



CHAPTER 1

General introduction

1. INTRODUCTION

“Nothing about us without us”, Alzheimer Europe’s Working Group of people with dementia explicitly states. Members of this group implemented this statement during the Alzheimer Europe Conference in Glasgow in 2014 by participating in all kinds of activities, e.g., telling personal stories, giving oral presentations, and chairing sessions. Their contributions impressed me. Despite their disease, they showed strength, power, and a strong drive to give meaning to their life with dementia by revealing to visitors of the conference what living with dementia means to them. It was not a one size fits all story, but there were as many stories as there were people with dementia (“you only heard my story, not theirs”). Their frankness in sharing with us what they go through, what it is like to live with dementia, their struggles and their happiness. Increased professional expertise and researchers’ studies notwithstanding, we still have no idea what goes on in their minds, what it is really like to live with dementia. We can only try to understand by asking them, listening to them, and involving them. We can only support them by familiarizing with their preferences, needs and wishes.

When it comes to decision-making “nothing about us without us” means that decisions about people with dementia’s lives should be made with them. However logical this may sound, deciding with people with dementia is still no daily routine for informal and professional caregivers (Dupuis, Gillies, Carson, & Whyte, 2011; von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). So, decision-making in dementia care can be improved. Shared decision-making (SDM) is an approach that involves patients in decision-making (Elwyn et al. 2010). SDM is often supported by decision aids, i.e. paper based or web based tools (Stacey et al., 2014). Web based tools can be used individually and by multiple involved persons living nearby or at distance, at a preferred moment, and information is recorded in the system. A web based tool facilitating shared decisions might help to improve decision-making with people with dementia. It is important in the development of such a tool that the “nothing about us without us” statement is addressed: developing a tool for people with dementia is developing it with them.

This thesis concerns the development an interactive web tool facilitating shared decision-making in care networks of people with dementia. Community-dwelling people with dementia are often supported by their beloved, their informal caregivers. Professionals like case managers support both. Professional support for people with dementia focuses on living independently as long as possible (Koch et al., 2012; Peeters et al., 2012; van Mierlo, Meiland, van Hout & Dröes, 2014). A care network in this thesis consists of the person with dementia, his or her informal caregivers (e.g., spouse, children close or further away, other relatives, friends, neighbors), and the case manager and other professionals involved (e.g., community nurses, occupational therapists). The perspectives of all these network members matter and the per-

spective of people with dementia may easily be overlooked (Dupuis, Gillies, Carson & White, 2011). Since these network members have different capacities and interests, this will challenge the development trajectory. We therefore expect this trajectory to be more like a journey, more specifically, a participatory journey; a journey that does not emphasize its destination but its road towards it, a useful and user friendly tool supporting SDM in dementia care networks.

In this chapter we will first describe the background of this thesis addressing the following topics: dementia, impact of dementia, professional caregivers in dementia care, decision-making in the context of dementia, shared decision-making, technology in dementia care, patient participation in decision-making and research, and IT development. Next, we will describe the objectives and research questions of this thesis. We will end this chapter with an outline of this thesis.

1

2. BACKGROUND OF THE STUDY

2.1 Dementia

Dementia is a syndrome that can have various origins and affects people's cognitive abilities. Alzheimer's disease is the most common type of dementia (60-80%). Vascular dementia, often occurring after a stroke, is the second most common type. Less common are Lewy Body dementia, Frontotemporal dementia, and dementia caused by Parkinson's disease (Prince, Albanese, Guerchet, & Prina, 2014).

The number of people living with dementia is increasing. In a recent review (Prince et al., 2013) it was estimated that in 2013 44.35 million people lived with dementia worldwide. That number will be nearly doubled to 75.62 million by 2030, and more than tripled to 135.46 million by 2050. The estimates in this review are far higher than those in the 2009 World Alzheimer Report. This increase affects low and middle-income countries more than high-income countries. A study by Wu, Matthews, & Brayne (2014) suggests stable or decreased prevalence of dementia for high income countries over the past 20 years.

People with dementia have a shortened life expectancy. After diagnosis, dementia leads to death within 6-10 years (Todd, Barr, Roberts, & Passmore, 2013). During the period of living with dementia, people have to make various decisions about their own situation (Livingston et al., 2010). Most people with dementia in Europe prefer to stay at home, where family members, friends and neighbors provide most care and support (WHO and ADI, 2012). However, institutionalization is sometimes inevitable (Alzheimer's Society, 2013). This is experienced as one of the most difficult decisions to be made (Livingston et al., 2010).

Living at home for as long as possible is stimulated by national health policies due to increasing health care costs (Schippers, 2012). However, these years of living at home are often difficult for both people with dementia and their beloved. There is a continuous change of situation caused by changes in the person with dementia, and changes in the roles of care network members (Carpentier & Ducharme, 2003). The balance between people with dementia and their informal caregivers can be easily disturbed. Potential stressors that affect this balance involve psychological, medical, social or environmental elements (MacNeil Vroomen et al., 2013). Therefore, supporting people with dementia and their informal caregivers is important. To do so, well-equipped and competent professionals are needed as well as smart solutions, possibly in the form of Information Technology (IT) tools.

