

Still Here: An Exhibition on Identity and Relational Mutuality Through Music for People Living with Dementia

Kristine Gustavsen Madsø and Inger Hilde Nordhus

Following the completion of a clinical research project assessing music therapy for home-dwelling people with dementia and their significant other, we developed an interactive photo exhibition, "Still here," that was launched on World Alzheimer's Day, September 21st, 2021, in the city center of Bergen. We aimed to communicate to the local citizens how music may facilitate experiences of positive identity and relational mutuality for people with dementia and their significant others. Stereotypes about loss and decline still characterize the mainstream discourse of dementia. Myths, misconceptions, and stigma are associated with dementia and have a significant impact on the people who live with the condition. We aimed to portray a different narrative of dementia to the public, a narrative of resilience and creative capacity—and, in so doing, to knowingly recuperate and communicate the idea of psychological resilience in contradistinction to the neoliberal constructions of this concept. We intended to reflect a perspective closer to how individuals describe or experience living with dementia. This paper tells the story of how the exhibition was developed to disseminate the findings of our research project, elaborating on the challenges current narratives on dementia present in our field and how the photographs became narrators of another story of dementia.



Figure 1: Front photo of the exhibition "Still Here: Music Therapy for People Living with Dementia" which asked: How can we support and portray a narrative of dementia from the perspective of the individual? Is there still a narrative to tell? Photo: Ingvild Festervoll Melien©

INTRODUCTION

After a clinical research project assessing music therapy (Madsø et al., Madsø, Pachana, et al.), we developed the "Still Here" photo exhibition launched on World Alzheimer's Day, September 21st, 2021. This exhibition aimed to communicate via photographs and interactive elements our main research findings in the research project, namely how music provides well-being, agency, and relational mutuality for people with dementia. Through the exhibition, we also wanted to challenge the stereotypes commonly associated with dementia. This paper provides selected photos from the exhibition, vignettes with qualitative descriptions of music therapy from the research project (Madsø, Pachana, et al.), and recent research findings of music therapy in our field. Through this material, and our reflections, we illustrate how music may facilitate such relational and interpersonal experiences.

Our intention with this text is twofold. First, we encourage the reader to approach this text as a report of how an open, outdoor exhibition may challenge stereotypes in the public. Second, we attempt to support and elaborate on the

more recent initiatives in our discipline (psychology), where the voices of people with dementia are increasingly given more attention. The article offers information on the original research and the subsequent exhibition, which can be navigated in several ways. The vignettes and the photos are – in the same way as the exhibition – meant to familiarize the reader with the power of music in dementia. The reader is further invited to 'visit' textboxes one to four to better understand the exhibition and how it was developed. Finally, this article as a whole provides empirical support for and reflections on how music may sustain a narrative of dementia that includes agency, resilience, identity, reciprocity, and connectedness.

Our contribution to this interdisciplinary issue of *ACH* is written from the position of clinical psychology. Our terminology is, by consequence, sometimes more therapeutic than humanistic. We acknowledge that from a critical humanistic perspective, the use of terms such as *diagnosis*, *symptoms*, and *interventions* may be read as alienating and medicalized. The term 'resilience' is also, we are aware, a contested one in critical dementia studies (Katz), but it has a clinical meaning and value within our psychological field. We use it in this constrained and precise sense and reflect on it in our work and this paper (see the section below on this topic). These terms, therefore, represent the clinical context and conditions in which this research is carried out. The terms are relatively neutral compared to stigmatizing terms like "demented" or "impaired," which we strongly advocate avoiding. In a psychological discourse and clinical practice, we maintain that terms such as symptoms and interventions are useful and necessary. Even so, we do share with critical dementia studies the conviction that persistent negative stereotypes about dementia are still present in our society (i.e. Katz; Patterson et al.). The way we talk about dementia, commonly in terms of loss and decline, may enforce negative attitudes and detachment (i.e., Patterson et al.). Thus, a tragic effect of the diagnosis may be that, when most needed, there is an absence of closeness, endangering well-being and increasing social exclusion of those living with dementia.

Conceptualizing dementia as a brain disease and investigating it through biomedical research have both led to a better understanding of the aging brain and neuropathology. However, there is an urge among health professionals to apply a more comprehensive model of dementia in care and society in general, encompassing the relationship and interaction between biological, psychological, and social factors in dementia as it unfolds for people living with such a challenging condition (2019 INTERDEM manifesto; Vernooij-Dassen et al.). Thus, the leading narrative of dementia, both in our field and in society at large, should not only include a biomedical framework but also psychological, cultural, and social aspects of living with dementia.

