Everyday Sounds of Dementia: Design with and for dementia

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Abstract

With technology and design we can contribute to the positive well-being and quality of life of people living with dementia, and their carers. One under-researched strategy to do this is sound, and the use of soundscapes. Whereas there is a high potential for sound to support day-to-day functioning and during times of transition to higher levels of care. In this position paper, we sketch our ambition to research the potential of sound and develop interactive Soundscapes (collages of everyday ambient sounds) to calm, reduce agitation, stimulate, excite and engage people living with dementia in times of anxiety, stress or boredom, and promote meaningful activities in high-risk situations.

Author Keywords

Dementia; Design; HCI Research; Soundscapes.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

Introduction

As the global population ages, the number of people living with dementia is predicted to increase to unprecedented levels (Prince et al. 2013). Most often people living with dementia and their carers prefer to

remain in their own homes as long as possible, transitioning to residential care only when absolutely necessary. While care demands for this group of people will inevitably rise, care budgets will likely remain stable. Thus, there are both social and cultural drivers and an economic push to keep people living with dementia and their caring partners at home longer, be more self-sufficient and rely less on formal care services.

Dementia is an umbrella term for a wide range of conditions, of which Alzheimer's disease and cardiovascular dementia are the most prevalent at more than 95% (Prince et al. 2013). People living with dementia have less opportunities to socially engage outside of the home and spend increasingly longer amounts of time at home. While this provides a trusted comfortable environment, it can also be limiting, frustrating and lead to boredom (Wikinson et al., 2015). As the disease progresses, care demands and living arrangements may need to change as individuals move to higher levels of care such as for example residential care, respite centers, or hospital environments. The transition from home towards a care environment can be an anxious time for both the person living with dementia and their informal caregivers. Such a change can cause discomfort and stress resulting in challenging behaviors. Therefore, there is an ongoing need for stress-reducing strategies in both the home environment, the more formalized care environment and the transition between these.

The role of design
Additionally, the quality of life of people living with dementia and their family members can greatly be improved by relieving stress, frustration, and boredom, and by empowering individuals to be engaged and active through social and meaningful activities. This approach promotes a sense of self, independence, and autonomy, contributes to general health and wellbeing, and reduces the need for pharmacological interventions

There are opportunities for the creative industries to design non-pharmacological interventions that can occupy, refocus attention, and re-engage people living with dementia in the day-to-day and empower people through activity, providing a sense of normalcy and build social resilience (Kenning 2015, Treadaway, et al. 2015). Well-designed technology can play a crucial role in supporting people to live independently at home. The need to involve people living with dementia, and their carers actively in the collaborative design of technology is increasingly being recognised (Treadaway, et al. 2015, Brankaert & den Ouden, 2017) but, remains an under-addressed issue.

Sound and dementia
This project will build on existing knowledge related to the benefits of sound and music in relation to dementia and develop design-research co-design approaches to explore it as non-pharmacological intervention.

Our ambition is to explore sound and dementia, and the hypothesis that listening to curated sets of sounds can reduce stress, soothe or excite; relieve boredom; and support the wellbeing of people living with dementia. Familiar sounds may support reminiscence, while unfamiliar sounds might trigger emotional or cognitive responses, potentially leading to new experiences. It will investigate how sound can be used to create experiences and add to quality of life—particularly for those with limited opportunities to do so by

themselves.

We know that Music can have an impact affectively and at a profoundly deep level (Http://www.musicandmemory.Org, 2011). It has shown to be beneficial for people with dementia, mild cognitive impairment and limited cognitive functioning (Gold 2013). But, music is just one aspect of the many sounds we experience in our daily lives. Sound empowers human beings, it supports us in our everyday lives through signaling, communication, and by providing pleasure. Sound is omni-directional and can provide information about our environment (Bakker, et al. 2012), or inspire imagination. Sound communicates, not only as language, but also by providing contextual information about the environment, think for example about an empty room, a railway station, or a lively forest. Sound can provide detailed information about the context, build expectations and cue behaviors (Eggen, et al. 2008).

