

Shared decision-making in dementia care networks: beyond verbal deliberation

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**Shared decision-making in dementia care networks:
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*In herinnering aan mijn oma die zelf nooit de kans heeft gehad om te studeren,
maar de liefde voor lezen en leren doorgaf aan volgende generaties.*

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CHAPTER 1

GENERAL INTRODUCTION



The case of Mrs. van Dijk

Mrs. Van Dijk is a 75-year-old widow living on her own who has recently been diagnosed with vascular dementia. She has a daughter, Maria, who lives some distance from her, and a son, Peter, who lives nearby. Case manager Anneke visits regularly. Recently, Mrs. Van Dijk went out in the middle of the night because she thought she had an appointment for a pedicure. She couldn't find her way back and was brought home by a friendly young man. This incident increased Maria's worries about her mother. Mrs. Van Dijk agreed that it was not smart of her to go out in the middle of the night. Maria called the case manager, who arranged a meeting with Mrs. Van Dijk and her children to discuss how to handle the possibility of Mrs. Van Dijk's wandering again. A lot was brought up in this discussion, starting with Maria's worries. Now that mum has started wandering, what will happen next? Occasionally Maria finds sour milk or other contaminated foods in the fridge. Does mum eat enough? Can she still cook, or is that becoming dangerous as well? Besides, mum could do with a little company, she and her brother can't visit often. Has Anneke got any solutions? Anneke suggests that daycare in combination with home care might help here. But this is something to be discussed first. Peter disagrees with his sister; he thinks she is over-reacting. Yes, mum went out one night by mistake, but that doesn't mean she has 'started wandering'. He says mum realises she has done something stupid, so she won't do that again anytime soon. Besides, Peter comes by after work three times a week, and finds mum happily knitting in her chair. What could go wrong? Anneke asks Mrs. Van Dijk what she thinks about the situation. Mrs. Van Dijk is a bit overwhelmed by everything that's being said. She quickly hushes the quarrel between her children. About the incident at night, she says she has learned her lesson and it won't happen again. But she's not sure about it. She worries because her daughter worries so much about her. Anneke explains that incidents with wandering could happen again. They are part of the process of dementia, but it's hard to predict when they will happen. Anneke again suggests that daycare in combination with home care might be a good solution. This will help structure Mrs. Van Dijk's day and give her some company as well. Maria thinks this would be really good. It would be a relief to her to know that her mother is being taken care of. She does not want anything to happen to her. Peter says it's not about allaying her worries, but about doing what's good for mum. Daycare might be a good idea, but homecare is simply not necessary yet. Mum has always said that she doesn't want to be monitored by 'those strangers' in her own home. Mrs. Van Dijk says the two of them should stop quarrelling. If Anneke thinks this is a good idea, she will try it. Anneke tries to explain that Mrs. Van Dijk can make her own decision, but Mrs. Van Dijk says she's done with it. She will try daycare and home care and then she'll see.

Anneke reports on this case in her next team meeting. She is not satisfied with how she handled this situation. It is difficult to work with families with such divergent views of the situation. How to unify all these perspectives? How great is the actual risk in Mrs. Van Dijk's situation? Her children seem to disagree about the level of risks involved. Did she explore this enough? Anneke must admit that she is somewhat relieved that Mrs. Van Dijk accepted daycare and home care try-outs – she herself had reservations about Mrs. Van Dijk living alone without professional support. It would be good to monitor the situation a little more. However, she is afraid that Mrs. Van Dijk merely accepted try-outs to please her daughter and because she, the case manager, presented this as a solution. She realises she did not really explore this enough. Anneke acknowledges that she often tries to establish daycare in combination with home care when people with dementia live alone. To what extent are daycare and home care a solution for the issue of wandering? What other possibilities could have been explored?

This PhD study started when professionals for the care and well-being of people with dementia stated that the care and support provided often did not meet the values and preferences of people with dementia and their informal carers. These professionals turned to Windesheim University of Applied Sciences with questions about their role in the decision-making and the possibilities for shared decision-making in this particular context (Smits & Jukema, 2010). However, evidence about models or approaches to facilitate shared decision-making for people with dementia was lacking. The professionals asked for knowledge and tools to help them involve people with dementia and their carers in decision-making about daily life issues. Their need was in line with the mission of the research group Innovating with Older Adults which includes supporting professionals in their efforts to include patients and families in innovations in care for older adults. Our study initiated close collaboration of the research group Innovating with Older Adults with the research group Transitions in Long-term Care, Rotterdam University of Applied Sciences, and the Department of IQ Health Care, Radboud University of Nijmegen. The research group Transitions in Long-term Care focuses on developing coordinated care for people with dementia and their informal carers. IQ Health Care's mission is to improve the quality of care for patients from the viewpoint that patients should receive the best care according to research evidence, and that care must be fully compatible with the patient's values. The best quality of care for people with dementia is the aim of all three research groups. In their study of shared decision-making in dementia care networks, these research groups wanted to develop (1) knowledge about shared decision-making in the complex context of dementia care and (2) evidence-based tools to support professionals in practising shared decision-making. This study is part of a larger research programme, Shared decision-making in

care networks of people with dementia, which also included the development of an online support tool for shared decision-making (the Decide Guide) as well as professional competencies for shared decision-making.

Background

Dementia

Dementia is a generic term for a range of conditions that are characterised by progressive cognitive decline (Winblad et al., 2016). Alzheimer's disease is the most common form. Other forms include vascular, Lewy body, and frontotemporal dementias. The symptoms of dementia include memory loss, disorientation, confusion, and behavioural changes. In the later stages, problems with walking, and difficulties with speaking and swallowing may occur (Winblad et al., 2016). These symptoms increase over the dementia trajectory, which can span 7 up to 10 years (Todd, Barr, Roberts, & Passmore, 2013). The life expectancy of people with dementia appears to be influenced by age at onset, sex, and type of dementia (Winblad et al., 2016). Most people with dementia die before they reach the advanced stages of the dementia (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016).

Dementia is among the ten most burdensome conditions. It has a major impact on the daily and social functioning of people with dementia and their informal carers (Prince et al., 2015; Winblad et al., 2016). As the risk of having dementia increases with age, the number of people with dementia is likely to rise given the aging population (Winblad et al., 2016). The number of people with dementia is expected to grow from 46.8 million people worldwide in 2015, of whom 10.5 million live in Europe, to 131.5 million people worldwide in 2050, of whom 18.7 million live in Europe (Prince et al., 2015). In the Netherlands, the number of people with dementia is currently estimated at 270,000 people, with an expected rise to 690,000 people with dementia by 2055 (Alzheimer Nederland, 2016). The accuracy of the estimated prevalence of people with dementia for high income countries is currently being debated (Qiu, von Strauss, Backman, Winblad, & Fratiglioni, 2013). In high-income countries, there is a general trend towards better lifestyle and cardiovascular factors regarding smoking, physical activity, cholesterol, and blood pressure. These factors are associated with the incidence of dementia, and thus may affect the prevalence in the long-term (Prince et al., 2015). Recent studies estimate that reductions in raised blood pressure, blood cholesterol, obesity, and diabetes could prevent between 3% and 20% of the predicted new cases of dementia in 20 years (Lincoln et al., 2014). Notwithstanding the uncertainty about the predicted rises in incidence and prevalence, dementia has a great impact on current and future

care budgets worldwide. The worldwide costs associated with dementia in 2015 were estimated at US\$ 818 billion (Prince et al., 2015; Wimo et al., 2016). Of these costs, 20% are direct medical costs; 40%, social sector costs; and 40%, informal care costs (Prince et al., 2015).

Care networks for people with dementia

Good quality care for a person with dementia requires close collaboration of the informal and professional carers (Jacobs, van Tilburg, Groenewegen, & Broese van Groenou, 2016; Lethin, Rahm Hallberg, Karlsson, & Janlov, 2016; Quinn, Clare, McGuinness, & Woods, 2012; World Health Organisation, 2012). This close collaboration is achieved in care networks consisting of the person with dementia and multiple carers, including both informal and professional support (Jacobs et al., 2016). The compositions of these care networks change over time as the situation of the person with dementia changes. The care trajectory often starts with emphasis on informal care before the person with dementia starts to use professional care (Forbes et al., 2012). The levels of support needed from informal and professionals carers increase during the course of the dementia (Fortinsky & Downs, 2014).

Informal care, as part of the care networks, is very important for people with dementia (Wimo et al., 2011; Winblad et al., 2016; World Health Organisation, 2012). The types of informal care change over the course of the dementia: there is emphasis on transportation and housekeeping in the mild stage of the dementia, on safety and mobility in moderate dementia, and on personal care in the advanced stages (Huang et al., 2015). Eventually, almost constant supervision from informal carers is often necessary to guard the safety of the person with dementia (World Health Organisation, 2012). Informal care is provided by different types of carers with respect to relationship, primacy, living arrangements, and contribution to the caring process (World Health Organisation, 2012). Multiple informal carers may share caring tasks for the person with dementia, but typically one or two of them take up most of the care (Peacock et al., 2009). These primary carers are often spouses, children, or daughters-in-law (World Health Organisation, 2012). There may be secondary informal carers with supplementary caregiving roles, including children, other relatives, friends, and/or neighbours. Informal care for people with dementia is often required for many years. It is lengthier and more intense than the formal care, or care for people who do not have dementia (Lethin et al., 2016; World Health Organisation, 2012). In time, informal care is often no longer enough, and professional care is also needed for the person with dementia to be able to continue living at home.

A range of professionals based in health care, social care, daycare, housing, transport, and leisure may support people with dementia and their informal carers over the course of the dementia (Winblad et al., 2016). The types of professionals include general practitioners and specialists, nurses, case managers, social workers, physiotherapists, occupational therapists, psychologists, and daycare employees (Prince et al., 2016; World Health Organisation, 2012). Professional care for people with dementia should be continuous, holistic, and integrated. This requires coordination of health and social care, welfare, and housing (Prince et al., 2016; Winblad et al., 2016). Currently, many health-care systems are fragmented and not well coordinated, so that they do not respond in a timely way to the specific needs of people with dementia at different stages of the disease (Koch et al., 2012; Prince et al., 2016). Case management is often presented as a way of working towards well organised and coordinated care for people with dementia (Minkman, Ligthart, & Huijsman, 2009; Winblad et al., 2016). It constitutes the necessary link between the formal and informal care systems, and it has an important role in achieving the close collaboration of carers that is necessary to meet the specific needs of the person with dementia in the different stages of the dementia. Over the course of the dementia case managers may be responsible for care assessment, providing relevant information about the disease and care options, planning and organizing care, and providing support and counselling to the person with dementia and the informal carer (Minkman et al., 2009; Verkade et al., 2010). Several factors seem to be important for case management to be effective: a manageable case load, a clear role definition, proper training, and empowerment of the case manager as the coordinator of care providers (Prince et al., 2016).

Despite studies reporting positive outcomes, the effectiveness of case management on quality of life has not been confirmed (Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Prince et al., 2016). This lack of evidence for case management may be due to the absence of research with long follow-up, the unclear conceptualisation of case management, a lack of knowledge about the specific population that could benefit from case management, and the choice of outcome measures (Koch et al., 2012; Pimouguet et al., 2010). The positive effects of case management that have been demonstrated include: reduced carer burden or stress, improved carer confidence, fewer negative feelings about the patient, improved functioning, and increased uptake of community services (Koch et al., 2012). As such, case management may impact the quality of life of people with dementia and their informal carers. When this PhD project started in 2010, the Dutch State Secretary of Health had described case management as an essential element of good-quality care for people with dementia. Currently, the funding of case management is under pressure, and in many regions of the country the continuity of case management is insecure (Francke & Peeters, 2015).

