



CHAPTER 7

General discussion

1. INTRODUCTION

Decision-making in care networks of people with dementia is complex because multiple participants are involved, who have different capacities and interests, and because the cognitive decline associated with the syndrome of dementia is progressive (Wolfs et al., 2012). Although shared decision-making has become the preferred way of making decisions in dementia care in the Dutch Dementia Care Standard, professionals such as case managers supporting people with dementia and their care network find it difficult to help people with dementia making shared decisions (Dutch Alzheimers's Association & Vilans, 2012). Involving people with dementia in decision-making is not yet part of a daily routine. Caregivers often tend to shield people with dementia with the best of intentions. However, this does not do justice to the experiences and perspectives of people with dementia. Professionals put a lot of effort into personal relationships with their clients, but lack supportive tools for shared decision-making.

This thesis concerns the development of an interactive web tool, a network tool, to facilitate shared decision making in dementia care networks, called the *DecideGuide*. Involving all stakeholders in the development process and especially involving the most vulnerable target group, people with dementia, was a key feature. The *DecideGuide* (still a prototype) can be used by professionals to support shared decision-making in care networks of people with dementia.

The *DecideGuide*, an interactive web tool facilitating shared decision-making in care networks of people with dementia, was developed in an iterative participatory design process. People with dementia, informal caregivers, case managers and other professionals are all users of the *DecideGuide*. It enables them to communicate in a *chat*, to give individual opinions about dementia related topics, and to make decisions step by step. Each user has a personal log in.

The prototype of the *DecideGuide* is not a traditional decision aid such as used in clinical encounters (Med-Decs, 2012) but addresses the complexities of decision-making in the dementia context. It contributes to the broader approach that is called for in the discussion about SDM (Epstein & Gramling, 2013; Epstein & Street, 2011; Stiggelbout et al., 2012). This call for a broader approach can also be seen in the development of supportive patient decision aids. The Ottawa Hospital Research Institute, the leading institute on decision aids, recently developed generic decision aids for any health-related or social decision (OHRI, 2014).

The main research questions of this thesis as described in the introduction of this thesis are:

1. In which ways are people with dementia involved in developing supportive IT applications? (Chapter 2)
2. What needs and preferences do people with dementia, informal caregivers, and community professionals such as case managers have regarding an interactive

- web tool facilitating shared decision-making in dementia care networks? (Chapter 3)
3. What design issues can be identified for a user-friendly interactive web tool facilitating shared decision-making in dementia care networks and what unique contribution can people with dementia make? (Chapter 4)
 4. How do people with dementia, informal caregivers, and case managers rate the user-friendliness of the interactive web tool, the DecideGuide, are they satisfied with it, and how do they evaluate the DecideGuide for decision-making? (Chapter 5)
 5. In which ways did people with dementia participate in developing the interactive web tool, the DecideGuide, and what was the impact of their participation? (Chapter 6)

In this final chapter we look back on the subject matter of this thesis, the participatory journey of developing an interactive web tool, the *DecideGuide*. We will start by summarizing the key findings per chapter. After that some methodological considerations will be described. Next, we will discuss the relevance of our findings and present recommendations for future research and practice. We will end this chapter with a final conclusion.

2. MAIN FINDINGS AND CONCLUSIONS

We started developing an interactive web tool by conducting a systematic literature search into how people with dementia have been involved in the development of supportive IT applications (Chapter 2). We wanted to find out what lessons could be learned for the development of our interactive web tool. The extensive search was executed up to July 2011 without restriction of date and language using Cochrane Library, PubMed, PsychInfo, EMBASE, and CINAHL. From a list of 893 relevant citations, 26 publications were included. The oldest publication to be included was dated 2003. Our findings suggest that most researchers acknowledge the importance of involving people with dementia but they differed in the ways in which they involved people with dementia. Most people with dementia were chiefly involved in the first phases of the development process, the explorative and technical phases of development. People with dementia mainly played the role of study objects and informants ($n = 24$) rather than being co-designers ($n=2$). We concluded that involving people with dementia in developing supportive IT applications is a recent phenomenon as the oldest publication that could be included dated back to 2003. We also concluded that people with dementia were able to participate in developing supportive IT applications and provided useful feedback leading to user friendly and usable IT

applications. The results of the review confirmed our intentions of involving people with dementia.

To determine the content of the interactive web tool we identified the needs and preferences of end users: people with dementia, their informal caregivers, and case managers (Chapter 3). Consecutively, we conducted 50 semi-structured interviews with end users, eight separate focus group interviews with the different end user groups, a dementia experts consultation and two multi-disciplinary workshops. Two sets of user requirements were identified. The first set was based on problems experienced and decisions to be made by end users. This set of requirements addressed social contacts, daily activities, mobility and transport, safety, living, future, care, and finances. The second set of user requirements was based on additional needs and preferences of end users addressing: 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 by the person with dementia. The iterative participatory approach – individual interviews followed by two sequential focus groups per target group – helped us identify these two sets of user requirements. Decision making in dementia care networks mainly concerns problems of well-being for people with dementia and their informal caregivers rather than care related problems. The views of all people involved were important to come up with two well-founded sets of user requirements.