The term 'soundscape' was coined to focus attention on the coherent set of auditory events that people listen to, consciously and unconsciously, and that allows them to understand, function and enjoy their everyday lives. As summarized by Schine (2010): " Acoustic cues and signals are aural reminders and temporal nods to the rhythms of daily life; they help define an area spatially, temporally, socially and culturally." Over many years of listening people become part of 'acoustic communities' and develop strong associations with their soundscapes. So, in the same way that research shows that people with dementia can engage with past experiences by playing them songs they once liked and creates possibilities for communications. We support Schine's (2010) suggestion that soundscapes can do

the same. Whereas Shine (2010) focused on so-called Soundwalks, as a method to retrieve memories through sound, we aim to investigate the role of 'in the moment' soundscapes to provide positive experiences for people with dementia and asks; what are the most important sound signals, keynotes and soundmarks that capture a person living with dementia's current environment? What impact do these soundscapes have on people living with dementia? And, can the most relevant elements of these soundscape be transferred to new situations and settings, such as in transition to care homes?

We will explore how state-of-the-art sound technology can support the (re) generation of high quality soundscapes that go beyond the traditional 'soundwalk' to provide people with dementia and their caregivers fully interactive soundscapes adaptable to situations, preferences and past experiences of the individual.

One example of how design could achieve this is the "Discover Dementia" pillow for people with dementia (Brankaert, 2016). This pillow allows people with dementia to listen to sound fragments, personal messages and music through a soft fabric interface (figure 1). First explorations with this pillow show that emotions and memories can be elicited through sound, that cannot be reached in conversation.
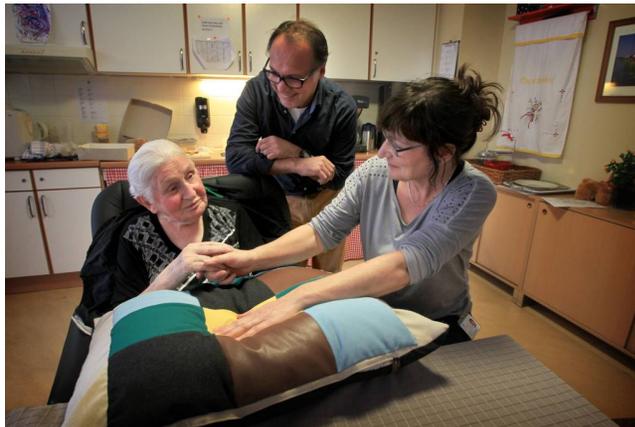
Figure 1. The discover dementia sound pillow. A video can be found on Vimeo: https://vimeo.com/110290394.

Discussion

To achieve this we will will use co-design and participatory and reciprocal design approaches that provides social engagement and meaningful activity during the design process of identifying affective everyday sounds, establishing a categorized collection, and exploring easy to use technologies and interfaces to access them. We will develop research artifacts (design proposals in the form of interactive digital or physical objects used in the research through design process to investigate how sound and sound interventions can have a sustainable role in a real-life context of dementia care and wellbeing.

Dementia impacts cognitive and physical functioning such that each person's experience of dementia is different. People live in different physical and social environments and have different support mechanisms and social network structures in place. Therefore, for interventions to be successful the design approach needs to take into account individual wants, needs, likes and dislikes, circumstances, personal context and environment, and existing relationships with family members and caregivers (Brankaert, 2016). Research shows that design for dementia has often been carried out by only using proxy caregiver and formal care perspectives. This is primarily due to the difficulty of working with co-design approaches with people with dementia who might have trouble focusing, apply their cognitive abilities and challenges with reflection. This project uses person-centered approaches, which centralizes the perspectives of individuals with dementia to improve their experience and engage with them in design (Brankaert, 2016).

Conclusion

To conclude, we aim to investigate the potential of sound and soundscapes the context of people with dementia and their close social network through design. With this we want to develop a body of knowledge to understand the affective ability of sound, and explore the opportunities to translate this to concrete design interventions such as the discover dementia pillow.

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