



Re-conceptualizing the gap as a potential space of becoming: Exploring aesthetic experiences with people living with dementia

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Abstract

Purpose: In this paper we describe how co-creative art practices can involve people living with dementia as active citizens. We build on the Nordic Relational Model of Disability (GAP model) that conceptualizes levels of functioning as a mismatch between individual abilities and requirements from the environment.

Design: We explore how reciprocal aesthetic experiences from two residential care homes in Northern Norway can broaden a narrow biomedical understanding of dementia. Arts-based research and sensory ethnography are our methodological frames. We present three field descriptions that open an aesthetic universe through fine art, poetry and applied theatre.

Findings: We find in our research that the gap between individual abilities and social requirements can become a space for creativity, in which everyone becomes connected and contributes to shared aesthetic experiences. We argue that broadening our understanding of the gap can result in new ways of relating to and being with each other.

Originality: The paper advances aesthetic perspectives in dementia research.

Keywords

dementia, GAP model, aesthetic model of disability, situated art intervention, aesthetic analysis

At the hospital

The musician: My mom has just been diagnosed with Alzheimer's disease. Can you tell me what it means to live with dementia?

Doc: People with dementia experience memory loss, they will find communicating or finding words challenging, have difficulty with visual and spatial abilities, such as getting lost while driving, have difficulty reasoning or problem-solving, they will experience difficulty in handling complex tasks and difficulty with planning and organizing, but also difficulty with coordination and motor functions, confusion and disorientation, personality changes, depression, anxiety, inappropriate behaviour, paranoia, agitation and hallucinations.

The musician: That sounds terrible, not a single positive term. I am scared. What can I do? Isn't there any possibility to associate dementia with something else than frailty, loss and decline? What about spontaneity, improvisation, or creativity?

Introduction

This opening scene is a fictional vignette. Still, it represents dominant western perspectives on dementia. Dementia research, dementia care, and popular representations of dementia are widely informed by a biomedical understanding of dementia as an incurable progressive cognitive impairment in the brain. This understanding is complemented by psychological, social, philosophical and spiritual perspectives (Cantley, 2011). Aesthetic perspectives, however, are rare in dementia research (Bellass et al., 2018; Hughes, 2014). Nevertheless, the ground-breaking potential of the arts and arts-based practice to fundamentally re-frame what it may mean to live with dementia is being acknowledged to an increasing degree across academic disciplines. Recent research on arts and creativity points toward innovative understandings of dementia. Arts-based practices specifically have shown the potential to guide everyday life with dementia (Basting, 2020). Citizenship research has further become a driving force in an ongoing paradigm shift that seeks to understand dementia beyond human individual loss (Birt et al., 2017; Keyes et al., 2019). Aesthetic-based research (Bresler, 2006) and applied arts research (Jensen & Torrissen, 2020) are methodological approaches with the potential to shift the focus from the condition itself towards new forms of citizenship in which people contribute to society through creative expressions (Gray & Kontos, 2018; Lotherington, 2019). Within this framework the arts and creativity enhance social relationships as a major determinant for health (Yoeli et al., 2021).

In this article we develop aesthetic perspectives on dementia by exploring reciprocal aesthetic experiences and how they impact our understanding of dementia. The article is divided into four parts: 1) We describe our methodological approach, based on situated art intervention research developed within Artful Dementia Research Lab at UiT The Arctic University of Norway 2) we build on the Nordic relation theory model, also called the GAP model, and re-conceptualise the gap as a potential space for creativity 3) we analyse reciprocal aesthetic experiences within three scenes derived from our fieldwork and 4) we provide a meta-discussion of the scenes and sum up how broadening our understanding of the gap can result in new ways of being together with people living with dementia.

Methods

Artful Dementia Research Lab at UiT The Arctic University of Norway is a space to develop situated art intervention research together with people living with dementia and their companions, health care professionals, artists, and policy makers. The overall aim for the lab is to work collectively towards an understanding of dementia beyond human individual loss. Situated art interventions open up for mutual aesthetic experiences that complement sensorial ethnographic methods and impact the quality of data sets derived from observations, audio and video recording, interviews and field notes (Gürgens & Mittner, in print; Mittner & Gürgens, 2021). In our roles as research artists, we explore how engaging co-creatively with multisensorial art forms affects our relations and creates moments of connectivity and shared aesthetic experiences.

