8.8.3 Dissertation summary and conclusion

The overarching methodological strategy of this PhD project is derived from the concepts of intra-action and diffraction (Barad, 2007) and anchored in the performative research paradigm (Østern et al., 2023). The diffractive field of my performative research explorations and this dissertation comes about via three overarching waves (Chapter 3):

1. Literature studies, including music and dementia research; critical gerontology; posthuman approaches; neuroscience and psychology; and discursive and macro-ethical discussions.
2. Auto-ethnographical impulses, including my private and professional experiences with singing throughout my life and particularly within dementia care.
3. The research intra-action with Lilly and Emma, an older woman with dementia and her daughter, who collaborated with me in exploring everyday-life singing activities based on their interests, their needs and our ideas.

The ripples and curls of these waves have flowed and fluctuated in different streams throughout the project and dissertation, constituting their own diffractive subfields and illustrating co-singing in families living with dementia as a relational material-discursive practice. Rather than proposing any final conclusions, a closing question perpetuates this lapping at the shore: What more might be possible in the diffractive field of singing and dementia, especially when we move beyond the organised, institutionalised, therapeutic and medical regions of music and dementia and into the relational, everyday-life potentials of singing?

The answer (and the question itself) will never be fixed; it will always be situated and materially-discursively constituted. In alignment with the non-conclusive and open-ended impetus of agential realism and the performative research paradigm, then, I will introduce another metaphor and suggest that looking at the diffractive patterns arising from this PhD project and dissertation is like looking into a kaleidoscope. Depending on the angle and tilting of the kaleidoscope, it will cycle through a variety of potential diffraction patterns. This dissertation's patterns and conclusions, that is, are created intra-actively with the reader and with new, not yet emergent be/coming explorations and discussions. From my situated angle, however, and my body-mind's tilting of the PhD kaleidoscope at this moment, these are the patterns which are clearest:[99]

1. There is an untapped potential for (relational) singing in the context of dementia, and there are possible synergetic effects to be gained from organised and therapeutic interventions, coaching, and singing at home between sessions (Chapter 2).
2. Singing has great potential as a re/source for close relationships and embodied relationality beyond language (Chapters 4 and 7) – a potential which is inherent, accessible, and affirmative.
3. Broader societal discourses connected to dementia (and music) have ethical implications (Chapter 5) and influence the diffractive fields of dis/ability, dis/order, dis/ease and ultimately dis/connection, thus actualising music and dementia as ethico-onto-epistemological and material-discursive phenomena.
4. Concepts and terminology such as co-singing (Chapter 6) and musified togetherness (Chapter 7) can help us transcend the organised, therapeutic and biomedical connotations of terms such as care singing or caregiver singing.
5. In this dissertation, co-singing is featured at three levels (Chapter 6):
    a) a broad term,
    b) a relational approach, and
    c) a situated practice in the context of dementia and close relations.
6. My research intra-action with the dyad (Chapter 7) explored and exemplified co-singing's flexible, low-threshold potential as musified togetherness within four main areas (out of many possible ones):
    a) musified daily-life activity;

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[99] I have put the main chapters in parentheses to indicate their influences, although many of these ten points derive from entangled perspectives.

    b) musified communication and (post-verbal, embodied) reminiscence;
    c) musified physical activity; and
    d) musified locomotion.

7. From a practice perspective (Chapters 7 and 8.6), a "co-singing palette" can be derived from these explorations of different intra-acting aspects of situations, movements, vocal expressions and structural, rhythmic and dynamic intensities.
8. Philosophically (Chapter 8.4), the informal, low-threshold potential of co-singing, independent of equipment and professional and organised settings, can be framed as a missed (de-territorialised) practice – and it can be reclaimed (re-territorialised) as a "minor", (small-c) co-creative and relational practice anchored in affirmative ethics (Chapter 5).
9. From a social and educational perspective (Chapters 2.5 and 8.7), singing's relational potential actualises the relevance of strengthening singing's position in general life and education and, more specifically, extending coaching and training programmes for singing and dementia beyond professional settings to include families living with dementia.
10. Ethico-onto-epistemologically, the practice of singing (Chapter 7), its material and situated conditions (Chapter 4), our concept of singing (Chapter 6), and various broader societal discourses and ethical implications connected to dementia and music (Chapter 5) reciprocally and intra-actively influence each other and in/form what can and cannot be done in the material-discursive-practical field of singing and dementia – and even beyond.

8.9 The main research contributions

Aside from indicating and summarising the above general research outcomes, I will also specify how my dissertation can contribute to new knowledge in four areas: methodology, theory, concepts and ideas.