The sets of user requirements were the basis for a mock-up, a first paper prototype. In four iterations design issues were identified using the feedback of people with dementia, their informal caregivers, and case managers (Chapter 4). We conducted two separate focus group sessions with all end user groups, in which we presented mock-ups (paper prototypes). Using the feedback of the end users in these two rounds an interactive prototype was built and tested by researchers in a cognitive walkthrough. After this prototype had been improved on the basis of researchers' feedback, individual usability tests with three individuals of all end user groups were carried out. The design of the interactive web tool, the *DecideGuide*, was the result of four iterations. These iterations included feedback of all end users groups. Participating end users reported weaknesses that mainly concerned the system quality: user-friendliness of the tool (e.g., too many screens and too much information per screen, difficulties operating a touch screen, confusing interface, meaning of buttons), complexity of navigation (within screens and between screens) and persuasiveness of design (presentation of information, use of icons, size of icons/smiley). Weaknesses regarding the content quality concerned accuracy of wording and relevance of content. Experienced strengths were possible future extensions, monitoring caregivers' well-being, use of smileys and the green interface color. Participants disagreed on the following design issues: number of screens and examples, use of smileys, and the design rationale of open communication and transparency. People with dementia

provided us with detailed and unique feedback about: their focus on the present, the 'here and now' of their perception of time; careful use of language; and an agreeable graphical layout. We concluded that designing an interactive web tool for people with different capacities and interests is challenging but possible. All perspectives were included and special attention was paid to the perspective of people with dementia, the most vulnerable target group. The specific and detailed feedback by people with dementia was very valuable and quite unique as a contribution. However, some informal caregivers and professionals doubted whether the tool would be useful and usable for people with dementia.

After determining the content and design of the *DecideGuide*, the *DecideGuide* was used and tested on a day-to-day basis by people with dementia, by their informal caregivers, and by case managers. We were interested in their evaluation of user-friendliness and usefulness of the *DecideGuide*, and in how satisfied they were with it (Chapter 5). We conducted a 5-month field study with four dementia care networks (n = 19) consisting of people with dementia (n=4), informal caregivers (n=12), and their case managers (n=3). After being instructed, they used the *DecideGuide* in their daily lives. Data collection consisted of three individual, structured interviews in the course of the field study: at the start (t0), midway (t1), and at the end (t2), of observations of case managers' home visits, and of log files in the tool. Findings of the field study showed that the user-friendliness of the *DecideGuide* was in need of improvement, in particular for older adults (70+) (people with dementia and older partners). The *deciding together* part provided insufficient guidance and the navigation in the user interface needed further simplification. User acceptance and satisfaction were sufficient: all participants appreciated the easy way of communicating in the *chat* function, and the option to express individual views. Participants felt more involved and shared more information with each other about daily life issues. Informal caregivers and case managers appreciated the *DecideGuide* as a tool in decision-making: it structured their thoughts and provided a frame for making decisions. These findings show that using the *DecideGuide* is feasible in dementia care practice but that the navigation of the prototype needs further refinement in order to become a robust tool. Participants found the *DecideGuide* a valuable tool in decision-making, regardless of the way they used the tool. The *DecideGuide* has a meaningful impact on its users: it stimulates people with dementia and their care networks in communicate more frequently, stimulates difficult issues to be discussed, takes into account all perspectives, and leads to more involvement of informal caregivers and case managers in the daily lives of people with dementia.

People with dementia being the most vulnerable target group in our research we were interested in the ways in which they participated in developing the *DecideGuide* and what the impact was of their participation (Chapter 6). We did a secondary analysis of data gathered in the development process consisting of individual, semi-struct-