In this article, we present our field experiences from situated art interventions, poetically described as three scenes from within the fields of visual art, poetry, and storytelling. The field data was collected at two residential homes in Northern Norway in 2019 and 2020. The scenes were written individually by the three authors, and then analysed collectively (Eggebo, 2020) within the lab by five researchers from the academic fields of music, visual art, drama and sociology. The overall aim of the analytical process was to understand in-depth mutual aesthetic experiences involving people living with dementia.

All the three scenes are drawn from a blend of memory, field notes, writings, photographs and video recordings. As such, they are ‘/.../ not data but offer variations of ethnographers’ experience of reality that are as loyal as possible to the context, the embodied, sensory and affective experiences’ (Pink, 2013, p. 35). Scene 1 derives from the final exhibition in the project curated by the research artist Dragana Lukić in Tromsø, August 2019. This was the closing event of a series of art interventions conducted as a part of her PhD project at a residential care home. Family members, friends and the broader public were invited to join the exhibition prepared by the residents, and to engage in a co-creative art workshop in the activity room. Scene 2 is derived from the kick-off session of the ‘Shorelines’ project in Harstad, February 2020. A group of musicians, applied theatre facilitators, a visual artist, social scientists, health care workers, people with dementia, and their relatives came together at a local residential care home and collectively created aesthetic encounters across the arts. The scene is created as a sensory ethnographic explorative short text, which opens a poetic universe. Scene 3 builds on storytelling that derives from the ‘Shorelines’ project (2020–2021). In the project, we improvised, tested, and developed methods from the fields of drama and applied theatre, inviting people with dementia to become co-creators in research (Artful Dementia Research Lab, 2021). Through the different materialities of the three scenes – a visual art product, a poem and a video recording – the reader is invited to take part in the aesthetic experiences we build our arguments on.

Ethical considerations

This paper is based on fieldwork data collected during the situated art intervention projects, ‘Multisensorial Entanglements’ and ‘Shorelines’, that received permission from the Norwegian Centre for Research Data. Regional Committees for Medical and Health Research Ethics were contacted, but an application was not required since no health-related data was collected. The researchers gained written and oral consent or proxy consent from all group members to analyse and publish fieldwork notes, film, photos and oral quotations from the sessions. The names used in the article are pseudonyms to ensure anonymity. Recruitment was facilitated via close collaboration with healthcare professionals and the leadership of the residential care homes. The recruitment process was self-selective in the sense that all

arts-based activities were optional, and the residents could withdraw or leave the session at any point.

Involving people living with dementia in qualitative research is challenging in the traditional sense of analysing by talking, writing, and reasoning (Lepore et al., 2017). Since we wanted to involve the residents to build collective understanding, we based our aesthetic analysis on ‘ethics in practice’ (Guillemin & Gillam, 2004; Carter, 2017), which enabled us to bring reciprocal aesthetic experience into the process of knowledge creation. Building the processes of meaning-making on situated art intervention allowed people living with dementia to become involved in knowledge creation precisely through ongoing interaction and entangled relationship. Our conceptualization of a space for creativity based on connectedness and relational practices leads to an ethical obligation to consider the ethics of those relations that are formed. Even though the aesthetic analysis is based on artistic experiences reported by the three authors and enhanced through creative writings and discussion in the lab, the results are crucially rooted in non-individual but relational experiences that are based on mutuality, reciprocity, and co-creativity (Zeilig et al., 2018). What might appear to some readers to be an analysis of three different situations created solely by individual research artists, roots – from our ontological standpoint – in socio-material entanglements in which the artist becomes only one part of the apparatus that is designed for collecting arts-based data at a specific site within a specific group.