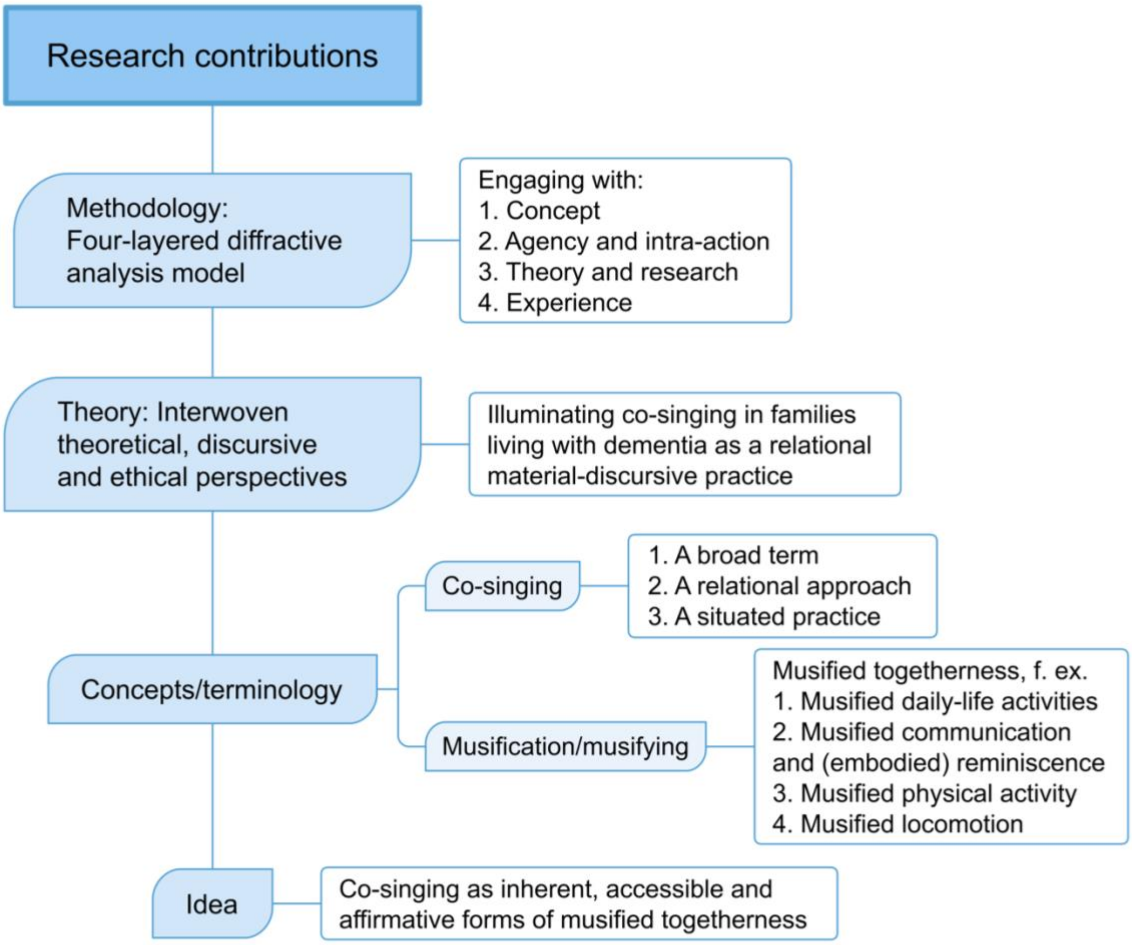

Figure 10. The main research contributions

8.9.1 Methodology: Multi-layered diffractive engagements

My exploration of singing as a resource in the daily lives of people living with dementia and their close ones developed into a web of attitudes, research, theories and strategies. The rhizomatic exploration of a wide range of intra-acting phenomena connected to dementia, relatives and singing ultimately followed the principles of intra-play – the intertwined cycles of co-attending, co-responding, co-forming and co-rendering. I have attempted to unpack an entangled and integrated "universe" of knowledge regarding singing in families living with dementia by transcending my academic preconceptions and venturing into new and unknown territory while still drawing on my hands-on experience with music and dementia. An essential part of this process was my engagement with Karen Barad and other posthuman thinkers' works and research strategies. During my research journey, this also manifested in new ways of approaching "case study analysis" and an awareness of how my research intra-action with the dyad was entangled with a multifaceted theoretical investigation.

In the research-intra-action with the dyad, I was inspired by the work of Jackson and Mazzei (2012) and Ellingson and Sotirin (2020b) as well as the diffractive readings in posthuman scholarship, especially Barad's. Nevertheless, my display of the layers of diffractive engagement with the research material, derived from the intra-actions of the empirical and theoretical material and my sensations, affects, thoughts and experiences. As I mentioned in Chapter 3.6.8, my analytical strategy and structure were not predetermined but instead a way to retrospectively recapture and reorganise my engagements and insights from the research process. In addition, the layers were intertwined, not separated, because each new layer drew on content or aspects of previous layers.

I consider the multifaceted diffractive engagement structure created in Chapter 7 to represent a contribution to the broader field of diffractive reading and analysis. Posthuman research strategies are still developing, and bringing in more layers is a way to deepen, extend and structure their diffractive multiplicity. I chose the diffractive modes or engagements of concept, agency, theory and experience for my project, but other layers might apply to other projects – and even to mine. I hope my methodological contribution will inspire others to explore different forms of diffractive engagements with their research material.

8.9.2 Theory: Entanglement of theories with implications for practice

When I started the project, I was primarily interested in the polyvagal theory (Porges, 2011) and its implications for singing and dementia, but other theoretical perspectives soon came to the fore, and I was struck by the subsequent entanglements. The connections between the therapeutic and empowering application of singing and music to (1) the communicative musicality model (Malloch & Trevarthen, 2009), or what Stige (2012) calls protomusicality, (2) Stern's (1985/2018, 2004) outline of affect attunement and meaningful moments, and (3) Dissanayake's (2017) artification hypothesis are well-known in music therapy theory and research. Likewise, the polyvagal theory has been utilised in music therapy and dementia research (Ridder, 2007, 2011). Ridder (2007) is also a proponent of integrative theoretical foundations and explanations regarding singing and dementia. Nevertheless, the broader field of music therapy and dementia research remains largely oriented toward biomedical approaches.

Scholars engaging with arts and dementia who incline towards the social sciences and posthumanism have begun to move beyond abiding notions of a “fragmenting” self and “challenging” behaviours and to propose alternatives to the instrumental attitudes associating music with issues of memory or behaviour. Moreover, posthuman thinkers have interrogated central aspects of what it means to be human altogether, as well as what it means to be a human being living with dementia and what new roles the arts might play in such a context.