In this paper and in the exhibition, we have attempted to present direct observations of the experiences of those living with dementia and to base our arguments on qualitative research representing the voices of people living with this condition (i.e., Harding et al.; Reilly et al.; Bjørkløf et al.). The research literature demonstrates that people with dementia are attentive toward the affective, intersubjective, and relational dimensions of their experience. As Patterson et al. assessed, when we have dementia, we may perceive and be affected by attitudes and reactions from other people towards us. We may experience being treated as "different" instead of "one of us" and not being perceived as a full member of society, and thus, less valued. Various types of losses and challenges will affect us when living with dementia, but our interpersonal environment will nevertheless continue to influence the way we see ourselves.

In short, the basic human needs for attachment and belonging do not cease throughout the development of dementia. We still need to feel engaged and included in meaningful interactions. We still have the capacity to enjoy pleasant experiences and to engage in creative expressions alone or together with significant others. The assumption that an absence of such basic human needs is a symptom of dementia poses a major threat to the well-being of people with dementia. Therefore, the environments people with dementia take part in must provide and adapt their interactions to meet these needs.

Research increasingly supports that music can facilitate experiences of interpersonal relationality; through personalized musical interactions, spaces of mutuality and connection with oneself and others can be developed and strengthened (i.e., Brancatisano et al.). This finding was replicated in our study, where people with dementia and their close caregivers were invited to participate in such interactions together with a music therapist (Madsø et al.). Conducting our intervention study, we experienced that by observing the response to the musical interactions, we gained insight into the shared human needs of the person, as well as how these needs were met through music. Additionally, as we studied videotapes of music therapy, we were touched by how powerfully these videos demonstrated the facilitation of meaningful relational experiences. As neurologist Oliver Sacks expressed: "Once one has seen such responses, one knows that there is still a self to be called upon, even if music, and only music, can do the calling" (Musicophilia 346). The intent of recording videos in the research project were to gather observational research data and sharing them were naturally restricted due to ethical obligations and confidentiality. Nevertheless, we asked ourselves, is there an alternative way we can effectively communicate this observable effect of music to the public and challenge the stereotypical attitude of being "lost" or "gone" when living with dementia? Could we ask people with dementia and a significant other to participate in the same intervention as in our study, but this time with the intent of capturing and communicating the effect in an exhibition?

"STILL HERE" – AN EXHIBITION

With the idea of creating a communication project regarding dementia and music, we invited a music therapist, a photographer, and the head of the clinic at NKS Olaviken Gerontopsychiatric hospital to join our discussion on how an exhibition could take issue with stereotypical presentations of dementia. Could participating in such a project be too risky for this group? Or could participation also lead to empowerment? Our experience with recruiting people with dementia to participate in qualitative interviews regarding their situation or the health care they were offered supported both arguments. As long as

participation was under informed consent, and the people were given the opportunity to influence the content of the exhibition and withdraw at any time—we found that this could be an empowering experience. Thus, we decided to replicate our intervention, asking new participants to be portrayed in an exhibition, and visualize the effect of music through photographs. The participants were invited to take part in five music therapy sessions with a professional music therapist. As in the research project (Madsø et al.), the music therapist visited the participants in their homes, and the interaction included both the person with dementia and a significant other. The music therapy was resource-oriented (see textbox 2) and based on the protocol developed and tested by Madsø et al.

The findings we wanted to replicate in the exhibition were connected to positive experiences during music therapy. When dementia is diagnosed through medical and cognitive assessment, the focus is to detect areas of impairment and functional disabilities. Thus, the dialogue and communication around dementia from health care are often describing the loss of functions. However, it is our clinical experience that the person with dementia and their carers benefit from information about which capacities dementia does *not* change. It seems that emphasizing psychological symptoms such as anxiety, depression, and delusions is less fruitful when we search for the meaningful effect of psychosocial interventions such as music therapy. In our study, these domains did not change significantly. However, the prominent gain was associated with positive emotions and the facilitation of meaningful interactions. We found that during musical interventions, people living with dementia expressed more well-being and sociable interaction compared to participation in regular conversations (Madsø et al.). Specifically, we saw that those living with dementia expressed aspects of their identity, positive affect such as happiness and enjoyment, became calmer and more relaxed, interacted in the relation, and gave more positive feedback and responded more to questions from the carer or music therapist during the sessions.

As the communication project began to take form, a transdisciplinary expert panel was invited to contribute to developing the textual content. Textbox 1 provides further information about the exhibition.



Figure 2: An illustration of the outdoor exhibition. Photo: Ingvild Festervoll Melien©

Textbox 1

Still here – music therapy for people living with dementia

This exhibition was first presented in the public place *Torgallmenningen* in the city center of Bergen on September 21, 2021. This date is the International Alzheimer Global Awareness Day. September is World Alzheimer’s Month, and the topic of the month in 2021 was “We need to talk about dementia.” The specific topic for 2021 was to make people more aware of the stigma people living with dementia often experience. We wanted to describe well-preserved capacities in people living with dementia and support a narrative of still “being here” as opposed to the common everyday language of gradually becoming “lost” or “gone” (see, e.g., Barry in this issue). Through photos (1m x 1.5 m), text, and sound clips, we aimed to tell an alternative narrative

of dementia compared to the prevailing discourse mentioned above using non-stigmatizing language (Alzheimer's Society UK).

