

Exploring your soundscape: Engaging with stakeholders in dementia care to explore the potential of sound

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Abstract: The number of incidences of dementia is predicted to increase. Alternatives to clinical and medical approaches are needed to improve their general wellbeing and quality of life. Research has shown how music can positively impact people living with dementia in advanced stages of the disease. This paper will introduce a project that explores the relation and potential of (ambient) sound and dementia. The specific study in this paper examines the impact of personalised soundscapes of everyday sounds through a workshop. Stakeholders in dementia care at a care provider in the Netherlands were invited to engage with researchers and explore their own relationship with ambient non-musical sounds and discuss the potential for dementia care.

Introduction

With the increase in number of people living with dementia, there is an ongoing need for non-clinical and non-medical approaches, experiences and activities that can improve mood, alleviate tension and reduce stress in the care task (Treadaway & Kenning, 2016). It is well established and documented that music can achieve this and have positive effects on people living with dementia (Baird & Samson, 2015). Music is used for therapy, to prompt memories, to relive past experiences, to stimulate and to calm, relax and soothe. However, the impact of (ambient, non-musical) sounds on the wellbeing and quality of life of people living with dementia is less well researched and understood.

Sound is an important element of our everyday. The ambient sounds of our environment are pervasive. They shape responses, behaviours and mood, provide cues and triggers, bring comfort and provide warnings, and help us to navigate spaces, both physically and mentally. This paper will report on the first phase of a design research project that explores the role of everyday sounds in the lives of people living with dementia. The aim of the project is to explore how ambient and everyday sounds can positively support people living with dementia in a care environment.

While research in relation to sound and music has often focussed on therapeutic aspects (i.e. Bulsara, Seaman, & Steuxner, 2016), this project will use soundscapes in context of leisure time, and to offer comfort and support in times of transition, for example from the home environment to residential care, or during visits to the hospital. In addition, while soundscapes may prompt memories, the project is not intended to focus on reminiscence, but on explorative possibilities and potential (Morrissey, McCarthy, & Pantidi, 2017). Researchers will explore the development of personalised soundscapes for different purposes and experiences. To understand what sounds have an impact on people living with dementia and stakeholders in their care, researchers will explore sound through design research activities with them. The project has received funding in the Netherlands and work has begun to explore the role of sound. Later, the project will be extended to work with care organisations and people living with dementia in Australia.

Background

Music abounds in the everyday. It is a companion in our daily lives. We are often accompanied by music as we move through public spaces such as supermarkets or train stations, and in the private spaces of our cars and homes, we choose to listen to radio stations and personalized playlists. Music is often one of the choices we make in our everyday lives, it asserts our sense of self and individuality. While music can remain a background noise, when we choose to focus on it, it can have a profound affective impact. So too, for people living with dementia. Research has increasingly shown how music can stimulate, calm, excite and affect people living with mild cognitive impairment, limited cognitive function, and dementia (Baird & Samson, 2015; Gold, 2013).

We recognize the importance of music in our everyday lives, but so often do not recognize the impact of ever-present environmental and ambient sound. All too often non-musical sounds grab our attention when they are loud, highly repetitive, or at an uncomfortable pitch. When a consistent noise suddenly

stops, it is often only then that our attention is drawn to it. Ambient sounds support us in scenarios of the everyday by, for example, signalling and cueing behaviours. Sound is omnidirectional and can communicate information about our environment (Bakker, van den Hoven, & Eggen, 2012; Eggen et al., 2008). We may choose to close our eyes and block out sights we do not want to see. But, we cannot simply close our ears. When we do choose to block out sounds, we often simply replace noise with other noises. For example we might use music to mask unpleasant sounds (Hayne & Fleming, 2014). When we use devices such as earphones, or technologies such as noise cancelling headphones (without music), we are often drawn to the sounds of the movement of air, or the sounds of our own bodies. New knowledge in the area of peripheral interaction and the related field of psychoacoustics, offer advanced means to focus the human auditory system and bring sounds to the foreground of the listener's attention when intended or needed (Bakker, Hausen, & Selker, 2016). This provides other ways to mask unwanted sounds by making them non-informative, but pleasurable as with, for example, information decoration (Eggen & Van Mensvoort, 2009).