Decision-making and dementia

People with dementia and their informal carers make many decisions during the dementia trajectory about issues of health and social care, medication, general medical decisions, legal and financial matters, car driving, relocation to a nursing home, and making plans for treatment, care, and well-being at the end of life (Hamann et al., 2011; Livingston et al., 2010). The process of reaching these decisions is complex, time-consuming, emotionally challenging, and continuously changing (Wolfs et al., 2012). It is embedded in and shaped by the quality and dynamics of longstanding spousal and family relationships (Fetherstonhaugh, Rayner, & Tarzia, 2016; Samsi & Manthorpe, 2013; Smebye, Kirkevold, & Engedal, 2012) and the ongoing process of accepting the progressive decline caused by the dementia (Wolfs et al., 2012). The decision-making starts with identifying individual needs, goes on with exploring options, and then gradually evolves to making the choice (Wolfs et al., 2012). Information exchange is important during this process, but it is necessary to balance the thorough explanation of matters so as not to overwhelm or confuse the person with dementia with too much information at once (Smebye et al., 2012). Decision-making in dementia requires teamwork, and it includes the person with dementia, the informal carers, and often multiple professionals. The roles of people with dementia in the decision-making diminish over time, which makes it important to anticipate future decisions and roles (Samsi & Manthorpe, 2013; Wolfs et al., 2012).

People with dementia are aware that their decision-making capabilities decrease over time, and they understand that they need to hand over decision-making responsibilities to others eventually (Fetherstonhaugh, Tarzia, & Nay, 2013; Samsi & Manthorpe, 2013; Smebye et al., 2012). However, they want to be involved in decision-making about their lives for as long as possible. Being involved in decision-making provides them with the feeling of being a person and being useful, and it gives them a sense of control over their lives (Fetherstonhaugh et al., 2016; Fetherstonhaugh et al., 2013). Further, involvement in decision-making has a positive impact on the quality of life of both the person with dementia and the informal carers (H. Menne, Judge, & Whitlatch, 2009; H. L. Menne, Tucke, Whitlatch, & Friss Feinberg, 2008). Unfortunately, people with dementia are often not involved in the decision-making, even in the early stages of the dementia (Boyle, 2014; Fetherstonhaugh et al., 2013; Samsi & Manthorpe, 2013; Taghizadeh Larsson & Österholm, 2014; Tyrell, Genin, & Myslinski, 2006; Wolfs et al., 2012). They are thought to lack decision-making capacity (Boyle, 2014), and they report that they are neither listened to, nor invited to provide their perspectives on the decisions (Tyrell et al., 2006). Consequently, informal carers along with professionals often take the lead in considering options and making decisions. This is problematic because proxies feel unsupported in making decisions for their loved ones and

tend to act on their assumptions of the person's preferences even though they are not good at predicting these preferences (Samsi & Manthorpe, 2013; Smebye et al., 2012; Whitlatch & Menne, 2009; Whitlatch, Pijparinen, & Feinberg, 2009). There is a real danger of informal carers or professionals dominating the decision-making agendas and manipulating the information to try and convince the person with dementia of their opinions (Boyle, 2013; Fetherstonhaugh et al., 2016; Smebye et al., 2012). Shared decision-making could be helpful to professionals who want to support the involvement of people with dementia in the decision-making.

Shared decision-making

Shared decision-making has been embraced over the years as the gold standard for decision-making about treatment and care (Charles, Gafni, & Whelan, 1997; Hauser et al., 2015; Makoul & Clayman, 2006; Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010; Stiggelbout et al., 2012). It can be defined as the process of professionals and patients working together towards informed preferences for health care options on the basis of the best available evidence and the patient's values (Elwyn et al., 2012; Joosten et al., 2008; Stiggelbout et al., 2012). Shared decision-making is essential to person-centred care and evidence based practice. Professionals contribute to the core of person-centred care by engaging patients, and eliciting their values and beliefs in relation to life-impacting decisions (Barry & Edgman-Levitan, 2012; Edvardsson, Winblad, & Sandman, 2008; McCormack & McCance, 2006). Eliciting patients' values is important for evidence-based practice as well, since this approach combines three types of knowledge: research evidence, clinical expertise, and patients' values (Friesen-Storms, Bours, van der Weyden, & Beurskens, 2015; Greenhalgh, Howick, & Maskrey, 2014). The patient values become more important in cases where: (1) the level of evidence is low, (2) there are multiple intervention options, (3) the impact of the options on the daily lives of patients is great, (4) patient group values are variable, and (5) there is a large impact on resources (Friesen-Storms et al., 2015). In such cases, shared decision-making is especially important.

In extending their first conceptual model of shared decision-making (Charles et al., 1997), Charles, Gafni, and Whelan (1999) introduced three steps of shared decision-making: (1) information exchange, (2) deliberation, and (3) deciding. It has been recognised in primary and chronic care that additional elements may be necessary, such as agenda setting, embedding the decision-making in the ongoing partnership between patients and clinicians, and revising decisions as necessary (Montori, Gafni, & Charles, 2006; Murray, Charles, & Gafni, 2006). However, these additional elements have not been incorporated in the step-wise models of shared decision-making for professionals. A number of other models have been developed since Charles et al.

(1999) published their work. These models specify what professionals need to do in order to work through the decision-making with their clients (Elwyn et al., 2012; Makoul & Clayman, 2006; Stacey et al., 2010). The essential elements of these models are: defining or explaining the problem, clarifying the fact that patients have a choice (equipoise), presenting options, exchanging knowledge about the pros and cons of the options, checking for understanding, expressing values and preferences, making or deferring the decision, implementing the decision, and arranging follow-up.

There is a growing body of knowledge about the effects of shared decision-making, even though the evidence is still preliminary for some elements (Hauser et al., 2015; Joosten et al., 2008; Stacey et al., 2014). Positive effects have been confirmed for the use of decision aids. Decision aids are tools that help patients consider their options to prepare themselves for the decision-making encounter with their professionals (Stiggelbout et al., 2012). Decision aids have a positive impact on patients' knowledge about options, feeling informed, clarity about preferences, patient–professional communication, and the active role of patients in the decision-making (Stacey et al., 2014). Shared decision-making may also have an effect on treatment adherence and patient health-related outcomes. However, the evidence for this is still inconclusive; some studies report positive outcomes and others show no effect (Hauser et al., 2015; Joosten et al., 2008). Nonetheless, shared decision-making is likely to contribute to the social health of patients. Social health involves the dynamic balance of opportunities and patient limitations on the one hand and social and environmental challenges on the other hand (Huber et al., 2011; Vernooij-Dassen & Jeon, 2016). Social health has several dimensions, including the capacity to fulfil one's potential and social obligations, and the ability to manage one's life with some degree of independence. Shared decision-making can help patients choose treatments that suit the way they want to live their lives, which supports them in managing their lives independently. However, more research is necessary to confirm and specify this.

In recent years, the complexity of shared decision-making in the daily practice of the clinical encounter has received more attention (Epstein & Gramling, 2013; Hargraves, LeBlanc, Shah, & Montori, 2016). Even though Charles et al. (1999) had acknowledged that shared decision-making is embedded in the patient–professional encounter and in the patient's family relationships, the focus has long been merely on how to best inform individual patients so that they could make their choices (Elwyn et al., 2014; Entwistle & Watt, 2006; Hargraves et al., 2016). Now, the debate has shifted to a broader conceptualisation of shared decision-making. First, there is the addition of the necessity of building trusting relationships with mutual respect so that the participants feel safe having dialogues about what really matters to patients and about how they

want to work together (Elwyn et al., 2014; Entwistle & Watt, 2006; V. A. Entwistle, Carter, Cribb, & McCaffery, 2010; Epstein & Gramling, 2013; Hargraves et al., 2016; Matthias, Salyers, & Frankel, 2013; Montori et al., 2006; Morant, Kaminskiy, & Ramon, 2015). Second, it has become clear that a focus on exchanging evidence-based information alone is too limiting for working out what is best for a given patient. It is often difficult to translate evidence-based information to the particular situation of the individual patient (Greenhalgh et al., 2014), evidence-based information does not address the emotional elements (Hargraves et al., 2016), and it is often non-existent for complex problems (Berger, 2015; Epstein & Gramling, 2013). Third, there is a growing realisation that family members are important for shared decision-making because much of the decision-making work occurs outside the medical consultation and is distributed amongst family members (Elwyn et al., 2014; Morant et al., 2015). The decision-making roles of families have largely been neglected in shared decision-making research and models (Epstein & Gramling, 2013; Morant et al., 2015; Stacey et al., 2010). This recent debate about shared decision-making discusses issues that are relevant to care networks of people with dementia. However, there is still no model that incorporates all the elements of the debate into a model for complex shared decision-making.

Shared decision-making in dementia care networks

Miller, Whitlatch, and Lyons (2014) report that there is a lack of a clear definition of what shared decision-making entails in the context of dementia. On the basis of a systematic review of the literature, they conclude that the focus should be on the type and degree of involvement of the person with dementia in the decision-making. The currently available research indicates that people with dementia are involved to varying degrees (Samsi & Manthorpe, 2013; Smebye et al., 2012), but most are prematurely excluded from the decision-making (Miller et al., 2014). People with dementia feel poorly informed, not invited to express their views, and pressed into make decisions (Tyrell et al., 2006). Informal carers inadequately estimate the values of the person with dementia, and underestimate their preferences for being involved in the decision-making (Hamann et al., 2011; Reamy, Kim, Zarit, & Whitlatch, 2011, 2013; Whitlatch & Menne, 2009; Whitlatch et al., 2009). Even more troubling, these discrepancies in the estimated values and preferences tend to increase over time (Reamy et al., 2013). This implies that care often does not fit the values and preferences of the people with dementia themselves, which leads to suboptimal care.

Notwithstanding the importance of the involvement of people with dementia in the decision-making to adjust care to their preferences, involvement alone seems inadequate for successful shared decision-making in the context of dementia. Decisions in dementia must address the needs and preferences of people with dementia as well

as their informal carers (Whitlatch & Menne, 2009). This is essential for their quality of life and well-being because people with dementia and their informal carers are highly interdependent. A difficult balancing act involving the preferences and interests of multiple participants is inevitable. Decisions are likely to be acceptable only if this balance is achieved (Fetherstonhaugh et al., 2016; Samsi & Manthorpe, 2013; Smebye et al., 2012; Whitlatch & Menne, 2009). Unfortunately, there is often great miscommunication about the preferences for care and well-being within care networks of people with dementia (Whitlatch & Menne, 2009). People with dementia and their informal carers need help from professionals to have conversations about what really matters to them and to find solutions that fit their preferences and capacities to care. However, professionals have trouble engaging in such conversations, which are difficult, and they often think people with dementia cannot participate in decision-making. There is a lack of evidence about what constitutes shared decision-making in the context of dementia, what models are relevant, and how professionals can promote shared decision-making (Miller et al., 2014).

Setting

Shared decision-making in dementia is likely to change in various stages of the dementia and the living arrangements of the person with dementia. When the dementia progresses, the care networks are likely to change as people with dementia enter into new areas of the health care system (Carpentier & Ducharme, 2003). Some types of decisions may be more relevant for community-dwelling people with dementia than for those in nursing homes. People with dementia who live alone have significantly more unmet needs than those living with their carers (Miranda-Castillo, Woods, & Orrell, 2010). This thesis focuses on community-dwelling and institutionalised people with dementia in the early, moderate, and advanced stages. Including these different decision-making situations in our research has provided rich information about shared decision-making for people with dementia.

