

Unforgetting Music: Exploring the role of music in the daily lives of people with dementia living at home.

Rik Wesselink¹, Marike Hettinga², Geke Ludden³ and Berry Eggen⁴

¹University of Twente, NL; Windesheim University of Applied Sciences, NL

²Windesheim University of Applied Sciences, NL

³University of Twente, NL

⁴Eindhoven University of Technology, NL

ABSTRACT *People with dementia (PwD) risk a deterioration in quality of life (QoL) as the dementia progresses. A growing number of studies show that music can increase QoL. Unfortunately, loss of initiative and problems during product-use hinder access to music. In this paper we first depict a gap in knowledge on the needs of PwD in relation to listening to music in daily life. We then describe how we applied contextmapping to gain in-depth insights in the role of music in the daily lives of PwD, using an ‘activity case’ and semi-structured interviews. Finally, we discuss the insights gained from a thematic analysis of these interviews and explain how these insights contribute to the current body of knowledge and provide pointers for future studies.*

Keywords: dementia, music, home, daily life, contextmapping

Introduction

As the disease progresses, people with dementia (PwD) require more help in performing routine daily tasks and risk a deterioration in quality of life (QoL). Music can increase QoL (Elliott and Gardner 2018). Executing recreational, meaningful and pleasurable activities is an important need for PwD (Meiland et al. 2017) and music can meet this need. Unfortunately, impairment in executive functioning, apraxia and apathy are common amongst PwD and result in problems in product-use and loss of initiative. This hinders their access to music.

There is a growing number of studies that show the effect of listening to music on PwD. Listening to music can have positive effects on mood and quality of sleep (Chan, Chan, and Mok 2010), decrease symptoms of depression (Elliott and Gardner 2018), and increase activity in the ‘rewarding system’ in the brain (Snowdon, Zimmermann, and Altenmüller 2015). Other studies show that listening to preferred music can decrease agitation (Garland et al. 2007), anxiety (Sung, Chang, and Lee 2010) and pain (Park 2010).

A recent scoping review (Elliott and Gardner 2018) highlights three gaps in the existing body of knowledge. First, a narrow range of used methodologies. To study the effect of music on PwD, quantitative methods are used predominantly. These quantitative studies do not provide insights into *how* we can provide access to music for PwD, nor into the role music plays in their daily lives. Second, current studies predominantly focus on the context of care facilities and professionally led music interventions. This excludes a large population, for 60-70% of PwD live at home (Elliott and Gardner 2018). Studies that do focus on the home context, primarily look at the beneficial effects of music rather than at an implementation in the daily routine. Listening to music is an integral part of the daily lives of many people and could provide meaning and help holding on to one’s identity (Elliott and Gardner 2018). Third, the lack of input from PwD themselves: In most studies, caregivers acted as the voice of the PwD and they were the main source of information (Elliott and Gardner 2018). This is understandable since communicating with PwD becomes more complicated as the disease progresses, but it can lead to losing the perspective of PwD.

In current literature, knowledge on how to embed music in the daily lives of PwD living at home is still lacking. Therefore, improving everyday access of PwD to music requires knowledge on their needs and difficulties. This study aims to increase our understanding of these needs by exploring the role music plays in the daily lives of PwD living at home. Our study contributes to the three gaps by taking a person-centred qualitative research approach. Results inform future studies on how smart technology can support PwD to benefit from positive effects of listening to music in daily life.

Method

We used contextmapping (Visser et al. 2005) to gain in-depth insight into the role of music in the daily lives of PwD. The set-up of the study allowed PwD to actively participate and to do this at home, in their own time and at their own speed.

In contextmapping, data is gathered in two phases (Visser et al. 2005). The first phase is used to sensitize participants for the topic of the study. This is usually done in a period of two weeks and

often involves a variety of creative assignments for the participants. For this phase, we developed an *activity case* (Figure 1) with assignments tailored to PwD and focused on music in daily life. Informal carers were asked to support participants in executing the assignments.



Figure 1 – A completed *activity case*. The case contains a booklet with creative assignments that take about five to ten minutes a day. They vary from taking pictures of music at home to creating a timeline of a day. The goal of the assignments is to sensitize participants for the interview.

