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# Summary

## SUMMARY

This thesis reports on the development of an interactive web tool, the *DecideGuide*, facilitating case managers in supporting shared-decision making in care networks of people with dementia. Developing the *DecideGuide* was part of a larger research program on Shared decision making in care networks of people with dementia that ran between 2010 and 2014.

**Chapter 1** elaborates on the background and aims of this study. Worldwide, the number of people that are affected with dementia is increasing. Regardless of what causes the dementia syndrome, dementia is characterized by a progressive cognitive decline leading to increased dependence on informal and formal caregivers. Living with dementia is not easy, neither for the person afflicted by it nor for the informal caregivers. Besides having to deal with the symptoms and disabilities related to dementia they also have to deal with public stigmatization. Negative perceptions about dementia in society result in social exclusion and isolation rather than support for people with dementia in maintaining their personhood. Although negative aspects predominate, there is growing attention for positive aspects of dementia caregiving.

The average life expectancy of people with dementia after diagnosis is 6-10 years. Most of that time people with dementia stay at home, which they prefer, although admission to a nursing home is sometimes inevitable towards the end. This is one of the many difficult decisions people with dementia and their caregivers face. However, involving people with dementia in decisions about their own situation is not common. Informal caregivers and professionals tend to shield them and decide for them rather than with them. Although this is often done with the best of intentions, it does not do full justice to people with dementia. Research shows that people with dementia can express their needs and preferences even in advanced stages of dementia and that they want to be involved in decision-making as long as they possibly can.

Shared decision-making (SDM) is an approach that supports patients in making decisions together with their professional. It has its roots in the clinical encounter and is included in the Dutch Dementia Care Standard as the preferred way of making decisions in the context of dementia. This standard is the basis of the assistance that is offered to people with dementia and their informal caregivers by case managers. However, case managers find it difficult to facilitate SDM in dementia care networks. As decision aids, paper or web based, often support SDM, similar tools for the dementia context might help case managers in supporting SDM in the dementia context. Unfortunately, these specific tools are not available although the development and use of Information Technology (IT) based tools for the dementia context have increased over the last decade.

IT tools can be helpful because they can be used at preferred moments and because they can record all activities. Dementia care networks could benefit from such a

web based tool as it may also enable informal caregivers at a distance to participate in decision-making. Many new IT tools are not implemented because they do not match users' capacities, though. This might be due to poor involvement of end users. In the case of dementia, researchers have mainly focused on informal caregivers and professionals, rather than on people with dementia participating in developing IT tools. We therefore aimed to develop a tailor-made and interactive web tool together with the end users: case managers, informal caregivers, and people with dementia.

**Chapter 2** presents the results of a systematic literature search on the involvement of people with dementia in developing supportive IT applications. Although supportive IT applications are increasingly developed in the field of dementia, involving people with dementia in development and research is not self-evident. Inclusion of people with dementia in the development process of user-friendly, supportive IT applications may be especially useful to improve the quality of these applications and thus help the person with dementia. The aim of this study was to gain insight into involving people with dementia in developing supportive IT applications. The focus of involvement was on phase, methods, role and impact on the quality of the IT application and on the person with dementia. A systematic search was undertaken using Cochrane Library, PubMed, PsycInfo, EMBASE, and CINAHL. Publications were selected up to July 2011 using the following inclusion criteria: publications had to address a development process of an IT application involving people with dementia. The BMJ checklist was used to assess the quality of the included publications. The search strategy resulted in 893 potentially relevant citations. After screening titles, abstracts, and full papers followed by hand-searching the references, twenty-six publications relating to 15 IT programs met the inclusion criteria. People with dementia were mainly involved in the first phases of Brender's classification of development phases: the exploratory and technical development phases. The methods most frequently used to involve participants were interviews, observations and usability try-outs. In most studies, participants were involved as objects of study and informants rather than co-designers. When they were involved, people with dementia provided useful feedback and gave valuable recommendations for researchers and designers regarding the development of user-friendly, supportive, IT applications. They enjoyed being involved and liked learning new skills. Furthermore, researchers observed empowering results in people with dementia. To develop valuable, user-friendly, supportive IT applications that increase the quality of life of people with dementia involvement in all phases of the development process is of great importance.

**Chapter 3** explores to identify user requirements to determine the content of an interactive web tool facilitating case managers in supporting shared decision-making in care networks of people with dementia. Based on the results of the review, a multiple

method study with an iterative, participatory design was conducted. Data collection involved 50 semi-structured interviews with end users (people with dementia, informal caregivers, case managers and other professional caregivers), eight focus group interviews with end users and experts, a dementia expert consultation, and two multidisciplinary workshops. Content analysis was applied to the data and resulted in two sets of user requirements for the interactive web tool. The first set of user requirements consisted of topics related to care and well-being, all addressing decision making in dementia. The most important topics were: care, daily activities, mobility, safety, future, finances, living, and social contacts. The second set of user requirements addressed additional needs and preferences of end users such as: participation of the person with dementia in decision-making, insight into the decision history, anticipation of possible future problems and decisions, and the degree of self-management and preservation of autonomy of the person with dementia. The two sets of user requirements formed the basis for further development of the interactive web tool: identifying design issues.

**Chapter 4** describes the design issues that should be considered for a user-friendly, interactive web tool that facilitates shared decision making in care networks of people with dementia. This study focused on identifying the design issues and the unique contribution of people with dementia to the design. It included six separate focus group sessions with people with dementia, informal caregivers, and case managers; a cognitive walkthrough with researchers; and usability tests with case managers, older adults, informal caregivers, and people with dementia. The design issues identified were: a screen design based on agreeable and harmonious colors, obvious and uniform buttons throughout the interface, multiple-choice questions with smileys as answering options, a foldable menu bar that is closed (for people with dementia) or open (for caregivers) by default, and a *chat* function that specifically keeps all end users involved in conversation. The specific and detailed contribution of the participants with dementia concentrated on their focus on the present, accuracy of language, and graphical layout. However, some of the other participants doubted whether the tool would be useful and usable for people with dementia.