Aim and outline of the thesis

Person-centred care has long been recognised as the gold standard of good-quality care for people with dementia (Brooker, 2003; Mitchell & Agnelli, 2015). It includes valuing people with dementia, treating them as individuals, exploring the care situation through their perspectives, and creating social environments that support them as individuals (Brooker, 2003). Involving people with dementia in shared decision-making about their lives is an essential element of person-centred care (McCormack & McCance, 2006; Mitchell & Agnelli, 2015). However, in practice, shared decision-making

is seldom used, given the complex character of the decision-making in dementia. This leads to suboptimal care for people with dementia. Professionals who want to use shared decision-making feel unprepared to do so because the existing shared decision-making models tend to be dyadic. They focus on information exchange without acknowledging the important roles of informal carers in the decision-making. The recent debate about broadening shared decision-making models lacks knowledge about the specific complexity of the decision-making in dementia. The next step is to translate this knowledge into interventions, guidelines, and tools for professionals. This thesis contributes to the knowledge about how shared decision-making proceeds by describing the decision-making in the care networks of people with dementia and comparing the descriptions to the existing theory about shared decision-making. We show the conditions in which shared decision-making in the complex context of dementia care networks can be achieved. Such findings in this thesis may have an impact on the competences of professionals, including their knowledge, skills, and attitudes.

Aim of the thesis

The overall aim of this PhD thesis is to gain insight into how shared decision-making takes place in care networks of people with dementia.

For this purpose, we conducted a prospective, qualitative, multi-perspective study including three rounds of semi-structured interviews to answer the following research questions:

1. What are the decisions and related key events in the trajectories of the care networks that include the people with dementia, and their informal and formal carers?
2. What are the challenges of shared decision-making for people with dementia, their informal carers, and their professionals?
3. What are the process elements of decision-making in dementia care networks?
4. How can these elements enrich the model of collaborative deliberation in order to facilitate shared decision-making in dementia care networks?
5. What types of participation trajectories can be distinguished in the decision-making about daycare?

Outline of the thesis

Chapter 2 answers research question 1 to specify the issues of relevance for shared decision-making in dementia care networks. We present the results of our multi-layered qualitative analysis of the data from the three interview rounds. **Chapter 3** answers research question 2 and shows the particular challenges of shared decision-making

encountered by people with dementia, their informal carers and their professionals. These challenges were derived from the content analysis of the first round of interviews. **Chapter 4** answers research questions 3 and 4. We define the process elements of decision-making in dementia care networks. We also enrich the model of collaborative deliberation for the context of dementia care networks, on the basis of a framework analysis approach. This approach enabled us to compare our data with the concepts of model of collaborative deliberation, a model underlying shared decision-making. The enriched model as we describe it can help professionals use a step-wise approach to shared decision-making. **Chapter 5** provides an answer to research question 5, on the basis of a combination of content analysis and typology construction. This chapter outlines how the interaction between people with dementia, their informal carers, and professional carers evolves for the frequent decision about daycare. **Chapter 6** contains a general discussion. It discusses the main findings of this thesis, provides theoretical and methodological considerations, and describes the implications for practice, education, future research, and policy making. The chapter ends with our concluding remarks about shared decision-making in dementia care networks.

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CHAPTER 2

DECISION TRAJECTORIES IN DEMENTIA CARE NETWORKS: DECISIONS AND RELATED KEY EVENTS

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Abstract

Aim: This prospective multiperspective study provides insight into the decision trajectories of people with dementia by studying the decisions made and related key events.

Method: This study includes three waves of interviews, conducted between July 2010 and July 2012, with 113 purposefully selected respondents (people with beginning to advanced stages of dementia and their informal and professional carers) completed in 12 months (285 interviews). Our multilayered qualitative analysis consists of content analysis, timeline methods, and constant comparison.

Results: Four decision themes emerged—managing daily life, arranging support, community living, and preparing for the future. Eight key events delineate the decision trajectories of people with dementia. Decisions and key events differ between people with dementia living alone and living with a carer.

Conclusion: Our study clarifies that decisions relate not only to the disease but to living with the dementia. Individual differences in decision content and sequence may effect shared decision-making and advance care planning.

Introduction

The erratic course of dementia makes the dementia trajectory unpredictable and leads to uncertainty for people with dementia and their carers (Harman & Clare, 2006; Steeman, Dierckx de Casterle, Godderis, & Grypdonck, 2006). This uncertainty makes them feel unable to control their situation and to plan for future problems (Dickinson et al., 2013; Graneheim, Johansson, & Lindgren, 2014; Svanstrom & Dahlberg, 2004). Instead, they try to integrate the dementia into their lives so that they can maintain their daily patterns to a certain extent (Steeman et al., 2006; Steeman, Godderis, Grypdonck, de Bal, & Dierckx de Casterle, 2007). The day-to-day experience of living with dementia involves dilemmas of maintaining life as it is while acknowledging and acting upon inevitable losses and changes (Harman & Clare, 2006; Steeman et al., 2007).

Meeting the daily challenges of living with dementia requires people with dementia and their carers to form care networks that keep a delicate balance of facilitating independence while ensuring safety (MacNeil Vroomen, Bosmans, van Hout, & de Rooij, 2013). These care networks change because of the dementia progression and changes in care network structure, the roles of network members, and the organisation of care (Carpentier & Ducharme, 2003). Given their changing situation, people with dementia and their carers must make many decisions with consequences for daily life (Wolfs et al., 2012). Research in decision-making in dementia has focused on decisions related to treatment and social care (Hamann et al., 2011; Livingston et al., 2010; Smebye, Kirkevold, & Engedal, 2012; Wolfs et al., 2012) and legal–financial issues (Boyle, 2013), as well as everyday decisions such as what to wear or eat (Samsi & Manthorpe, 2013). However, a systematic empirical overview of decisions over the course of time is lacking. Such an overview might help in preparing for future changes. Documented illness trajectories can provide insight into the key moments for patients. However, dementia trajectories have been based on research that focuses on professional support (Forbes et al., 2012; Fortinsky & Downs, 2014).

To our knowledge, no systematic empirical research yet describes the decisions in the lives of people with dementia over time. Therefore, longitudinal empirical research is needed to explore relevant changes and related decisions (Steeman et al., 2006). The current study examines the decisions made and the related key events in the trajectories of care networks including people with dementia, their informal and formal carers.

Method

Design

Our study has a prospective, qualitative, multiperspective design, which provides rich information about the decisions over time (Kendall et al., 2009; Murray et al., 2009).

Setting

This study followed community-living and institutionalized people with dementia in the Netherlands in the beginning, the moderate and advanced dementia stages. Dutch dementia care is provided in three settings: (1) general care for acute and chronic diseases, (2) mental health care, and (3) longterm institutionalized care, including sheltered or nursing homes (Minkman, Ligthart, & Huijsman, 2009).

Participants

We purposefully selected care networks. Care networks consist of a person with dementia and his or her informal and formal carers (Jacobs, van Tilburg, Groenewegen, & Broese van Groenou, 2016). Informal carers are spouses, children, other relatives, friends, or neighbours. Formal carers are professional carers. We pursued maximum variation (Coyne, 1997) regarding the characteristics of the person with dementia and the type of informal carers. The inclusion criteria were a diagnosis of any form of dementia, and the ability to be interviewed, as judged by the informal carer. People with mild cognitive impairment were excluded. We used three recruitment routes: case managers of different health-care organisations asked their clients to participate; we visited local Alzheimer Cafe ´ meetings and invited people to participate; and, we put a notice on the Dutch Alzheimer's Society website. We invited a second informal carer and two involved professionals through the person with dementia and the first informal carer. In line with Creswell (1998), we expected to reach data saturation between 20 and 30 care networks.

Data collection

We interviewed the individual participants of our care networks 3 times at 6-month intervals, between July 2010 and July 2012. Twenty-two interviewers were trained in conducting the semistructured interviews using an interview guide. They received feedback after each interview. All network members were interviewed by the same interviewer at a given interview round. The interviews lasted averagely 1 hour, were audiotaped, and transcribed verbatim. The interview guides of the three rounds contained similar topics based on key issues in shared decision-making (Elwyn et al., 2012): the changes that had occurred, the decisions made, what happened before these decisions, who was involved, and what people thought of the decision-making.

We stressed the importance of interviewing the participants alone to avoid influence from others (Nygård, 2006). However, in three care networks, the person with dementia was willing to participate only in the presence of the informal carer.

Data analysis

We used a multilayered analysis approach with different analytic methods, each step building on the previous steps. First, we used content analysis to define the decisions made. This involves line-by-line coding and thereafter the classification of codes into categories and themes with corresponding meanings (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). To ensure rigor, L.G. and K.O. independently coded relevant interview fragments. Codes were constructed from (1) the information of the five perspectives in each care network and (2) the three interview rounds (Kendall et al., 2009; Murray et al., 2009). We used Atlas.ti software, version 6.2. Codes were discussed until consensus was reached. The research group discussed the resulting coding list. Then, we had a group session involving L.G., K.O., and an independent researcher from our department. This session used affinity diagramming to cluster, label, and define categories and themes (Johnson, Barach, & Vernooij-Dassen, 2012; Martin & Hanington, 2012; Scupin, 1997). Second, we used the timeline method to describe when decisions occur. Developing timelines is a way of improving the understanding of illness trajectories (Patterson, Key, & Somers, 2012). We constructed timelines for each care network by placing the coded decisions in chronological order, based on the information from the five perspectives and three interview rounds. The timelines of four care networks that opted out after the first interview round were based on the first interview round. L.G. and K.O. independently constructed the timelines and discussed differences in chronology to reach consensus. L.G. wrote memos concerning contextual information. Third, we used the method of constant comparison (Corbin & Strauss, 1990; Patterson et al., 2012) within and between the timelines to delineate characteristic patterns in the sequence of decisions. (Knafl & Ayres, 1996; Patterson et al., 2012).

Ethical considerations

The Isala Clinics's ethical board approved this study (number 10.11113). Participation required double consent. Respondents received information beforehand. We treated the participants' consent, especially the person with dementia, as a process (Murphy, Jordan, Hunter, Cooney, & Casey, 2015) and were alert to signs that the participant wanted to stop (Meulenbroek et al., 2010). We did not share interview information with other network participants (Kendall et al., 2009).

Results

Study participants

Twenty-five of the 30 invited care networks consented to participate. The burden from the study was the reason for refusing to participate. We excluded two care networks that did not meet the inclusion criteria. The remaining 23 care networks included 23 people with dementia, 44 informal carers, and 46 professional carers—113 respondents altogether. Four care networks opted out after the first interview round because of the burden from the study. We used the information from the first interview rounds of these networks. Figure 1 visualizes the inclusion, exclusion, and dropout of participants. Table 1 lists the participants' characteristics. The total number of interviews was 285 (Table 2).

