Active Collaboration in Healthcare Design: Participatory Design to Develop a Dementia Care App

Karin Slegers

CUO | Social Spaces,
KU Leuven - iMinds
Parkstraat 45, bus 3605
B-3000 Leuven, Belgium
karin.slegers@soc.kuleuven.be

Niels Hendriks

Social Spaces | CUO,
MAD-Fac – LUCA – KU Leuven
C-mine 5
B-3600 Genk, Belgium
niels.hendriks@khlim.be

Andrea Wilkinson

Social Spaces | CUO,
MAD-Fac – LUCA – KU Leuven
C-mine 5
B-3600 Genk, Belgium
andrea.wilkinson@khlim.be

Abstract

This paper describes a research project aimed at developing a mealtime data registration tool for people with dementia. As to actively involve all stakeholders in this healthcare design project and to generate empathy and involvement, methods from participatory design were used. For each of the three research phases (ethnography, ideation & conceptualization and prototyping) we describe our approach towards stakeholder involvement and active collaboration. We

discuss lessons learned in terms of good practices and the issues we struggle with.

Author Keywords

Participatory design; Healthcare; Dementia; Prototyping

ACM Classification Keywords

H.5.2 [Information interfaces and presentation]: User interfaces: User-centered design; H.5.2 [Information interfaces and presentation]: User interfaces: Prototyping

Introduction

When designing a new product or application it is essential to thoroughly understand the users, their contexts and practices; we need to empathize with the users. This is especially important when designing healthcare products. Users of such products may be particularly vulnerable, as they have to deal with disease or impairments. As a result, their experiences might be very different from those of the researchers and designers, making it difficult to empathize with these users, and more specifically to understand the issues they face because of their limitations [3].

A possible approach in healthcare design projects is to work with multidisciplinary teams of researchers,

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CHI 2013 Extended Abstracts, April 27–May 2, 2013, Paris, France.

ACM 978-1-4503-1952-2/13/04.

designers, developers and healthcare professionals. However, when working with such teams, it is important to find a way to enhance mutual empathy and to achieve high levels of involvement from each partner, which is not always straightforward. Though participatory design methods are being used for this purpose in information systems design for healthcare [9], it has been recognized that a generalized and integrated participatory approach in healthcare design is still lacking [6]. With this work-in-progress paper we want to contribute to the process of working towards such a generalized and integrated approach. We present the participatory design research from an ongoing design project in the domain of dementia care. We specifically focus on how all stakeholders are involved in the design, and how we aim to realize mutual learning between the stakeholders to enhance empathy and involvement [5].

Context: dementia care project

In dementia care, it is important for caregivers to get to know the persons they take care of. Information about personal preferences (e.g. regarding music, conversation topics, food) for instance, can help caregivers to personalize the care they provide. Unfortunately, many people with dementia suffer from impaired expressive and receptive language abilities [7], making it difficult for them to communicate about their preferences. An additional challenge is the fact that personal preferences can change over time. A preference that is often reported to change with dementia is food preference [4].

The goal of the research project described here is to develop a mealtime data registration system that allows caregivers to keep track of variables that may affect

the meal experience (e.g. food preferences, environmental factors and physical factors). The combined data that is registered as well as recognized patterns in this data provides caregivers with information about the state of wellbeing of patients, allowing them to adjust care.

This research project has a highly participatory approach. Several relevant stakeholders are involved, such as people with dementia, family members and various caregivers. In addition, all members of the project team are involved, including a technical development team, a research and design team (also acting as the moderating force behind the research process), and professional care organizations.

Participatory design research in a dementia care project

Our research process consists of three research phases: ethnography, ideation & conceptualization, and prototyping. In each of these phases the involvement of the stakeholders is organized in a way that optimally takes into account their expertise, experiences and skills. Throughout the entire process, mutual learning is a central aim, with the goal to enhance empathy and encourage stakeholder involvement [1]. In this paper, we describe our approach in each of the research phases. With respect to the more general issue of a generalized and integrated participatory approach in healthcare design, we discuss lessons learned and share recommendations.