tured interviews (n=23), four focus groups (n=19), usability tests (n=3), a field study (n=4). Also, researchers kept a log book of the development process. In total, 49 people with dementia participated in most phases of the CeHRes roadmap (van Gemert-Pijnen et al., 2011) and in different roles of Abma's patient participation ladder (Abma & Broerse, 2007): during the contextual inquiry phase they were research subjects, during the value specification phase they were informants, and during the design and operationalization phase they were informants and advisors. People with dementia did not participate in the summative evaluation phase as the *DecideGuide* is still being developed and they did not participate in the roles of referent, interviewer and co-researcher. Their participation yielded special feedback leading to a better adjusted version of the *DecideGuide*. The impact of participating on people with dementia was evident from their intrinsic motivation to participate, from their enjoyment in learning new skills, from their wish to be of use for research activities for as long as possible, and from their wish to contribute to a better quality of life for future dementia patients. They knew that they themselves would not benefit immediately from participating. Still, they were eager to get the hang of using a tablet computer and the *DecideGuide*. The intrinsic motivation that people with dementia showed, their wish to give something back and to be useful, is a fine example of reciprocity. We made a great effort to involve people with dementia in developing the *DecideGuide*. Taking time is the key for meaningful inclusion of people with dementia taking time, e.g., for small talk before research activities, taking time to get to know each other better, taking time during research activities, and taking time for an ongoing consent to be sure about their voluntary participation (Murphy, Jordan, Hunter, Cooney, & Casey, 2014). Furthermore, a safe environment is important, such as their own home or the day care center they are attending. We involved people with dementia in the same phases of development as informal caregivers and case managers and we listened to them carefully. People with dementia were especially involved in the roles of information providers and advisors.

3. METHODOLOGICAL CONSIDERATIONS

The studies described in this thesis have their own methodological strengths and limitations that are discussed in the different chapters. In this section we will describe some main methodological aspects.

3.1 Selection and recruitment of dementia care networks

In this study we focused on participants of dementia care networks consisting of peo-

ple with dementia, informal caregivers, case managers, and other professionals. Case managers from regional case managers' networks in two regions of the Netherlands recruited most of the networks. In order to achieve information-rich cases the researchers instructed the case managers about the recruitment as we aimed at diversity of characteristics of the people with dementia and the networks. Inclusion criteria were: a person with dementia willing and able to participate in a conversation, usability test and/or the field study, and the availability of a care network consisting of a person with dementia and a minimum of two informal caregivers. As case managers decided whether they would ask people with dementia and their informal caregivers to participate on the basis of researchers' inclusion criteria, this may have biased the sample selection. We may have missed out people with dementia who would have liked to participate but were excluded on the basis of case managers' view of their capacities and willingness.

3.2 Diversity of sample

We aimed for a maximum in diversity of participants and networks (subtype diagnosis, gender, age, marital status, and socio-economic status) in the different phases of the development (Coyne, 1997). We succeeded in this partially. Except for the individual interviews at the start of this study (Chapter 3), in which two persons with dementia living in a nursing home participated, all people with dementia lived in the community. The level of education of people with dementia and informal caregivers participating was mainly medium or high. There were only a few participants with a low educational level. Alzheimer's disease was the main type of dementia that occurred in our sample. Other types of dementia were vascular dementia, Lewy Body dementia, and fronto temporal dementia. The severity of dementia of the participating people was mild to moderate corresponding with a Reisberg score of 2 to 4 (Reisberg, Ferris, de Leon, & Crook, 1982).

3.3 Participation of end users

We included perspectives of all end users in all phases of development. To enable all participants to speak for themselves we started by interviewing them individually. People with dementia and their informal caregivers are often interviewed as dyads, but we emphasized the importance of the individual character of the interviews (Nygård, 2006). For the same reason we conducted focus group interviews and sessions in which end users of the same target group took part and did not use mixed focus groups. This approach facilitated the experience of safety in discussing personal issues. People with dementia (and all older participants) appreciated the researchers' visit, especially during the field study when the visits were more frequent. This may have influenced re-

sults, as older participants might have wanted to please the researchers. Furthermore, a prototype of the *DecideGuide* was evaluated during a 5-month field study in a small sample of dementia care networks, rather than a robust tool in an RCT. The findings of this thesis, therefore, cannot be generalized to the use of the *DecideGuide* in all dementia care networks, and should be treated with caution.

3.4 CeHRes roadmap

We used the CeHRes roadmap to guide us through the development process. The CeHRes roadmap is rooted in Human Centered Design. We chose this roadmap because it offers a holistic framework for developing eHealth technologies paying maximum attention to the involvement of all stakeholders. With a view to raising the uptake of eHealth technologies the holistic approach of the framework considers human characteristics, socio-economic and cultural environments, and technology to be inseparable. Adhering to the phases of this roadmap guided us through the development process step by step. This step-by-step approach supported anticipation of what was coming next. The CeHRes roadmap also provided us with methods (criteria to assess the design of the *DecideGuide*, e.g.) that we could use in consecutive phases. Using the CeHRes framework showed that we had not involved all those concerned sufficiently in the first phase of contextual inquiry. We used the CeHRes assessment of design quality evaluatively, after we had finished all iterations. However, using this assessment from the start, formatively rather summatively, might be helpful in improving and adapting the design at an early stage. Especially, it enables researchers to reflect on the results of an iteration, learn from them and identify what is needed for the next iteration.