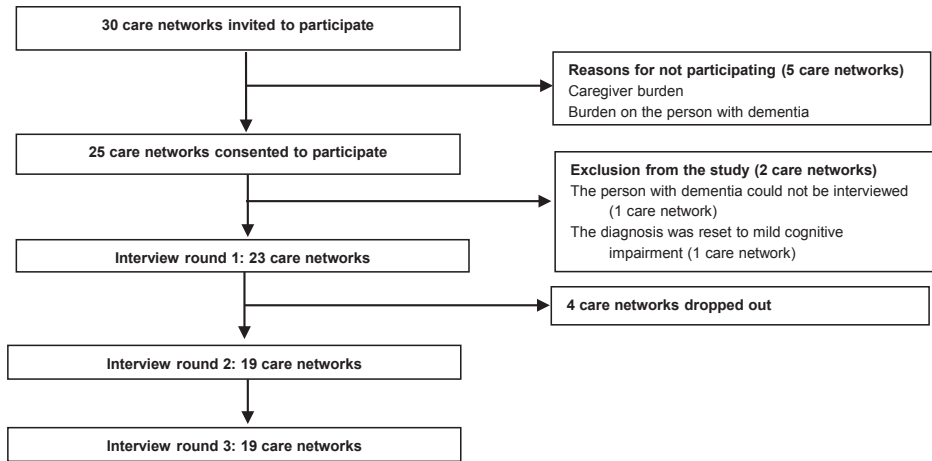


Figure 1. Flowchart of the inclusion, exclusion, and care networks drop-outs among the study respondents.

Table 1. Characteristics of the care networks in the study

	Gender	Age	Time since diagnosis	Dementia stage ¹	Living alone	Living arrangements at baseline	Type of informal carers interviewed	Type of formal carers interviewed
1	Man	82	2.84 years	M	No	Elderly home	Spouse	Principal attendant
2	Woman	82	3.17 years	A	Yes	Nursing home	Daughter	Case manager
3	Woman	83	0.83 years	M	Yes	Elderly home	Daughter	Principal attendant
4	Man	77	0.17 years	?	No	Nursing home	Niece	Case manager
5	Woman	83	0.58 years	B	Yes	Community dwelling	Niece	Principal attendant
6	Woman	62	6 years	M	No	Nursing home	Daughter	Case manager
7	Woman	?	?	M	No	Community dwelling	Son-in-law	Daycare employee
8	Man	80	6.42 years	B	Yes	Community dwelling	Daughter	Case manager
9	Woman	74	3.83 years	M	No	Community dwelling	Spouse	Home care nurse
10	Man	?	3 years	M	No	Community dwelling	Daughter	Case manager
11	Woman	79	1.5 years	B	No	Community dwelling	Spouse	Home care nurse
12	Woman	80	3 years	M	No	Community dwelling	Spouse	Creative therapist
13	Woman	84	0.42 years	M	Yes	Community dwelling	Spouse	Daycare employee
							Daughter	Case manager
							Spouse	Daycare employee
							Daughter-in-law	Case manager
							Grandson	Home care nurse
							Granddaughter-in-law	Team leader for nurses

Table 1. Characteristics of the care networks in the study (*continued*)

	Gender	Age	Time since diagnosis	Dementia stage ¹	Living alone	Living arrangements at baseline	Type of informal carers interviewed	Type of formal carers interviewed
14	Man	70	4.75 years	M	No	Community dwelling	Spouse Son	Daycare employee Home care nurse
15	Woman	89	4.58 years	M	Yes	Community dwelling	Daughter Son-in-law	Home care nurse Case manager
16	Woman	87	5 years	M	Yes	Community dwelling	Daughter-in-law Daughter-in-law	Home care attendant Case manager
17	Man	83	?	M	No	Community dwelling	Spouse Daughter	Daycare employee Case manager
18	Woman	73	6 years	M	No	Nursing home	Sister Niece	Principal attendant Case manager
19	Man	86	1.25 years	B	Yes	Community dwelling	Son Son	Care coordinator Home care nurse
20	Woman	89	?	B	Yes	Community dwelling	Nephew Niece	Home care nurse Care coordinator
21	Woman	87	2.58 years	M	No	Community dwelling	Spouse Daughter	Home care nurse Team leader for nurses
22	Woman	?	?	M	No	Community dwelling	Spouse Brother	Daycare employee Case manager
23	Man	78	2 years	M	Yes	Nursing home	Granddaughter Daughter	Principal attendant Attendant

Note: ¹ Judgment by professional interviewed; B = beginning stage, M = middle stage, A = advanced stage

Table 2. Participants Interviewed in the three rounds of interviews.

Round 1 t0	Round 2 t1 (6 months after t0)	Round 3 t2 (6 months after t1)
People with dementia	23 People with dementia	18 People with dementia
Primary informal carers ^a	23 Primary informal carers	19 Primary informal carers
Secondary informal carers ^b	21 Secondary informal carers	15 Secondary informal carers
Professionals involved daily	23 Professionals involved daily	18 Professionals involved daily
Case managers or similar professionals	23 Case managers or similar professionals	18 Case managers or similar professionals
Total interviews in round 1	113 Total interviews in round 2	88 Total interviews in round 3
Total interviews in the study		285

Note. ^aPrimary informal carers are informal carers who are closely involved in the lives of the person with dementia and who often have the main responsibility in the decision-making process besides the person with dementia. ^bSecondary informal carers are informal carers who are more distantly involved.

Decisions in the care networks of people with dementia

We found four themes for decisions: managing daily life with the dementia, arranging care and support, living in society, and representing the person with dementia (Table 3). We observed theme differences for people with dementia living alone or living with an informal carer (Table 4).

Decisions About Managing Daily Life With the Dementia

These decisions focus on self-care, structuring the day, mobility, and handling finances (Table 3). Examples include medication administration, household chores, being home alone, daycare, car driving, and home bookkeeping. Such decisions differ between those living alone and those living with an informal carer (Table 4). Decisions about self-care and handling finances are more prominent for people living alone. Decision-making about managing daily life for those living alone often starts before the diagnosis. One reason might be that live-in informal carers often implicitly take over self-care-related tasks.

You take away more and more of that independence when you see that she can't handle it anymore —Spouse of a woman with dementia, care network 7, quote 22.

Decisions About Arranging Health Care and Support

These decisions focus on getting the diagnosis, starting medical treatment, and arranging care and support (Table 3). Examples include visiting the family physician after the first symptoms, starting case management and home care, dividing care tasks,

and arranging respite care. The kind of support differs for in-living informal carers and informal carers living elsewhere (Table 4). Respite care is arranged for in-living carers so that they can have some free time.

*My husband went on holiday on his own. That was very difficult for me.
[Interviewer: Can you tell me a bit more about the reason?] Well, that it would be
good for him to have a break.—Woman with dementia, care network 9, quote 1.*

Table 3. Themes of decisions made in dementia care networks

Themes and categories	Codes
Managing daily life	
<i>Self-care</i>	Activities of daily living Taking medication Mealtime delivery and monitoring food intake Household chores and buying groceries Being at home alone Assistive devices aimed at safety
<i>Structuring the day</i>	Daily activities and hobbies Daily rhythm (being active and resting) Daycare Extending or reducing daycare
<i>Mobility</i>	Driving a car or cycling Going out alone Assistive devices aimed at mobility
<i>Handling finances</i>	Home book-keeping Handling money Shopping and small purchases Big purchases Decisions about subscriptions or memberships
Arranging health care and support	
<i>The diagnosis and medical treatment</i>	Diagnosis (including memory tests) Starting, stopping or changing medication Visiting the family physician Hospitalisation
<i>Arranging professional care for a person with dementia</i>	Case management Home care Extending or reducing home care Domestic help Psychological care Physiotherapy Making or revising a care plan

Table 3. Themes of decisions made in dementia care networks (continued)

Themes and categories	Codes
<i>Arranging support for the informal carer</i>	Division of informal care tasks Respite care Volunteer taking over care from the informal carer Paying expenses for the informal carer and care leave
Community life	
<i>The social network of the person with dementia</i>	Maintaining social contacts for the person with dementia Church attendance Going out together Visiting family Visitor schedule
<i>Living arrangements</i>	Moving house Registering for a care home or nursing home Being admitted to a care home or nursing home Decorating the room Switching to another group or ward within an institution Visiting home after being admitted to a nursing home
Representing the person with dementia	
<i>Decision-making roles</i>	Involving adult children in the decision-making Involving the person with dementia in decision-making Power of attorney and mentorship Making decisions for the future
<i>Advance decisions about the end-of-life</i>	Living will (euthanasia) Non-resuscitation statement Arrangements for the funeral, and burial or cremation

Decisions about community life

These decisions concern the social network of the person with dementia and living arrangements (Table 3). Examples are maintaining social contacts, going out together, moving house, and nursing home registration. Differences between those living alone and those living with a carer mainly involve the social network (Table 4). In-living informal carers decide about making trips or doing things together while this is still possible.

She turned 75 and [her spouse] gave a lot of thought to that. He wrote a letter to their friends saying that it would be nice if they would remember her birthday. [. . .] I think what was behind it was that it might be the last time that she could really enjoy the attention.—Case manager of a woman with dementia, care network 9, quote 7.

Social network decisions for people living alone focus mainly on arranging a visitor schedule that also serves to monitor the person with dementia at home and to decide about reducing family visits.

We used to invite her over for dinner more often. But it's not so sociable anymore. You hear the same story again and again. So, we still do it, but less often—Son of a woman with dementia, care network 15, quote 9.

Table 4 Prominent decisions in care networks of those living with an informal carer and those living alone

Themes and categories	Prominent decisions for people with dementia living with an carer	Prominent decisions for people with dementia living alone
Managing daily life with the dementia		
<i>Self-care</i>	Being home alone; Household chores; Activities of daily living	Assistive devices for safety; Taking medication; Mealtime delivery and monitoring food intake; Activities of daily living; Household chores including shopping for groceries; Being home alone
<i>Structuring the day</i>	Daycare; Daily activities; Extending daycare	Daycare; Daily activities
<i>Mobility</i>	Going out alone; Assistive devices for mobility; Car driving or cycling	Going out alone; Assistive devices for mobility; Car driving or cycling
<i>Handling finances</i>	Home administration	Handling money; Home administration; Withdrawing subscriptions
Arranging daily care, health care, and support		
<i>Diagnosis and medical treatment</i>	Getting the diagnosis	Getting the diagnosis; Changes in the medication; Hospitalisation
<i>Arranging care for the person with dementia</i>	Case management; Home care; Domestic help	Case management; Home care Extending home care; Domestic help
<i>Arranging support for the informal carer</i>	Respite care	Care leave; Division of tasks among carers

Table 4 Prominent decisions in care networks of those living with an informal carer and those living alone (continued)

Themes and categories	Prominent decisions for people with dementia living with an carer	Prominent decisions for people with dementia living alone
Community life		
<i>The social network</i>	Going out together	Visitor schedule; Visiting family
<i>Living arrangements</i>	Registering for a nursing home; Nursing home admission; Changing wards	Registering for a nursing home; Nursing home admission; Decorating the room; Changing wards
Representing the person with dementia		
<i>Decision-making roles</i>	Involving the adult children in decision-making; Decreasing the involvement of the person with dementia in decision-making	Decreasing the involvement of the person with dementia in decision-making; Power of attorney or mentorship
<i>Advance decisions about the end-of-life</i>	Non-resuscitation statement	Making arrangements for the funeral

Decisions About Representing the Person With Dementia

These decisions are about the decision-making roles of care network members and advance decisions at the end of life (Table 3). Examples are the degree of involvement of the person with dementia and his or her children, legal arrangements such as power of attorney and mentorship, living wills, and nonresuscitation statements.

Recently [my grandma and her physician] discussed whether she wants to be resuscitated if something happens. They tried to work that out together.—Granddaughter of a woman with dementia, care network 13, quote 11.

Some couples explicitly decide about whether to involve their children in decision-making.

I asked whether the children wanted to be involved, but [the couple] didn't really answer.—Case manager of a couple of whom the woman has dementia, care network 11, quote 19.