2.2 Impact of dementia

Dementia is characterized by a progressive cognitive decline. Regardless of the type of dementia, memory loss, problems with finding words, communicating, going through daily routines, and orienting, as well as changes in personality and behavior are main characteristics (Prince et al., 2014). In the course of time, this results in a growing dependency of people with dementia on informal and formal care.

Dementia mainly affects older adults (Prince et al., 2014). Besides dealing with symptoms related to their age, people with dementia not only have to deal with the symptoms and disabilities associated with dementia, but also with public stigmatization: prejudices, stereotypes, and discrimination that result from misconceptions about dementia (Devlin, MacAskill, & Stead, 2007; Rusch, Angermeyer, & Corrigan, 2005; Werner & Heinik, 2008). Misconceptions about dementia can be often related to what people know about the more severe end stages of dementia (Devlin et al., 2007).

Stigma is a process of disqualifying people in which a normal person is reduced to a person with whom something is wrong (Goffman, 1963). Werner and Heinik (2008) report high levels of structural discrimination. They observed that people with dementia were treated differently by relatives, friends, and neighbors after they had been diagnosed. Vernooij-Dassen and colleagues (2005), noticed a dementia related stigma in professionals, who thought that there was little to offer in the early phase of dementia. This attitude resulted in delayed diagnosis and pessimism about prognosis. Recently, Gove, Downs, Vernooij-Dassen & Small (2015) found that GP's perceived that stigma still hindered a timely diagnosis.

Negative perceptions about people with dementia's capacities and abilities by relatives, friends, neighbors and professionals influence their view of people with dementia, as socially alive and social actors or as socially dead (Brannelly, 2011). As a result of increased dependency and of the stigma that dementia carries, social contacts that people with dementia have decline. Making contact with people with

dementia becomes more difficult over time, and this can easily lead to passivity, loneliness, and isolation on the part of people with dementia (Werner & Heinik, 2008).

Although these negative aspects associated with dementia and the burden related to caregiving to people with dementia are paid a lot of attention, there is a growing awareness of positive aspects of dementia caregiving and how these positive aspects can be supported in informal caregivers (Cheng, Mak, Lau, Ng, & Lam, 2015; Lloyd, Patterson, & Muers, 2014). Cheng and colleagues (2015) for example identified insight into and acceptance of dementia, feelings of gratification, mastery skills, letting go of things, increased patience and tolerance, and feeling useful in helping other informal caregivers as gains obtained in caregiving by informal caregivers. Lloyd and colleagues (2014) identified several positive dimensions in their review: emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity. Some of these positive dimensions depended on previous positive relationships between relatives. Emphasizing the positive aspects of caregiving, e.g., by professionals, can help decrease feelings of burden in informal caregivers (Lloyd et al., 2014). Furthermore, cultural aspects may influence how people experience caregiving. For example, informal caregivers of older adults in the Suryoye community experience caregiving as positive as it is part of community expectations and opinions about good care (Groen-van de Ven & Smits, 2009).

1

2.3 Professional caregivers in dementia care

Community-dwelling people with dementia and their informal caregivers are often supported by professionals like case managers, who help people with dementia live independently as long as possible (Verkade et al., 2010; Koch et al., 2012). Case management in dementia care is a fairly recent phenomenon. Community-dwelling patients diagnosed with dementia and their caregivers are entitled to assistance in the form of case management in the Netherlands (van Mierlo, Meiland, van Hout & Dröes, 2014), as they are in most European countries, in Canada and in The United States (Koch et al., 2012; Peeters et al., 2012). Different forms of case management in dementia care exist (Alzheimer Europe, 2008; van Mierlo, Meiland, van Hout & Dröes, 2014). Essential components of case management are sharing information, offering support and counseling, coordinating the care provided and practical help (Verkade et al., 2010). In daily practice, this implies that case managers have to balance the possibly competing interests and values of the person with dementia, the spouse, and other informal caregivers (who may be the adult children of the person). Informal caregivers who are close often perceive the situation of the person with dementia differently from informal caregivers who are at a greater distance. Moreover, they do not always share the same information. This complicates reaching shared decisions. This complicated situation requires skilled case managers and supportive tools for

shared decision-making in order to do justice to all network members involved in decision-making (Smits & Groen-van de Ven, 2014). Unfortunately, no such supportive tools for dementia care practice are available.

Nowadays, Dutch health policies advocate using SDM as the preferred way of making shared decisions. This is laid down in the Dutch Dementia Care Standard (Dutch Alzheimers's Association & Vilans, 2012). As case management for dementia is a fairly recent phenomenon, and decision-making in dementia is complex, case managers need support to address the complex needs and preferences of people with dementia and their caregivers. Supportive tools, paper or web based, might help in addressing the incapacitation of case managers.

2.4 Decision-making in the context of dementia

Decision-making in dementia is complex because multiple participants are involved, who have different capacities and interests, and because the cognitive decline associated with dementia is progressive (Wolfs et al., 2012). People with dementia and their beloved need to make many decisions about daily life over a prolonged period of time, e.g., decisions concerning living, driving a car, daily activities (Livingston et al., 2010). Unfortunately, involving people with dementia in decision-making about their own situation is not self-evident (Nygård, 2006). Informal and professional caregivers tend to shield people with dementia, often with the best of intentions (Dupuis, Gillies, Carson, & Whyte, 2011). Some of them believe that people with dementia are no longer capable of making decisions and that it leads to restlessness in them (Dupuis, Gillies, Carson, & Whyte, 2011; Boyle, 2014).