The project group of “Still Here” included Professor in Clinical Psychology Inger Hilde Nordhus (project leader), clinical psychologist Kristine Gustavsen Madsø (project coordinator), Ingvild Festervoll Melien (photographer), Stine Andrea Sognnes (music therapist), and clinic head Minna Hynninen (project partner).

The researchers used updated literature reviews from clinical psychology on the effect of music on people living with dementia to decide which aspects we needed to communicate in the exhibition (van der Steen et al.; Särkämö et al., Baird and Thompson, Brancatisano et al.). Based on our literature review, we focused on the benefits of music therapy for people living with dementia in four domains: cognition, emotions, connectedness, and identity. The photographer, Ingvild Festervoll Melien, was instructed about which aspects we wanted to communicate before visiting the participants. She chose the best photographs from her appraisal and presented them to the team. The team (IH, KGM, IFM, the graphic designer Siv Mannsåker, and the music therapist Stine Andrea Sognnes) assessed the photographs in terms of which best communicated the different aspects from the research literature descriptions. Based on the four aspects we wanted to illustrate, we wrote short sentences describing the effect of music, such as “music supports attention” or “music brings contemplation.” We chose the photos that best illustrated the texts and edited and adjusted them according to the contents of the photos as well. The music therapist knew the participants best, having visited them several times. She was attentive to their reactions toward the photographer. She was alert to any signs of discomfort or uncertainty from both the carer and the person with dementia during the photographed sessions. When the photos and accompanying text were selected, KGM and the music therapist visited all participants to present them with their respective photos for comments and approval. Participants were given the opportunity to discuss the photos and the descriptions under the photos, reject any photos, and withdraw from the project at any time.

Further, we developed the exhibition's interactive elements by using sound clips from music therapy sessions permitted to be used by a person with dementia and their family and a music therapist from the original research project. Interviews with people with dementia, caregivers, and professionals were also recorded and presented in the exhibition.

Some recordings were anonymized and originated from a parallel study (Madsø, Pachana, et al.) developing an observational instrument to assess well-being during music therapy for people with dementia. Graphical elements communicated research results and knowledge about music therapy and dementia. These elements were presented to an extended team of experts including the expert on living with dementia and participant in music therapy Målfrid Litlere, professor in music therapy Brynjulf Stige, psychologist and head of clinic Minna Hynninen, professor in French literature Margery Vibe Skagen, communication advisor Margareth Barndon, music therapist Solgunn Knardal, music therapist Johan Klætte and music therapist Guri Dypvik.

The exhibition also presented an overview of music therapy services in western Norway and ongoing music therapy research, including people with dementia all over Norway. QR codes connected the exhibition to a website containing the interactive elements. This was to make sure people living with dementia, including family members, in our region were made aware of where music therapy services or relevant research projects could be available for them to participate.

NARRATIVES OF DEMENTIA

Narratives of dementia in our field have for many decades been predominantly constructed from the perspectives of biomedicine and public health, as well as from the caregiver perspective. These perspectives often focus on the negative consequences of dementia in terms of pathology and burden. Biomedical narratives of dementia place decline at the very core of the condition. This implies associating dementia with progressive cognitive impairment, an incapacity for self-care, and loss of autonomy in the advanced

stages of the disease. The narratives of the public health perspective also emphasize the social, health, and economic burden of dementia. Biomedicine and public health research narratives describe scientific attempts to "attack" or "combat" the disease and use terms such as "epidemic," "crisis," or "plague" to describe the prevalence and impact of dementia (Katz). Finally, presentations of caregivers' narratives about dementia in research and society often highlight the emotional burden associated with the diagnosis and progression of the disease, as well as the challenges and stress associated with giving care (i.e., Cheng et al.).