**Chapter 5** reports on a field study with the prototype of the interactive web tool, the *DecideGuide*, facilitating shared decision-making in dementia-care networks. Participants in the field study used the *DecideGuide* on a tablet. The *DecideGuide* provides three main functions: a *chat* function for easy communication between network members, a *deciding together* function for step-by-step decision-making, and an *individual opinion* function for eight dementia-related life domains. The aim of this study was to gain insight into the user-friendliness of the *DecideGuide*, into user acceptance and satisfaction, and into participants' opinions of the *DecideGuide* for making decisions. In a 5-month field study four dementia-care networks (19 participants in all) were in-

cluded. Data were derived from structured interviews, observations, and information about participants logging in to the *DecideGuide*. Structured interviews with people with dementia, informal caregivers, and case managers took place at the start, half-way, and at the end of the field study. Four observations of case managers' home visits focused on participants' responses and use of the tool. The findings of the field study suggest that the user-friendliness of the *chat* and *individual opinion* functions was adequate for case managers and most informal caregivers. Older participants, with or without dementia, had some difficulties using a tablet and the *DecideGuide*. The *deciding together* function did not yet provide adequate instructions for all. Also, the user interface needed simplification. Regarding user acceptance and satisfaction the results showed that all participants liked the *chat's* easy communication and handling of difficult issues for discussion, and the option of individual opinions. Regarding decision-making the findings showed that the *DecideGuide* helped informal caregivers and case managers especially to structure their thoughts. They felt more involved and shared more information about daily issues than they had done previously. Regardless of participants' use of the tool, it can be concluded that they saw the *DecideGuide's* added value and found the *DecideGuide* valuable in decision-making. The *chat* function appeared powerful in helping members engage with one another constructively. Such engagement is a prerequisite for making shared decisions.

**Chapter 6** elaborates on the participation of people with dementia, being the most vulnerable end user group, in developing the *DecideGuide*. To develop user-friendly supportive IT applications and improve their quality, end users must be involved in the development process. However, it is unusual for people with dementia to participate in research, design and development. The aim of this study was to accurately and critically describe in which ways people with dementia participated in designing and developing the *DecideGuide*. We used the development process of the *DecideGuide* as a case study. We conducted a secondary analysis of the data gathered from people with dementia in semi-structured interviews (including 23 interviewees), four focus groups (18 participants in all), three usability tests, and a field study (4 participants). Moreover, the researchers kept a log. The development phases of the Center for eHealth Research and Disease Management (CeHRes) roadmap and the roles of Abma's patient-participation ladder were used to analyze in which ways people with dementia participated in designing the *DecideGuide*. Findings suggest that people with dementia participated in various roles in four of the five phases of the CeHRes roadmap: during the contextual inquiry phase in the role of research subject, during the value specification phase in the role of informant, and during the design and operationalization phases in the role of informant and advisor. People with dementia enjoyed learning new skills, they wanted to be useful by contributing to research activities as long as they could, and they wanted to contribute to a better quality of life for future dementia patients. The



researchers came to realize the importance of building a relationship with people with dementia and of giving them time to express themselves. In conclusion, people with dementia mainly participated as informants and advisors in most phases of designing and developing of the *DecideGuide*. Obviously, these roles are feasible for some of them in developing IT applications with various end user groups whether other roles are to be further explored. The feedback of some of the participating people with dementia taught us that it is important to them to be significant to others and to use their reciprocal capacities. Participation of people with dementia in research, design and development may therefore contribute to their social inclusion.

**Chapter 7** summarizes the main findings and conclusions of the studies, and the methodological considerations. Furthermore, this chapter discusses the relevance of the studies for science, for society, and for dementia care practice. Recommendations are given for future research (e.g., deciding about user involvement in an early phase, revealing perceptions of people with dementia need individual sessions with them), for health care and social practice (e.g., being attentive and sensitive to personal views, wishes and values of the various network members and to their own perceptions of the reciprocal capacities of people with dementia), and for health and social education (e.g., focusing on bridging the gap between care and well-being professionals).

The findings of this thesis contribute to the information and expertise about involving end users with different capacities and interests in the development of supportive IT applications. The studies in this thesis also contribute to the trend to support communication in health care by a tool that helps communication about decision-making on care and well-being related decisions. The findings of this thesis are relevant to society. Seeing that people with dementia in our study were very well able to give comments and feedback, and thus reciprocate, participation in research might contribute to their social inclusion. Furthermore, results of the field study indicate that the *chat* function is a powerful instrument in facilitating network members to interact and engage with another constructively. Such engagement is a prerequisite for making shared decisions. The results of the field study also indicated that using the *DecideGuide* was helpful in structuring thoughts.

Recommendations for further research concern improving the *DecideGuide* by simplifying the interface and the *deciding together* function in order to make the tool more robust and more user-friendly for older adults. Adding 'nice to haves', e.g., a photo gallery, an agenda, (memory) games, and a notification for new activities in the *DecideGuide* might increase its use. The adjusted *DecideGuide* might not only be a valuable tool for facilitating SDM in dementia care networks. It might be also a good training instrument in educating health and social professionals to get familiar with the steps of SDM in the context of dementia. Future research should also focus on the effects of using the adjusted *DecideGuide* in dementia care practice.