Decisional capacities of people with dementia decrease over time (Livingston et al., 2010). The rate at which this occurs differs from individual to individual. This decrease of decisional capacities does not automatically mean that people with dementia cannot decide about their situation anymore or that they do not want to be involved in decision-making. They want to be involved in decision-making as long as possible (Fetherstonhaugh, Tarzia, Bauer, Nay, & Beattie, 2014). Research shows that people with dementia can consistently express their needs (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012) and preferences (Miller, Whitlatch, & Lyons, 2014), even in advanced stages of dementia (Whitlatch, 2009).

Wolfs and colleagues (2012) observed that decision-making in dementia differs from decision-making in the context of other chronic diseases: the difficulty of accepting dementia, the progressive nature of dementia, patients' reliance on surrogate decision-making, and strong emotions make decision-making in dementia a time consuming process. Accepting the diagnosis might reduce anxiety and resistance to care, which may prove to be beneficial in the future.

In the dementia trajectory, patients cannot but rely on their informal caregivers

for making decisions more and more. Family caregivers find it difficult to decide with (Caron, Ducharme, & Griffith, 2006; Caron, Griffith, & Arcand, 2005) and for people with dementia and are in need of strategies (Livingston et al., 2010). Livingston and colleagues (2010) found that family caregivers emphasized problems in decision-making due to resistance of the person with dementia. People with dementia's dignity can only be retained when they and their family caregivers agree. Strategies for agreement are: introducing change slowly, organizing legal changes for both informal caregiver and person with dementia, involving a professional to persuade people with dementia to accept services, and emphasizing that services optimize rather than impede independence (Livingston et al., 2010).

According to Wolfs and colleagues (2012) decision-making in dementia consists of three different phases: 1) identifying individual needs, 2) exploring options (the most important phase), and 3) making a choice. They state that dementia is a complicated, emotional, time consuming, and continuously changing process during which personal preferences are more important than practical issues.

2.5 Shared decision-making

Shared decision-making (SDM) has its roots in the clinical encounter and is an approach that involves patients in making medical decisions together with their clinician (Elwyn et al., 2010). It is an interactive process including: sharing information and opinions, discussing patient preferences and providers' responsibilities. Shared decision-making results in better-informed patients who have an active role in decision-making, more satisfaction with decisions made, and a better quality of life (Elwyn, Edwards, & Kinnersley, 1999; O'Connor et al., 2009; Stiggelbout et al., 2012). It increases patient autonomy and empowers patients (Duncan, Best, & Hagen, 2010). In the context of dementia SDM results in increased autonomy (Dupuis et al., 2011) and well-being (Menne, Tucke, Whitlatch, & Feinberg, 2008) of both the person with dementia and the informal caregiver. SDM is part of person-centered care that aims to see patients as individual persons and as equal partners (McCormack & McCance, 2010; Munthe, Sandman, & Cutas, 2012). Person-centered care is essential for good quality of health care for people with dementia (Kitwood, 1997; Dutch Alzheimers's Association & Vilans, 2012), and for person-centered decisions shared decision-making is required (McCormack & McCance, 2010). SDM, therefore, is the focus of this thesis. A supportive tool might help professionals such as case managers in facilitating SDM in the complexity of dementia care.

Over the past two decades, SDM models have been developed for various health care settings: acute care (Charles, Gafni, & Whelan, 1999), primary care (Murray, Charles, & Gafni, 2006), and chronic disease (Montori, Gafni, & Charles, 2006). The SDM approach and its elements have developed over time (Matthias, Salyers, & Fran-

kel, 2013). Charles, Gafni, and Whelan (1997; 1999), early adopters of SDM, advocated four essential elements: involvement of patient and clinician, sharing information, expressing treatment preferences, and agreeing to implement the treatment decision. Elwyn and colleagues (2003) emphasized that involving patients in decision-making was a necessary element if there were more treatment options and they argued that it included a perspective that clinicians do not have, whereas Makoul and Clayman (2006) added the patient's ability to achieve the goals of the treatment plan as an important element of SDM. In their systematic review, Makoul and Clayman (2006) identified essential elements in SDM literature: define problem, present options, discuss pros/cons, take into account patient values and preferences, discuss patient ability/self-efficacy, doctor knowledge/recommendations, check/clarify understanding, make a decision, and arrange a follow-up. In the same period Entwistle and Watt (2006) advocated a broader conceptual framework of involving patients in making decisions on treatment because contexts in health care differ. For patients with chronic conditions, Montori, Gafni, and Charles (2006) advocated an ongoing partnership as a prerequisite for SDM. This partnership had been a neglected aspect of SDM. Matthias, Salyers and Frenkel (2013) stated that in the clinical encounter SDM mainly focused on a single decision between two parties, the patient and the clinician, rather than on the entire encounter and investing in a partnership.

So SDM has developed from a view that focuses on making one decision to a view in which more attention is paid to various contexts and the difficulties that those contexts create. In the latter view the decision is not central, the process of decision-making is. In the context of dementia there is growing attention for the needs and wants of people with dementia, person centered care (Epp, 2003; Edvardsson, Fetherstonhaugh & Nay (2010). SDM contributes to person centered care since people with dementia who are part of the decision-making process experience personhood to a greater degree (Miller et al., 2014).