These narratives of dementia may have negative implications because they affect our attitudes and expectations towards people living with dementia (i.e., Patterson). However, complementary narratives about dementia continue to gain terrain in health research, where concepts such as *agency*, *resilience*, and *human rights* are central (Barry; Hedman et al.; Shakespeare et al.; Wild et al.; Clarke et al.). These narratives and the numerous contributions from humanities should also be presented and made more available for the public to challenge our attitudes towards dementia. Therefore, the outdoor exhibition "*Still Here*" was hosted in the middle of the city center of Bergen to make this narrative available to a broader audience. To illustrate the results of our clinical study (Madsø et al.) as well as recent models and reviews on music therapy and dementia (i.e., Brancatisano et al., Särkämö et al.), we utilized large-size format photos (1m x 1.5 m), text and graphics. The photos allowed the observer to explore the narrative. By demonstrating music as a therapeutic tool to support positive identity and contribute to fulfilling relationships with significant others, we aimed to improve the general knowledge about resilience, capacities, and possibilities of people with dementia. The function of the photographs was not merely visual but allowed the observer to intuitively interpret and perhaps empathize with the persons being portrayed in each scene. All scenes were

photographed during the last of five weekly music therapy sessions in the participants' homes, where the photographer sought to capture significant moments during the interactions without interfering with the music therapy process (See textbox 4). Throughout the exhibition, the photographs became the narrators of other more nuanced stories of human transition and relationships.

Textbox 2

Resource-oriented music therapy

In the protocol of our research project, we based the therapeutic approach on the overarching principles of resource-oriented music therapy (Rolvsjord et al.). This approach lays the ground for creative co-creation and supports agency in the participants. Some central therapeutic principles determine the work of the music therapist: primarily, the therapist needs to focus on the potential and competence of the participant. The goal of the intervention is set together with the participant. The therapeutic work is based on the musical identity of the participant and should include facilitating emotional involvement in the music as well as positive feelings and experiences. The therapist focuses on engaging the participant in the musical interplay and encourages musical expressions. The therapist also tunes into these expressions, interacts in an empathic manner, and acknowledges the participants' contributions (Rolvsjord et al.)



Figure 3: Portraying how music builds relational closeness. Photo: Ingvild Festervoll Melien ©

Expanding the biomedical narrative

The fact that an increasing number of people are living with a neurodegenerative condition with no cure so far should strengthen our focus on optimizing individual well-being. At the core, dementia changes our ability to remember and reason, our social perception, and our emotions, making us more vulnerable¹ and in need of support and care. In a biomedical narrative of dementia, common terminology includes the *syndrome of behavioral and psychological symptoms* (BPSD) or *neuropsychiatric symptoms*. Apathy, depression, anxiety, delusions, and sleep disturbances are typical examples of such symptoms and their terminology (Kales et al.; Livingston et al.). Even if these terms may ease communication between health workers, such terms may indirectly communicate that they are biological and perhaps unmodifiable. At an individual level, there is also a risk when being diagnosed with dementia that

¹ We use the term “vulnerable” mindfully, having considered the discussion in the Contested Terms issue of ACH. The term “vulnerable” has a useful clinical meaning in our field, and also in our view is a universal characteristic in humans, only increased in degree by developing dementia.

any behavior or reaction is interpreted as a sign or indicator of dementia and a symptom of the disease. When dementia as a diagnosis is the only frame of reference for perceiving the individual, we may neglect her or his actual needs and preferences and the eventual context or situation that has triggered a reaction or challenging behavior (Wolverson et al.; Kolanowski et al.). However, it is acknowledged in complementary perspectives such as Kales et al. Kolanowski et al.; Livingston et al. and Spector & Orrell that what may be perceived as dementia-related symptoms may better be understood as experiences of unmet needs and distress. Thus, a contextual understanding of these behavioral expressions or symptoms of distress is vital (Wolverson et al.). In relation to this, the knowledge of how to enhance well-being in dementia and help people access their resources despite cognitive decline is increasing. Music therapy is such a central approach in achieving this for people with dementia (Sihvonen et al.; Särkämö; van der Steen et al.). Personalized music interventions for people with dementia is not merely an activity that may support cognition and increase positive emotions. At its core, the therapeutic principles also seek to increase and contribute to a positive narrative of the client (Rolvsjord et al.) (Fig. 2), expanding the biomedical narrative.

The social narrative

Dementia is also a matter of social knowledge. As previously mentioned, the traditional terminology used to describe neurodegenerative disorders also influences how we talk about and think about the persons affected. Dementia originates from the Latin word *demens*, which means “out of mind,” suggesting an inability to think and feel. It is common in everyday language to label people living with dementia as “demented,” describe people with dementia as “not all there,” or talk about their life and interests in the past tense (George; Swaffer; Hughes et al.). Due to significant progress in early detection, people receive their diagnosis earlier in the dementia process, where language and memory are generally less affected. This may considerably impact the individual who may be in a better position to speak up against stigmatizing terminology and attitudes and respond personally to significant human rights issues (Shakespeare et al.).