Scoping the research

When we choose to focus on ambient sound, it can also have a profound affective impact—as music does. It can promote pleasure, nostalgia, familiarity and wellbeing. We might think for example of the pleasure and nostalgia in hearing the sounds of church bells from a familiar village or town, the sound of water running, the wind in the trees, the joy for a car enthusiast of a specific car engine, or the sound of machinery. They may prompt recall about time, place, or people. Some sounds, of people talking in a different language, an urban soundscape, or sounds of nature unfamiliar to us, may make us think about places we would like to visit.

In this study we aim to explore the sounds of the everyday in context of dementia care and investigate how we can use sounds to stimulate and comfort, provide triggers and cues, and to improve quality of life for people living with dementia and stakeholders in their care. To do this we need to understand what types of everyday sounds are more likely to promote an affective response. What sounds do people favour and respond to? Is this the same for a general population as it is for people living with dementia, or with mild cognitive impairment? Therefore, we need to engage with stakeholders in dementia care and directly with people living with dementia using participatory design approaches.

Before engaging directly with people living with dementia, we chose to explore the potentiality for ambient sound, with a broader network of stakeholders involved in dementia care. This broader network needs to be included in design for dementia projects as early as possible to increase the chances of a higher impact (Brankaert, den Ouden, & Brombacher, 2015). For this study, we worked together with a group of spokespersons for people with dementia, as representatives of people with dementia. This allowed us to: 1) Reflect more deeply on the potential of sound to impact dementia care in a broad context across all levels of care, and 2) to test assumptions and experiment with sound to enable us to establish parameters for the subsequent work with populations of people living with dementia. Therefore, in this study we researched the potential of sound and personal sound reminiscence for people with dementia, with a close stakeholder network.

Method

For this study we chose a workshop setting, as it provides an open and safe space to discuss and explore sound in the context of dementia care. Throughout the workshop we drew on mindful practices and reflective approaches to encourage participants to think about and focus on sound (Webster Wright, 2013). They were asked to reminisce and reflect, to imagine and create, and think about their everyday environment and the role of sound for them individually. The participants in the workshop included family members, informal carers, staff and management of a care organisation in the Netherlands.

The workshop was hosted at care organisation Pleyade, located in the area of Arnhem, the Netherlands, by their in-house innovation team: PIT (Pleyade Innovation Team) in collaboration with the authors Dr Gail Kenning and Dr Rens Brankaert. The workshop ran for 90 minutes and was audio recorded with consent of all participants.

In excess of twenty people attended the workshop (Figure 1). The participants were given an overview of the project (Everyday Sounds of Dementia) and were provided with information on the theoretical, practical and technical opportunities for sound and design in the context of dementia care. They were then invited to start exploring ambient sounds in a personal way. This happened in four exercises:

1. Participants were asked to close their eyes and focus on the now. They were asked to listen to the sound of the space they were in at that moment. After

two minutes the participants were asked to share what they heard and how they felt about their experience.

2. Participants were asked to close their eyes and to think about a time in their life that they were completely relaxed and comfortable. It could be, for example, on a holiday, at a beach, walking in a forest, in a room in their house etc. They were asked to think about the space in a sensory way, to 'look' around the environment, in their mind, as if they were there. Once they were comfortable 'seeing' the space they were asked to focus on the sounds they heard. After two minutes they were asked to stop, reflect and share their experience with the group (if they wanted).



Figure 1. Impression of the workshop setting.

3. Subsequently, the participants were again asked to close their eyes and to place themselves in a space or time where they were uncomfortable or restricted. An example was given of being a child when you are told when to go to bed, when to go to school etc. Once they were immersed in this scenario participants were asked to imagine the sounds (the footsteps outside your door, the sound of the wind or rain outside). After 2 minutes the participants were then again asked how they felt and reflected on the experience as a group.