SDM is often supported by decision aids (Med-Decs, 2014; Stacey et al., 2014). Decision aids vary a lot, some are very brief, others more extended. Option Grids are the briefest ones, offering one-page sheets outlining the possible options. Brief decision aids (BDAs) and SDM sheets are leaflets with more detailed information. Patient decision aids (PDAs) occur as computer programs, DVDs, mobile apps and interactive websites (NHS England, 2015). Unfortunately, they are only available for a limited number of conditions and therefore a broader approach is needed. The Ottawa Hospital Research Institute recently developed more generic decision aids for any health-related or social decision (OHRI, 2014).

In the context of dementia SDM is a fairly recent phenomenon (Miller et al., 2014) and supporting tools are scarce. Stirling et al. (2012) developed a decision aid for caregivers of people with dementia about respite care. Murphy and Oliver (2013) supported interaction about decisions between people with dementia and their care-

givers by representing decisions and options on picture symbol cards. As SDM in the context of dementia is new and professionals such as case managers in the Netherlands find it difficult to facilitate SDM in care networks of people with dementia, supportive tools might help them.

2.6 Technology in dementia care

In the clinical encounter tools often support shared decision-making. These tools can be paper based or web based (Stacey et al., 2014). The advantages of web-based tools include their flexibility as to the individual's preferred time and place for using them, their relatively anonymous use, and their functionality to record all activities and information. Dementia-care networks could benefit from such a web-based tool because it enables network members, whether close or a long distance away, to participate in decision-making and to give individual opinions.

Development and use of information technology (IT) based solutions for people with dementia and informal caregivers have grown over the last decade (Lauriks et al., 2007; Magnusson, Hanson, & Borg, 2004). Examples of such IT based solutions are: reminding (e.g., prompting devices), social contacts (e.g. reminiscence tools and picture dialing), safety (e.g. tracking devices), and daily activities (e.g. music players). The growth of supportive tools was triggered by the increasing number of dementia patients, which taxes health care systems.

Consequently, more people with dementia stay at home and only people in advanced stages of dementia will receive residential care. So, solutions are needed that focus on preserving autonomy, self-management, and well-being to support community living people with dementia and their informal caregivers to stretch living independently. Policy-makers and researchers often see IT tools as promising solutions in this area (Magnusson et al., 2004; Nugent, 2007; Schippers, 2012; WHO & ADI, 2012). Despite the benefits of supportive IT solutions, implementing these solutions is difficult. Sometimes these tools do not match the needs and capacities of end users like people with dementia. Tools may be too difficult, may have too many functionalities, or may not be attractive (Hanson et al., 2007).

Shortcomings of tools that have been developed may be to the result of poor involvement of people with dementia in development processes of IT applications. Their voice is often ignored (Savitch & Zaphiris, 2006; Wilkinson, 2002). Researchers, designers and clinicians mainly focus on the information provided by caregivers because of the increasing cognitive impairment and frailty of people with dementia. Involving people with dementia in development processes may lead to better adjusted IT applications. Furthermore, it has been suggested that such involvement promotes their autonomy and empowerment (Cubit, 2010; Hellström, 2007; Nygård, 2006).

2.7 Patient participation in decision-making and research

Patient participation is not standard, not in decision-making (Dupuis, Gillies, Carson, & Whyte, 2011; von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012), nor in research (Murphy et al., 2014). Excluding people with dementia, either living in institutions or in communities, from decision-making is sometimes voluntary because they do not want to participate. In that case it is their decision not to participate. Sometimes they are not given the chance to participate, even if they are perfectly able to participate in decision-making (Fetherstonhaugh et al., 2014). Many countries have laws that give patients the right to participate in decision-making about their health care situation. Not all patients, however, want to be involved in decision-making or be involved to the same extent (Levinson, Kao, Kuby, & Thisted, 2005). Although decisional capacities of people with dementia decline, they are not completely incapable of making decisions. They may have retained some capacity (Smebye, Kirkevold, & Engedal, 2012). Excluding people from participating in decision-making can result in depression, frustration, and anger (Sabat, Napolitano, & Fath, 2004). Family caregivers who see that relatives with dementia are more involved in decision-making, report better quality of life, less depression, less negative strain, and more understanding of the values of the person with dementia (Menne et al., 2008; Reamy, Kim, Zarit, & Whitlatch, 2011). To understand people with dementia, it is important for informal caregivers to be aware of their values and preferences. Informal caregivers' preferences do not always coincide with those of people with dementia (Reamy et al., 2011). Seeing that maintaining dignity is a key problem for people with dementia it is important to involve them in shared decision-making: it gives them the opportunity to contribute to reciprocity, takes into account their wishes and autonomy, and stimulates their dignity (Vernooij-Dassen & de Lange, 2015).

Patient participation is nowadays part of sound research in social sciences (Abma, Pittens, Visse, Elberse, & Broerse, 2014; Smit, van der Valk, & Wever, 2011; Visse, Abma, & Widdershoven, 2012). Besides, empowerment, self-management and participation are important topics in governmental and health policies (RIVM, 2013; WHO, 2013, 2014). Furthermore, since 2000, people have become more assertive and they now ask to participate (Alzheimer Europe, 2012). Research topics do not always match their needs and wants and patients no longer accept being patronized. Patient participation in research enables patients to influence what is important to them. This shift, from exclusion to inclusion changes both the position of patients and that of researchers in research.