The thorough approach of the CeHRes roadmap for development processes takes time, though. The CeHRes roadmap is related to the Waterfall method that dates from the 70s. The Waterfall method outlines systematic development from one phase to another in a downward fashion like a waterfall (Royce, 1970). It consists of phases: requirements, design, implementation, verification, and maintenance. The next phase only starts when the previous one has been completed. Disadvantages of the Waterfall model are its model testing at the end and the impossibility of taking into account the client's evolving needs (Thomas, 2005). Nowadays, the use of the Agile method in IT development processes is increasing (Thomas, 2005). The Agile method is an answer to the sequential approach of the Waterfall method but requires a culture change of organisations. The Agile method is characterized by short interactive cycles that take place in close co-ordination with the client. Less attention is paid to structure and documentation.

3.5 Strengths

One of the strengths of this study is its thorough, extensive and step-by-step approach in all phases of development, trying to stay close to the end users by exploring their views. Per sub study we used multiple methods to gather our data: individual semi-structured interviews, structured interviews, focus group interviews, focus group sessions, observations, workshops, usability tests and a field study. By using multiple methods we ensured data triangulation. We used the same methods for all end user groups. Only the time needed differed. The development process was supported by the multi-disciplinary approach of the research team and a large multi-disciplinary consortium. This strengthened the rigor and validity of this study. The *DecideGuide* is an instrument developed together with people with dementia, informal caregivers and case managers. However, the findings of the field study showed that the interactive prototype of the *DecideGuide* needs improvements before it can be used in practice. These improvements concern the usability and user-friendliness of the tool for 70+ people and simplification of the *Deciding together* function.

4. DISCUSSION

In this section we will elaborate on the scientific and societal relevance of this study and on the relevance for dementia care. Next, we will make some recommendations for future research, for health care and social practice, and for health care and social education. We will end with a final conclusion.

4.1 Scientific relevance

4.1.1 Involving people with dementia in the development of an interactive network tool

The scientific implications of the studies described in this thesis are various. We started by indicating that involving people with dementia in all phases of the development of assistive IT applications is a recent and rather rare phenomenon (Chapter 2). We assumed that, in order to develop a valuable IT application, involving all end users would be essential. Particularly so because intended end users had different capacities, interests, needs, and preferences, and because vulnerable target groups like people with dementia are easily overruled. We succeeded in involving people with dementia and other network members in the development process (chapters 3 and 4) and the field study (chapter 5).

This is by no means self-evident. Although researchers find it important to involve all end users in developing supportive IT applications, practical implications are often a hindrance. Van der Roest and colleagues (2009) also aimed to involve people with dementia as one of the intended end user groups in the development of their tool (DEM-DISC) but did not succeed. The tool turned out to be too difficult to use for people with dementia and was therefore adjusted and tested by informal caregivers and professionals. A recent study evaluated the DEM-DISC as a useful and user-friendly tool for informal caregivers and case managers (van Mierlo, Meiland, Van de Ven, Van Hout, & Droes, 2015).

Our study also contributes to the trend to aid communication in health care by developing a tool that supports communication about decisions related to care and well-being. IT tools that support SDM in the dementia context are scarce. Available tools mainly focus on medical decisions, rather than on decisions related to care and well-being (Med-Decs, 2012). Researchers (O'Connor et al., 2009; Robben et al., 2012) and families (Carenzorgt.nl; Familienet.nl) who try to find solutions for inadequate care have initiated a growing interest in IT tools that support communication in health care. Most of these applications support communication and organization of care between informal caregivers or between informal caregivers and professionals. Decision-making tools that include people with dementia themselves as users are hardly available. Robben and colleagues (2012) report that involving frail older people as one of the end user groups was less successful than they had aimed for. They developed the Health and Welfare Information Portal (ZWIP), a personal and internet-based conference table for multi-disciplinary communication and information exchange for frail older people, informal caregivers and professionals. ZWIP aims to support SDM by providing facts about personal health, by gathering information about goals and preferences, and by educating professionals in self-management support. However, involvement of frail older people proved to be difficult and did not work out to the extent that the researchers had aimed for.

Some researchers tried to avoid difficulties in involving people with dementia by replacing them by others to assess their perspective, e.g., professionals (Boger et al., 2006; Kikhia, Hallberg, Synnes, & Sani, 2009), informal caregivers (Horwitz et al., 2008), students (Gelhaus, 2002), researchers and older adults (Riley, Alm, & Newell, 2009), or actors (Boger, Hoey, Fenton, Craig, & Mihailidis, 2010). Other researchers conclude that feedback by people with dementia proved to be essential and that feedback by researchers and older adults was insufficient (Riley et al., 2009). Meiland and colleagues (2014) considered the involvement of people with dementia in the Rosetta project as useful for their relevant feedback regarding the selection and the technical development of the system. Our study showed that involving people with dementia in developing an interactive network tool such as the *DecideGuide* is challenging but feasible. People with dementia participated meaningfully as informants and advisors and they gave useful and unique feedback (Chapter 6). This indicates that their perspective cannot be replaced by others in the development process.