Key events in the decision trajectories

We distinguished eight key events with related decisions. At the beginning stage of the dementia prominent key events are the concerns before the diagnosis, the diagnosis, the inactivity of the person with dementia, and safety incidents. Prominent decisions in the middle dementia stage are safety incidents, inactivity of the person with dementia, 24-hr monitoring, hospitalisation, and nursing home admission. At the advanced stage, prominent key events include nursing home admission, adjustment issues, and switching between wards. Our analyses showed a pattern with several key events typical for people living alone, whereas others were typical for those with an in-live informal carer (Table 5).

Key Event 1: Concerns before the diagnosis

These are the informal carers' concerns about the safety in homes of people with dementia before the diagnosis has been set. They are typical for people living alone (Table 5).

Her medications were lying around everywhere, she was mixing up day and night, she was looking for her wallet all the time, and she was eating really poorly.—Granddaughter of a woman with dementia, care network 13, quote 54.

Related decisions involve administering the medication, doing household chores, being at home or going out alone, the home paperwork, car driving, and arranging home care and domestic help.

I tried to consult with her about her finances. In the beginning it went well and she asked me to take care of it. I found a payment slip, sometimes two, three, four. It turned out that she was not in control. Her bank account showed double payments and other mistakes.—Niece of a woman with dementia, care network 3, quote 10.

Decisions can remain implicit.

At a given moment she said, 'I'm still dusting and doing this and that', but you see it's not done. And then you start taking over this kind of thing—Niece of a woman with dementia, care network 20, quote 11.

Key Event 2: Diagnosis

This key event occurs when the first signs of dementia become apparent, and care networks turn to the family physician or geriatrician for memory tests and a diagnosis. Related decisions are about starting Alzheimer medication, case management, home care, and daycare (Table 5).

The doctor encouraged me to go to daycare.—Woman with dementia, care network 5, quote 14.

Prominent decisions for people with dementia living alone involve car driving, meal delivery, medication intake, and activities of daily living.

The family doctor referred us to a case manager. She helped us that first week by saying we should duplicate her home keys and buy a microwave so she wouldn't have to cook anymore.—granddaughter of a woman with dementia, care network 13, quote 57.

Decisions about involving their children in decision-making take place mainly in the care networks of people with dementia living with a spouse.

It is still between my husband and me. We have children and they can give their advice, they can even critique us, not too much, but they can, but the decisions is mine, it's supposed to be between me and my husband—Spouse of a man with dementia, care network 14, quote 10.

Key Event 3: Inactivity of the Person With Dementia

This key event includes the concerns about the activities or lack thereof of the person with dementia. They are typical for people with dementia living with a carer (Table 5). A prominent related decision is arranging daycare. Daycare is partly intended to relieve some of the burden on the informal carer.

[Daycare] is not only pleasant for me, but also for him of course. Because at home he doesn't do so much and at daycare they keep him busy and I think that's good for him—Spouse of a man with dementia, care network 14, quote 9.

Table 5 Key events in the decision trajectories of people with dementia and the related decisions

Key events	Decisions	People with dementia living alone
Key event 1. Safety concerns before the diagnosis	People with dementia living with an informal carer	<i>Managing daily life</i> Administering medication Household chores Being alone at home Home administration Car driving Going out alone
		<i>Arranging health care and support</i> Home care Domestic help
		<i>Managing daily life</i> Meal delivery Administering medication and activities of daily living
Key event 2. Diagnosis	<i>Arranging health care and support</i> Starting Alzheimer medication Case management Home care	<i>Arranging health care and support</i> Starting Alzheimer medication Case management Home care
	<i>Representation of the person with dementia</i> Involving adult children in the decision-making Power of attorney	
Key event 3. Inactivity of the person with dementia	<i>Managing daily life</i> Grocery shopping Daily activities Daycare	
	<i>Arranging health care and support</i> Volunteer care Home care	

Table 5 Key events in the decision trajectories of people with dementia and the related decisions (continued)

Key events	Decisions	
	People with dementia living with an informal carer	People with dementia living alone
Key event 4. Safety incidents	<i>Managing daily life</i>	<i>Managing daily life</i>
	Being at home alone	Being at home alone
	Cooking	Household chores
	Grocery shopping	Grocery shopping
	Going out alone	Meal service
		Handling finances
	<i>Arranging health care and support</i>	Activities of daily living
	Extending daycare	Cancelling subscriptions or memberships
	Volunteer care	
	Home care	<i>Arranging health care and support</i>
<i>Representing the person with dementia</i>	Reducing the involvement in decision-making of the person with dementia	Extending home care
		Daycare
		Extending daycare
		<i>Representing the person with dementia</i>
		Reducing the involvement in decision-making of the person with dementia
Mentorship or power of attorney		

Table 5 Key events in the decision trajectories of people with dementia and the related decisions (*continued*)

Key events	Decisions	
	People with dementia living with an informal carer	People with dementia living alone
Key event 5. Prelude to nursing home admission <ul style="list-style-type: none">24-Hour monitoring becomes necessary	<i>Managing daily life</i> Being at home alone Household chores Cooking Extending daycare	<i>Managing daily life</i> Being at home alone Grocery shopping Extending daycare Going out alone Handling money
• 24-Hour monitoring becomes necessary	<i>Living in society</i> Choosing an institution Registering at a nursing home	<i>Living in society</i> Choosing an institution Registering for a nursing home
	<i>Representing the person with dementia</i> Reducing the involvement in decision-making of the person with dementia	<i>Arranging health care and support</i> Extending home care <i>Representing the person with dementia</i> Reducing the involvement in decision-making of the person with dementia Mentorship or power of attorney

Table 5 Key events in the decision trajectories of people with dementia and the related decisions (*continued*)

Decisions		
Key events	People with dementia living with an informal carer	People with dementia living alone
<ul style="list-style-type: none">Hospitalisation because of a lack of self-careCarer overburdening	<i>Managing daily life</i> Assistance with medication Assistive devices for safety Being home alone Daily activities Daycare Going out alone	<i>Managing daily life</i> Activities of daily living Household chores Assistive devices for safety Assistive devices for mobility, Home book-keeping
	<i>Arranging health care and support</i> Crisis help from the case manager Respite care Volunteer care Home care Extending home care	
	<i>Living in society</i> Choosing an institution Registering at a nursing home	
	<i>Representing the person with dementia</i> Reducing the involvement of people with dementia in the decision-making	

Table 5 Key events in the decision trajectories of people with dementia and the related decisions (*continued*)

Key events	Decisions		
	People with dementia living with an informal carer	People with dementia living alone	
Key event 6. Nursing home admission	<i>Managing daily life</i>	<i>Managing daily life</i>	
	Daily activities	Daily activities	
	Household chores	Household chores	
	Activities of daily living	Activities of daily living	
	Going out alone	Going out alone	
		Handling money	
	<i>Living in society</i>	<i>Living in society</i>	
	Decorating the room	Decorating the room	
	Weekend leave from the nursing home	Visitor schedule	
	Visitor schedule		
	<i>Representation of the person with dementia</i>	<i>Representation of the person with dementia</i>	
	Reducing the involvement in decision-making of the person with dementia	Reducing the involvement in decision-making of the person with dementia	
	Non-resuscitation statement	Non-resuscitation statement	
Key event 7. Adjustment issues	<i>Managing daily life</i>	<i>Managing daily life</i>	
	Daily activities	Daily activities	
	<i>Arranging health care and support</i>	<i>Arranging health care and support</i>	
	Psychologist	Psychologist	
	<i>Living in society</i>	<i>Living in society</i>	
	Visitor schedule	Visitor schedule	
	Changing wards or institutions	Changing wards or institutions	

Table 5 Key events in the decision trajectories of people with dementia and the related decisions (continued)

Key events	Decisions	
	People with dementia living with an informal carer	People with dementia living alone
Key event 8. Switching wards	<i>Managing daily life</i>	<i>Managing daily life</i>
	Activity schedule	Going out alone
	Taking over activities of daily living	Activity schedule
	Monitoring food intake	Activities of daily living
		Handling money
	<i>Arranging health care and support</i>	<i>Living in the community</i>
	Prescribing medication	Decorating the room
		Keeping up social contacts
	<i>Living in society</i>	Visiting home
	Reducing weekend leave	Visitor schedule
	Visitor schedule	
	Going out together	
	Being in the room alone	<i>Arranging health care and support</i>
		Quitting informal care
	<i>Representation of the person with dementia</i>	<i>Representation of the person with dementia</i>
	Power of attorney	Informing the person with dementia less
	Informing the person with dementia less	

Other related decisions are grocery shopping and arranging volunteer or home care. Sometimes the decision to reduce the amount of information given is made to increase the chance that the person with dementia will accept daycare.

I deliberately choose not to call it daycare, but therapy.—Spouse of a man with dementia, care network 14, quote 7.

Key Event 4: Incidents Regarding Safety Issues

This is the time after the diagnosis when care network members experience incidents where the safety of the person with dementia is at stake. These incidents start soon after people with dementia living alone have been diagnosed. For those living with an informal carer, such incidents begin after a period of concerns about the inactivity of the person with dementia. The main decisions for those living alone are about being home alone, doing household chores and getting groceries, meal service, handling finances, and assistance with activities of daily living (Table 5).

And she doesn't cook anymore. So that's a worry less. Today someone will cook for her, and then a portion will go into the fridge so she can put it in the microwave later on. She eats at the daycare centre twice a week, and then on Saturday it's fish. So, that takes care of the whole week—Friend of the family of a woman with dementia, care network 5, quote 59.

The main decisions for those living with an informal carer involve the person with dementia being at home or going out alone, cooking and grocery shopping.

Taking a stroll, for instance. He doesn't dare anymore because something might happen.—Musical therapist of a man with dementia, care network 10, quote 3.

Professional care is often extended to resolve the increasing safety incidents.

These last four months it went from no care to quite intensive home care four times a day combined with daycare three times a week.—Homecare nurse of a woman with dementia, care network 13, quote 3.

Decisions about reducing the involvement in decision-making of the person with dementia are also seen.

Key Event 5: Prelude to Nursing Home Admission

At some point, the person with dementia is registered for a nursing home. Three circumstances seem to function as a prelude to nursing home admission: 24-hr monitoring, hospitalisation of the person with dementia, and carer burden.

The necessity of 24-hr monitoring. This involves the situation where continuing safety incidents have made informal carers or professionals feel that the person with dementia cannot be left alone, not even for a short time. This occurs both in care networks of people living alone and in those living with an informal carer (Table 5). The related decisions are about being at home or going out alone, taking over household chores, handling money, extending daycare and home care, reducing the decision-making involvement of the person with dementia, and arranging mentorship. In care networks of those living alone, the main decisions concern being home alone and going out alone.

She is registered for a nursing home now. Because she wandered around at night twice. [. . .] We stay there every night now, then she sleeps well. But, we don't dare leave her alone: we are afraid that she will change night into day again—Daughter of a woman with dementia, care network 5, quote 2.

The main decision in the care networks of those living with an informal carer is about the person with dementia being home alone.

Over the years you see the circle around her getting smaller and smaller, and you notice that she is just really afraid and you can't leave her alone at all anymore.—Quote Sister of a woman with dementia, care network 19, quote 58.

Twenty-four-hour monitoring is difficult to maintain in the long run, which leads to a nursing home registration.

He wanders so much, it's too dangerous. And having someone with him 24 hours a day is difficult too.—Granddaughter of a man with dementia, care network 23, quote 16.

