Access to Music for People with Dementia

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ABSTRACT

How can smart technology support people with mild-moderate dementia to benefit from the positive effects of listening to music in daily life? The quality of life of people with dementia decreases rapidly when they experience difficulties in using everyday products and lose initiative. With a focus on the interaction with music, we study how smart technology can enable human-product-interaction while adapting to loss of initiative. As a result, knowledge on interaction design will be developed to help designers create better products for people with dementia.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Interaction design; Accessibility.

KEYWORDS

Music, Loss of Initiative, Interaction Design, Dementia

1 CONTEXT, MOTIVATION AND RELATED WORK

1.1 General

The aging society poses great societal challenges. One of them is the rapid growth of costs of our healthcare system. Being able to live at home, independently, could help to reduce these costs, and technology can play an important role to support independent living [1]. Moreover, people prefer growing old independently in their own trusted environment [2].

As a result of the aging society the number of people with dementia shows an impressive growth. Worldwide around 55 million people live with dementia. It is expected that this number increases to 78 million in 2030 and to 139 million in 2050 [3].

1.2 Interaction with Products & Quality of Life

Difficulties and inabilities in using everyday products decrease quality of life and hamper independent living for people with dementia. Impairment in executive functioning, apraxia and apathy are common amongst people with dementia and they progress as the dementia progresses. Next to problems in understanding how to interact with a product, this results in loss of initiative.

This doctoral project therefore focuses on how interaction design for people with mild-moderate dementia can be improved (1), and how the loss of initiative can (partly) be countered (2).

1.3 Music & Quality of life

Music can have a great positive impact on quality of life of people with dementia. In a previous study on designing applications and interactions for a social robot for people with mild dementia we found that being able to listen to music was a wish of many participants [4]. Several other studies show the positive effect of listening to music on quality of life. Listening to music can have positive effects on mood and quality of sleep [5], decrease symptoms of depression [6] and decrease fear [7]. Research has shown that listening to music increases activity in the 'rewarding system' in the brain [8].

We use 'listening to music' as the context for this doctoral project.

1.4 Related Work

In related studies and commercially available products [4, 9-13] one main design strategy can be identified: simplifying the interaction and with it (extremely) limiting the product's functionality. This strategy takes away important values of the interaction with music, it does not take the changing capacities of the person with dementia into account and does not provide a solution for the loss of initiative. These products often aim at moderate-severe stage dementia and do not suit people with mild-moderate dementia. No products or studies were found that address both difficulties in product-use and loss of initiative.

Guidelines support designers in developing user-friendly products. Some recommendations and design principles have been found [14], but unfortunately, guidelines on designing for people with dementia are limited. We will therefore also study – and build on knowledge in – adjacent areas, such as design for elderly, children, people with perceptual or motor impairments, 'inclusive design', and errorless learning.

1.5 Challenge

For most people turning on music is a standard routine, performed without any difficulties and without actively thinking about the actions involved. For people with dementia however, this appears to be quite challenging or even impossible. In previous studies [4,

15], the two aforementioned causes, difficulties in human-product-interaction and loss of initiative, are discussed. This means that designing a product that is easier to use is only a partial solution: with the loss of initiative, the product will not be used, even if people are still able to use it.

A lack of fundamental knowledge that can inform design for people with dementia makes it hard to design user-friendly products for them. The challenge therefore lies in understanding how the interaction with electronic devices or systems may take shape and could adapt to the capacities, relating to both the interaction as to the level of initiative, of the person with dementia. Smart technologies are required to enable such adaptive products or systems. If well-designed they could enable people with dementia to use them for a longer period of time.

1.6   Smart technology

In our definition a smart product can take initiative, at an appropriate moment, resulting in something meaningful for the user. Using a diversity of sensors and techniques for data analysis, products and systems become smarter every day. This opens the door to new possibilities in human-product interaction, product behaviour, and functionalities. To support human-product-interaction, smart technology could actively guide the user through the interaction, for example by showing only the available options. To counter loss of initiative, a smart product could draw attention, invite users, or even take over initiative to turn music on or off.

Studying how smart technology should behave and how people with dementia respond to this are crucial aspects of this doctoral project.

1.7   Needs for music in daily life

In this doctoral project we focus on people with mild-moderate dementia living at home. As described before, music can enhance quality of life in different ways, but what are the actual needs and wishes of these people in relation to music? What is already known from literature about the benefits of music at different moments in daily life (for example: listening to music before going to bed can improve the quality of sleep [5])? Before we can study possible solutions, we must understand the current situation.

Studying the needs of people with dementia in relation to music in daily life ([16]) was therefore the first step in this doctoral project.

2   SPECIFIC RESEARCH OBJECTIVES, GOALS OR QUESTIONS

Design methods need to be adapted when involving people with dementia because of their impairments and because of the important role of their social context. Most studies on this topic therefore focus on the process of designing for people with dementia and the methods that can be used to include them and their social context in the research and design process [14, 17]. In our research methodology we make use of and build on the findings from those studies. Our focus, however, will be on acquiring knowledge and insights in human-product-interaction and the integration in daily life. This brings us to the following research questions:

2.1   Main research question

How can smart technology support people with mild-moderate dementia to benefit from the positive effects of listening to music in daily life?

2.2   Sub-questions

- SQ1. Which guidelines are available on interaction design for people with dementia?
- SQ2. What are the needs of people with mild-moderate dementia in relation to music in daily life?
- SQ3. How can smart technology support the interaction with music?
- SQ4. How can smart technology compensate for the loss of initiative?
- SQ5. Which guidelines on interaction design for people with mild-moderate dementia can be derived from this case?