Models of Disability

Dementia as an experience of disability is understood within a cultural and contextual frame (Shakespeare et al., 2019). Disability is traditionally constructed in ways that emphasise the impairment, the functional limitation that the individual experiences. This way of defining disability is referred to as the medical model of disability and linguistically one makes the claim within this paradigm that a person ‘is disabled’. However, we can also see disability as a product of the environment the person lives within and claim that a person ‘becomes disabled’ in certain contexts. This way of understanding disability is referred to as the social model of disability, and the model itself derives from the British disability movement (Shakespeare, 2004). A third model of disability is the relational model of disability where one understands disability as the result of the individual-environment interaction (Kassah & Kassah, 2009). 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’. If the gap is large, the disability will arise as a challenge in the relationship, but if one is able to narrow the gap, disability researchers (such as Kassah and Kassah, 2009) claim that it is possible to limit or even erase the notion of disability in specific contexts. The GAP model thereby situates ‘disability’ in the space between individual abilities and societal requirements. The GAP model was developed in the tradition of Critical disability theory (CDT) (Shildrick, 2015) that seeks to theorize and understand disability as a social, cultural and political phenomenon, instead of an individualized, medical matter attached to the body (Hall, 2019). A central issue in CDT is ‘critical ableism studies’ that argues for a ‘critical need to investigate internalized ableism and its effects on the psychic life of our community’ (Campbell, 2008, p. 160). In our research, we follow the tracks from CDT who reject the deficit model and embrace a more holistic and relational approach. ‘Disability politics, arts, scholarship and culture offer new ways of conceiving and living life, existing with one another and recreating communities that include, augment and emphasise the qualities we

all hold as human beings' (Goodley et al., 2019, p. 972). CDT draws on arts-based research and gives priority to aesthetic, embodied knowing and relational practices through disability art and culture researchers (Currans et al., 2015), disability-led arts organisations, activists and artists (Disability arts international, 2021).

Our aim is to: a) work against ableism that people with dementia can experience and b) try to understand that people living with dementia can grow as human beings by contributing within creative encounters understood within the aesthetic model of disability: This is because disability is something that is done or performed as an aesthetic phenomenon based on social and cultural expectations and norms (Edvardsen & Gjørum, 2021).

Aesthetic encounters

In this context, aesthetics means what you experience through your senses. According to John Dewey (1934), all aesthetic experiences are interactions: 'Experience is the result, the sign, and the reward of that interaction of organism and environment which, when it is carried to the full, is a transformation of interaction into participation and communication' (Dewey, 1934, p. 22). Dewey argues that there is a difference between our unconscious everyday experiences and what he calls 'an aesthetic experience' when your whole body is present, concentrated and fulfilled in a way that 'time stands still' and you are totally in-the-moment (Gürgens, 2004). Presence is when you fully observe, feel and participate in a moment of being. An object, a sound or a smell can all carry a 'presence effect' that communicates to you as an aesthetic experience during a workshop or in your everyday life (Feral, 2012). Entanglements of sounds, paper, painting, furniture, and other props in the aesthetic processes can create such presence effects. Aesthetic experiences are, according to Dewey (1934), shared experience. They cannot exist without such things as people, materials, rooms, music or the movements involved (Burnside, 2017, p. 34). By aesthetic experience in the moment, we mean in-the-moment interactions within a continuum of moments (Keady et al., 2020). As an analytical category, aesthetic experiences in-the-moment relate to the concept of *awe*, an amazement that you can feel when you are faced with something wonderful – epic, wondrous and overwhelming (Basting, 2020). The term has been described as 'a guiding principle of how to invite other people living with dementia into meaningful relationships with the world' (Basting, 2020, p. 124). Julian Hughes (2014) describes the aesthetic approach to people living with dementia by using intuition and imagination in a way to understand behaviour that challenges us. An aesthetic approach to dementia and disability entails a variety of interesting implications for analysis of both 'reciprocal aesthetic experiences' and 'disability as a performed phenomenon'. Our research design is based on two overall premises: 1) that the ability to connect, create or communicate does not reside within a person's brain or body, but arises through interactions and 2) it is not the individual (dis)ability, but the aesthetic experience in the moment that transforms relations and perceptions of dementia.

Aesthetic analysis

We will now analyse and discuss three scenes from the field, study the reciprocal aesthetic experiences, and look into how they impact our understanding of dementia. We are especially interested in investigating what shifting our understandings of dementia from an experience of 'disability' towards an experience of 'possibility' may imply for future research in the field of art and dementia.

Scene 1: Fine art universe



Picture 1.