2.8 IT development

For a long time designers have been excluded consumers and patients from development processes. At best, they were involved towards the end of the process, to test the device that had been developed. Consequently, IT-based solutions did not fit end users' needs (van Kuijk, Christiaans, Kanis, & van Eijk, 2006).

Because these solutions were hardly used end users came to be the focus of attention. In order to develop useful and user friendly IT-based solutions that can and will be used by people with dementia, such as an interactive web tool to facilitate SDM, their needs and wishes have to be taken into account. Developing IT-based solutions thus shifted from expert and technology driven to end user driven. Human Centered Design (HCD) is an approach that supports end user driven development trajectories (Steen, 2008). HCD emphasizes the involvement of end users and stimulates constructive collaboration between developers, designers (representing technology) and end users. However, to develop sustainable eHealth innovations, such as the IT-based solution in this thesis, a third component is necessary: besides technology (design and usability) and people, the health care environment or organization also matters.

Contextual Design (Beyer & Holzblatt, 2010) and the Center for eHealth Research and Disease Management (CeHRes) roadmap (van Gemert-Pijnen et al., 2011) are holistic approaches emphasizing these three interrelated components: technology, people, and organization. Both approaches have their roots in HCD. For our development process we used the CeHRes roadmap because it focuses on the health domain.

The CeHRes roadmap is a holistic framework to develop sustainable eHealth technologies (van Gemert-Pijnen et al., 2011). It combines HCD principles with Business modeling and consists of five phases: contextual inquiry, value specification, design, operationalization, and summative evaluation. In the contextual inquiry phase relevant information is gathered from the environment where the technology will be implemented. In the value specification phase user requirements are identified based on the information gathered in the contextual inquiry phase. In the design phase, the determined user requirements are translated into technical specifications. The operationalization phase focuses on activities that are needed to implement the technology in practice. Summative evaluation concerns determining what has been achieved at a certain moment.

3. OBJECTIVES OF THIS THESIS

This thesis takes you on a journey. A journey that describes the development of a supportive interactive web tool that facilitates case managers in supporting shared decision-making in care networks of people with dementia. The users of this interactive web tool are community professionals such as case managers, people with dementia, and their informal caregivers. They each have different capacities and interests that have to be taken into account

The aims of the interactive web tool are: (1) to facilitate case managers and other community professionals in supporting SDM in dementia care networks, (2) to make the voice of people with dementia heard, and (3) to involve informal caregivers at a distance.

In order to develop such an attuned tool it is essential that all end users participate. However, developing an application for people with different capacities and interests is complex and uncommon. Therefore, this thesis aims to give insight into the development of such a tool and takes you on this participatory journey.

Various questions have to be answered to explore step-by-step what is needed for this application with regard to its content and design, and to maximize its use in care networks of people with dementia. The main research questions of this thesis therefore are:

1. In which ways are people with dementia involved in developing supportive IT applications?
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?
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?
4. How do people with dementia, informal caregivers, and casemanagers 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?
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?

4. OUTLINE OF THIS THESIS

In Chapter 2 we will answer research question 1. We will present the results of a systematic literature search aiming to give an overview of people with dementia's involvement in developing supportive IT applications. The extensive search was executed up to July 2011 without restriction of date and language.

Chapter 3 will elaborate on the results of research question 2. In a thorough and step-by-step approach, based on the findings of our systematic review, we identified user requirements for the content of an interactive web tool facilitating shared decision-making in dementia care networks. These user requirements were based on conversations with people with dementia, their informal caregivers and case managers. They provided us with information about the problems in their lives with respect to decision-making and the decisions they were facing.

On the basis of the identified user requirements, we will in Chapter 4 describe the design issues, weaknesses, and strengths that should be considered when designing a user-friendly interactive web tool. Together with the end user groups we decided on the design step-by-step. We gathered feedback from them and they gave us advice for improvements. This resulted in a first prototype of the interactive web tool, the *DecideGuide*.

This first prototype was tested in a field study addressing research question 4. In chapter 5 the results of this field study will be presented. Four people with dementia, their informal caregivers, and case managers used the first prototype of the *DecideGuide* on a day-to-day basis in a 5-month field study. Those participating in the field study provided us with information regarding the user-friendliness of the *DecideGuide*, their satisfaction with it, and how they rated the *DecideGuide* for decision-making.

In Chapter 6 we will answer research question 5. In this chapter we will reflect on people with dementia participating in developing the *DecideGuide*.

Chapter 7 contains a general discussion. In this chapter we will reflect on the results of the studies that we reported on in this thesis, will discuss them, and draw conclusions. Finally, we will describe practical and societal implications of this study.