4.1.2 Decisional capacities

Our study showed that people with dementia were able to collaborate based on abilities to have a conversation rather than including them on the basis of a capacity measurement score (Chapter 6). Our study, therefore, contributes to the debate on the use of measures for decisional capacities of people with dementia (Levinson, Kao, Kuby, & Thisted, 2005; Miller, Whitlatch, & Lyons, 2014; Smebye, Kirkevold, & Engedal, 2012). To make autonomous decisions, cognitive abilities like understanding relevant information, appreciating the significance of information for one's own situation, reasoning by considering alternatives and finally expressing choice are necessary. To assess a person's decisional capacity, the McArthur Competence Assessment Tool for Treatment (MacCat-T) and the Mini Mental State Exam (MMSE) are accepted tests (Smebye et al., 2012). These tests may indicate decisional capacities, but they are not sensitive to the capacity to state preferences and make daily care decisions. In Feinberg and Whitlatch's study (2005) some people with dementia were screened out because of a low MMSE score who would, in hindsight, have been able to participate and express valid and consistent preferences. As a result of low MMSE scores, important and valuable information coming from people with dementia was not taken into account. The question may be asked whether researchers can afford not to take into account the perspective of people with dementia as they give valuable information about their experiences that others cannot provide. Furthermore, recruitment of vulnerable people like people with dementia is difficult, takes a lot of effort, and many drop-outs have to be taken into account.

4.1.3 Decision-making: cognition versus intuition

The discussion about people with dementia's decision-making capacities and how these should be measured also revealed a contradiction, an interesting and striking contradiction about cognitive and intuitive aspects of decision-making.

For a long time, decision-making has been seen as a cognitive task. This view is changing. Nowadays researchers increasingly emphasize emotional and relational aspects in decision-making (Munthe, Sandman, & Cutas, 2012) and decision-making in health care (Elwyn et al., 2014; Epstein & Street, 2011). This emphasis on relational aspects and emotions reveals that people do not decide as rationally as they think they do. We know from Munthe, Sandman & Cutas (2015) that our choices are often made within split seconds by our emotions. In a clever way the choice made is immediately adopted by our cognitive brain, suggesting we decide rationally. But in fact we do not.

Likewise, decision-making in the context of dementia is not always based on logic and deliberation (Smebye et al., 2012) but predominantly influenced by strong emotions (Wolfs et al., 2012). Many decisions are made intuitively, based on needs, emotions, personal values, preferences, and relationships (Smebye et al., 2012). The influence that relational aspects and emotions have on decision-making seems to be

similar for people with and without dementia. Nevertheless, we assess decision-making capacities of people with dementia on the basis of their cognition, worse even, on their declining cognition. We require people with dementia to show cognitive or rational decision-making capacities, even when we ourselves, able people, do not decide that way. Thus, it is appropriate to acknowledge people with dementia's abilities to participate in decision-making by expressing themselves intuitively. From Smebye and colleagues (2012) we know that positioning people with dementia as capable of influencing decisions supports their optimal involvement in decision-making.

Dilemmas in decision-making are often related to people with dementia being insufficiently involved in decisions about their own situation (Miller et al., 2014). From Miller et al. (2014) we also know that being involved in decision-making gives people with dementia a feeling of control and a sense of contributing to their situation and a grander meaning of personhood, regardless who made the decision. Our study revealed that people with dementia could express their opinions and preferences very clearly (Chapters 3,4, and 5).

4.2 Societal relevance

4.2.1 Participation enables people with dementia to be useful for themselves and society

We know from Vernooij-Dassen and colleagues (2011) that focusing on peoples' strengths and wishes to give might help to preserve dignity and social inclusion. In our study, people with dementia enjoyed participating in the development process. They knew that they would not benefit from the findings of the study themselves, but participating was important to them because they wanted to contribute to a better quality of life for future dementia patients. Some people with dementia were outspoken about wanting to participate as long as possible; they wanted to be of use. This response by people with dementia shows their reciprocal capacities and their wish to do something in return for the people around them. They also liked learning new skills, such as learning to use a tablet. They saw it as a chance to find out if a tablet would be a helpful tool in their situation.

