

Developing eHealth Technology for People With Dementia: Towards a Supportive Decision Tool Facilitating Shared Decision-Making in Dementia

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Abstract— People with dementia are confronted with many decisions. However, they are often not involved in the process of the decision-making. Shared Decision-Making (SDM) enables involvement of persons with dementia in the decision-making process. In our study, we develop a supportive IT application aiming to facilitate the decision-making process in care networks of people with dementia. A key feature in the development of this SDM tool is the participation of all network members during the design and development process, including the person with dementia. In this paper, we give insight into the first phases of this design and development process in which we conducted extensive user studies and translated wishes and needs of network members into user requirements.

Keywords: *shared decision-making; decision tool; co-creation; dementia; eHealth*

I. INTRODUCTION

Most western countries are currently facing demographic changes that will result in a dramatic increase of the number of people with dementia. Worldwide there are 35.6 million persons with dementia. It is to be expected that this number will be doubled by 2013 and tripled by 2050 [1, 2].

People with dementia are confronted with many decisions in the dementia process regarding daily life and well-being issues. Involving people with dementia in decision-making is not self-evident. They are often ignored [3]. This lack of involvement of people with dementia in decision-making is also noticed in research and design and development processes. Researchers and designers often develop tools *for* people with dementia

rather than *with* them. People with dementia belong to one of the most neglected groups in research and development [3, 4].

Adequate care of people with dementia demands involvement of people with dementia in decision-making [5, 6]. In other fields of health care Shared Decision-Making (SDM) has proven its positive results regarding quality of life [7-9]. Moreover, SDM increases satisfaction with decisions and results in better informed patients [10]. Furthermore, SDM increases the autonomy of patients and empowers them [10]. This could also be beneficial to persons with dementia.

One of the supporting tools in SDM are decision aids, paper or IT-based. Thus far, a supportive tool facilitating SDM in dementia is lacking. In our study, we aim at designing, developing, implementing and evaluating such a tool.

Many IT applications have been developed to support people with dementia and their family and formal caregivers [11, 12]. Unfortunately, many IT applications are not used by them because they do not match their needs and capacities [13]. Therefore, in our study, involving network members and inclusion of people with dementia in the development and design process are key features.

In comparison with existing SDM tools that primarily facilitate the patient-clinician relation this involvement of all network members in the SDM process is new. Another new element is the focus on the process of SDM instead of on the decision itself.

In this paper, we describe the first phases of the development process of a supportive SDM IT application.

We identified user requirements based on user studies to determine the content of this tool.

II. BACKGROUND

The present study is part of a major research program on SDM in care networks of persons with dementia. This program consists of three studies and aims to improve professional care.

SDM is a process of interaction and communication between a patient who wants to be involved and his or her care providers in making health care decisions, taking into account the preferences of the patient and the best available evidence [14]. In clinical practice patients and their clinicians are involved in this medical decision-making process. In our research program, concerning care and well-being related decisions in care networks of people with dementia this means involvement, interaction and communication between people with dementia, informal caregivers and professionals.

The first study of this research program on SDM aims to provide insight into decision-making processes within care networks of people with dementia in order to improve SDM. In this longitudinal study 25 care networks (each consisting of the person with dementia, two informal caregivers and two professional caregivers) are individually interviewed in three measurement cycles with six-month intervals.

In the second study, specific SDM competencies of professional caregivers (e.g. case managers) are developed. Furthermore, best practices of shared decision-making in care networks of dementia will be developed.

The third and present study, developing a supportive IT application that facilitates SDM in care networks of dementia, uses data from the first two studies. Research questions of this third study focus on the requirements for a SDM tool concerning the most suitable content, user-friendly design and effectiveness, and on the requirements for implementation in daily practice.

In the following section we describe the approach for this third study.

III. APPROACH

Although involvement of end users in developing eHealth technologies still is not self-evident, we consider involvement of end users as one of the key factors for developing a user-friendly and usable IT application. Too many IT applications have been developed without ever being used. Another important factor is sustainability in practice. Researchers and developers become more aware of the importance of making their innovations sustainable. Tools and roadmaps are developed to support developers in increasing the structural embedding of IT applications in health care. One example is the eHealth Innovation Matrix (eHix) [15]. Another approach is the ceHRes

roadmap. It connects a Human Centered Design with eHealth Business Modeling [16].

Both eHix and the ceHRes roadmap emphasize involvement of stakeholders in all phases of the development. In our research program, a multi-disciplinary consortium consisting of a variety of dementia experts and advocates achieves this. Furthermore, we use a stepwise approach in order to systematically translate user studies (needs and wants) in functional requirements of the tool (figure 1) [17].

We started this study by conducting a systematic review regarding the research question: how are people with dementia involved in the development of supportive IT applications [18]. We were interested in the state of the art regarding this question to discover which implications the results would have for our own development process, especially, in identifying user requirements.