REFERENCES

- Abma, T. A., Pittens, C. A. C. M., Visse, M., Elberse, J. E., & Broerse, J. E. W. (2014). Patient involvement in research programming and implementation. *Health Expectations*, n/a-n/a. doi: 10.1111/hex.12213
- Alzheimer Europe (2008). *Alzheimer in Europe Yearbook 2008*. Retrieved from: <http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>
- Alzheimer Europe (2012). Personal experiences of living with dementia. from <http://www.alzheimer-europe.org/Living-with-dementia/Personal-experiences-of-living-with-dementia>
- Alzheimer's Society (2013). Leading the fight against dementia. Retrieved from: <http://www.alzheimers.org.uk/>
- Beyer, H., & Holzblatt, K. (2010). *Contextual Design. Defining Customer-Centered Systems*. : Morgan Kaufmann Publishers.
- Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society*, 29(7), 1130-1144.
- Brannelly, T. (2011). Sustaining citizenship: people with dementia and the phenomenon of social death. *Nurs Ethics*, 18(5), 662-671. doi: 10.1177/0969733011408049
- Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Can J Aging*, 25(2), 193-205.
- Caron, C. D., Griffith, J., & Arcand, M. (2005). End-of-life decision making in dementia: The perspective of family caregivers. *Dementia*, 4(1), 113-136. doi: 10.1177/1471301205049193
- Carpentier, N., & Ducharme, F. (2003). Care-giver network transformations: the need for an integrated perspective. *Ageing & Society*, 23(4), 507-525.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean (or it takes at least two to tango). *Social Science & Medicine*(44), 681-692.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651-661. doi: [http://dx.doi.org/10.1016/S0277-9536\(99\)00145-8](http://dx.doi.org/10.1016/S0277-9536(99)00145-8)
- Cheng, S.-T., Mak, E. P. M., Lau, R. W. L., Ng, N. S. S., & Lam, L. C. W. (2015). Voices of Alzheimer Caregivers on Positive Aspects of Caregiving. *The Gerontologist*. doi: 10.1093/geront/gnu118
- Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse*, 34(2), 230-236.
- Devlin, E., MacAskill, S., & Stead, M. (2007). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of Nonprofit and Voluntary Sector Marketing*, 12(1), 47-58. doi: 10.1002/invsm.273
- Duncan, E., Best, C., & Hagen, S. (2010). Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews*(1. Art. No: CD007297.).
- Dupuis, S. L., Gillies, J., Carson, J., & Whyte, C. (2011). Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia*, 11(4), 427-452.
- Dutch Alzheimer's Association, & Vilans (2012). Dutch Dementia Care Standard [Zorgstandaard Dementie]. Retrieved from: <http://www.alzheimer-nederland.nl/media/18837/Definitieve%20Zorgstandaard%20Dementie%20september%202013.pdf>
- Elwyn, G., Edwards, A., & Kinnersley, P. (1999). Shared decision-making in primary care: the neglected second half of the consultation. *British Journal of General Practice*, 49, 477-482.
- Elwyn, G., Edwards, A., Wensing, M., Hood, K., Atwell, C., & Grol, R. (2003). Shared decision making: developing the OPTION scale for measuring patient involvement. *Qual Saf Health Care*, 12(2), 93-99.

- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *BMJ*, *341*, c5146. doi: 10.1136/bmj.c5146
- Epp, T.D. (2003). Person-centered dementia care: a vision to be refined. *The Canadian Alzheimer Disease Review*, 14-18.
- Edvardsson, D., Fetherstonhaugh, D. & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, Vol. 19, issue 17-18, 2611-2618.
- Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: the case for a broader conceptual framework. *Patient Educ Couns*, 63(3), 268-278. doi: 10.1016/j.pec.2006.05.002
- Fetherstonhaugh, D., Tarzia, L., Bauer, M., Nay, R., & Beattie, E. (2014). "The Red Dress or the Blue?": How Do Staff Perceive That They Support Decision Making for People With Dementia Living in Residential Aged Care Facilities? *J Appl Gerontol*. doi: 10.1177/0733464814531089
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity* New York: Simon and Schuster Inc.
- Gove, D., Downs, M., Vernooij-Dassen, M., & Small, N. (2015). Stigma and GPs' perceptions of dementia. *Aging Ment Health*, 1-10. doi: 10.1080/13607863.2015.1015962
- Groen-van de Ven, L., & Smits, C. (2009). Attention, acceptance, and understanding: informal care to older adults in the Suryoye community [Aandacht, acceptatie en begrip; mantelzorg aan ouderen in de Suryoye gemeenschap]. *Culture Migration Health [Cultuur Migratie Gezondheid]*, 6(4), 198-208.
- Groen - van de Ven, L., Smits, C., de Graaff, F., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2015). Deciding together through considerations, emotions and actions: Shared Decision Making about day-care in dementia *submitted*.
- Hanson, E., Magnusson, L., Arvidsson, H., Claesson, A., Keady, J., & Nolan, M. (2007). Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. *Dementia: The International Journal of Social Research and Practice*, 6(3), 411-434.
- Hellström, I., Nolan, M., Nordenfelt, L., Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-619.
- Kitwood, T. (1997). The experience of dementia. *Aging and Mental Health*, 1, 13-22.
- Koch, T., Iliffe, S., Manthorpe, J., Stephens, B., Fox, C., Robinson, L., Livingston, G., Coulton, S., Knapp, M., Chew-Graham, C. and Katona, C. CARE-DEM. (2012). The potential of case management for people with dementia: a commentary. *International Journal of Geriatric Psychiatry*, 27, 1305-1314.
- Lauriks, S., Reinersmann, A., Roest, H. v. d., Meiland, F. J. M., Davies, R. J., Moelaert, F., Mulvenna, M.D., Nugent, C.D. and Dröes, R. M. (2007). Review of ICT-based services for identified unmet needs in people with dementia. *Aging Research Reviews*, 6(3), 223-246.
- Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making. A national study of public preferences. *J Gen Intern Med*, 20(6), 531-535. doi: 10.1111/j.1525-1497.2005.04101.x
- Livingston, G., Leavet, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K. and Cooper, C. (2010). Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ*, 341(aug 18 1) c4184.
- Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*. doi: 10.1177/1471301214564792
- MacNeil Vroomen, J., Bosmans, J. E., van Hout, H. P., & de Rooij, S. E. (2013). Reviewing the definition of crisis in dementia care. *BMC Geriatrics*, 13(10), doi:10.1186/1471-2318-1113-1110.