I have merged such approaches and insights from neurophysiology, psychology, critical (embodiment) gerontology and posthuman theory to construct a broad and nuanced foundation for daily-life relational singing in families living with dementia. Hence, I have broadened the theoretical, discursive and ethical substrates of singing in the context of dementia and close relations and in the wider field of singing as part of daily life. These entangled theories inform my reworked notion of what singing might be and become in the context of dementia and relations, including its terminology and new conceptualisation of singing in daily life.

8.9.3 Concepts: Co-singing and musification

What I see as the main contribution of this dissertation is its groundwork for the concepts of co-singing and musification and the ways in which they might unfold as a daily practice in the lives of people with dementia and their close ones. Co-singing represents an alternative to the terms “caregiver singing” and “care-singing”, which are already associated with professional dementia care and, to some extent, describe a functional approach to singing as a “tool” for care. Co-singing signals a wider context for relational singing on more equal terms and specifically “in the moment” as a form of artification – or musification – to enhance or embellish daily-life activity. I presented examples of four forms of musified togetherness: musified daily life activity, musified communication and (post-verbal, embodied) reminiscence, musified physical activity and musified locomotion. They illustrate co-singing’s musifying potential in the contexts of activity, communication, movement and moment.

8.9.4 Idea: Co-singing as musified togetherness

The idea of co-singing as musified togetherness encompasses inherence, accessibility and affirmation. It is anchored in our neurophysiological substrates and inherent inclinations towards embodiment, co-regulation and social engagement. It is accessible in that it is independent of technology, tools and specialists, and it is an affirmative, resource-oriented alternative to more instrumental approaches to music in the context of dementia. In these ways, it is therefore a supplement to music provided or facilitated by professionals and care facilities, and to the functional (and sometimes even negatively biased) approaches to music found in professional dementia care and research. If we want to reclaim singing as a universal property and let the idea and potential of co-singing as togetherness spread and unfold, we must continue to reshape our approaches to singing in daily life and education. I hope my research can contribute intra-actively to such an endeavour as part of a wider material-discursive intra-play of singing and society.

8.10 Epilogue: *Stroll and troll and roll*

> *My three-year-old granddaughter is sitting in her trolley, belting out "Let it go" from the movie* Frozen. *We are walking home from the main library in Oslo and have reached the park near her home. Kids and parents are walking and playing at the nearby playground. Her overenthusiastic singing elicits some gentle smiles from passersby. She, however, is absorbed by the singing and not noticing other people at all.*
>
> *The next evening, my granddaughter, her mother (my daughter) and I are driving out of Oslo. They are moving to a new place, and she is saying goodbye to everything we pass, partly talking, partly singing spontaneous phrases to fit with her farewells. She goes on and on and on, her intensity escalating. After a while, her mother puts on some of her favourite music. Soon, she is singing at the top of her voice, and eventually her mother and I join in.*
>
> Let it go, let it go
> I am one with the wind and sky
> Let it go, let it go
> You'll never see me cry (Anderson-Lopez & Lopez, 2013)

Singing while walking or driving seems natural to children, and such situational singing adds to our singing experiences and memories. As we grow older, though, it tends to trail away. Still, I believe it is possible to reanimate informal, spontaneous singing to elaborate and energise trivial daily-life events. When the usual forms of togetherness and communication encounter limitations because of certain health issues, simple forms of musified togetherness might fill a gap, refresh implicit, dormant singing memories, and facilitate renewed ways of being together.

However, for this to happen, there need to be singing memories in the first place. I dream about a society which encourages and facilitates singing from the cradle to the grave – in kindergarten, school, higher education, and throughout adulthood. If we allow singing to entangle and musify our living and relations, we will be able to draw on it as a multifaceted, joyful resource in troubled times and as an enhancement – and enchantment – of the glimmering moments already present in our lives.

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Appendices

Appendix A. Approval from NSD

Meldeskjema for behandling av personopplysninger 03.06.2020, 11:05

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering

Prosjekttittel

Sang som samhandling - Pilot og case-studie med 4-6 personer med demens og deres pårørende

Referansenummer

744482

Registrert

14.03.2020 av Helene Waage - helene.waage@uia.no

Behandlingsansvarlig institusjon

Universitetet i Agder / Fakultet for kunstfag / Institutt for klassisk musikk og musikkpedagogikk

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Helene Waage, helene.waage@uia.no, tlf: 99022176

Type prosjekt

Forskerprosjekt

Prosjektperiode

01.04.2020 - 01.04.2023

Status

06.04.2020 - Vurdert

Vurdering (1)

06.04.2020 - Vurdert

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet den 06.04.2020 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD VESENTLIGE ENDRINGER
Dersom det skjer vesentlige endringer i behandlingen av personopplysninger, kan det være nødvendig å

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melde dette til NSD ved å oppdatere meldeskjemaet. Før du melder inn en endring, oppfordrer vi deg til å lese om hvilke type endringer det er nødvendig å melde:
https://nsd.no/personvernombud/meld_prosjekt/meld_endringer.html
Du må vente på svar fra NSD før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle særlige kategorier av personopplysninger om helse og alminnelige kategorier av personopplysninger frem til 01.04.2023. Data med personopplysninger vil dersom det innhentes samtykke for dette oppbevares til 01.04.2026 ved behandlingsansvarlig institusjon eller ved NSD Arkiv (avhengig av forskers tilhørighet på tidspunktet) for videre forskning.

LOVLIG GRUNNLAG UTVALG 1 OG 2
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake.

Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a, jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

LOVLIG GRUNNLAG TREDJEPERSONER
I forbindelse med intervjuer, lyd-logger og/eller video-observasjoner kan det framkomme opplysninger om andre familiemedlemmer eller nærstående personer. I den grad dette skjer vil de aktuelle personene bli orientert for å kunne gi sitt samtykke, eller de aktuelle opplysningene kan fjernes eller anonymiseres.

Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

PERSONVERNPRINSIPPER
NSD vurderer at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:

- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER UTVALG 1 OG 2
Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20).

NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

DE REGISTRERTES RETTIGHETER TREDJEPERSONER
Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), protest (art 21).

Det unntas fra informasjonsplikt etter art. 14 nr. 5 b), i tilfelle der personopplysninger ikke samles inn fra den registrerte, og det vil kreve en uforholdsmessig stor innsats å skulle informere, sett opp mot nytten de vil ha av dette.

Eventuelle opplysninger om tredjeperson vil i første rekke anonymiseres eller ev. slettes. Dersom ikke dette er mulig eler hensiktsmessig, vil det utarbeides individuell informasjon til aktuell tredjeperson basert på hva slags informasjon og sammenheng det gjelder.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

Office 365 – OneDrive, samt TSD er databehandler i prosjektet. NSD legger til grunn at behandlingen oppfyller kravene til bruk av databehandler, jf. art 28 og 29.

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og eventuelt rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

Kontaktperson hos NSD: Karin Lillevold
Tlf. Personverntjenester: 55 58 21 17 (tast 1)

Appendix B. Letter from REK

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord	Lill Martinsen		04.03.2020	60934
			Deres referanse:	

Tormod Wallem Anundsen

60934 Sang som samhandling: Sang i kommunikasjon og interaksjon mellom personer med demens og deres pårørende, sett i lys av polyvagal-teorien

Forskningsansvarlig: Universitetet i Agder

Søker: Tormod Wallem Anundsen

Søkers beskrivelse av formål:

Studien er del av ph.d.-prosjekt ved UiA og vil undersøke hvordan personer med demens og pårørende kan bruke tilpasset sang i kommunikasjon og samhandling. Det gjennomføres en pilot og fem øvrige case-studier med personer med demens (Alzheimers/vaskulær) og pårørende, i et deltakende aksjonsforsknings-design. I samråd med deltakerne utformes individualiserte sangtiltak som skal gjennomføres av deltakerne, støttet av prosjektleder, i 6-8 uker. Semi-strukturerte intervjuer, videoobservasjoner, pårørendes lydlogger og prosjektleders feltnotater inngår i datamaterialet som analyseres med kvalitative metoder. Deltakende aksjonsforskning gir deltakerne større mulighet for å påvirke prosessen, og åpner også for en nyanserikdom i innsamlet materiale. «Omsorgssang» i sykehjem har vist positiv effekt på kommunikasjon og samhandling mellom personer med demens og omsorgsgivere. Det er nærliggende å tro at tilpasset sang kan være en ressurs også for personer med demens og pårørende.

REKs vurdering

Vi viser til tilbakemelding mottatt 18.12.19. i forbindelse med ovennevnte forskningsprosjekt. Tilbakemeldingen ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk REK nord i møtet 13.02.20.

Formål
Det framgår av revidert protokoll: *«The purpose of the study is to explore how persons*

with dementia and their relatives in an easily accessible way, based on their natural "competence" and lifetime experiences, can apply singing as part of communication and interaction in their daily life, to offer supplemental strategies when the illness makes former strategies insufficient. At the end of the study, the researcher will outline some basic principles for possible ways of applying singing in the person with dementia–relative dyad.

The case studies will particularly contribute to answering the following of the Ph.D.`s research questions: «How do persons with dementia and their relatives experience singing as part of communication and interaction, and how can the concept of "care singing" be adapted and extended to fit their experiences and meet their needs?"

Second, the case studies can contribute to feeding new questions into the theoretical part of the Ph.D. project, and also, to some degree, to contribute to answering the other research questions:

"How can the polyvagal theory shed light on the mechanisms in play during care singing with persons with dementia?"

"How can the polyvagal perspective contribute to supporting the condition for singing as part of communication and interaction for persons with dementia and their relatives?"

Om prosjektet
Søknaden ble første gang behandlet i komitemøte 28.11.2019. Ut fra de opplysningene som forelå, var REK i tvil om prosjektet falt innenfor helseforskningsloven virkeområde. Det ble fattet et utsettelsesvedtak, hvor REK ba om ytterligere informasjon i form av utfyllende protokoll for prosjektet.

Revidert protokoll er innsendt og vurdert av komiteen.

De prosjektene som skal framlegges for REK er prosjekt som dreier seg om *«medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger»* , jf. helseforskningsloven § 2. *«Medisinsk og helsefaglig forskning»* er i § 4 a), definert som *«virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom»*. Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet er formålet å få svar på hvordan personer med demens og pårørende erfarer sang som en del av kommunikasjon og interaksjon.

Selv om dette er en helsefaglig studie og funnene i studien indirekte vil kunne gi en helsemessig gevinst faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Vedtak

Avvist (utenfor mandat)

Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke framleggingspliktig, jf. helseforskningsloven § 2.

Vi gjør oppmerksom på at etter personopplysningsloven må det foreligge et behandlingsgrunnlag etter personvernforordningen. Dette må forankres i egen institusjon.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

Appendix C. Information and consent form

VIL DU DELTA I FORSKNINGSPROSJEKTET

«SANG SOM SAMHANDLING»?

Om personer med demens og pårørendes erfaringer med sang i dagliglivet

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å undersøke hvordan personer med demens og deres pårørende opplever å bruke sang som en del av samværet i dagliglivet. I dette skrivet gir vi deg informasjon om målene for prosjektet og hva deltakelsen vil innebære for deg.

