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Dementia, music, and fields of care

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ABSTRACT

The number of elderly people is rising in many countries and a marked increase in people susceptible to dementia can be expected. Research in the field of arts and health shows that culture and art can have a positive effect for dementia sufferers. The author takes his starting point in earlier research in this field and shows that systematic use of biographically adapted music and song can have a positive effect for dementia sufferers. Music and song can provide pleasure, activity, merriment, reduced uneasiness, and emotions, which to a certain degree help them to awaken and recognize memories. He examines the relationship between place as fields of care, music, dementia, and memory, and addresses how humanistic geography and awareness of place may contribute to increased understanding of the effect that use of music and song can have for alleviating suffering. The main findings are that biographically adapted music and song can have positive effects in reawakening and recognition of memories for people suffering from dementia, and through memories sufferers can maintain emotional ties to places embodied in their earlier life. The author concludes that a humanistic geographical approach could indicate the importance of place and home for dementia sufferers.



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Introduction

Report published in 2014 as the basis for this article

In my research report on culture and health (Wollan 2014), I discuss the importance of biographically adapted music and singing by health workers and nurses for people suffering from dementia. Biographically adapted music and song are understood as music that has been selected with the help of close relatives and friends, and stored in a musical medium, and/or suitable music or songs that health workers and the person with dementia have selected together (Myskja 2012). In the report I argue that biographically adapted music and song can give positive experiences for dementia sufferers at different stages of their dementia-related disease. In the individual care situation, music and song can have a positive effect for the dementia sufferer when waking up and going through their morning routines, during the day, and when going to bed at night. The report was based theoretically on the humanistic-psychological approach of Martin Buber (1958; 2002), Carl Rogers (1980; 2004), Kenneth N. Cisna & Rob

Anderson (2002), and I used the phenomenological method of Edmund Husserl (1977). In-depth interviews were conducted with six health workers and observations of health workers were undertaken while they were caring for dementia sufferers at a care institution. It was found that music could provide pleasure, generate activity and merriment, reduce uneasiness, and give rise to emotions that to a certain degree helped the dementia sufferers to recall and recognize memories. Furthermore, singing stimulates activity and can open up for good conversations between health workers and dementia sufferers. In the research report, I conclude that systematic use of biographically adapted music and song provides important support for dementia sufferers who are unable to tackle everyday tasks and are in a care institution. At the same time, the relational dimension of the health worker's physical presence and meeting (Buber 1958; Rogers 2004) with the dementia sufferer is decisive for music and song, and that in turn has a therapeutical effect for the dementia sufferer.

In this article I use as my starting point the empirical material from my previous report (Wollan 2014) and

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take a step forward through an explorative approach in which I attempt to show possible relationships between research in the field of arts and health, music, dementia, and geography. My research question is as follows: *In what ways can humanistic geography and awareness of place contribute to increased understanding of the effect that music and song may have for alleviating the symptoms of dementia?* The results of the previous report are considered and expanded upon with reference to more recent literature on dementia, especially regarding how music and singing can increase attentiveness and stimulate episodic memory. I begin by presenting some key concepts in humanistic geography and explaining why humanistic geography is relevant for the study of dementia and music. I then present the field of arts and health, and I show which understandings of music underlie the research question. I further discuss the extent and characteristics of dementia-related diseases and conclude the discussion with a brief presentations of episodic memory, dementia and geography, and fields of care, with reference to empirical examples in my previous report, before presenting my main conclusions.

Humanistic geography

The humanist tradition within geography emphasizes the concept of place, and works such as Yi-Fu Tuan's *Space and Place* (1996 [1974]), Edward Relph's *Place and Placelessness* (1976), and Anne Buttner & David Seamon's *The Human Experience of Space and Place* (1980) emphasize the subjective qualities of place. Many humanistic geographers reject positivism and turn to phenomenology and existentialism as the philosophical basis for investing in people's homes, sense of place, and being-in-the-world. Heidegger's notion of dwelling and being-in-the-world has influenced the work of Tuan, Relph, and Seamon. In this article, I find it useful to combine Tuan's concept of fields of care (Tuan 1996 [1974]) with a critical perspective on aging and dementia, both by focusing on the importance of biographically adopted music and song for persons suffering from dementia, and by placing care and human dignity before the disease itself.

Arts and health

The field of arts and health encompasses different art forms, such as performing arts, visual arts, literature, and online digital arts, as well as the importance they have for health (Fancourt & Finn 2019, 1). The focus in this article is on performing arts, especially the importance of music and song for dementia sufferers.