The second phase is used to generate data, often through a generative group session. We did not use group sessions but interviewed participants in the safe environment of their home. This encouraged participants to share their perspective on music in their daily life, and it provided the possibility to show the spaces and objects that were discussed.

The overall process followed these steps:

1. **Selecting participants:** participants were selected by a dementia care professional based on our inclusion (recently diagnosed with dementia, living at home, informal carers can support the participant in this study for two weeks) and exclusion (mentally not ready to participate, does not accept help from informal carers) criteria. Selected participants were approached by the dementia care professional and informed using an information brochure. If they wanted to participate, the researcher contacted them for the next steps. We included four participants in this study. They varied in age, gender, type of dementia and living situation. All participants were able to sign an informed consent and the informal carers were involved in the study.

Table 1 - Participant information

Participant	Age	Gender	Living situation	Dementia type
P1	65-69	Female	Alone	Lewy body
P2	80-84	Male	With partner	Mixed: Alzheimer's/Vascular

P3	70-74	Male	With partner	Alzheimer's
P4	80-84	Female	With partner	Lewy body

2. **Sensitizing:** We visited the participants, informed them in detail about the study and the purpose and content of the *activity case*. After signing an informed consent, the *activity case* stayed with the participants for two weeks. After one week we made a phone call to the participants to check on the status, and if required help them move forward.
3. **Interview:** After two weeks, we collected the *activity case* and interviewed the participants at home. These semi-structured interviews were recorded and transcribed.
4. **Analysing:** The interviews were analysed using a thematic analysis with an inductive approach (Boeije 2009) by the first author and a second researcher. Insights were compared to current literature.

Results

We first describe the needs uncovered, followed by a more detailed description of the two types of listening to music we identified.

Needs Relating to Music in Daily Life

In the thematic analyses we grouped the needs in three themes: needs relating to (1) emotional state, (2) content, and (3) products. The first theme (emotional state) represents needs that do not specifically relate to music (autonomy, dealing with negative emotions, enjoyment, social awareness, liveliness and distraction, reminiscence, and tranquillity). We found that music can play an important role in fulfilling these needs. Participants, for example, play music to overcome negative emotions (P1), purely for enjoyment (P1, P2, P3) and to make the home livelier (P2).

The second theme (content) represents needs that relate to the carrier of the music and their preference in music. Personalized music was an important content-related need. P1, for example, explained she experiences an overload of digital radio channels, mainly with music 'that is just not for me, so much screaming'. This abundant offer of music she doesn't like makes it hard to find the channels that play music she does like.

The third theme (products) represents the needs relating to the design and functionality of the products they use to play music. Most reported issues in this theme relate specifically to the field of interaction design.

Needs relating to content and products reveal the 'music' barriers PwD run into in their daily lives. When these needs are not met, this has a negative effect on fulfilling the needs relating to emotional state. Autonomy, for example, declines when PwD cannot operate a music player. Difficulties in interacting with music players were reported often. P4, for example, could not turn on music at all, and P3 reported that he prefers listening to his CDs, but when he is alone, he cannot do this, so he turns on the radio. Remarkably, most participants required richer functionality than what is

commonly considered in the design of music players for PwD. In our study PwD indicated they want to be able to play music from several sources, including records, CDs and YouTube (P1, P3). Furthermore, they like a remote control (P1), and when they live with a partner, they like to listen privately (P2, P3).

Ways of Listening to Music

We identified two ways of listening to music: *music as background* and listening to *music as a focused activity*. The reasons to turn on music, music sources, role of the music, and related needs vary between these two ways of music consumption.

Music as Background

The need for music as background varied between participants. One participant (P2) continuously played the radio during the day. Reasons for this were eliminating the silence, adding liveliness to the room, and keeping up with what's happening in the world (P2). For background music, our participants only used FM radio and sometimes switched between radio channels. When other activities required them to focus, such as when they wanted to read the newspaper, the volume was lowered (P2). Other participants (P1, P4) explicitly explained they did not want the radio on all day, because 'those commercials make me crazy, and it all goes so fast!' (P1) or 'every now and then you hear a nice song on the radio, but it is followed by a lot of chatter and fuzz' (P4). Moreover, in contrast to P2 they liked the silence sometimes. It provided tranquillity.