FORMÅL

Denne studien er del av Helene Waages doktorgradsprosjekt ved Universitetet i Agder, og vil kunne bidra til mer kunnskap om hvordan sangtiltak kan tilpasses personer med demens og deres pårørende, for å kunne være en ressurs i hverdagen.

Ansvarlig for prosjektet

Universitetet i Agder er ansvarlig for prosjektet.

HVORFOR FÅR DU SPØRSMÅL OM Å DELTA?

Jeg (Helene) har fått tips om at det kan være aktuelt for deg/dere å være med i undersøkelsen. Slike tips har jeg fått enten fra private kontakter, eller fra personer som er knyttet til helse og omsorgstjenesten, særlig dagtilbud, i kommunen.

Undersøkelsen retter seg mot personer med vaskulær demens og/eller Alzheimers sykdom og deres pårørende, enten samboer/ektefelle eller voksne barn. Dette er en liten, kvalitativ studie med bare 4-6 deltakende par.

HVA INNEBÆRER DET FOR DEG Å DELTA?

Prøve ut sang-aktivitet

Prosjektet innebærer at du, din pårørende og jeg (forskeren) møtes til noen samtaler og uformelle intervjuer. Der vil jeg først undersøke hva slags erfaringer dere har med sang. Dette blir både en del av forskningen, men også for å finne ut hvordan vi sammen kan legge opp til sang-aktivitet som dere kan være sammen om i dagliglivet. Sang-aktiviteten skal være enkel, og vi skal tilpasse den deres erfaringer og ønsker.

Når dere og jeg i fellesskap har laget en plan for hvordan dere kan bruke sang i dagliglivet, vil dere få litt instruksjon og informasjon av meg slik at dere blir trygge på hvordan dere kan bruke sang-aktiviteten. Siden møtes vi ca. 40 minutter en gang i uka i 6 uker til samtale med sang og kanskje litt mer instruksjon. Da går det også an å gjøre endringer i sang-aktiviteten underveis, dersom dere ønsker det.

Deltakere som «med-forskere»

Dersom du/dere har lyst, inviteres dere også til å delta mer aktivt i selve forskningen ved å lage korte «lyd-logger» hvor dere forteller litt om opplevelsene deres med syngingen, eller kanskje bare synger og prater litt. (Dersom dere foretrekker å skrive korte notater kan dere godt det.)

Intervjuer

Underveis i prosessen kommer jeg til å ha to uformelle intervjuer med dere av omtrent en times varighet. De ligner på vanlige samtaler, men jeg har noen temaer jeg vil komme innom. Omtrent 2-3 måneder etter perioden med sangmøtene våre ønsker jeg dessuten en avsluttende samtale.

Lydopptak

Jeg ønsker å gjøre lydopptak både av intervjuer/samtaler og sang-møtene våre.

Eventuelt video-opptak

For noen av deltakerne kan det være aktuelt at vi gjør noen få video-opptak underveis, men dette er ikke noe krav for å være med.

Frivillig MMS-test

Det kan være aktuelt å gjøre en enkel kognitiv test, kalt Mini-mental state (MMS) av deg i forkant av studien. En helsearbeider som kjenner deg vil i så fall utføre denne testen som tar omtrent 15 minutter. Dette kan være nyttig for forskeren for å vite noe om hvor langt demenssykdommen har kommet, men det er ikke avgjørende for å kunne være med i studien.

Helseopplysninger

Personer med Alzheimers demens og/eller vaskulær demens og deres pårørende er deltakere i dette forskningsprosjektet. Det vil ikke bli innhentet andre helseopplysninger enn bekreftelse på en av disse diagnosene og eventuelt MMS-status (ikke hele skjemaet, bare samlet poengsum).

DET ER FRIVILLIG Å DELTA

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Hvis du velger å delta, kan du når som helst trekke samtykket tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Selv om du underveis skulle ønske å trekke deg fra selve forskningsprosjektet, kan dere fullføre sang-møtene med meg i de 6 ukene de pågår, dersom dere ønsker det.

Dersom du senere ønsker å trekke deg eller har spørsmål om prosjektet, kan du kontakte Helene Waage, tlf 99 02 21 76, e-post: helene.waage@uia.no

DITT PERSONVERN – HVORDAN VI OPPBEVARER OG BRUKER DINE OPPLYSNINGER

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrivet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket.

Lyd- og ev. videoopptakene oppbevares trygt, enten innelåst eller på forskningsserver, og er til intern bruk i forskningen. De skal altså ikke publiseres eller presenteres for andre.

Alle opptakene og opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opptak og opplysninger gjennom en navneliste. Det er kun Helene Waage og hennes to veiledere ved Universitetet i Agder som har tilgang til denne listen.

Når forskningen presenteres skal du som hovedregel ikke kunne gjenkjennes. Dersom en del av presentasjonen kan føre til gjenkjennelse, vil jeg kontakte deg, slik at du enten kan godkjenne dette på forhånd, eller kreve at det utelates eller anonymiseres.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Opptakene og opplysningene om deg vil bli anonymisert eller slettet tre år etter at prosjektet er avsluttet. Prosjektet forventes avsluttet 01.04.2023. Materialet vil være lagret trygt, på forskningsserver.

Dersom det skulle bli aktuelt å bruke materialet utover det som er beskrevet her, for eksempel i videre forskning, vil du bli bedt om nytt samtykke.

DINE RETTIGHETER

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- få slettet personopplysninger om deg,
- få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

HVA GIR OSS RETT TIL Å BEHANDLE PERSONOPPLYSNINGER OM DEG?