In 1948, the World Health Organization (WHO) defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (Fancourt & Finn 2019, 2). Today, this rather absolute definition is toned down and health is considered rather as a dynamic process in which quality of life and the ability of individuals to self-manage are the core elements in the concept of health (Fancourt & Finn 2019, 2).

Extensive biomedical and social scientific research has shown the effect of music and song on dementia sufferers (e.g. Fancourt & Finn 2019). To date, the most comprehensive survey of research in arts and health is presented in the report *What is the Evidence on the Role of the Arts in Improving Health and Well-being? A Scoping Review* (Fancourt & Finn 2019). The report, which was prepared for the World Health Organization, builds on more than 3000 English and Russian language studies with differing theoretical and methodological approaches to the field, including 200 earlier systematic reviews, as well as quantitative and qualitative meta-analyses. The report shows at an overarching level that there is a solid scholarly basis for asserting that artistically based activities, including the use of music for dementia sufferers, can give positive health effects (Fancourt & Finn 2019, 44–45, 52–53). Similarly, Brean & Skeie argue that, despite the fact that there is not sufficient knowledge of all areas of music, 'There are good grounds to say that music has a positive effect on important areas such as depression, behavioural difficulties, anxiety, and general quality of life among dementia sufferers' (Brean & Skeie 2019, 215, my translation).

Music

In arts and health, music is often considered an artistic expression that can promote emotions, raise the hairs on one's skin, and reduce stress (Theorell 2009; Vickhoff et al. 2012). In this article, I show how music is linked to such feelings and effects. In a phenomenological perspective, emotions are understood as an intentional interaction with the world and not merely as subconscious characteristics or as an isolated response (Husserl 1977). Music can hence awaken emotions and contribute to the recalling and recognizing of memories by connecting to previous events and experiences. The ability to listen to music, play music, and sing is among the last of the abilities that dementia sufferers lose (Brean & Skeie 2019, 216). According to Cho (2018), active participation in musical activities contributes to increased quality of life among dementia sufferers because a person is physically active when they sing, does something together with others, and has the feeling of engaging in meaningful activities.

Aging and dementia-related diseases

Societies in the Western world are experiencing a growing population of elderly people, as people live longer than in the past. According to statistics reported by the Norwegian Institute of Public Health (Folkehelseinstituttet) (FHI 2021), c.50 million people in the world have one or other variant of dementia-related disease and the number is expected to triple by 2050; in 2020, c.101,000 people suffered from dementia in Norway and the number is expected to increase to c.237,000 by 2050. Regarding Alzheimer's disease, it is estimated that there are c.57,000 sufferers in Norway, of whom 2100 are younger than 65 years of age, and of those aged 65 or more, dementia is more common among women, while among those under 65 it is more common among men (Mjørud & Røsvik 2021).

Dementia is a term that covers several different diseases of the brain that gradually result in failure of intellectual and cognitive functions, loss of language (aphasia), and disability in undertaking day-to-day tasks (Kitwood 1997; Brean & Skeie 2019; Mjørud & Røsvik 2021). The most common brain disease leading to dementia among the elderly is Alzheimer's disease (57%), followed by vascular dementia (10%). Currently, there is no cure for dementia, and only palliative measures can be provided. Almost all our memories are connected to place (Eikeseth 2018). Dementia can affect a sense of direction and spatiality, orientation ability, sound judgment, sleep patterns, and emotional control. The most important symptom of cognitive impairment is memory loss, which in turn leads to difficulty in performing daily tasks. Identity confusion – knowing who and where one is – is characteristic of dementia sufferers because the connections between past, present, and future become unclear. In his book *Dementia Reconsidered: The Person Comes First*, Kitwood (1997) lays the basis for new practices in care institutions by focusing on the resident person's quality of life and dignity, and not letting the disease define the person's identity. In my study of culture concerning health and dignity (Wollan 2014), I investigated the practice of person-oriented and relational care because in person-centred care individuals are supported, facilitated, and enabled to contribute to their own care through shared decision-making, communication, respect, and recognition (Kitwood 1997).

Episodic memory, recall, and recognition

An intact memory is a prerequisite for the ability to function as a human being. Groome et al. (2002) refer to classical works by William James on long-term and

short-term memory, and by Endel Tulving on episodic and semantic memory. Short-term memory is often defined as the ability to maintain information and awareness shortly after something has occurred, while long-term memory is a depository from which 'things' can be brought out and remembered later. Episodic memory is distinguished from fact-based semantic memory in that the former relates to a specific event or episode in a person's life and is connected to a specific context or place. Episodic memory is hence connected to earlier events and experiences in time and space. Short-term memory is one of the first faculties lost by people who have a dementia-related disease such as Alzheimer's. This can affect daily tasks and is often considered the most important symptom of dementia-related disease (Mjørud & Røsvik 2021).