There are several examples of dementia activists taking the stage (e.g., Helga Rohra, Keith Oliver, Kate Swaffer, and Christine Bryden), writing works with titles such as *Dementia Activist* and *Nothing About Us Without Us*.² These stories challenge the common language describing people as “demented,” and propose a narrative where people living with dementia can speak up for themselves. The notion of a deteriorating self in dementia is also challenged when we investigate the experiences of people with dementia in qualitative interviews (i.e., Bjørkløf et al.). The experience of being *oneself* is still present, but we may struggle to overcome obstacles to execute what we want or need. The neurodegenerative processes will eventually lead to an increase in functional difficulties but never reduce the person’s status *as* a human. There will always be a way to connect despite the obstacles, and as professionals, we should guide caregivers to continue to connect to the person. As the following vignette, described based on video-data from a parallel study by Madsø, Pachana et al., illustrates, even when our attention is severely challenged through the course of dementia, there is still an opportunity for valuable shared moments.

1. ***A vignette on attachment and shared attention:*** *She is a woman who loves dancing. Rhythms always made her legs move. Now, her Alzheimer’s dementia is in a moderate to severe state, and her gaze is often absent, as if her mind is elsewhere. Her daughter sits beside her, but her attention seems challenging to catch today. The music therapist sits across them and starts playing some familiar chords while singing the chorus of Abba’s “Dancing Queen.” She is not looking at the music therapist but looks at the guitar for a while. The music therapist sings, “See that girl, watch that scene...digging the...” The music stops. The air is filled with expectations for a second. Then, after a few moments, she looks straight into the eyes of the music therapist and pronounces “dancing queen” in a quick voice. She turns her head towards her daughter, who is smiling back. A moment of attention and engagement is shared, making the daughter reach for*

² *Dementia Activist* is written by Helga Rohra, and *Nothing About Us Without Us* is written by Christine Bryden.

her hand. It is as if the apathy is broken, and a possibility for attachment is made.

It is often described that dementia makes us more vulnerable to the loss of our personal narratives. Asking people to participate and be publicly portrayed as a person living with dementia was, in this context, an opportunity for the participants to actively contribute to the story of dementia from their perspective. On the one hand, even if people transform and change due to a neurodegenerative disease, the notion of being “lost” or “gone” does not fit with how persons with dementia perceive and describe themselves. On the other hand, social expectations may facilitate and hinder expressions of our perceived identity (Neisser). The exhibition offered visibility, affirmation, and inclusion in a social space. Inclusion in a project of this format could also yield careful reflections on the ethical aspects of sharing such intimate relational moments and disclosing one’s diagnosis of dementia. Still, if a large group in society is not invited to social spaces, this is also a threat to democracy. The ethical considerations in the project are elaborated in Textbox 3.

Textbox 3

Ethical aspects

Participating in a public exhibition like "Still Here" raised several ethical dilemmas. It was imperative that the exposure to which the exhibition would contribute should not be an added burden for the participants. However, to confront stigma, people are challenged to be open and expose themselves, and thus contribute to a more nuanced story. All the participants in "Still Here" actively showed interest in and signed up to participate in the project. They were recruited through social media, networks of friends and connections, and by handing out pamphlets in NKS Olavikens outpatient clinic. All participants were given time to discuss their participation beforehand with a person they trusted. Both the person with dementia and their caregiver participant gave oral and/or signed consent to participate in the music therapy, to be photographed,

and to use the photos in the project. The capacity of the person with dementia to give informed consent was discussed with our team after the first meeting with the music therapist and KGM, where information about the project was provided. In this first meeting, before the music therapy was planned and initiated, the aim of the project was explained to participants and carers.

As the photographs are protected by The Intellectual Property Act (1961), they are owned by the photographer Ingvild Festervoll Melien. Even so, all the participants were shown the photos before the exhibition and were given the opportunity to give feedback. The participants were invited to the opening of the exhibition, and music therapist Stine Andrea Sognnes and psychologist Kristine Gustavsen Madsø visited the participants in their homes after the exhibition was closed for a conversation about their experiences.

Use of the sound clips featured during the exhibition was granted by the participants or their caregivers. Sound clips with citations from caregivers were anonymized and re-recorded using actors as their voices.

The vignettes in *this* paper originate from a parallel study (Madsø, Pachana et al.), where written consent to participate was given by all the participants, and ethical approval was granted by the Regional Committees for Medical and Health Research Ethics in Norway (2016/1374). The excerpts and musical examples in the vignettes have been changed to similar songs or music to further anonymize them.

Writing a text like this article where we challenge current discourses on dementia in our field, also challenges us on how representative our story is for people living with dementia. Eventually, the reader must make the decision on representativeness.

A narrative of resilience

Research findings have for some years depicted a more vital story of how people *experience resilience* in psychological terms through the process of

developing dementia (Casey and Murphy; Williamson and Paslawski; Buggins et al.). This knowledge base is strengthened in detailed studies also relating to caregivers. From a broad focus on narratives of loss and decline, there is a more nuanced story about experiencing and living with dementia. This story is *not* a re-telling of the previous controversial paradigm of “successful aging” (Harris and Keady) nor the concept of resilience as a neoliberal demand or individualistic responsibility (King; Katz). The perspective of living well with dementia is rather a recognition of the personal and social strengths and resources of people with dementia — an essential perspective to advance further our knowledge base in research as well as in public policy.