Co-creating a mandala pattern.

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I find myself sitting next to a resident, Mari. Neither of us knows what the situation might become. We hear people chatting while wandering through the exhibition. There is no instruction, no activity leader. The items on the table – such as brushes, white pottery and small glasses with colours on a pink table – invite us to take a seat and paint. Someone is opening small glasses filled with colours. People around the table start to make decisions on which object to paint, which brush to choose, and which colour to dip into. Those actions are accompanied by phrases such as: ‘It has been a long time ago’ or ‘Oh no, this is nothing for me’ or ‘I am very bad in painting’.

Confidence is low for most of us around the table. However, as the group starts to interact with the materials, something changes within and between us. I wonder what would happen if I invited Mari into a creative expression by simply starting to paint? I choose a white dinner plate, a brush and colour, and start to make small red dots in a rhythmic movement. Mari follows my movement with her eyes. She seems to me neither comforted nor confident. But she stays and observes my actions. I choose another brush, dip it into the paint-pot and hand it over to Mari, asking her with both my eyes, words, brush and movement about colours, shape, size and pattern – all of which seek to express: ‘Can we do it together?’. Mari gives it a try and suddenly we are creating a beautiful mandala pattern on the plate which we all appreciate.

(Written by Lilli Mittner based on fieldnotes from 26.08.2019.)

I entered the residential care home with a high level of engagement. Mari was neither highly engaged, especially interested, nor motivated to participate in any creative activity. The gap between us arose not only due to health condition, age, aesthetic preferences, and engagement, but also the fundamental difference that one of us was unwillingly bound to living here, while the other had come for a short visit and could leave at any moment. In the beginning Mari and I were unknown to each other and there was a huge distance between us, producing feelings of being disabled and diminishing our ability to create something together. However, we started making the plate together during a continuum of moments (Keady et al., 2020). What was initially brought into the encounter, our individual abilities, and the requirements of the environment, became less important and we started to figure out how to become ‘part of each other’s lives’, as Ann Therese Lotherington describes it in the film ‘Artful Dementia’ (Mittner et al., 2021). The way the other group members in the room increasingly engaged in the art-making session further impacted how we related to each other. People started appreciating sitting together. The initial lack of inspiration about how to create, made by the pressure to create something beautiful and meaningful transformed into the believe in the creative potential of the moment. Through painting the plate, we entered a good relationship as a major determinant of health (Yoeli et al., 2020). It was in that specific aesthetic experience that the gap transformed into a space of becoming.

Scene 2: Poetic universe

We melted together in a big circle in the living room at the local care home. We improvised and played for an hour, with no dramaturgic plan or directed roles:

Gather thoughts

The circle contained a hope for another future.

Hope for a different framing.

Laughter as glue.

Handshakes as pulse.

The binding agents between us

are occasionally unsteady.

But in your eyes

I sense a well

of initiative.

Behind the usually

closed curtains

between you and the world.

I suddenly found you.

(Written by Rikke Gjørums Gjerum based on fieldnotes from 17.02.2020.)

The session started by placing an old suitcase in the middle of the circle and opening it – showing the group a lot of props – while acting out a sense of ‘awe’ (Basting, 2020) every time the applied theatre facilitator introduced a new prop. Then we circulated the items across the circle. After a while the musicians improvised and the group danced. The

gap (Kassah & Kassah, 2009) experienced at the opening of the session slowly disappeared because we moved towards each other through the creative process, where everything was allowed, and nothing was right or wrong, as it actually is in our everyday life where we unconsciously play our roles as ‘health workers’, ‘teachers’, ‘parents’ etc. As a research artist, I experienced that the gap between us was neither narrowed nor broadened, but rather disappeared – because no one had a disability anymore.

The aesthetic experience (Dewey, 1934) described in the poem can be analysed as a micro-experience: when seeing someone’s smile, hearing the laughter, feeling connected to your dancing partner or communicating in a way that has opened a feeling of presence (Feral, 2012). I experienced the gap in the opening of the session as a slightly tense communication between the group members, reinforced by the fact that we were unknown to each other and some of us live with a disability. However, after a while the relational space between us was simply filled with no prejudice. I did not experience any expectations to how we all should behave because this bricolage of the arts as a ‘cultural bridge’ between age, positions and diagnoses was new to all of us. My understanding of dementia changed in the aesthetic experience of the moment and I was able to suddenly connect to several of the group members and I observed that they also *discovered me, just by catching the look in their eyes.*

Scene 3: Applied theatre universe



Film 1.