- Magnusson, L., Hanson, E., & Borg, M. (2004). A literature review study of information and communication technology as a support for frail older people living at home and their family carers. *Technology and Disability, 16*(4), 223-235.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Educ Couns, 60*, 301-312.
- Matthias, M. S., Salyers, M. P., & Frankel, R. M. (2013). Re-thinking shared decision-making: Context matters. *Patient Educ Couns, 91*(2), 176-179. doi: <http://dx.doi.org/10.1016/j.pec.2013.01.006>
- McCormack, B., & McCance, T. (2010). A Theoretical Framework for Person-Centred Nursing *Person-Centred Nursing* (pp. 21-39): Wiley-Blackwell.
- Med-Decs (2014). The international meeting-place for help with medical choices [De internationale verzamelplaats voor hulp bij medische keuzen]. Retrieved, from: <http://www.med-decs.org/nl/>
- Menne, H. L., Tucke, S. S., Whitlatch, C. J., & Feinberg, L. F. (2008). Decision-Making Involvement Scale for Individuals With Dementia and Family Caregivers. *American Journal of Alzheimer's Disease & Other Dementias, 23*(1), 23-29.
- Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2014). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia (London)*. doi: 10.1177/1471301214555542
- Montori, V. M., Gafni, A., & Charles, C. (2006). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expect, 9*(1), 25-36. doi: 10.1111/j.1369-7625.2006.00359.x
- Munthe, C., Sandman, L., & Cutas, D. (2012). Person Centred Care and Shared Decision Making: Implications for Ethics, Public Health and Research. *Health Care Analysis, 20*(3), 231-249.
- Murphy, J., & Oliver, T. (2013). The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health Soc Care Community, 21*(2), 171-180. doi: 10.1111/hsc.12005
- Murray, E., Charles, C., & Gafni, A. (2006). Shared decision-making in primary care: tailoring the Charles et al. model to fit the context of general practice. *Patient Education and Counseling, vol. 62*(2): 205-211, 10.1016/j.pec.2005.07.003s.
- NHS England (2015). Tools for shared decision making. Retrieved from: <https://www.england.nhs.uk/ourwork/pe/sdm/tools-sdm/>
- Nugent, C. (2007). ICT in the elderly and dementia. *Aging & Mental Health, 11*(5), 473-476.
- Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scand J Occup Ther, 13*, 101-112.
- O'Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Col, N. F., Eden, K. B., Entwistle, V.A., Fiset, V., Holmes-Rovner, M., Khangura, S., Llewellyn-Thomas, H. and Rovner, D. (2009). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*(3), CD001431. doi: 10.1002/14651858.CD001431.pub2
- OHRI, Ottawa Hospital Research Institute (2014). Patient Decision Aids. Retrieved from: <http://decisionaid.ohri.ca/index.html>
- Peeters, J., de Lange, J., van Asch, I., P., S., Veerbeek, M., Pot, A. M., & Francke, A. (2012). National evaluation of dementia case management [Landelijke evaluatie van casemanagement dementie]. Utrecht: NIVEL.
- Prince, M., Albanese, E., Guerchet, M., & Prina, M. (2014). World Alzheimer Report 2014. Dementia and Risk Reduction. An analysis of protective and modifiable factors. Retrieved from: <http://www.alz.co.uk/research/world-report-2014>
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dement, 9*(1), 63-75 e62. doi: 10.1016/j.jalz.2012.11.007
- Reamy, A. M., Kim, K., Zarit, S. H., & Whitlatch, C. J. (2011). Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers. *Gerontologist, 51*(4), 473-483. doi: 10.1093/geront/gnr010

RIVM, Rijksinstituut voor Volksgezondheid en Milieu. Ministerie van Volksgezondheid,

Welzijn en Sport. (2013). National Compass Public Health. Participation: What is the relation with health and care? [Nationaal Kompas Volksgezondheid. Participatie: Wat is de samenhang met gezondheid en zorg?] <http://www.nationaalkompas.nl/participatie/samenhang/>

Rusch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *Eur Psychiatry, 20*(8), 529-539. doi: 10.1016/j.eurpsy.2005.04.004

Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias, 19*(3), 177-185. doi: 10.1177/153331750401900311

Savitch, N., & Zaphiris, P. (2006). *Accessible websites for People with Dementia: a Preliminary Investigation into Information Architecture*. Paper presented at the ICCHP.