4. Finally, the participants were asked to close their eyes again. The final scenario asked them to imagine a fictive future place where they always wanted to go to, or something they always wanted to do. For example, go to China, visit a farm, or go skiing. They were asked to imagine themselves there, and were asked again to imagine the environment, visual, smell and sound. After 2 minutes again, they were asked and to reflect on their experience and feelings one final time.

Each of the scenarios asked people to be mindful, reflective and think about sounds in the context of now; comfort, familiarity, or nostalgia; discomfort, restriction or concern; and finally in terms of desire and future potential. After the four scenarios had been explored, discussion took place about participants' experiences and how these experiences might translate and impact on people living with dementia and particularly those in the advanced stages. Participants were asked to consider how sound can impact on how they feel and understand the world around them.

In the final stages of the workshop participants were shown a movie clip (Pirates of the Caribbean boat scene <https://www.youtube.com/watch?v=rn9V0cN4NWs>) with different soundtracks representing triumphant and victorious, scary and foreboding, comical, and sad and thoughtful sounds. This illustrated how we make meaning and gain understanding through sound cues, and how different sounds can create different assumptions and interpretations.

The participants and researchers engaged in open discussion about how ambient sound can support dementia care providing cues to past, present and future actions and events; ease and assist with transition; provide comfort and entertain; or by being calming or stimulating.

Findings

In this section we will cover the findings from the discussions with the participants, and the researchers, during the four exercises described above.

Exercise 1: Sound of the now

The first exercise was intended to make the participants aware of their current environment, familiarise them with the setting and make them comfortable with exercises they were being asked to do. It was also intended to heighten their awareness of the space and the sounds around them.

In response to the first scenario participants suggested that, when they closed their eyes and listened to the sounds in the space it focused their attention. One participant commented that they felt: "Separate from the real world." This response was echoed throughout the group as they commented on the acoustics in the room that gave them a sense of being inside a secluded space. They suggested there were layers of sounds as they listened to the surrounding sounds of cars outside, and the air-conditioning inside the space. Another participant mentioned how far the sounds travelled and suggested: "I

Could hear talking outside, and also the door in the hallway.” The first exercise showed that people were comfortable in performing the tasks, and willing and able to verbally reflect on their experiences of listening.

Exercise 2: Sound of relaxation and comfort

In the second exercise participants were asked to recall a positive experience and listen to the sounds around them in that space. Two participants suggested they were at a beach setting. One participant mentioned: “It feels relaxed ... I was on a beach, it was warm, [I was] at the sea.”. A second participant gave very specific examples of sound for her relaxed scenario. She said: “I was in the spa, I could hear water around me and hear people talking.”

A third participant commented that he struggled with the exercise suggesting that while: “I was also on the beach, [but] I could not hear anything, or place myself [at the location].” Discussion later returned to this point as the participant mentioned: “I don’t have a recall of sound at all, [but] I felt things.” This was an important learning for researchers as they recognised that imagining and recalling sounds was difficult for some people, and less important to them. Discussion centred on how people might be more visual (and ‘see’) whereas others might ‘feel’ or ‘hear’ an imaginative scenario more intensely, and there was nothing ‘wrong’ with not ‘hearing’ anything during the exercise.

An interesting observation was that most people had a water related experience as the beach and spa examples above reflect. It could be that people associate water with relaxation, or that the example we described in setting up the exercise used a beach (and forest).

Exercise 3: Sound of discomfort and restriction

Participants were asked to recall an uncomfortable experience, and think about a situation where they were restricted, confined or not in control. Such as, being sent to bed as a child, or made to go to school or visit a place they did not want to.

The rationale for this exercise was to encourage thinking about how as adults we often make or own decisions about where we go and what we do. Even if we are required to be in a space or place we are usually not forced against our will. Participants were encouraged to think about how everyday sounds of space may become frightening or foreboding, when we do not want to be in a place.

People living with advanced dementia may have little control over where they are taken, how, and at what time. Therefore, unfamiliar, loud or jarring sounds may heighten fear in a scenario where individuals lack control.

Less people were keen to share their experiences during this exercise than in the previous two. Their privacy was respected and researchers did not push people to share experiences. It does suggest however, that there is more research that needs to be carried out in this area.