Resilience is a broad concept found in various research traditions in psychology that may differ from the contested concept of resilience, which is also debated in cultural gerontology and other social sciences (Wild et al.). Medical anthropologist Catherine Panter-Brick defines resilience as “*a process to harness resources to sustain well-being*” (Southwick et al. 4). Conceptualizing resilience as a process avoids labeling people as resilient or non-resilient as if it is merely a capacity or a trait. If resilience is a process, it may be supported or counteracted in society, personal interaction, and the contexts of care. At a societal level, it may be facilitated by political and infrastructural support (King; Rose & Lentoz). It may also be conceptualized as a social or community resilience (Wild et al.). In a classic paper from 2004, George A. Bonanno raises the issue of the human potential to continue to have positive emotional experiences even after severe traumas and losses. Even though dementia is not a trauma from which one can recover (being a severe and incurable condition as well as an example of trauma or loss), the concept of resilience encompasses protective factors that may still foster positive emotions during the highly challenging development of the condition itself. As stated by George A. Bonanno:

It is imperative that future investigations of loss and trauma include more detailed study of the full range of possible outcomes; simply put, dysfunction cannot be fully understood without a deeper understanding of health and resilience. (26)

In a clinical assessment of dementia, we try to describe the characteristics and degrees of severity of cognitive capacity losses. However, we may still underestimate resilience factors. Resilience can be elicited in individuals with dementia by supporting environments and having access to protective factors (Wild et al.). In our study and the exhibition, we elaborated on the resources and capacities present in people with dementia and how they could be facilitated through music. We hope that communicating this message could inform a narrative of resilience in dementia for the audience visiting the exhibition. As Clarke and Bailey explored, resilience for people with dementia includes the perception of being socially included and supported. As vignette two demonstrates, I become me when I am supported by you:

2. A vignette on identity: *The man sits in his living room with the music therapist. His body is sunken together, and his arms are crossed over his chest. He has always loved the mountains, and singing in choirs is a big part of his life story. The music therapist is talking about a picture in the living room, showing a mountain in the fog, and gently reminds the man of the phrase of a poem from a choral song he is familiar with: "...when you describe this picture, it reminds me of..." "There is a place..." ...the man continues the phrase "above the sea..." He laughs and says, "Yes...these were the words that came to my mind, too!" He opens his arms and continues to cite the poem with a strong voice and tenderness. When he finishes the last line, the therapist says "Fantastic!" whereby the man responds, touched: "Is that your opinion?" He sits up more straight as if he is correcting his bodily position to match the praise from the music therapist.*

Textbox 4

Photographer Ingvild Festervoll Melien describes the process of portraying narratives of dementia

In my work at the intersection of documentary and press photography, I meet people in various life conditions. My job is to capture their daily lives through the camera lens.

The photograph is a medium with the capacity to touch everyone. Pictures may trigger associations with our own experiences and challenges. In our society, photos are part of our everyday experience through social media, papers, magazines, and exhibitions. As a professional photographer, you always look for situations that are not easily or commonly captured.

Illustrating clinical research through photography, you may communicate important research results, as you can capture and convey feelings and expressions in a way that is different from text or sound. You come very close to the people you meet, and you may observe from a distance and catch an overview of the situation. The photo lets you be both a participant and an observer simultaneously. The research findings may be made more available to the general public through specific and tangible pictures. Illustrating the research findings through photographs allows people to interpret and validate the research findings. Eventually, this may change their attitudes and knowledge about capacities in people with dementia.

It was vital for me that the participants and the music therapist led and created the situation together. I placed myself in the background and wanted the communication between the participants and therapist to continue as it would have if I were not present. Everybody should be comfortable with the situation, which was a prerequisite to ensuring that the photos illustrated the natural emotions that followed during music therapy.

I always need to be respectful and sensitive towards the people I portray. Many people may experience being photographed as uncomfortable. When preparing this project, I chose situations that demonstrated responses like happiness, sadness, positive relational interactions, and contemplation. The photos show moments in a life that is in transition but where the person is still here.