Research has shown that musical memory is partly independent of other memory systems and can be relatively well preserved in the late stages of Alzheimer's disease and other dementia-related diseases (Jacobsen et al. 2015). The area in the brain that processes music and the associated emotional centre is one of the last to be affected by dementia-related disease, and the ability to be affected by music is one of the last abilities that dementia sufferers lose (Brean & Skeie 2019). Särkemö et al. (2014) demonstrate that both singling and listening to music can have positive cognitive effects, leading to high spirits, increased attentiveness, and stimulation of episodic memory in people who have mild forms of dementia. Brean & Skeie (2019, 215) assert that in all phases of dementia-related disease both musicality and memory of music can be remarkably well preserved and, even if persons suffering from dementia suffer considerable loss of language, they can both remember and sing known songs. Even in the very late phases of the disease, when dementia sufferers no longer react to other stimuli, they can react in a remarkable manner to music. Hence, experiences connected to biographically adapted music and song can contribute to moments of recall and help to revive episodic memory, thereby leading to strong emotions on the part of the dementia sufferer. Recall is the ability to remember spontaneously without help from the surroundings and is negatively affected even by a low degree of dementia. Recognition is the act of remembering with the help of conversation, music, or pictures, in other words with help from the surroundings. The ability to recognize is negatively affected by a high degree of dementia (Mjørud & Røsvik 2021). According to Kitwood (1997), it is precisely biographically adapted measures that are important in a care situation, such as help to tell stories about one's life or photographs of persons and events, because they can help dementia

sufferers to recognize and recall fragments of their earlier life.

Aging, dementia, and geography

Aging is a phenomenon that has been relatively little investigated by geographers (Gagen 2014). Research contributions in geographical gerontology have been primarily concerned with demography, planning, and social policy (Gagen 2014, 251). Little research has been undertaken on the connection between dementia and place. An important exception is Ann Varley's autobiographical account of living with her father, who had Alzheimer's disease (Varley 2008). Her starting point is the place where everyday activities often take place, namely the home. With reference to Young (1997), she demonstrates how the home helps to materialize people's identity in two ways. The first is through artefacts and people's use and organized association with them, which in turn contributes to habits and a feeling of context in life, which, too, are an important basis for people's memories. The second way concerns the significance of the home and its artefacts as bearers of 'sedimented personal meaning as retainers of personal narrative' (Young 1997, 150). Hence, social relations and materiality help to connect the past, present, and future. Without this anchor, a person is literally lost as far as memory is concerned. Varley shows how her father, a widower, did not want to live in a care institution but the whole time wanted to return home. She refers to a statement by one of the staff of the care institution where her father was living: 'They all want to go home' (Varley 2008, 57). Furthermore, Varley (2008, 61) states:

Having seen how being at home helped my father sustain his narrative of self, and how not being able to go home causes him and some other residents of his care home such distress, I can no longer read denunciations of the dysfunctional home without feeling a chill of unease. We are none of us autonomous at home, but there may come a time in our lives when we too desperately wish we *were*.

Habits and fields of care

What is the existential fundament for episodic memory? For Merleau-Ponty (1974), human perception is the fundamental condition for how we gain access to the world, and one's own living body (*le corps propre*) gives access to and knowledge of the world. Casey (1987) argues that it is through perception and the use of all our senses that memories are activated in the body, and that it is more bodily than consciously that

humans gain a fundamental attachment to places. Tuan (1996 [1974]) understands places as fields of care when people have repeated experiences and develop emotional ties to the material and social surroundings in which they live and act. In this way, place becomes embodied through repeated everyday activities, which over time creates an emotional attachment to places (Tuan 1990; 1996 [1974]; Schlemper et al. 2023). Fields of care are created over time through using the body and all its senses: 'other than the all-important eye, the world is known through the senses of hearing, smell, taste, and touch. These senses, unlike the visual, require close contact and long association with the environment' (Tuan 1996 [1974], 446).