Exercise 4: Sound future

The final exercise asked participants to imagine a place where they would like to go, or something they wanted to do in the future. During this exercise participants showed more interest in discussing the sound in the context of their 'new' experience. In contrast to when they talked about reflections on personal experiences. Most participants thought a combination of modalities would work best for people with dementia, a participant asked: "Does it have to be sound solely, or can it be combined with visuality [visuals]."

Closing insights from workshop

Participants also began to think and talk about how to explore ambient sound with people living with dementia, saying: "You have to record the reaction of your patient, and see whether the patient likes to touch, see or hear You have to try everything." Participants often returned to discussion of projects that use headphones to play music at Pleyade, and it became important to distinguish between what has been done with music and to emphasize the difference between what focussing on ambient sound and not only music can offer. This prompted a reflection across the four exercises as a participant recalled enthusiastically: "I liked your example of the church bells" [refer to previous part in presentation] and continued: "My parents have a clock, and it used to be at my grandparents [house], it is such a familiar sound you know [already] your whole life, and it gives you a kind of trust". The participant thought further and reflected: "It is nice to use this [feeling of trust]". As discussion continued we became aware that the participants began to understand the value of sound and became increasingly enthusiastic about our ambitions for the project to work with sound for people living with dementia.

After the exercises the participants responded enthusiastically to the movie clips that demonstrated the power of sound (Pirates of the Caribbean example). The movie clip also inspired talk of another example of a sound related project at Pleyade, the participant began: "I want to give you a beautiful example

[from long-term care facility], we have beleaf TV [Experience-TV], and on that TV there are pictures of babies with a smile, the pictures are beautiful but also the sound behind it is from babies laughing, and when we play that everybody is laughing along with it." The others responded positively, and the participant reflected: "yes, you can really do a lot with sound". The participants began to think, along with the researchers, about the potential uses of sound in context of dementia care.

Many participants had engaged in co-design projects with people living with dementia. However, concern was also expressed by one participant with regard to the design of the research. She began by commenting: "I have a very important question" and asked "how do you involve people from [long-term dementia care wards] ... Are they guinea pigs?" This highlighted the challenges faced by professional care staff, care organizations, designers and researchers working across disciplines. Work needs to be ongoing with regard to how research projects operate from a position of dignity and respect for all participants, and the philosophy of best practice participatory projects that focus on doing 'with', and not doing 'to.' It is important to elaborate on how this is carried out and precautions taken to allow for process and continuous consent, over just informed consent.

Discussion and conclusion

In this study we worked together with different stakeholders in dementia care to explore how ambient sound can support people living with dementia. In a workshop setting we did exercises to reflect on and explore personal experiences of sound. This facilitated wider discussion on the potential for sound in the context of dementia care, particularly because of the diminishing social and physical environment of people living with dementia, and their 'shrinking' sonic landscapes. In the workshop we demonstrated the powerful potential of sound to instil experiences and emotion, which could be projected on and transferred to situations in dementia care.

Some consideration is needed for follow up studies with regard to how people responded very differently to the sound-based exercises. Some people were more prone to sound triggers, and it was apparent people prioritise different sensorial modalities. While some people could 'hear' recalled sounds clearly, others could not. This needs to be taken into account in exploring a range of modalities to support positive experiences in dementia care as well.

Participants were highly supportive of the notion that a person with dementia does not need to remember or recall a situation, to still experience the state of a certain moment. Most participants felt this had high potential, especially when people with dementia would be restless, agitated or as a leisure time activity for them.

During the workshop it was apparent that music often dominated participants thinking about sound and explaining the differences between music and sound was challenging. The participants did grasp the concept towards the end of the workshop, after some discussions. However, the participants did appreciate the direction of the project especially in terms of supporting care staff when a person with dementia was agitated or uncomfortable after for example a transition in care environments. Therefore, sounds could play a crucial role in making their care environment feel comfortable and more like 'home'.

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Maarten Houben is a PhD candidate researching the impact of interactive sounds and soundscapes on people with dementia. With a background in architectural engineering, he is interested in ambient technologies and interactive spaces, that have a meaningful impact on vulnerable user groups.

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