Figure 4. Portraying how music brings contemplation. Photo: Ingvild Festervoll Melien ©



Figure 5. An overview of the exhibition at an indoor venue (Alrek Health Cluster). Photo: Ingvild Festervoll Melien ©

COUNTERACTING LONELINESS THROUGH MUSIC

A meta-ethnography based on the perspective of people with dementia demonstrated that the two most common distressing experiences were *feeling*

fearful and *lonely* (Petty et al.). These basic human experiences may be easier to relate to than the diagnostic categories "anxiety" and "depression." Feeling fearful and lonely communicates the basic need for safety, relationships, and companionship. If persons with dementia experience loneliness (Petty et al.), using music as a tool to create belonging and social interaction seems obvious. The social capacities of music invite people with dementia to take part in meaningful interactions (Brancatisano et al.). Music may support a close non-verbal interaction, even when language is affected by dementia. (See [Figure 3](#), [Vignette 1](#), and [Figure 6](#)).

Musical activities can facilitate participation, where we contribute and participate as *equals* (Dowlen et al.). The nonverbal aspects make it easier to overcome the obstacles created by the loss of verbal language, which is common in dementia. A study by Johnston et al. found that when significant others experienced how individualized music impacted the person with dementia living in a care home, their beliefs about the disease and their loved ones were changed. The connection between the person with dementia and the caregiver was reinvented momentarily, and the caregiver experienced prolonged eye contact and interaction compared to when the personalized music was not present. Such processes were replicated in our clinical project, where the person with dementia participated more in the interactions and social turn-taking during music therapy (Madsø et al.). We sought to document these significant findings in the public exhibition, as we believed they could also empower caregivers to approach music therapy with their loved ones.

Maintaining identity

In our exhibition, sound clips from music therapy were used to demonstrate how music can connect a person to themselves, as illustrated in [Vignette 1](#) and [Vignette 2](#). Baird and Thompson maintain that music may connect a person to their identity in dementia. They use a classical theory of the self, postulated in 1988 by Neisser. According to this theory, the self may be represented schematically as, respectively, an ecological self (in the physical environment), an interpersonal self (through our interactions), an extended self (the memory

of who we were and what we wish to become in the future), a private self (our internal experiences) and a conceptual self (the social roles we have). The musical interaction in [Vignette 2](#) demonstrates that the music connects the person featured to their conceptual and extended self by citing a poem related to their life, interests, and former social roles. Even if the dementia may have transformed the person's ecological self into a person often lacking initiative, the musical interaction brought this individual out of apathy and into initiative.

[Figure 4](#)—"Music brings contemplation"—also illustrates another way music may maintain identity by connecting the person to the private self, according to Neisser's terminology. Feelings of anxiousness or fear that are also commonly experienced (Petty et al.) may be relieved during music. Music can be relaxing and may significantly decrease arousal in the nervous system (Brancatisano et al.). As illustrated in [Figure 4](#), music may bring contemplation and help us connect to our inner world. The exhibition clarified how music could strengthen identity and agency. Music may easily foster positive emotions and enhance agency in people with dementia (Dowlen et al.). If music can facilitate identity and support a person with dementia to express agency, this challenges the notion of them being "gone." Qualitative studies describe how participation in musical activities can boost confidence and give a sense of mastery, as illustrated in [Vignette 2](#); it is something I can do and am good at doing. I can remember melodies and text. The musical activity may also reinforce autobiographical memory (Baird and Thompson; Dowlen et al.). Listening to personalized music could sustain both the ecological- and private selves while engaging in a moment of contemplation. These examples illustrate how music may support agency in people with dementia.

Our previous references to shared negative social attitudes towards dementia may imply an undermining of the humanity of people living with dementia. According to McNess, a tendency to depersonalize those with dementia on the part of others protects those others from the typical fear and aversion of dependency and fragmentation generally associated with dementia. When research continues to discover and explain which capacities and abilities people with dementia may still have and how we can facilitate these capacities, one

effect may be that this fear may cease. Meanwhile, it is important not to overstate the potential of living well with dementia, and we also need to acknowledge the struggles that may follow the condition (Bartlett et al.). In our work with the exhibition, we focused on describing dementia in terms of empowerment and freedom from stigma. In addition, however, we tried to avoid portraying life with dementia in an unreasonably positive way. As dementia activist Keith Oliver has expressed in Bartlett et al.:

I don't see myself as a sufferer, but I do suffer from dementia. I find dementia extremely challenging and frustrating, but I am not a sufferer because if I become a sufferer, that's how I'm defined and that's how I'm treated (177)

Thus, acknowledging both sides of the story is essential.

RECIPROCITY IN CARE

As the progression of dementia necessitates dependency on others, it may lead to challenging changes in relational reciprocity. Caregivers of people with dementia face struggles, losses, and transitions that should not be devaluated. However, a common narrative of dementia in our field may also focus too much on caregiver burden and "BPSD," presenting an assumed caregiver perspective that may be unrepresentative. Experiencing caregiving as overwhelming and meaningful is possible, and supporting the person with dementia may also be perceived as emotionally rewarding (Wadham et al.). Some couples even describe an increased closeness between them after dementia onset (Ablitt et al.). Thus, carers should be taught about the possibilities music therapy may give them. People with more severe dementia may seem to signal a lack of attachment when the capacity to participate in communication is decreased. This includes lack of joint attention, not having eye contact, or not following the natural turn-taking. Signalling detachment through these symptoms of communication breakdown is probably not the intention of the person with dementia.