The results of this review show that involvement of people with dementia is not self-evident. Included studies dated from 2003-2010. Researchers and developers differ in how they involve people with dementia, depending on how they value the capacities of people with dementia. In most studies people with dementia were involved in the first phase of the development process. Recently, researchers and developers are more aware of the benefits of involving people with dementia in development processes; it results in more attuned and usable IT applications [18].

A. User studies

In the first developmental phase we explored the needs and wants of all stakeholders. Fifty semi-structured interviews were undertaken with persons with dementia, informal caregivers and professional caregivers to get insight into their experiences in decision-making in dementia. Framework analysis was used to analyze the interviews with AtlasTi software. In addition eight focus groups were conducted, two with persons with dementia, two with informal caregivers, two with professional caregivers and two with experts in the field of dementia. These focus group interviews had a twofold goal. One goal was to double-check the results from the interviews. The second goal was to retrieving additional information about the process of SDM and on the needs and wishes concerning (digital) support. AtlasTi software was used to analyze the focus group transcripts addressing the topics mentioned. Furthermore, an analysis of interactive dementia websites was conducted to identify needs of network members regarding decision-making.

B. User requirements

In a multi-disciplinary user requirement workshop (researchers specialized in older adults, dementia and IT, technicians and developers) we used Affinity

Diagramming in order to determine user requirements based on the information retrieved in the above described user studies. In addition these user requirements were compared to national dementia standards in order to check whether they match with these standards [19, 20].

C. Functional requirements

In a multi-disciplinary functional requirement workshop (researchers specialized in older adults, dementia and IT, technicians, developers and designers) the user requirements will be translated in functional requirements.

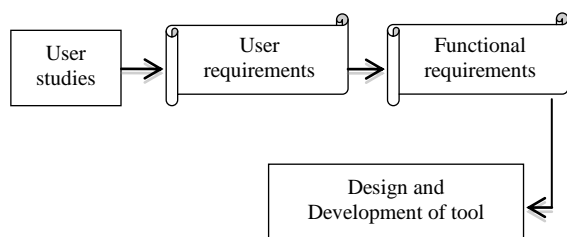


Figure 1 Process from user studies to design and development [17]

D. Experiments

The interface of the supportive SDM IT application will be determined in an iterative, participatory design process. Products of the design and development phases (mock-ups, prototypes) will be the subject of end user focus groups and experiments. Feedback thus obtained informs the next design and development phase in order to improve the content and design of the tool. Special attention will be paid to the adaptability interface of the tool because of the declining cognitive abilities of persons with dementia over time. Experiments will also focus on comparing different ways of implementing the tool in daily practice: network members using the tool individually as a preparation of face-to-face meetings, compared with a shared way using it during such a meeting.

E. Pilot study

When the adapted tool becomes robust enough a pilot study will be conducted to evaluate the usability of the tool in daily practice. Five different care networks of persons with dementia (each care network consist of a person with dementia, two informal caregivers and two professionals) will use the tool for a period of five months. The evaluation focuses on design and content of the tool; interface of the tool; usability of the tool by professionals using SDM; and obstacles and benefits of the use of the tool. Furthermore, the impact of the tool on

the care network members, including the person with dementia, and the decisions made will be evaluated.

IV. RESULTS

At this point in time we obtained the results of the user requirements. The interviews with persons with dementia, informal caregivers and professional caregivers gave insight into the issues and decisions network members of people with dementia experience regarding dementia. Important domains are: care, well-being, daily activities, living, mobility and financial and legal matters. Based on the results of these interviews we constructed a persona. This persona served the purpose of aligning the perspectives of the multi-disciplinary project members' view.

Subsequently the results of the interviews, focus groups and analysis of interactive dementia websites were screened for wishes and needs of end users of the tool. This resulted in a selection of more than two hundred relevant items. The principal researcher clustered these items stemming from the data. The selected items and first clustering were peer-reviewed by a second researcher. During the user requirement workshop multi-disciplinary teams checked the clustering and determined the user requirements per cluster. User requirements were discussed until consensus was reached. The user requirements determined concerned the following clusters: participation of the person with dementia, information, role of informal caregivers, role of case manager, role of other professionals, decision history, communication, anticipation, support, self-management and autonomy, and administrative load.

Our check with National dementia care standards learned that the user requirements are in line with these standards.

V. CONCLUSION AND FURTHER WORK

The extensive exploration and translation of the user studies into user requirements created valuable input for the functional requirements process. This study is now midway. The next step is designing and developing the tool, testing it in experiments and improving the tool using the feedback of involved end users, followed by the pilot study and its evaluation.

Developing a tool to facilitate the SDM process in care networks of people with dementia is a real challenge. Involvement of all stakeholders in the design and development process is needed in order to develop a robust IT application. In the current project we aim to involve people with dementia. In the first phases of the development process people with dementia participated successfully.

The participation of people with dementia in this development processes is a *conditio sine qua non* in order

to get an attuned and user-friendly tool. Researchers, developers and clinicians should be aware of that.

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