3   RESEARCH PROGRESS TO DATE

Figure 1 shows the overall planning of this research. I have currently completed Phase 1 (study current situation) and most of the work for Phase 2 (explore and define solutions). Phase 1 resulted in a conference paper on the role of music in the daily lives of people with dementia living at home (SQ2) and is published at the Design4Health conference [16].

In Phase 2 we studied related literature on design for dementia (SQ1), addressed a gap in knowledge relating to *loss of initiative*, translated our insights into the design of a music player, and evaluated it with a high-fidelity prototype in the homes of four people with dementia (SQ3, SQ4). Results of this phase are described in a paper that we submitted to CHI2022, and we have material for one other paper that specifically focusses on SQ1.

Although we are still on track, we did have to update our original plan for Phase 2 because of limited contact with people with dementia due to Covid19-related restrictions.

4   RESEARCH APPROACH, METHODS AND RATIONALE

4.1   Phase 1

Since knowledge on the needs of PwD in relation to listening to music in everyday life is lacking, we used a person-centred qualitative research approach (contextmapping [18]) to gain in-depth insight into these needs and barriers. We designed probes (for PwD [19]) to sensitize participants (Figure 2). Results from the probes functioned as input for the interviews. 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.

Results from this study informed our next studies on how smart technology can support PwD to benefit from positive effects of listening to music in daily life.

4.2   Phase 2

We first performed a literature study on interaction design guidelines for people with dementia (SQ1). Results from this study, and the results from phase 1, informed our exploration of possible solutions.
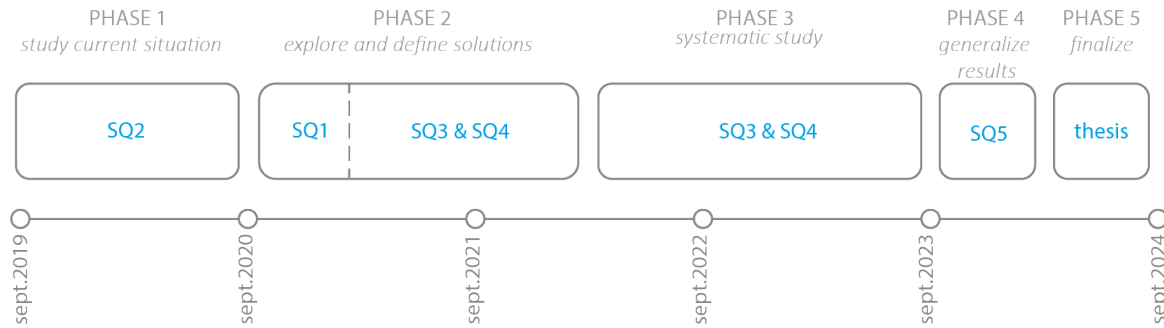
Figure 1: Five-year planning of doctoral project

Figure 2: In Phase 1 we used an activity case with assignments that sensitize participants for the interview on the role of music in their daily lives.

Figure 3: High-fidelity prototype of our inviting music player, used for in-situ evaluations in the homes of people with dementia.

We took a research-through-design (RtD, [20]) approach to study possible futures: how we can transform the world from its current state to a preferred state? We aimed to execute fast RtD cycles to move from exploring to defining solutions. However, due to Covid19-related restrictions, access to PwD was very limited. We therefore updated our study design and worked towards in-situ testing with a high-fidelity prototype, which required less-intense contact with participants.

Results from phase 1, a literature study on SQ1 (current literature on design for dementia), and the missing guidelines we defined in this phase, informed the design of a music player that we prototyped and evaluated for several weeks in the homes of PwD (Figure 3).

RtD is inherently suitable for research on potential futures [20], which makes it especially suitable for this part of our research. In RtD, design activities "not only contribute to achieving a local improvement in a single product or situation but also serve to discover, exemplify, clarify, and promote more general principles, which can be used elsewhere." [21]. Careful qualitative in-situ evaluations are essential in the gathering of new knowledge and insights. Literature studies and relevant validated theories informed the design process and were used to reflect on the outcomes in the evaluations.

4.3 Phase 3

In phase 2 we found strong indications that designing for loss of initiative can increase access to music for PwD. In phase 3 we aim to study this more systematically in a longitudinal study, using interaction-data logging and interviews (with both the users and their caregivers).

Secondly, in phase 2 we describe one way to address loss of initiative in a design: in phase 3 we aim to explore the design space for designing for loss of initiative.

4.4 Phase 4

We aim to explore and define the transferability of our results by comparing our findings to relevant and validated theory (literature review). Our goal is to make the acquired knowledge available to other designers. By deriving general design guidelines for people with mild-moderate dementia from our findings in the previous phases, we aim to support design for dementia.

4.5 Phase 5

Phase 5 is used to assemble and write the doctoral thesis.

5 EXPECTED NEXT STEPS

Our last study showed promising results regarding a design principle we introduced to address loss of initiative in design for dementia. This study, however, focused on one potential solution and used a small sample size. In our next steps we will explore three directions in parallel.

1. Study the impact of our design intervention more extensively.
2. Explore the design space for designing for loss of initiative in dementia.
3. Explore how a music player could adapt (autonomously) to the needs of the users.

The first direction will be my personal focus. The second and third directions will be explored in parallel and in cooperation with design students and colleagues.

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