Vi behandler opplysninger om deg basert på ditt samtykke.

På oppdrag fra Universitetet i Agder har *NSD – Norsk senter for forskningsdata AS* vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

HVOR KAN JEG FINNE UT MER

Hvis du har spørsmål til prosjektet, eller ønsker å benytte deg av dine rettigheter, kan du ta kontakt med Universitetet i Agder ved Helene Waage, tlf 99 02 21 76, e-post: helene.waage@uia.no

Personvernombud ved Universitetet i Agder er Ina Danielsen, e-post: ina.danielsen@uia.no

Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med: *NSD – Norsk senter for forskningsdata AS* på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

Med vennlig hilsen

Helene Waage, forsker

JEG HAR MOTTATT OG FORSTÅTT INFORMASJON OM PROSJEKTET *«SANG SOM SAMHANDLING»*, OG HAR FÅTT ANLEDNING TIL Å STILLE SPØRSMÅL. JEG SAMTYKKER TIL:

- ☐ å delta i prosjektet som beskrevet i informasjonen, med sangmøter og samtaler/intervju
- ☐ at det kan gjøres lydopptak av meg som beskrevet i informasjonen
- ☐ at mine personopplysninger og opptakene av meg kan lagres tre år etter prosjektslutt. (Eventuell videre bruk, for eksempel til ny forskning, skal i så fall godkjennes av meg).

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Eventuelt, i tillegg:

- ☐ at det kan gjøres video-opptak av meg som beskrevet i informasjonen
- ☐ at helsearbeider som kjenner meg kan utføre MMS-test og oppgi poengsummen til forskeren
- ☐ at opplysninger om meg publiseres slik at jeg kan gjenkjennes, men på de vilkår som er beskrevet i informasjonen, slik at opplysningene kan godkjennes av meg.

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Appendix D. Simplified information (for people with dementia)

VIL DU DELTA I FORSKNINGSPROSJEKTET

«SANG SOM SAMHANDLING»?

Dette er et spørsmål til deg om å være med i en undersøkelse av hvordan personer med demens-sykdom og deres nærmeste familie opplever å bruke sang i dagliglivet. Dette er del av Helene Waages doktorgradsprosjekt ved Universitetet i Agder.

HVA INNEBÆRER DET FOR DEG Å DELTA?

Prøve ut sang-aktivitet

Prosjektet innebærer at du og en av dine nærmeste møter meg (Helene) til noen samtaler. Der lager vi i fellesskap et enkelt, lite sangprogram, etter deres ønske. Så synger vi litt sammen så dere blir trygge på hvordan dere kan bruke sangene selv i hverdagen. Siden møtes vi ca. 40 minutter en gang i uka i 6 uker til samtale med sang. Hvis dere ønsker det kan vi endre litt på sang-programmet etter hvert.

Intervjuer

Jeg ønsker også å ha to uformelle intervjuer med dere av omtrent en times varighet. De ligner på vanlige samtaler og jeg vil høre litt om deres erfaring med sang. Omtrent 2-3 måneder etter perioden med sangmøtene våre ønsker jeg dessuten en avsluttende samtale.

Opptak

Jeg ønsker å gjøre lydopptak både av intervjuer/samtaler og sang-møtene våre.

Noen deltakere kan også være med i video-opptak, hvis de vil, men det er ikke nødvendig for å være med i undersøkelsen.

Opptakene oppbevares trygt og skal bare brukes i undersøkelsen. De skal ikke vises for andre.

Helseopplysninger

Personer med Alzheimer og vaskulær demens og deres nære familie er deltakere i denne undersøkelsen. Jeg ønsker derfor å vite om du har en av disse sykdommene. Utenom dette trenger jeg ikke å vite noe spesielt om deg eller helsen din.

Frivillig MMS-test

Det kan være nyttig for meg som forsker at en helsearbeider som kjenner deg gjør en enkel og veldig vanlig test før møtene våre starter. Det er en såkalt MMS-test med noen oppgaver som det tar omtrent et kvarter å gjøre. Dette er frivillig, og ikke avgjørende for å kunne være med i prosjektet.

DET ER FRIVILLIG Å DELTA

Det er helt frivillig å være med i undersøkelsen. Dersom du ønsker å være med, skriver du og/eller din nærmeste pårørende under på samtykke-skjemaet på siste side. Du kan når som helst og uten å oppgi noen grunn trekke deg igjen. Det vil ikke føre til noen ulemper for deg. Du kan også be om at opptakene og opplysningene om deg blir slettet.

Dersom du senere ønsker å trekke deg eller har spørsmål om undersøkelsen, kan du eller din pårørende kontakte Helene Waage, tlf 99 02 21 76, e-post: helene.waage@uia.no

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene om deg skal bare brukes slik det er forklart, altså bare for denne undersøkelsen som er del av Helene Waages doktorgradsprosjekt.

Når forskningen presenteres skal du som hovedregel ikke kunne kjennes igjen. Dersom det er tvil om dette, kontakter jeg deg eller din nærmeste og spør om spesiell tillatelse fra dere.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Opptakene og opplysningene om deg vil bli anonymisert eller slettet tre år etter at prosjektet er avsluttet.

RETTIGHETER

Du har rett til å få vite hvilke opplysninger som står om deg og at de skal rettes hvis noe er feil. Du har også rett til å få slettet opplysninger og å få vite hvordan opplysningene blir brukt og oppbevart på en trygg måte. Du har dessuten rett til å klage til Datatilsynet hvis noe virker ugreit.

Vi behandler opplysninger om deg basert på ditt samtykke.