Hospitalisation because of a lack of self-care. This hospitalisation means the person with dementia is being admitted to the hospital because of a lack of self-care (e.g., falls in the home or infectious disease). This especially happens to people with dementia living alone (Table 5). The hospitalisation of two people with dementia who lived with a spouse (care networks 4 and 12) were not related to self-care, but to heart disease. The decisions concern nursing home admission or discharge to the home situation, taking

over activities of daily living and household chores, obtaining assistive devices aimed at safety and mobility, taking over the bookkeeping, starting pain or other medication, starting case management, physiotherapy, and increasing home care.

We changed a lot in the house. We took away a lot of stuff. We had an occupational therapist come over for advice. Rugs, little tables have been put away . . . and everywhere there are handgrips now—Son-in-law of a woman with dementia, care network 17, quote 3.

Hospitalisation usually follows safety incidents. However, care networks 2 and 3 are exceptions because their decision trajectories start with hospitalisation. The care network 2 person's Lewy body diagnosis was missed at first, and she was hospitalized because of her delusions. The network 3 person with dementia always kept to herself. Her two nieces think she concealed her progressive decline because of a fear of losing her independence.

I think she had the idea all that time that they must not notice how confused she was becoming . . . everything that was going wrong—Niece of a woman with dementia, care network 3, quote 4.

After hospitalisation, people with dementia are often admitted to a nursing home, although some are discharged to go home with extra care.

Carer overburdening. This includes the situation where primary informal carers reach the limit of their ability to care. This is more prominently related to people with dementia living together with a carer (Table 5). For people living alone, the primary carer can often hand over tasks to other informal carers before the limit is reached.

My sister can't take care [of my father] 24 hours a day. She has her family too, including my brother-in-law. She will go on holiday again in a while. [...] So, well, I have to go take care of him more often then—Son of a man with dementia, care network 8, quote 46.

Related decisions to carer burden concern daily activities, being home alone, going out alone, and self-care tasks such as taking medication and managing meals. Decisions about arranging daycare, home care, volunteer care, and respite are also made.

He [the spouse of the person with dementia] said ‘I noticed that I get more tired’ and then we made the decision. Well, maybe it is good for him to get away from it all for a little while—Case manager of a couple of whom the woman has dementia, care network 9, quote 5.

Key Event 6: Nursing Home Admission

This includes the nursing home admission. In 14 care networks, the person with dementia had been admitted to a nursing home by the end of our study. Related decisions are choosing an institution and accepting a place on the waiting list (Table 5). Right after the admission, decisions are made about an activity schedule and the extent of assistance with activities of daily living, including household chores.

When she came to live with us, she said that she wanted to remain as independent as possible. [...] She stated that in the intake report. She was keen on her privacy, wanted to do everything herself.... And so, with that in mind, we involved her in the events [of the ward]: for instance, the cooking.—Primary attendant of a woman with dementia, care network 3, quote 11.

Families make decisions about decorating the room and setting up a visitor schedule. A weekend leave is sometimes arranged when the person with dementia used to live with the informal carer.

My father takes her home for the weekend. He picks her up on Friday and she goes back on Sunday. [...] In fact, my father decided that before she was admitted to the nursing home. [...] Because, he said, in the weekend, he was not working, and then she could just come home—Daughter of a woman with dementia, care network 6, quote 67.

Some people with dementia sign a nonresuscitation statement after nursing home admission.

[During the family meeting] the subject of the resuscitation policy came up, whether she wanted to be resuscitated—Primary care assistant of a woman with dementia, care network 13, quote 6.

Key Event 7: Adjustment Issues

People with dementia who are unhappy after nursing home admission may have adjustment issues. They express their feelings with depressive or agitated behaviour.

She kept on repeating that [that she wanted to jump off the building]. Every time I was there, she cried and wanted to go home. She didn't want to stay there anymore, it was terrible, and all these frightening people. It made her desperate. [...] A psychologist was consulted then—Sister of a woman with dementia, care network 18, quote 63.

Adjustment issues occur in some, but not all care networks, both for those who used to live alone before and those who used to live with a carer. Related decisions entail daily activities, consulting a psychologist, changing the visitor schedule, and deciding about changing between wards or institutions (Table 5).

We discussed whether it was wise to bring him here [to the daycare centre] at all. Because, from the moment he arrived, he kept wanting to go home. So, we felt that if he was contented in the nursing home, maybe we should not do the program to reduce his daycare time step by step—Daycare employee of a man with dementia, care network 14, quote 7.

Key Event 8: Switching Wards

This means the person with dementia moving to another ward or group within the nursing home. Switches between wards can be related to the deterioration of the person with dementia.

My wife has, how should I put it, she has gone one step down. She was in this group, the activated group, but she couldn't do that anymore. My wife is now in the protected, cared for group. Here everything is done for you—Spouse of a woman with dementia, care network 6, quote 2.

Switching can also be related to organisational issues; for example, rebuilding the nursing home.

Two or three weeks ago, we were informed that the place where she lives now was actually one of their temporary locations. [...] If we had known this last year, maybe we would have waited a month or two longer and placed her somewhere where she could stay—Granddaughter of a woman with dementia, care network 13, quote 2.

Related decisions include setting up a new activity schedule and a care plan, reassessing going out alone, and decorating the room (Table 5).

Discussion

To our knowledge, this is the first study that systematically and empirically explores the decisions made for people with dementia over time. We found four relevant types of decisions and eight relevant key events. Our results contribute to understanding the dementia trajectory from the perspectives of people with dementia, their informal carers, and health-care professionals. Whereas studies until now focus mainly on care transitions (Forbes et al., 2012; Fortinsky & Downs, 2014), our study shows that decisions in the lives of people with dementia relate to more than just care: for instance, decisions about mobility, handling finances, and maintaining social contacts. Some key events have been described in earlier research (Forbes et al., 2012; Fortinsky & Downs, 2014): recognizing symptoms and obtaining a diagnosis, loss of independence, using home care or other community services, using respite care, hospital admissions, long-term care placement, and palliative or end-of-life care. Furthermore, our study reveals new points along the decision trajectory: activating the person with dementia, overburden of the carer, 24-hr monitoring, difficulties adjusting to residential care, and switching wards. Our study is unique in indicating both the key events and the types of decisions related to certain key events along the decision trajectory.

Knowing what types of decisions will be needed related to key events can facilitate advance care planning and shared decision-making. Advance care planning involves making plans about future care and treatment (Dickinson et al., 2013). Our results may reduce the delay in planning ahead for people with dementia and their carers. This delay has multifaceted grounds. First, people with dementia and their carers often do not know enough about what issues should be discussed (Brazil, Carter, Galway, Watson, & van der Steen, 2015; Dickinson et al., 2013; Hirschman, Kapo, & Karlawish, 2008). Second, they are reluctant to engage in decisions that are not relevant to themselves or over which they feel no control (Dickinson et al., 2013). Third, difficulties in coping with changes because of the dementia may hinder planning ahead (Hirschman et al., 2008; Piers et al., 2013). Our results may offer the knowledge and control needed by people with dementia and their carers because they illustrate the issues to be expected in the decision trajectory. Advance care planning can thus be shaped around the issues from the perspectives of care networks of people with dementia instead of preparing for transitions from an organisation-of-care position. Timely discussion of issues is important, since waiting too long can result in people with dementia having little say in the decision-making, and as such can obstruct shared decision-making (Dickinson et al., 2013; Hirschman et al., 2008).

Shared decision-making in the context of dementia means that professionals involve the person with dementia and the informal carers in decisions about their lives (Miller,

Whitlatch, & Lyons, 2014). Involving people with dementia in shared decision-making becomes increasingly difficult, as the dementia progresses. Samsi and Manthorpe (2013) have described how the mutual decision-making of people with dementia and their carers changes in time from supported decision-making to substituted decision-making. In our care networks, involving and informing the person with dementia in decision-making were discussed on multiple occasions, during many key events. This might indicate that reducing the involvement is not taken lightly. In any case, the involvement is often reduced during key events. Professionals facilitating shared decision-making in care networks should safeguard the involvement of the person with dementia in decision-making when much is at stake for them. Preparing for the key events ahead may ensure that the voice of the person with dementia is heard.

This study shows that professionals should pay attention to the voice of the person with dementia living alone. Decisions and key events differ for people living alone and those living with an informal carer. The emphasis for people with dementia living alone is on safety issues and for those living with an informal carer, on carer burden. The decisions of people with dementia living with an informal carer show more variety than of those living alone. They include issues of well-being that do not occur for those living alone: for instance, taking trips together. This may indicate that carers' worries about risks for people with dementia living alone predominate and overrule other decisions. Berry, Apesoa-Varano, and Gomez (2015) describe how family members try to manage risk for community-dwelling people with dementia. The person's diminishing awareness of his or her disabilities prompts families to restrict autonomy regarding the person's activities. This unawareness of the risks is especially problematic for people with dementia living alone (Gilmour, Gibson, & Campbell, 2003; Lehmann, Black, Shore, Kasper, & Rabins, 2010). Professionals must deal with the continuous tension of balancing their clients' rights and preferences against potential harms (Vaughn, 2009). The challenge to professionals is to work with their clients and informal carers toward a shared, negotiated understanding of risk that focusses on the well-being of the patient instead of merely avoiding risk (Gilmour et al., 2003). Meeting this challenge is an important step for shared decision-making in the care networks of people with dementia living alone. Further research could develop and evaluate interventions aimed at preparing care networks of people with dementia in thinking ahead about decisions in the future in order to facilitate shared decision-making in dementia care networks.

Strengths and Limitations

There are four strengths in our study. (1) The data are based on rich multiperspective information (Kendall et al., 2009; Koehly, Ashida, Shafer, & Ludden, 2015). Koehly, Ashida, Shafer, and Ludden (2015) demonstrated the added value of involving multiple carers

in dementia research, which leads to more comprehensive results. (2) Our prospective approach allowed for descriptions of care network's trajectories and to check information that was unclear in successive interview rounds (Murray et al., 2009). (3) The rigor in our study was ensured by a systematic and transparent process with multiple analytical techniques (Meyrick, 2006). This leads to comprehensive results grounded in the data. Two researchers independently constructed the timelines and the research group discussed the preliminary findings. (4) We involved both community-living people with dementia and others living in a nursing home.

This study has several limitations: (1) We only involved people with dementia who could engage in an interview at the start of the study. Consequently, we had no participants who were in the end stage of dementia. (2) The timelines of our care networks are partially based on retrospective information. (3) Our data are based on self-reporting. (4) Our data reflect the Dutch care system, which may differ in care and living arrangements compared to other countries.

Conclusion

This study shows that decisions in the lives of people with dementia over the course of time are mainly geared to living life with the dementia, and the decisions deal with managing daily life, arranging health care and support, living in the community, and representing the person with dementia. Over time, people with dementia have to deal with various key events in their decision trajectories. These trajectories differ for care networks of people with dementia living alone and for those living with an informal carer. The inactivity of a person with dementia and carer burden are predominant key events in the decision trajectories of those living with a carer. For a person with dementia living alone, the predominant key events along the decision trajectory include safety concerns and incidents and possible hospitalisation. The key events and related decisions can help professionals and informal carers prepare for the decisions ahead. The professional who facilitates shared decision-making along the trajectory should be aware that the role of the person with dementia is often at stake. In facilitating care networks of people with dementia living alone, the professional should be aware that safety issues may overrule issues about the quality of life of the person with dementia.

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CHAPTER 3

THE CHALLENGES OF SHARED DECISIONMAKING IN DEMENTIA CARE NETWORKS

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Abstract

Background: Decision-making is an important part of managing one's life with dementia. Shared decision-making is the preferred way of involving people in decisions. Our study aimed to describe the challenges of shared decision-making in dementia care networks.