Schippers, E. I. (2012). eHealth letter of Dutch Minister of Ministry of Health, Welfare and Sport [Kamerbrief eHealth]. Retrieved from <http://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2012/06/07/kamerbrief-over-e-health.html>

Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC Health Services Research, 12*(241). doi: 10.1186/1472-6963-12-241

Smit, C., van der Valk, T., & Wever, K. (2011). Fundamental research and patient organizations: a surprising combination! [Fundamenteel onderzoek en patiëntenorganisaties: een verrassende combinatie!]. Badhoevedorp.

Smits, C. & Groen van de Ven, L., 'Shared decision-making with vulnerable older adults' in *Perspectives on aging and the social professional*. ['Gezamenlijke besluitvorming bij kwetsbare ouderen' in *Perspectieven op ouder worden en de social professionals*], Joost van Vliet en Jan S.

Jukema (redactie) Boom Lemma uitgevers, Den Haag, 2014, ISBN 978-905931988-2.

Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., Trevena, L. and Wu, J. H. C. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD001431.pub4

Steen, M. (2008). *The fragility of human-centered design*. IOS Press Amsterdam.

Stiggelbout, A. M., Van der Weijden, T., De Wit, M. P., Frosch, D., Legare, F., Montori, V. M., Trevena, L. and Elwyn, G. (2012). Shared decision making: really putting patients at the centre of healthcare. *BMJ, 344*, e256. doi: 10.1136/bmj.e256

Stirling, C., Leggett, S., Lloyd, B., Scott, J., Blizard, L., Quinn, S., & Robinson, A. (2012). Decision aids for respite service choices by carers of people with dementia: development and pilot RCT. *BMC Medical Informatics & Decision Making, 12*(1), 21.

Todd, S., Barr, S., Roberts, M., & Passmore, A. P. (2013). Survival in dementia and predictors of mortality: a review. *Int J Geriatr Psychiatry, 28*(11), 1109-1124. doi: 10.1002/gps.3946

van Gemert-Pijnen, J. E. W. C., Nijland, N., Van Limburg, M. A. H., Kelders, S. M., Brandenburg, B. J., Ossebaard, H. C., Eysenbach, G. and Seydel, E. R. (2011). Introducing a holistic framework for eHealth technologies. *Journal of Medical Internet Research, 13* (4):e111.

van Kuijk, J. I., Christiaans, H. H. C. M., Kanis, H., & van Eijk, D. J. (2006). *Usability in the development of consumer electronics: issues and actors*. Paper presented at the IEA 2006: the 16th world congress on ergonomics, Maastricht, The Netherlands.

van Mierlo, L.D., Meiland, F.J., van Hout, H.P., Dröes, R.M. (2014). Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. *BMC Geriatrics, 14*:84. doi: 10.1186/1471-2318-14-84.

- Verkade, P.J., van Meijel, B., Brink, C., van Os-Meendorp, H., Koekkoek B., Francke, A.L. (2010), Delphi-research exploring essential components and preconditions for case management in people with dementia, *BMC Geriatrics*, 10:54
- Vernooij-Dassen, M., & de Lange, J. (2015). Balance control retention and dependence [Balans regiebehoud en afhankelijkheid]. In R. M. Droës (Ed.), *More quality of life. Integrative, person centered dementia care* [Meer kwaliteit van leven. Integratieve, persoonsgerichte dementiezorg]. Leusden: Diagnosis Uitgevers.
- Vernooij-Dassen, M. J. F. J., Moniz-Cook, E. D., Woods, R. T., De Lepeleire, J., Leuschner, A., Zanetti, O., de Rotrou, J., Kenny, J., Franco, M., Peters, V. and Illife, S. INTERDEMGROUP. (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *International Journal of Geriatric Psychiatry*, 20, 377-386.
- Visse, M., Abma, T. A., & Widdershoven, G. A. M. (2012). Relational responsibilities in responsive evaluation. *Evaluation and Program Planning*, 35(1), 97-104. doi: <http://dx.doi.org/10.1016/j.evalprogplan.2011.08.003>
- von Kutzleben, M., Schmid, W., Halek, M., Holle, B., & Bartholomeyczik, S. (2012). Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging & Mental Health*, 16(3), 378-390.
- Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging & Mental Health*, 12, 92-99.
- Whitlatch, J., Menne, H. (2009). Don't forget about me. Decision making by people with dementia. *Journal of the American Society on Aging*, 33(1), 66-71.
- WHO, World Health Organization (2013). Exploring patient participation in reducing health-care-related safety risks. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0010/185779/e96814.pdf
- WHO, World Health Organization (2014). Social participation. Retrieved from http://www.who.int/social_determinants/thecommission/countrywork/within/socialparticipation/en/
- WHO and ADI, World Health Organization and Alzheimer's Disease, International (2012). Dementia, a public health priority. Retrieved from http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf;
- Wilkinson, H. (2002). Including people with dementia in research: methods and motivations. In H. Wilkinson (Ed.), *The perspectives of people with dementia, research methods and motivation* (pp.9-24). London: Jessica Kingsley.
- Wolfs, C. A. G., de Vugt, M. E., Verkaaik, M., Haufe, M., Verkade, P. J., Verhey, F. R. J., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: A contradiction in terms? *Patient Educ Couns*, 87(1), 43-48.
- Wu, Y. T., Matthews, F. E., & Brayne, C. (2014). Dementia: time trends and policy responses. *Maturitas*, 79(2), 191-195. doi: 10.1016/j.maturitas.2014.06.020