NSD – Norsk senter for forskningsdata AS har vurdert at behandlingen av opplysninger i dette prosjektet følger reglene for personvern. NSD kan nås på epost (personverntjenester@nsd.no) eller på telefon: 55 58 21 17.

HVOR KAN JEG FINNE UT MER

Hvis du har spørsmål kan du ta kontakt med Helene Waage, tlf 99 02 21 76, e-post: helene.waage@uia.no

Personvernombud ved Universitetet i Agder er Ina Danielsen, e-post: ina.danielsen@uia.no

Med vennlig hilsen

Helene Waage, forsker

JEG HAR MOTTATT OG FORSTÅTT INFORMASJON OM PROSJEKTET *«SANG SOM SAMHANDLING»*, OG HAR FÅTT ANLEDNING TIL Å STILLE SPØRSMÅL. JEG SAMTYKKER TIL:

☐ å delta i prosjektet som beskrevet i informasjonen, med sangmøter og samtaler/intervju

☐ at det kan gjøres lydopptak av meg som beskrevet i informasjonen

☐ at mine personopplysninger og opptakene av meg kan lagres tre år etter prosjektslutt. (Eventuell videre bruk, for eksempel til ny forskning, skal i så fall godkjennes av meg, eller min pårørende).

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Eventuelt, i tillegg:

☐ at det kan gjøres video-opptak av meg som beskrevet i informasjonen

☐ at helsearbeider som kjenner meg kan utføre MMS-test og oppgi poengsummen til forskeren

☐ at opplysninger om meg publiseres slik at jeg kan gjenkjennes, men på de vilkår som er beskrevet i informasjonen, slik at opplysningene kan godkjennes av meg eller min pårørende.

Sted og dato		Deltakers signatur

Deltakers navn med trykte bokstaver

Stedfortredende samtykke:

Som nærmeste pårørende til _ (Fullt navn)
samtykker jeg til at hun/han kan delta i prosjektet.

Sted og dato		Pårørendes signatur

Pårørendes navn med trykte bokstaver

Appendix E. Interview guide

INTERVJUGUIDE – SEMISTRUKTURERT INTERVJU

Versjon 1: 05.11.2019, Helene Waage

Generelt

Det gjennomføres tre semistrukturerte intervjuer for hver deltaker-dyade: Før sangtiltakene implementeres, etter perioden med ukentlige oppfølgings-møter med sang, og 2-3 måneder etter at sang-oppfølgingen er avsluttet.

Hvis det er mulig, ut fra personen med demens sin tilstand, gjennomføres intervjuene med både personen og pårørende sammen. Pårørende får noen tilleggsspørsmål alene.

Spørsmålene er veiledende og må tilpasses deltakernes forutsetninger. Personer med demens vil ofte ha problemer med gjenkallingshukommelse, men lettere tilgang til gjenkjenningshukommelse. Noen ja/nei spørsmål til å begynne med kan kanskje være nødvendig for å komme i gang, og unngå følelsen av manglende mestring, selv om de kan virke ledende. Personen med demens kan også oppmuntres til å kommentere pårørendes fortelling, dersom de ikke gjør det spontant. F.eks. «Får du noen tanker eller minner når du hører nn fortelle dette? Fortell gjerne!»

I tillegg til de foreslåtte utgangsspørsmålene skal det også stilles oppfølgingsspørsmål knyttet til deltakernes fortelling.

FØR SANG-TILTAK

<u>Til pårørende (og personen sammen) før intervensjon</u>

Tema 1: Deltakernes opplevelser med sang gjennom livet

Fortell litt om hvordan dere har opplevd sang i livet.
(Har dere blitt sunget for? Sunget selv?)

Si gjerne noe om i hva slags situasjoner eller sammenhenger dere har hørt sang eller sunget selv. (F.eks. Godnattsang? Annen sang i hjemmet? Foreningsliv? Sosiale sammenkomster? Kor?)

Ev. Kan dere fortelle om en (eller flere) gang(er) dere har sunget sammen med hverandre? Eller med noen andre (i familien)?
Ev. Hvordan var denne/disse opplevelsen(e)?

Tema 2: Deltakernes tanker om bruk av sang nå og framover

Hvordan bruker dere sang nå for tiden? I hva slags situasjoner? Fortell.

Har måten dere opplever eller bruker sang på endret seg i den senere tid?
(Ev. hvis pårørende er alene eller personen med demens har et åpent og avklart forhold til demenssykdommen: Har måten dere opplever eller bruker sang på endret seg etter at du/NN fikk (demens)sykdommen din/sin?)
I så fall: Hvordan?

På hvilke måter kunne dere tenke dere å bruke sang framover?

Ev. Forklar også gjerne hvorfor.

Tema 3: Utfyllende fortelling

Har dere noe mer dere har lyst til å fortelle om opplevelser med synging? Og/eller tanker om sang?

Tilleggsspørsmål til pårørende alene, før intervensjon:

Fortell litt om noen av utfordringene, men også gjerne om gode øyeblikk, knyttet til demenssykdommen i familien.

Har du noe mer du har lyst til å fortelle om dine opplevelser med sang, eller situasjonen som pårørende?

ETTER PERIODEN MED DE UKENTLIGE SANG-MØTENE

Til pårørende (og personen sammen) etter intervensjon

Hvordan har dere brukt sang i den perioden vi har hatt møtene våre?

Fortell om noen av situasjonene hvor dere har sunget.

Fortell om noen av opplevelsene dere har hatt når dere har sunget (sammen).

Hvordan ser dere for dere at sangens plass i hverdagen kan bli framover?

(Ev. Hvis dere vil fortsette å bruke sang framover, på hvilke måter vil dere gjøre det? I hvilke situasjoner?