Methods: A multi-perspective qualitative study using face-to-face interviews with 113 respondents in 23 care networks in the Netherlands consisting of 23 people with dementia, 44 of their informal carers, and 46 of their professional carers. The interview guide addressed the decision topics, who were involved in the decision-making and their contributions to the decision-making. We used content analysis to delineate categories and themes.

Results: The themes and categories that emerged are: (1) adapting to a situation of diminishing independence, which includes the continuous changes in the care network, resulting in shifting decision-making roles and the need for anticipating future decisions; and (2) tensions in network interactions which result from different perspectives and interests and which require reaching agreement about what constitutes a problem by exchanging information in the care network.

Conclusion: The challenges in dementia care networks relate to all dimensions of social health. They have implications for a model of shared decision-making in dementia care networks. Such a model requires flexibility regarding changing capabilities to preserve the autonomy of the person with dementia. It needs working towards a shared view about what constitutes a problem in the situation. It asks for professionals to advocate for the involvement of people with dementia by helping them participate in ways that strengthen their remaining capacities.

Introduction

Making decisions is an important part of managing one's life with dementia. The progressive course of dementia implies continuous changes in the lives of people with dementia and their informal carers. It causes various problems that require decisions (Groen-van de Ven et al., 2016), both medical and social, both major and minor (Livingston et al., 2010; Hamann et al., 2011; Wolfs et al., 2012; Samsi and Manthorpe, 2013). The decisions include topics such as obtaining a diagnosis, using dementia-related health and social services, supervision and assistance in daily living, admission to a nursing home, and legal and financial matters (Livingston et al., 2010; Wolfs et al., 2012; Samsi and Manthorpe, 2013).

Studies show that people with dementia want to participate in decision-making about their situation as long as possible, although they realize it will become difficult as the illness progresses (Hamann et al., 2011; Fetherstonhaugh et al., 2013). Involving formal and informal carers in decision-making can promote autonomy for people with dementia by using their extant capacities (Boyle, 2014). Relatives and professionals can help people with dementia understand information and consider the preferences (Smebye et al., 2012). The aim of involving relatives is to reach decisions that people with dementia can identify with, regardless of who eventually makes the decisions (Peisah et al., 2013). Decision-making is thus defined as a complex process in the context of dementia care networks that involves people with dementia and their informal and professional carers (Wolfs et al., 2012).

Shared decision-making is widely promoted to get patients involved (Blanc et al., 2014). Shared decision-making models have not been developed for the context of dementia, so it is unclear how these models can support the decision-making of people with dementia and their carers (Peisah et al., 2013). The essential elements of shared decision-making are: the recognition that there is a decision to be made; the exchange of information; the deliberation about options; the expression of values and preferences; and making and implementing decisions (Stacey et al., 2010). Shared-decision-making models generally tend to focus on the patient-physician dyad (Stacey et al., 2010) and on verbally and rationally choosing options during consultations (Entwistle and Watt, 2006). This focus may be too challenging for people with dementia, and may hinder their involvement. A Relational approach to decision-making may be more suitable for promoting the agency of people with dementia (Boyle, 2014).

A relational approach to shared decision-making focuses on interdependence and the supportive or obstructive roles of others, such as professionals and informal carers in making decisions that patients can identify with (Entwistle and Watt, 2006; Peisah et

al., 2013). As such, a relational approach may contribute to the social health of people with dementia by responding to the dynamic balance between a person's capacities and limitations and his or her social environment (Vernooij- Dassen and Jeon, 2016). A recent literature review concludes that the descriptions of shared decision-making in dementia vary widely (Miller et al., 2014). The central theme is the involvement of the person with dementia in decision-making about their lives. Miller et al.'s review does not make any connection to the essential elements of shared decision-making in existing models. It is therefore unclear what challenges professionals experience when they want to facilitate shared decision-making in dementia care networks. Our research aim was to describe the particular challenges of shared decision-making for the people with dementia, their informal carers, and their professionals. This knowledge may contribute to the development of a model that does justice to the real-life experience of those who are involved in decision-making in dementia care networks.

Methods

Design

Our study has a qualitative, multiperspective design involving semi-structured interviews, and it is part of a larger longitudinal study of decision-making in dementia (Span et al., 2015; Groen-van de Ven et al., 2016).

Setting

The participating people with dementia and their informal carers were interviewed at home. Professional carers were interviewed at their workplaces. We stressed the importance of interviewing participants, especially people with dementia, alone so that they could share their perspectives without feeling influenced (Nygård, 2006). However, sometimes the person with dementia was willing to participate only if the informal carer was present during the interview.

Participants

To find information-rich cases, we purposefully selected care networks (Coyne, 1997) each consisting of a person with dementia, two informal carers, and two professional carers. We aimed at maximum variation in the characteristics of people with dementia (gender, socio-economic status, and stage of dementia) and type of informal carers, for instance spouses, children, other relatives, and friends (Coyne, 1997). We recruited care networks spread over the Netherlands. We used three recruitment routes: (1) healthcare organisations, (2) local meetings for informal carers and people with dementia, and (3) the Dutch Alzheimer's Society website. The inclusion criteria were a

diagnosis of any form of dementia and the availability of at least one informal carer. The exclusion criteria were not having a clear diagnosis of dementia and the person with dementia not being able to participate in an interview (as assessed by the informal carer). In line with Creswell (1998) we expected to reach data saturation between 20 and 30 care networks.

Table 1. Interview topics for the different types of respondents

Subject	Topics and questions for PWD	Topics and questions for informal carers	Topics and questions for professional carers
General information	Age Former profession Ethnicity Gender Living accommodation (community dwelling, home for the elderly, or nursing home)	Gender Relationship with the PWD	Professional background Tasks related to the care of the PWD Type of organisation where professional works Team composition Involved in care for the PWD since when? Diagnosis of the PWD (by whom and what is it?) Professional assessment of the stage of dementia
Decisions	<ul style="list-style-type: none"> • How are you? • What has changed for you lately? • What choices have you had to make because of these changes? • What do you think about your decisions now? 	<ul style="list-style-type: none"> • How do you feel the PWD is doing at the moment? • What has changed for PWD lately? • What choices have you had to make because of these changes? • What do you think about your decisions now? 	<ul style="list-style-type: none"> • What has changed for the PWD lately? • What choices have you had to make because of these changes? • What do you think about your decisions now?
Decision-making	<ul style="list-style-type: none"> • What was the cause of the decision? • What happened before the decision was made? • Who was involved? • What was your role in making this decision? • What did you want? What made this important to you? • What did others want? What made this important to them? • What were the alternatives? • How did you manage to reach a decision together? • What information did you need to reach a decision? 		

Data collection

Eleven interviewers used an interview guide to conduct the semi-structured interviews. All interviews in a given care network were done by the same interviewer. The topics included the decisions made, participants in decision-making, and ways of contributing to decision-making (Table 1). The interviewers included eight students studying for bachelor degrees (in nursing, speech therapy, or applied gerontology) whom the researchers (LG, MS, and KC) trained in qualitative interviewing and in interviewing people with dementia. The interviews lasted averagely 1 hour and were audiotaped and transcribed verbatim.

To maximize the person with dementia's responses we trained the interviewers to take time to build trust by engaging in informal talk before the interview started (Murphy et al., 2015). We chose to interview the primary informal carers as the first respondents in our care networks. The resulting information helped us use prompts in interviews with people with dementia.

Data analysis

The aim of our study was to describe the particular challenges of shared decision-making in the context of dementia care networks. Even though we were aware of the elements of shared decision-making in other contexts, we wanted to be open to the particulars of decision-making in dementia. Therefore, we used content analysis (Elo and Kyngas, 2008) based on open coding and constant comparison (Corbin and Strauss, 1990) to analyse our data. Open coding consists of reading the interview transcripts and labeling the relevant interview fragments. Constant comparison means comparing newly analyzed data with emerging codes and categories. To keep the focus on the care network story rather than the separate interviews, we read all the interviews of a care network before coding (Kendall et al., 2009). To ensure rigor, LG and MS independently coded the 15 interviews from the first three care networks and agreed on an initial coding scheme consisting of a description and an example quote for each code. The multidisciplinary research group then discussed and agreed on this coding scheme. This multidisciplinary group included researchers specializing in health science, psychology, gerontology, nursing science, medicine, sociology, and anthropology. LG used the scheme to code the remaining interviews. The research group discussed any new codes or refinements of the coding scheme. We reached data saturation after analyzing the data of 18 care networks, when no new codes emerged (Creswell, 1998). The next steps of our analysis included clustering codes into categories, followed by grouping categories into themes. For this part of the analysis, we used affinity diagramming (Johnson et al., 2012), which involved three sessions with the research group led by a process leader. We used Atlas.ti software for the analysis.

Ethical considerations

The regional ethical board of the Isala Clinics, (Zwolle, the Netherlands) approved this study (number 10.11113). Taking part required the consent of both the person with dementia and the informal carer. The participants received oral and written information before consenting. The person with dementia's consent was regarded as a process (Murphy et al., 2015). The interviewers remained alert to any verbal or nonverbal signs that the person with dementia did not want to continue the interview (Meulenbroek et al., 2010), and they did not share interview information with care network members, i.e., the participants (Kendall et al., 2009).

Results

Participants

Of the 30 care networks that we invited, 25 consented to participate. Refusals were due to the expected burden of the interviews on carers or people with dementia. Two care networks were excluded because a person with dementia unexpectedly could not participate in the interview due to stress (one care network), and a person's diagnosis of dementia was reset to mild cognitive impairment during the study (one care network). The remaining 23 care networks included 23 people with dementia, 44 informal carers, and 46 professional carers, resulting in a total of 113 interviews. Table 2 lists the characteristics of the care networks.

The challenges of shared decision-making in dementia care networks

In our analyses, we found two themes representing the challenges of shared decision-making in dementia care networks: (1) adapting to a situation of diminishing independence, which includes the continuous changes in the care network; the changing positions and roles of care network members; and, anticipating future decisions; and (2) tensions in network interactions, which result from different perspectives and interests and which require reaching agreement about what constitutes a problem in the situation by exchanging information in the care network. Table 3 lists the themes and categories that emerged from the analyses.

Theme 1: adapting to a situation of diminishing independence

This theme represents the continuous changes that challenge the independence of the person with dementia and that prompt decision-making. The theme consists of three categories: (1) the continuous changes in the care network, (2) the changing positions of care network members in the decision-making, and (3) anticipating future decisions.