People with dementia are aware that after diagnosis there will be a growing dependency on their informal caregivers sooner or later. They know they need their support to stay at home for as long as possible. People with dementia's quality of life has been reported as good when they felt a sense of being useful and doing something in return for people around them (Cahill et al., 2004). Participating in research by giving comments, feedback and advice, like people with dementia did in our study, enables people with dementia to do something in return for people around them

and for society (chapter 6). It demonstrates their reciprocal capacities. Their feedback is necessary in order to develop a valuable and user-friendly tool (Meiland et al., 2014). However, many members of society, including professionals, assume that people with dementia cannot reciprocate (Gove, Downs, Vernooij-Dassen, & Small, 2015; Gove, 2012; Hsu, 2007; Robben et al., 2012; Van Gorp & Vercruyssen, 2012). Enabling social participation and preventing social isolation of people with dementia are important for their social inclusion, but not enough. Reciprocity is a prerequisite for social inclusion. Our study contributes to the debate about reciprocal capacities of people with dementia. People with dementia can reciprocate and it is important to them to be of use. Thus, participating in research may contribute to the social inclusion of people with dementia.

4.2.2 Time, the necessary companion of people with dementia for meaningful participation

We found out that meaningful participation of people with dementia takes time (chapters 3,4,5, and 6). We needed time for personal relationships, to make them feel comfortable. Small talk and listening to their stories takes time. They need time to express themselves. Researchers have to adjust to their tempo and needs. Murphy and colleagues (2014) report the same finding. They advocate an inclusive approach by taking time for ongoing consent and “chitchat”. However, van der Roest and colleagues (2008) argued that involving people with dementia may slow down step-by-step development processes, and they thought this was a disadvantage. Considering this a disadvantage is prompted by the lack of time in grants. Although funders increasingly require participation of people with dementia as a condition for funding, they seem unaware of the financial implications of this condition. This might complicate meaningful participation of people with dementia and might lead to a meaningless form of co-operation: words rather than actions. Participation by people with dementia could easily become a sham. It cannot be overemphasized that participation by vulnerable target groups like people with dementia requires time.

4.3 Relevance for dementia care

4.3.1 The pitfall of thinking for people with dementia

We included people with dementia in the development process as we did the other participants. We asked people with dementia for information and feedback in the same way that we asked informal caregivers and case managers and other professionals. From the start informal caregivers and case managers have emphasized their concerns about people with dementia participating in all phases of the study. They

thought that participation would be too difficult and intrusive for people with dementia. Their concerns notwithstanding, we asked people with dementia themselves about their willingness to participate. We wanted to ask them instead of deciding for them, because we know from Reamy and colleagues (2011) that preferences of people with dementia often do not coincide with those of informal caregivers. People with dementia were willing to participate. They made no objections and showed no signs of distress. They were very well able to participate in conversations and give information during semi-structured interviews (chapter 3). They even liked these conversations and the fact that we were interested in their views, although they could not always believe their view was important. Not only informal caregivers, case managers, and other professionals were inclined to think for people with dementia. The researchers sometimes found they had been likewise inclined themselves, however good their intentions to the contrary.

In the design phase of the *DecideGuide* described in chapter 4, the paper prototyping (mock-ups) posed difficulties for people with dementia, which appeared to confirm findings of researchers such as Riley and colleagues (2009). We chose a fictional person with dementia for this session because we thought that it would be less intrusive for participating persons with dementia. They, however, commented that they thought the session was difficult because they could only speak and decide for themselves – doing so for the fictional person presented on paper was too confusing for them. The fictional person was not a problem for informal caregivers and case managers. Nevertheless, the paper prototype session proved to be difficult for them too. Informal caregivers and case managers found it hard to judge from paper what such an interactive web tool could look like.

Participation of people with dementia in the design phase resulted in valuable and unique feedback that we would have missed out on if we had not involved them. People with dementia gave explicit comments and feedback from a ‘here and now’ perspective. They related their feedback to their personal views rather than to the views of their informal caregivers and case managers, whose comments tended to focus more on the future and be more abstract.

4.3.2 Problems of well-being versus care decisions

Our study revealed that problems identified in dementia care networks were often related to well-being, whereas decisions were frequently related to care (chapter 3). This discrepancy may be due to the professionals’ focus on care. Most professional caregivers and case managers in dementia care in the Netherlands have a nursing background. Furthermore, many services are paid for in a care administration system. This might influence the options provided. It may be argued that, if professional caregivers focus on well-being more, the options they offer probably also be more well-being oriented. Improving person centeredness in dementia care may support

such a change of attitude by professional caregivers (Doyle & Rubinstein, 2014). Nurse education can support this change by increasingly focusing on gerontology and well-being. It is a change that can nowadays be seen in the Netherlands, which is transforming from a welfare state to a participatory society (Smits, van den Beld, Aartsen, & Schroots, 2013).

4.3.3 Chatting as a prerequisite for shared decisions

In the context of serious illness there has been more attention lately for relational aspects in decision-making as advocated by Epstein and colleagues (2011) in their 'shared mind'.