Nevertheless, significant others may experience or interpret them as inattentive and detach themselves. There may be a change from "caring about"

to "caring for." However, depersonalization and thinking about the person as no longer here may lead to a deprived relationship for the family caregiver as well as the person being cared for, followed by an increased experience of being abandoned in both. Telling both these stories is paramount.

Thus, music can be a tool to support the mutuality and reciprocity that couples strive to retain in their relationships. Music can provide a closeness the dyad may long for. Our research findings and the photographic evidence both point to the enhanced connection created by the musical intervention.

3. *A vignette on relational mutuality:* *A woman is looking towards her husband as if sharing a secret only the two of them know. He is smiling back, looking into her eyes with an expression of engagement and deep care. Although he is experiencing a lot of challenges with finding and expressing words, his body is vital, and his body language is easy to interpret. She explains: "We have a lot of musical memories together. We have always danced a lot. So even if things have changed now, we can still dance together to the music we love. And when we dance, everything is still the same...in those moments." As they rise to dance to the energetic rhythms from the speakers in the living room, he reaches for his wife's hand and swings her around to the charismatic voice of Jerry Lee Lewis: "As long as I live, baby, I'm gonna give you all of my heart. We can't be apart..."*

Music can also support capacities for social interaction. As previously mentioned, our research study showed that during music therapy, the person could experience more turn-taking, eye contact, and non-verbal prosocial behaviour (Madsø et al.). Disruptive behaviour may lead to detachment between family caregivers and the person with dementia (Cheng). Music therapy may support attention and help a person with more severe dementia to overcome barriers to communication, such as apathy and inattentiveness— as illustrated in [Vignette 1](#).

Engaging music may enhance attentiveness and help the person stay in the interaction longer (Brancatisano et al.). Here, music can extend the boundaries and limitations due to cognitive decline. In dementia, creative skills may still be

well preserved, and music can be a way to express oneself creatively. This is something a dyad can do together. It is vital to support people with dementia and their caregivers by enabling such moments of togetherness. This may facilitate a connection that the person with dementia and the significant other may long for. As Lisa Genova has stated:

You won't lose your emotional memory – you'll still be able to understand love and joy; you might not remember what I said five minutes ago, but you'll remember how I made you feel, and you are more than what you can remember.

Finding the right tool to make the person feel loved and connected is also essential and valuable for carers. As Figure 6 illustrates, music can help you communicate and connect without using words.



Figure 6. Portraying how music is communication without words. Photo: Ingvild Festervoll Melien ©

CONCLUSION

This article has sought to show aspects of our recent research project and of the exhibition "Still Here" and to demonstrate the evidence they offer—in both

scientific and artistic ways—for a narrative of connection, agency, and continued capacity in those living with dementia. These narrative challenges the familiar and distressing story of the loss of personhood and draws out aspects of resilience—construed in psychological rather than sociological terms—that are not predicated on neoliberal individualism or reliant on extensive economic means. This resilience is predicated on relationality, connection, and creativity rather than autonomy and personal challenge. Subsequently, this paper also offers an argument for the role of music and musical therapy in promoting these experiences of connection and mutual creation, conducive to psychological well-being, and for preserving a close and reciprocal relationship between the caregiver and recipient of care. The invitation extended to those living with dementia to be part of a public exhibition, as well as the consensual sharing of vignettes reflecting their subjective responses to the musical therapy, allowed those with dementia to have a part in creating an alternative narrative about agency, care, and connection founded on the insights of psychological research.

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Kristine Gustavsen Madsø is a clinical psychologist from Norway. Her research interests are psychosocial aspects of dementia, psychological health in old adults. She defended her PhD entitled "Momentary well-being in dementia: Observational assessment of psychosocial interventions and music therapy" in March 2022. Kristine aims to contribute to breaking down stigma around dementia, create dementia-friendly societies, and increase the knowledge about living with dementia from the eye of the beholder.

Dr Inger Hilde Nordhus is a clinical geropsychologist, community psychologist and professor emerita at the Faculty of Psychology, University of Bergen, Norway. She has an international recognition in the area of *mental health in old age*, particularly with her research on *late-life anxiety* and *sleep disorders*. Her research maintains an international health focus in collaborations and research interests including *assessment* and *non-pharmacological interventions* for anxiety and sleep disorders in older adults *living with or without dementia*. She served as a research dean at her faculty for several years and is still involved in her national initiative of a research leader program for young researchers in Norway.