Ev. Hva slags opplevelser ser dere for dere at sang kan gi i hverdagen deres framover?)

Tilleggsspørsmål til pårørende alene, etter intervensjon:

Fortell litt om noen av utfordringene, men også gjerne om gode øyeblikk, knyttet til demenssykdommen i perioden siden forrige intervju (før vi begynte sangmøtene våre)

Har du/dere brukt sang i forbindelse med slike hendelser? I så fall: Fortell om det.

Ev. Hvordan opplevde du/dere det?

Har du noe mer du har lyst til å fortelle om opplevelser med sang, eller situasjonen som pårørende, i denne perioden?

OPPFØLGING I ETTERTID

Oppfølgingssamtale 2-3 måneder etter intervensjon, med pårørende (og ev. personen sammen):
Har dere fortsatt å bruke sang i dagliglivet etter at vi var ferdige med sang-møtene våre? Uansett svar: Fortell om det.

Hvis fortsatt med sang: Fortell om noen konkrete situasjoner som dere har brukt sang i denne perioden (nå i det siste).
Hvordan opplevde dere å bruke sang i disse situasjonene?

Ut fra deres erfaringer: Har dere noen tanker om hvordan sang eventuelt kan gjøre en forskjell i hverdagen?

Tilleggsspørsmål til pårørende alene:
Fortell (igjen) litt om noen av utfordringene, men også gjerne om gode øyeblikk, knyttet til demenssykdommen, i perioden siden forrige intervju.

Har du/dere brukt sang i forbindelse med slike hendelser i det siste? I så fall: Fortell om det.
Ev. Hvordan opplevde du/dere det?

Har du noen flere tanker om bruk av sang i hverdagen sett i forhold til de opplevelsene og erfaringene du forteller om?

Har du noe mer du har lyst til å fortelle om opplevelser med sang, eller situasjonen som pårørende, i denne perioden? Eller mer generelt?

Kommentar til intervju-guiden:
Det vil først gjennomføres en pilot. Det kan være aktuelt å endre intervju-guiden etter piloten.

Det legges vekt på å stille åpne spørsmål og ta utgangspunkt i deltakernes fortelling og beskrivelse. Mot slutten er det likevel aktuelt å åpne for noe meta-refleksjon, særlig fra pårørende.

Appendix F. Research intra-action sessions overview

Date	Place	Participants	Activity	Documentation
2020.06.22	"Lilly's" home	"Lilly", "Emma" and H. W.	Getting to know each other, talking about the project and starting to sing together	Notes right after the encounter
2020.06.23	Lilly's home	Lilly, Emma and H. W.	Singing together, (informal) semi-structured interview and song preference mapping	Sound recording and written and spoken notes just after the session
2020.07.01	Lilly's home	Lilly, Emma and H. W.	Singing session: singing, moving and talking together and adjusting songs and activities	Sound recording and notes
2020.07.7	Lilly's home	Lilly, Emma and H. W.	Singing session: singing, moving and talking together and adjusting songs and activities	Sound recording and notes
2020.10.01	HW's place (Emma's wish)	Emma (daughter) and H. W.	Semi-structured interview	Sound recording
2020.10.01	Lilly's home	Lilly, Emma and H. W.	Singing session: singing, moving and talking together and adjusting songs and activities	Sound recording
2020.10.15	Lilly's home	Lilly, Emma and H. W.	Outdoor singing session: singing, moving and talking together	Written and spoken notes just after the session
2020.10.15	Lilly's home	Lilly, Emma and H. W.	Semi-structured interview	Sound recording and written and spoken notes just after the session
2021.02.25	Telephone	Emma and H. W.	Semi-structured interview	Sound recording
2021.10.25	Outside Lilly's home	Emma and H. W.	Conversation	Notes
2021.10.25	Lilly's home		Cancelled session – Lilly was ill when we arrived	
2022.06.27	Lilly's home	Lilly, Emma and H. W.	Singing and conversation	Sound recording and notes

University of Agder

Faculty of Fine Arts
Department of Classical Music and Music Education

With reference to Regulations for the degree of Philosophiae Doctor (PhD) at the University of Agder, dated 20 June 2012 *Section 15.4 Correction of formal errors in the thesis*, I apply for permission to correct the following formal errors listed below.

Date 2024-01-21 Signature Helene Waage

Errata list for formal errors in the thesis by Helene Waage, 2023

Page	**Line**	**Current text**	**New text**
xi	5		Figures…………………xviii
45	6	Särkämö et al. (2014, 2016)	Särkämö et al. (2015; 2014)
52	4–5	(Østern et al. 2022)	(Østern et al., 2023)
52	10	(Kontos & Martin, 2013)	(Kontos & Grigorovich, 2018b)
52	16	Artification (Dissinayake)	Artification (Dissanayake)
111	4	Kontos et al., 2017, p. 84	Kontos et al., 2017, p. 184
111	21	(Kontos & Grigorovich, 2018b, p. 44)	(Kontos & Grigorovich, 2018b, p. 45)
111	30 (last)	(Kontos & Grigorovich, 2018b, p. 44)	(Kontos & Grigorovich, 2018b, p. 45)
161	5	Kontos and Martin (2013)	Kontos and Grigorovich (2018b)
161	19–20	(Kontos & Martin, 2013, p. 46)	(Kontos & Grigorovich, 2018b, p. 46)
162	19	Kontos and Martin's (2013)	Kontos and Grigorovich's (2018b)
163	22–23	Kontos and Martin (2013)	Kontos and Grigorovich (2018b)
175	7	(Østern et al. 2021, p. 15)	(Østern et al. 2023, p. 286)