Ethnography phase

The ethnographic research phase contained several activities which covered multiple aspects of everyday life for people with dementia. Two 24-hour observations and two 12-hour observations were done in a care

residence and in a psychiatric hospital (at a unit specialized in dementia and the day care center for elderly people). Furthermore, several interviews were conducted with family members, a variety of professional caregivers and a coordinator of a self-help group for family members of people with dementia. In addition, we shadowed a psychologist visiting people with dementia at home to monitor how they are coping and whether increased care is necessary. This research phase resulted in qualitative insights into the lives of people with dementia and their caregivers. Besides a detailed report, these insights were aggregated in a series of six short stories, describing common situations that might occur during a typical day of a person with dementia.

The technical development team on the other hand, organized an information session introducing several technologies that might be of use in the project, in order to enhance the understanding of the technical context of the project. They explained the benefits and limitations in non-technical terminology to the project team.

LESSONS LEARNED

During the ethnographic phase we noticed that the topic of dementia is not easy to talk about. We were even advised by several caregivers not to use the word 'dementia' when talking to patients, but to refer to 'memory problems'. This required us to approach the subject with caution and to prepare our encounters with patients and family members very carefully.

In addition, it proved to be difficult to find people with dementia with a sufficient level of self-reflection for sharing their experiences with us. We discovered that in

early stages of the dementia process, when patients still have such a level of self-reflection, it is often too painful to talk about dementia with strangers.

In summary, we learned that it is important for researchers to invest time and effort in familiarizing themselves with the subject of dementia (or any other health-related domain). One needs to understand the sensitivities related to the subject. In addition, building a network of participants takes time. What we still struggle with is the question of how to get close enough to the target group to truly understand their experiences. We think this to be a methodological question in which the search for the best way to communicate, experience and understand the life of people with dementia is the focus.

Ideation & conceptualization phase

CO-IDEATION WITH PROJECT TEAM

As only two researchers were actively involved in the ethnographic research, an ideation workshop was organized for all members of the project team. To heighten the level of empathy with people with dementia we used a well-considered method taking into account the location, the group formation and the presentation of the ethnographic research. The workshop took place in the house of an elderly woman, providing a highly realistic and relevant context. As a starting point, we used the short stories that had been generated from the ethnographic research. Each story was placed in a relevant space (e.g. stories about preparing food could be found in the kitchen) and these stories triggered a series of collaborative brainstorming exercises. These exercises were done in small heterogeneous groups (consisting of members from the research & design team, the technical development

team and the care organizations) to stimulate mutual learning and multidisciplinary collaboration.

In several rounds of brainstorming, the groups were encouraged to imagine what it would be like to experience the stories. In addition, they were asked to generate concepts of possible design interventions based on a variation of the card set used in the Lillidot method for low-fidelity design [2]. The brainstorms were followed by a short session of low-tech prototyping in which the groups created a modeling clay prototype of one of their concepts. The workshop resulted in 12 design concepts.

PARTICIPATORY DESIGN WITH PEOPLE WITH DEMENTIA

After the co-ideation session, participatory sessions were held, each involving two members of the research and design team, a person with dementia and a trusted family member. Based on the MAP-it toolkit approach [8], basic texts and icons (either prepared or generated on the spot) were used to map routines, places, objects, etc. that were of importance to the person with dementia. A selection of these icons was placed on a sketch of the layout of a 'typical' house. The person with dementia was then asked to indicate in which way their condition affected these routines, objects, places or contact with persons.

Additionally, a fictitious super hero was used that could help overcome the issues typical to dementia. The person with dementia placed a super hero on the five issues that were most important to them. Next, they indicated how this issue could be solved using a 'super technology' with limitless possibilities, regardless of technical feasibility or integration in their life. The

results were used to further generate the concepts created in the co-ideation session.

CONCEPTUALIZATION BRAINSTORM

In a conceptualization brainstorm, the project team further elaborated on the concepts within the context of both feasible care and feasible technology. During this brainstorm, the decision was made to narrow down the focus to the meal experience. Meals are important to people with dementia and their family, as eating and drinking are relevant activities that, regardless of age, can take place without too much complexity. Consequently, mealtime is an important element of everyday dementia care, providing interesting opportunities to improve caregiving.