Being more involved in the lives of others and sharing daily issues appears to be a valuable basis for making shared decisions. This mutual interaction aspect is usually neglected in decision-making, which is often seen as an individual and cognitive task, assuming that a person decides as *homo economicus*. People are supposed to choose the best solution after weighing rationally what is in their best interest (Munthe et al., 2012). Elwyn and colleagues (2014), an early adopter of SDM, emphasizes the importance of interpersonal aspects in decision-making by developing the model of collaborative deliberation. They see the constructive engagement of involved people as a first requirement in this model. Groen and colleagues (2015) refined this model for the dementia context.

Our study revealed that most users appreciated the *DecideGuide* as a valuable tool in decision-making (Chapter 5). The tool supported the users in structuring their thoughts and offering a structured path towards decisions. It also opened up difficult issues for discussion. In particular the *chat* function proved to be important, more important than we expected in fact. It was a meaningful part of the tool, in which users easily communicated whether they were close or far apart. More daily issues were shared than previously and users were more involved in each other's daily lives. For some informal caregivers, who were at a greater distance, the problems experienced by the spouse of the person with dementia became more obvious. This triggered them to take initiatives to find a solution.

Traditional decision aids facilitating SDM are now under discussion for their limitations: they are hardly used, they are badly designed, they are outdated, and the effects they yield are not consistent (Todd, Barr, Roberts, & Passmore, 2013). New decision aids are being developed based on the model of collaborative deliberation and focusing on the unique conversation between patients and clinicians, with the latter providing tailored information and explanation (Todd et al., 2013). Our study showed that the *chat* function might help fulfill this essential aspect of mutual interaction in decision-making in the dementia context. The *chat* function appears to be a powerful function in helping network members to engage with one another constructively. From Elwyn and colleagues (2014) and Epstein and Street (2011) we know that such engagement is a prerequisite for making shared decisions. The *DecideGuide* is a supportive SDM network tool for members of dementia care networks

and developed with all intended end user groups. The *DecideGuide* contributes to existing tools supporting SDM because it involves people with dementia, it facilitates individual perspectives from all network members, and it supports open communication in dementia care networks. Furthermore, the *DecideGuide* focuses on exploring the decision-making process rather than on the decision itself. The *DecideGuide* addresses important decision-making topics, e.g., it identifies the issues which are to be involved, it establishes what values are important to those involved, it clarifies what their individual views are, it lists the options and the pros and cons of each option, it probes the (decisive) considerations, it spells out the decision, and it calls for an evaluation of the decision. In order to make shared decisions in dementia care networks by exploring the decision-making process chatting might be essential.

4.4 Recommendations

4.4.1 For future research

Developing a user friendly and usable interactive web tool facilitating shared decision-making in dementia, for people with different capacities and interests, is challenging but possible and feasible. It is essential that researchers do justice to the perspectives of all stakeholders, especially to those of the most vulnerable stakeholders. Stakeholders can be involved in several roles and phases of development (Chapter 2 and 6). Being aware of these roles might help researchers and designers to decide about user involvement and its consequences at an early stage. What information is needed from stakeholders in each phase and which roles suit them best? Our study indicates that people with dementia can participate meaningfully in development processes in various roles such as that of informant and advisor (Chapters 3, 4 and 6). Other roles are to be explored.

People with dementia and informal caregivers often operate as dyads. They know each other very well and are interviewed often as dyads. This is done for various reasons: it causes people with dementia distress; they have problems with word finding; and they experience feelings of uncertainty. However, this does no justice to the unique perspective that people with dementia have. Informal caregivers often think they know what people with dementia want, but Reamy and colleagues (2011) have shown this is a misconception. In our study we recognized this, so we emphasized the importance of the individual sessions. It is the only way to reveal the perception that people with dementia have (Nygård, 2006; van der Roest, 2009). However, meaningful participation of people with dementia takes time (Chapter 6). They need time to feel at ease and to express themselves. Researchers should be aware of this and adjust to their pace and needs.

This study looked into the development process of the *DecideGuide* and a 5-month field study testing the prototype of the *DecideGuide*. The results of the field study can-

not be generalized on account of the small sample. However, the results of the field study are promising and indicate that an improved version of the *DecideGuide* may be a valuable tool to support SDM in care networks of people with dementia. The main improvement needed is user-friendliness for older people including people with dementia. 'Nice to haves' such as a photo gallery, an agenda, (memory) games, and a notification for new activities might increase the use of the *DecideGuide*. Further simplification, especially of the *Deciding together* function is also needed. To obtain more generalizable results on using the *DecideGuide*, an effect study with an adapted version of the *DecideGuide* in a larger sample would be necessary.