For Tuan (1977), it is not the external surroundings, such as the house and building, that first and foremost provide the basis for close experiences and memories, but rather everyday episodes:

In smaller, more familiar things memory weaves her strongest enchantments, holding us at her mercy with some trifle, some echo, a tone of voice, a scent of tar and seaweed and the quay [...] This surely is the meaning of home – a place where every day is multiplied by all the days before. (Tuan 1977, 144)

What does Yi-Fu Tuan understand by the concept 'fields of care'? As I interpret several of Tuan's texts, 'care' concerns the repeated silent and bodily embedded everyday practices and the emotional ties created between people and places that give a feeling of meaning and care in people's lives. Such places have qualities that are important to protect because they define us as humans. Such a sense of place does not have to be conscious in the sense that one reflects over which qualities the place has. According to Casey (1987), bodily memories are often so ingrained that they do not need to be explicitly recalled. It can sooner be that when life first becomes difficult and 'falls into pieces' (Heidegger 1962) or when the home place is threatened by external forces that the meaning of home place and home stand forth with a more distinct 'personality' and identity.

Music and song can awaken emotions

In my earlier observations of the caring of dementia patients, I found that especially carers' singing can help dementia sufferers to show strong emotions and become moved by hearing a song or singing together (Wollan 2014). In conversation with health workers, Rose (pseudonym) expressed that especially old, known songs can awaken memories for people with advanced dementia (Wollan 2014, 53).

Even if one cannot express oneself through speech, both music and songs penetrate and lead to strong

emotions. My observation of singing used in dementia care showed that singing could serve as a door opener to a conversation about life, both in general and in particular. Nonetheless, music and singing do not necessarily function in this way in all situations, especially in cases of advanced dementia (Wollan 2014). If the dementia sufferer is open to the use of other approaches, other remedies can be used, such as a biographically adapted photo album or an artefact or a tool that the person has had a strong relation to earlier in their life. In a situation characterized by physical presence and assurance, such conversations can contribute to a feeling of connection and identity in the life of the dementia sufferer. With reference to the work of Kitwood (1997) and Varley (2008), it can be asserted that it is everybody's responsibility, both in public and private care situations, to contribute to narratives that can give the dementia sufferer a feeling of context.

Discussion

Both biomedical and social scientific research has shown that music and song can have significant positive effects for people suffering from dementia. Research has shown that the area in the brain where musical memory lies is relatively robust, even in cases of advanced dementia (Jacobsen et al. 2015; Brean & Skeie 2019). The personalities of people suffering from dementia are as varied as the personalities of those not suffering from dementia. The sufferers have individual backgrounds, histories, and preferences (Ekra & Dale 2020). Music and song can lead to excitement and joy, but also to sorrow and sadness. Music and song in a context characterized by authenticity and assurance can contribute to important human needs for belonging and identification with place being looked after to a certain degree. Often, people with advanced dementia suffer from aphasia, which means that the health workers must put emphasis on other forms of communication than verbal language, such as physical reactions and emotions. Such an open and attentive approach to individuals shows the significance of prioritizing human dignity over the illness itself (Kitwood 1997; Nyström 2002).

In answer to my research question of how humanistic geography and awareness of place can contribute to increased understanding of the effect that music and song can have for people suffering from dementia, it is especially noteworthy that music and singing by health workers can stimulate episodic and contextual memory. Hence, dementia sufferers can recall or recognize fragments of their earlier life and the places where they have lived and worked. When recall and recognition

occur, they can often produce strong reactions and emotions. Sense of place, understood as a field of care (Tuan 1996 [1974]), indicates how people over a long period of time develop emotional ties to their material surroundings, where home is in focus. In most cases, those suffering from advanced dementia and who can no longer tackle ordinary everyday tasks are moved to care institutions. Despite their disease, they often long to return home (Varley 2008). This indicates the fundamental, existential significance of geography and place also for those who are suffering illness. Hence, humanistic geography is relevant for studies of both aging and dementia.

Conclusions

In this article I have expanded on my previous report (Wollan 2014) that demonstrates how systematic use of biographically adapted music and song can have positive effects for people suffering from a dementia. In this article, I have shown how music and song can create happiness, stimulate activity, lead to merriment, reduce uneasiness, and produce emotions that to a certain extent help recall and recognition of memories. At the same time, the relational dimension – health workers' physical presence and meeting with dementia sufferers – is decisive for music and song to have a positive therapeutic effect. Music and song can help reawakening and recognition of memories. Dementia sufferers can listen to music and song, play music and sing themselves, and maintain emotional ties to places embodied in their earlier life and practice and to which they have a strong sense attachment. An increased interest among geographers in aging, especially a humanistic geographical approach emphasizing place and home, could potentially contribute to increased understanding of the significance of memory processes for people suffering from dementia.

Disclosure statement

No potential conflict of interest was reported by the author.

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