After the brainstorm, the research & design team created *scenarios of use* describing how a person with dementia and his/her caregivers would use the concepts in real life situations. The *scenarios of use* served as a starting point for the project team to combine their visions and to further detail the concepts collaboratively, taking into account user requirements, technical requirements, and care requirements. These scenarios became a mutual point of reference for the team.

LESSONS LEARNED

In our experience, the co-ideation session was one of the success factors of our project. The heterogeneous groups of a researcher/designer, a developer and a care professional (who both inspired and constrained each other), as well as the realistic context of the elderly woman's house worked especially well.

The fact that the participants with dementia were always accompanied by a family member in the participatory design sessions, turned out to be both crucial as well as risky. The family member stimulated the person with dementia throughout the session, repeated certain questions, 'translated' a (sub)task to make it clearly understandable, etc. Their help as a mediator turned out to be crucial. The major risk in asking family members to help in participatory design sessions, however, was the uncertainty of whether the results are still genuine reflections of the people with dementia: in what way is it not the family member who suggests a certain design choice? Our recommendation here would be to utilize the help of the family member while being critical of their influence.

Besides the recommendations mentioned above, we encountered a difficulty that we were not directly able to solve. As we mentioned before, in earlier stages of the dementia process, it is often too difficult for patients to discuss their situation with researchers. However, in later stages, when patients may be more willing to participate in research activities, cognitive declines typical for dementia make it difficult to actively involve patients in design exercises. We feel that it is important to find methods that allow patients in later stages of dementia, or more broadly, people with impaired abilities, to be actively involved in design activities.

Prototyping phase

PARTICIPATORY DESIGN WITH PROFESSIONAL CAREGIVERS

Professional caregivers were involved in two separate participatory design sessions. The first session aimed at mapping a positive and a negative mealtime experience for people with dementia. In the second session,

caregivers participated in low-tech prototyping based on the mealtime mappings. The caregivers were asked to translate the mappings to a digital mealtime data registration tool. They used a technical template (a mock up smartphone/tablet and accompanying interface elements) to sketch several interfaces of the tool. Working within this technical template provided a framework to explore mealtime care scenarios and yet provided us insight into the caregivers' preferences regarding interface and interaction design as well as how the tool could be integrated into their daily work.

INTERFACE DESIGN & EVALUATION

Departing from the input from the participatory design sessions with caregivers, the research and design team created an interface design, including sketches that were generated during the sessions with caregivers. The interface design was iteratively further refined and frequently evaluated by both caregivers and the technical development team. The final version of this interface design is the basis for the prototype that is currently being (technically) developed.

LESSONS LEARNED

The major lesson learned in the prototyping phase is, in our view, related to the collaboration between the different stakeholders. Where this collaboration worked really well in the ideation & conceptualization phase, there seemed to be less collaboration in the 'making' phase of prototyping. Although the research & design team that made the interface design evaluated their designs with the technical development team and with caregivers, there was no physical, active collaboration in this making process. Such a 'classical' cycle of *design – feedback – redesign* may result in a lack of sense of ownership by other project partners, which we

do not desire in this multidisciplinary and participatory project.

General reflection: Recommendations for participatory healthcare design

For healthcare design projects to become more successful, it is essential to understand how to facilitate a complex and heterogeneous group of stakeholders to continuously collaborate. Although our research contributed to this question by providing some starting points and recommendations, a lot of practical considerations still remain that make a fully generalized and integrated participatory approach quite challenging.

The most important insight that we gained from this project is that active collaboration sessions, stimulating stakeholders of very different backgrounds to create something together, work well. In our project, the sessions where the entire project team spent time (physically) together (such as the co-ideation session and the conceptualization brainstorm) resulted in the best progress. We feel that this is especially relevant for healthcare design projects that typically involve a complex group of multiple stakeholders who each have very different backgrounds and skills and a sensitive target group that is difficult to approach.

Acknowledgements

The research described is part of the iMinds AToM project co-funded by iMinds (Interdisciplinary institute for Technology), a research institute founded by the Flemish Government. Companies and organizations involved in the project are Televic Health, Pyxima and GS1 Belgium & Luxembourg, with project support of IWT.

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