4.4.2 For health care and social practice

From our study, some recommendations can be made for professionals working in the dementia context. They will be important partners for people with dementia and their informal caregivers for quite some time.

First, professionals need to be attentive and sensitive to personal views, wishes, values and preferences of various network members. Their good intentions notwithstanding, professionals do not always have a clear insight in these personal perspectives. As a result relevant personal information does not come to the fore in the network. Information that might be important to enable people with dementia to stay at home for as long as possible.

In our field study, professionals indicated that using the *DecideGuide* resulted in more information about the situation the person with dementia was in, more insight into the network, and personal views that network members had. A better insight into the network system provides a better picture of it, enables appropriate co-ordination of care by professionals, and thus, contributes to a better quality of life for people with dementia.

Second, professionals in dementia care should be more attentive to their own perceptions of the reciprocal capacities of people with dementia and the role they can play in supporting social participation by people with dementia. Professionals in dementia care are important for people with dementia participating because they are closely linked to the person with dementia and informal caregivers. Therefore, their perception of dementia and reciprocity matters. Professionals may promote participation of people with dementia in research by emphasizing their unique view that is necessary in order to develop user friendly and valuable tools. Tools, that enable community dwelling people with dementia to stay at home for as long as possible and contribute to a better quality of life for people with dementia and their informal caregivers.

4.4.3 For health and social education

In the Netherlands health care is changing from supply-led to demand-led (Dutch Ministry of Health Welfare and Sports, 2004). This shift has consequences for care receivers and caregivers. Both parties have to leave their supply-led comfort zone.

Care receivers have to take more responsibility towards coordinating their own care, whereas professionals need to adjust more to the needs and wishes of the care receivers, rather than offer standard care.

From chapter 3 of our study we know that professionals in dementia care tend to solve problems of well-being with care decisions. This mismatch might be due to the fact that more care professionals than social professionals work in the field of dementia. The shift in health care and the focus on well-being in dementia care requires competent and well-equipped professionals who know how to collaborate. Education for health care and social professionals is changing and trying to produce more generic professionals who can bridge the gap between care and well-being professionals (Boutellier & Jansen, 2014; Kaljouw & van Viet, 2015; Lambregts, Grotendorst, & van Merwijk, 2015). An IT application such as the *DecideGuide* can be used as a training instrument in education, e.g., in a skills lab. It may help students and professionals look into the different steps of SDM in the context of dementia and focus on identifying the real problem and on exploring the decision-making process rather than focus on the decision itself. Furthermore, it might give them a chance to practise using a network tool that includes participants with different capacities and interests. This might enhance their eHealth competencies and IT communication skills.

4.5 Final conclusion

This thesis reflects the journey of developing the *DecideGuide*, an interactive web tool facilitating shared decision-making in dementia care networks. The main conclusions that can be drawn from this thesis are as follows.

From a systematic literature review we concluded that people with dementia were able to participate in developing supportive IT applications and provided useful feedback leading to user friendly and usable IT applications. In identifying the content of the *DecideGuide* we found that decision-making in dementia care networks mainly concerned problems of well-being on the part of people with dementia and informal caregivers, rather than care related problems. Two sets of user requirements were identified based on problems experienced and on decisions made by people with dementia, informal caregivers and case managers, and on their additional needs and preferences. These sets provided the basis for the design of the *DecideGuide*. The design of this interactive web tool was the result of four iterations. These iterations were based on feedback by all end users groups. Various participants experienced weaknesses that mainly concerned the system quality: the tool's user-friendliness, its unclear navigation, and lack of persuasiveness of design. Weaknesses addressing the content quality concerned the accuracy of wording and relevance of content. A 5-month field study showed that the user-friendliness of the *DecideGuide* needs improvement, especially for older adults (70+) and for people with dementia. All participants appreciated the easy way of communicating in the *chat* function, and the op-

tion to express individual views. The findings show that the use of the *DecideGuide* is feasible in dementia care practice but that the navigation of the prototype needs further refinement in order to become a robust tool. Participants found the *DecideGuide* a valuable tool in decision-making, regardless of the way they used the tool.

People with dementia participated in developing the *DecideGuide* mainly in the roles of informant and advisor. Their participation resulted in unique feedback leading to a better adjusted version of the prototype of the *DecideGuide*. People with dementia provided us with detailed and unique feedback about their focus on the present, the 'here and now' of their time perception on the one hand and about careful use of language and an agreeable graphical layout on the other. They were intrinsically motivated to participate and to contribute to a better quality of life for future dementia patients and they enjoyed learning new skills.

During this participatory journey we emphasized the importance of the road towards the destination rather than the destination itself. Doing so provided us with valuable information to continue our journey and contribute to a better quality of life for people with dementia and their beloved.

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