Research film exploring an aesthetic experience in the moment (Dalby & Rolland, 2020).

<https://www.youtube.com/watch?v=JmiQLer1YkQ>

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I walk into the living room and sit down in front of a person named Anne. I come close to her and ask: ‘Do you want to do an exercise?’ She replies by saying she does not feel well. I ask again if she can make a simple movement. I move my hand towards her as a form of greeting. She starts milking cows with both of her hands. I mirror her movements and suddenly we find ourselves in the barn where we milk cows together. Then she comes up with a story about her brother Gunnar, who hypnotized all the chickens on the farm. This shared experience with Anne becomes a moment where the experience of time, place and space ceases for a few seconds. Anne says: ‘I don’t know what more to say.’ The story has ended, and I thanked her for wanting to share the story with me.

(Written by Karoline Dalby based on the research film cited above and fieldnotes from 17.10.2019.)

Something unforeseen happened as Anne began to share her story of milking the cows. For this moment to unfold, I had to let go of control and my own beliefs of how to undertake the exercise in the 'right way'. Anne's understanding and interpretation of the mirroring exercise was unique to her. Through actively using her imagination and creativity, she expressed her talented gifts as a storyteller. Anne's competence as a storyteller continued to develop throughout our aesthetic encounter. She had direct access to her imagination with just a simple movement. After this experience, I became more confident that we know nothing about each other until we dare to create something together in the moment. There was an element of transformation in both of us during this encounter. The play created a potential space for creativity (Winnicott, 2005), which led to a re-creation of ourselves. This re-creation of 'the story of dementia' revealed what we are capable of as creative and relational agents. This moment of interconnectedness can also be described as a feeling of 'awe'. According to Basting (2020), awe occurs when we experience something as bigger than our small selves, a feeling that connects to the notion of resonance (Mittner, 2021). When we understand the gap as a potential space for creativity, we can approach each other with curiosity and wonder.

Summing up

The scope of this paper was to scrutinize how analysing reciprocal aesthetic experiences can help us to broaden our predominant biomedical understanding of dementia. We learned from the field that the presumed gap between individual abilities and social environment dissolves within mutual aesthetic encounter. Aesthetic perspectives allow us to move broadly towards an aesthetic model of dementia. The three scenes show how people connect, share ideas and build relations through movement, voice, material and presence. All those who got involved in the scenes were playing within an imaginative universe. The situated art intervention created mutual encounters and presence effects. This can happen when the moment is understood as a 'theatre'. All those who are involved can take turns playing the main character, so that we are all both actors and spectators during the session, in relation to each other's contributions, as Rikke shows in scene 2. In scene 1, what unfolds is a negotiation process between Mari and the research artist about co-creating a mandala pattern on a plate. It is not only the brush or the painting that encourages the co-creative process, but the feeling of togetherness in the mutual encounter of the aesthetic experience. In scene 3 reciprocity grows from a kind of aesthetic imaginative universe. Embodied memory and everyday 'theatre' in the care home melt together for Anne and Karoline.

Acknowledging the ability to create to the very end of life affects the way people living with dementia are perceived and how they might perceive themselves. Based on aesthetic analysis of mutual aesthetic encounters with people living with dementia reported through arts-based data such as visual art, poetry and applied theatre, we argue that the gap between so-called individual abilities and social requirements can be understood as a space in which everyone and everything becomes connected and contributes to a shared moment, and hence as a potential space of becoming. 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. Differences then become a driving force for building (new) relations.

Finally, acknowledging multisensorial entanglements in the aesthetic encounter affects relational ethics. In this sense, the residents shape the shared aesthetic experience in the moment as much as the research artists do. Hence, we need to develop research designs that

allow us to reframe and simultaneously investigate relations that are no longer built on the division between individual and environment, but on shared experiences in which everyone and everything becomes equally important.

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Ethical considerations

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Statement of interest

The authors declare no conflicts of interest.

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