Listening to Music as Focused Activity

P1, P2 and P3 described moments where they listen or want to listen to music. In these situations, they really focus on listening and enjoying the music. They assigned an emotional value to the music. P1 explained that music makes her happy when she is feeling anxious, and it helps her to get rid of all the negative thoughts. P2 emphasized he loves classical music. The moments of the day on which participants focused on listening to music varied between the participants. P1, for example, listens to music 'while drinking coffee' and she takes the radio to the shed 'There is a nice table there, with a big white towel on it. Garden chair with a pillow, so I can sit comfortably. And there I can enjoy listening to music. And smoke a cigarette.' For P2 this focused listening to music was done 'when I feel like it'.

In contrast to music as background, where radio played a dominant role, listening to music as a focused activity involved a variety of music sources. Participants explained they play their own music, referring to their collection of CDs, records, and even tapes. CDs and records were linked to their preference and stories of the past. Playing music from USB, YouTube, Spotify and digital radio (via the TV) were also mentioned, occurred less often, but had its unique advantages (such as automatically playing related songs on YouTube).

Main Insights and Discussion

The insights we gained through this explorative study are based on activity cases and interviews with a limited number of participants. Although this limits the generalizability of the results, it does

provide in-depth insights into the lives of the participating PwD and the role music plays in it. We compared these insights to what is known from prior studies and set a path for future research.

Insight 1: Participants actively use music for their mental wellbeing.

Music is used by PwD to prevent negative feelings and to actively deal with them when they occur. In studies that focus on the effect of music, music is mainly selected and initiated by therapists or informal carers (Elliott and Gardner 2018).

Insight 2: Problems in product-use limit the feeling of autonomy for PwD, and hamper listening to preferred music.

Maintaining autonomy is important for PwD (Meiland et al. 2017). Most participants owned music stored on sources they could not play by themselves anymore (records, tapes and CDs), making them dependent on others.

Insight 3: There are two ways of listening to music, namely *music as background*, and listening to *music as focused activity*. Most challenges are experienced in *music as focused activity*.

In related literature (Elliott and Gardner 2018), we see that *music as background* is often not considered. This might be because most studies used musical therapy, which always is a focused activity (Favilla and Pedell 2013; Chan, Chan, and Mok 2010; Sung, Chang, and Lee 2010).

For using *music as focused activity* the required functionality of the music player is quite extensive. Most products that provide this functionality, such as the possibility to play from various sources, are too complex to use for PwD.

Insight 4: PwD require interfaces that are in line with and can adapt to diminishing capabilities.

In our study, many of the reported difficulties relate to interacting with the music player or missing functionality. These insights provide a direction for future studies on better interaction design for PwD, which is crucial not only for improving access to music, but for all product design. Better designs could increase the autonomy of PwD in daily living.

In our view, future studies on interaction design for PwD should focus on creating interfaces that are in line with the capacities of PwD, can adapt to the declining capacities of the user, require a low cognitive load, are self-explanatory, and are tangible. Some recent studies already implemented some of these aspects (Seymour et al. 2017; Thoolen, Brankaert, and Lu 2019).

The tangibility and visibility of the music source adds value. Tangible sources such as records, CDs, and tapes make browsing for music intuitive. They can easily be identified, they show the songs they contain, they can carry an emotional value, and they are personal (and therefore often preferred music). Moreover, they fit in the mental model PwD have for music players.

From a functional point of view, and in relation to music, we suggest focussing on one music player to provide rich functionality, make it (or part of it) portable, have high quality sound, and allow for private listening by allowing wired and wireless headphone connection.

Conclusion

This study provided new insights that contribute to the current body of knowledge. We exposed a gap in knowledge on the needs of PwD in relation to listening to music in daily life. By getting input from PwD themselves, and by embedding this study in their home setting, we gained valuable insights into their needs in relation to music in their daily lives. We explain how these needs are currently not met and provided pointers for future studies to improve this. This paper aims to inspire others to include PwD as primary source for data and intensify studies on design for PwD living at home.

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