Table 2. Characteristics of the participants with dementia and the carers interviewed

	Gender	Age	Stage of dementia ¹	Marital status	Living arrangements of PWD at baseline	Type of informal carers interviewed	Type of formal carers interviewed
1	Man	82	M	Married	Elderly home	Spouse Daughter	Principal attendant Case manager
2	Woman	82	A	Widowed	Nursing home	Daughter Daughter	Principal attendant Case manager
3	Woman	83	M	Single	Elderly home	Niece Niece	Principal attendant Case manager
4	Man	77	?	Married	Nursing home	Daughter Son-in-law	Principal attendant Case manager
5	Woman	83	B	Widowed	Community dwelling	Daughter Friend	Daycare employee Case manager
6	Woman	62	M	Married	Nursing home	Spouse Daughter	Principal attendant Head of department
7	Woman	?	M	Married	Community dwelling	Spouse -	Daycare employee Case manager
8	Man	80	B	Widowed	Community dwelling	Daughter Son	Home care nurse Case manager
9	Woman	74	M	Married	Community dwelling	Spouse Daughter	Domestic help Case manager
10	Man	?	M	Married	Community dwelling	Spouse -	Home care nurse Creative therapist
11	Woman	79	B	Married	Community dwelling	Spouse Daughter	Daycare employee Case manager
12	Woman	80	M	Married	Community dwelling	Spouse Daughter-in-law	Daycare employee Case manager
13	Woman	84	M	Widowed	Community dwelling	Grandson Granddaughter-in-law	Home care nurse Team leader for nurses
14	Man	70	M	Married	Community dwelling	Spouse Son	Daycare employee Home care nurse
15	Woman	89	M	Widowed	Community dwelling	Daughter Son-in-law	Home care nurse Case manager
16	Woman	87	M	Widowed	Community dwelling	Daughter-in-law Daughter-in-law	Home care attendant Case manager
17	Man	83	M	Married	Community dwelling	Spouse Daughter	Daycare employee Case manager
18	Woman	73	M	Single	Nursing home	Sister Niece	Principal attendant Case manager
19	Man	86	B	Widowed	Community dwelling	Son Son	Care coordinator Home care nurse

Table 2. Characteristics of the participants with dementia and the carers interviewed (continued)

	Gender	Age	Stage of dementia ¹	Marital status	Living arrangements of PWD at baseline	Type of informal carers interviewed	Type of formal carers interviewed
20	Woman	89	B	Single	Community dwelling	Nephew Niece	Home care nurse Care coordinator
21	Woman	87	M	Married	Community dwelling	Spouse Daughter	Home care nurse Team leader for nurses
22	Woman	?	M	Married	Community dwelling	Spouse Brother	Daycare employee Case manager
23	Man	78	M	Married	Nursing home	Granddaughter Daughter	Principal attendant Attendant

¹ Judgment by professional interviewed

A = advanced dementia, B = beginning dementia, M = moderate dementia, PWD = person with dementia

Table 3. Themes and categories of the challenges of shared decision-making in dementia care networks

Theme	Categories
Adapting to a situation of diminishing independence	The continuous changes in the care network The changing positions of care network members in the decision-making Anticipating future decisions
Tensions in network interactions	The different perspectives toward the situation and the urgency of a decision Longstanding relationships and positions in the network The challenge of exchanging information within the care network in an adequate and timely way Weighing conflicting perspectives and interests

The continuous changes in the care network

People with dementia and their care networks encounter continuous change over the course of time.

Normal, everything was normal, all fine, but it slowly became less, became less.

And, it goes on too. – Woman with dementia, care network 6

The lives of people with dementia and their informal carers are intertwined, especially when the informal carer is the spouse of the person with dementia. Changes in the situation for one care network member therefore often have implications for other care network members as well.

My driver's licence will expire in two years. So, I try to keep doing the groceries for at least two years. But, with [my partner's] eyes getting worse. Yes, I call on myself to keep taking that over from her. – Man with dementia, care network 10

An important source of continuous change includes the progressive nature of the dementia which results in the declining functioning of the person with dementia. Participants are more or less aware of the progressive nature of dementia, which requires decisions that often force the person with dementia to give up independence little by little. Examples of this involve stopping activities such as car driving, managing the financial matters at home or accepting increasing assistance with daily activities such as grocery shopping, household chores, going out alone, and washing and clothing oneself. The declining functioning of the person with dementia living in the community is often automatically counterbalanced by the informal carer providing more care. In this way, the continuous changes in the functioning of the person with dementia impact the roles of the other care network members.

For [my mother] a lot has changed too. You see, it used to be like this. When they were cycling together, my dad used to be in the front, because he knew his way everywhere, and my mother used to follow him. But now, my mother has to cycle in the front. ... She has to be in charge now. And, that's actually exactly opposite to what she was used to. So the roles have changed completely. – Daughter of a man with dementia, care network 17

Another source of changes in the situation of the care network is the levels of functioning of the informal carer. Unforeseen circumstances, for instance health issues or carer overburdening, may result in the informal carer relinquishing care, which other informal carers or professionals have to take over, or which in some cases, results in institutionalisation.

Then I fell, and I bruised my rib. So then I was out of the running a little while, so to speak. And then my husband ended up in [the care home].... – Partner of a man with dementia, care network 1

After institutionalisation, the progressive decline of the person with dementia requires decisions about, for instance, the activity program and relocation to another ward. The challenge for the care network members within this category represents the central dilemma in many decisions for people with dementia: weighing the independence and well-being of the person with dementia against safety risks and, especially in the context of community living, overburdening the primary informal carer.

Well, my wife. She's in two minds about it. She likes to have me home. But she's afraid something will happen to me. – Man with dementia, care network 4

The changing positions of care network members in the decision-making

As the dementia progresses, the decision-making capacities of the person with dementia diminish. This affects the positions of both the person with dementia and the informal carers in the decision-making, with spouses or children taking over the responsibility for the person with dementia.

If there is something that I can't manage, I will call my son and he will come to check on me. – woman with dementia, care network 13

As the role of the person with dementia diminishes, the informal carers take on more responsibility for the decision-making. This change of positions in the decision-making is gradual. In the initial stage their carers help people exchange information and share considerations. At this stage, they are actively encouraged to express their preferences in an open way.

If you have people who are still really in the initial phase of dementia, then it is really all about questions: what do you want to do today? What do you like? And then you can really try to meet the individual's wishes. – Activity coordinator of a woman with dementia, care network 22

When the dementia progresses an overview of their situation and the options can help people with dementia make decisions, particularly if the number of options is limited and the information is provided at shorter notice. Decision-making can become stressful in the later stages of dementia, and some informal carers and professionals then take charge of it.

That's under discussion with him too: that you shouldn't tell him things too much in advance. A lot was being written in his calendar, for example. That really makes him restless. ... So that's why we said: 'We won't put anything in

his calendar too much in advance anymore because it only causes restlessness. ... He loses his grip and doesn't know when and how. So we didn't really discuss that extra care we arranged with him. We just said that we would come by a bit more often, but not like, not very clear. We just go there on Friday afternoons and tell him we've come to do something fun. That's fine with him. – Home care nurse of a man with dementia, care network 8

It is in this later stage that informal carers may be faced with difficult decisions such as deciding about admission to a nursing home. Professionals help informal carers by being present, listening to them, legitimizing the informal carer's considerations, and functioning as messengers for difficult decisions.

I didn't tell her [that she would be admitted to the nursing home], and I didn't want to tell her either. I thought she wouldn't accept it from me. So we agreed a long time ago that [our case manager] would tell her. – Sister of a woman with dementia, care network 18

The challenge for people with dementia and their informal carers is the gradual accommodation of the change in decision-making responsibility from the person with dementia to the informal carers. For professionals and informal carers, the challenge is to involve the people with dementia in decision-making in accordance with their capabilities. For people with dementia this means trusting their carers in the decisions they make for them.

Interviewer: What has changed for you since you came to live here in the nursing home? [Silence] That is a very difficult question. I don't even know that anymore. Because, I lose everything so suddenly. Everything that's in my head, if I do like this, it is gone. Yes, it's going fast. [Silence]. That is why it's very difficult to answer your question. I don't even know myself. But, I trust my carers. I feel that they can help me. And that is a good feeling. – Woman with dementia, care network 18

Anticipating future decisions

Making decisions in a timely manner is important to people with dementia and their care networks because many care networks want to respect the independence of the person with dementia as long as possible.

[Interviewer: Is that important for you, your independence?] Oh yes! I would find it terrible if I would have to move to...if I walk past those homes over there... I

would find it terrible to live there. [...] Look, if I or the others would notice, he can't manage anymore, then it would be different. But, I feel I can still manage quite well. – Man with dementia, care network 8

Timing decisions rightly implies anticipating future problems. Future problems relate to the progressive decline in functioning of the person with dementia, the vulnerability of and burden on the informal carer, and organisational barriers such as waiting lists. The participants are aware that thinking ahead about decisions allows the person with dementia a voice in these decisions.

Now she is still good enough to be actively involved in [thinking about what to decide if something should happen to dad] – Daughter of a woman with dementia, care network 9

However, discussing future issues is emotional because they relate to either the deterioration of the person with dementia (and giving up independence) or to the informal carer (relinquishing care). Some participants tend to avoid thinking about these situations.

It is just as it is now, and I am very happy with things as they are. So why would I change that. Of course, I could, if the moment comes when I think: yes, now it's going all wrong. – Woman with dementia, care network, care network 18

But, if he weren't here at all, no, then I couldn't stay here [independent living] anymore. But yes, what then? But, well, I just won't think about that. – Woman with dementia, care network 9

The challenge for care network members is to discuss issues in a good time so that the person with dementia can have a say. This implies coping with the progressive nature of dementia in order to prepare for decisions ahead. The challenge for professionals facilitating shared decision-making in dementia care networks is to adjust their decision-making pace to that of the care network members by introducing issues and then checking whether the members are able to discuss these issues now or whether they should be postponed.

At a given moment I said to him [the spouse], how do you feel about nursing home admission, which can also be a prospect. Well, in the beginning he was really holding back: "O no" you know, like "No I won't do that to her. Everything is fine as it is. I want to take care of her until the end. We live very beautifully

here” You know? Like that. Then you notice that he’s not ready for it yet. Then you let it rest for a while. Then he comes up with something again and then you just touch the subject lightly again, let it settle in. Let him adjust to the idea for a couple of months. And then, when he has made the decision, then he speeds up, he will make calls and arrange things. – Case manager of a couple of whom the woman has dementia, care network 7

Theme 2: tensions in network interactions

This theme involves the ways in which the care network members work together and influence each other during the decision-making. It includes four categories: (1) the different perspectives toward the situation and the urgency of a decision, (2) long-standing relationships and positions in the care network, (3) the challenge of exchanging information within the care network, and (4) weighing conflicting perspectives and interests.

The different perspectives toward the situation and the urgency of a decision

Care network members differ in their views of the situation, their values, and their ideas about what constitutes a problem. This influences their appraisal of decisions. People with dementia and their primary informal carers face the dementia on a day-to-day basis so that they experience the changes in the situation as gradual and small. Some people with dementia are aware of the problems related to their dementia, others not.

At the checkout of the supermarket when I want to pay, that’s all really complicated. These days you have to put your bankcard in the back and it used to be in front. And meanwhile I have to watch that they won’t take my wallet and then this cash girl asks ‘Do you have ten cents extra?’ And I go ‘Can you speak louder, I can’t hear.’ And in the meantime I see the queue behind me waiting. They are thinking ‘That old buffer is not getting anywhere’. And that upsets me and then when I get home it appears I have forgotten things. Oh! I used to like shopping, but now I get drowned in. It is very hard. – Man with dementia, care network 10

I’m doing fine. I have no problems. I wouldn’t know. Going to the daycare is fine. Well, I actually don’t belong there. The daycare employee says it too: They can better put you on the pay role. –Woman with dementia, care network 11

The informal carers and professional report that people with dementia may overestimate their capabilities. However, even primary informal carers may have difficulties seeing the deterioration of the person with dementia or have difficulties taking away

independence. People with dementia and their primary informal carers often focus mainly on the present situation and tend to avoid thinking about the future.

But I am not going to sit there puttering about and thinking. What will be, will be. If it happens, then it happens by itself, and then I'll see. Doing that beforehand is not living. – Woman with dementia, care network 18

Secondary informal carers often have other views of the situation and urgency of decision-making. They see changes in functioning as more abrupt, which sometimes means they see the situation as problematic earlier on. Further, the situation of both the person with dementia and the primary informal carer concerns them, and the risk of overburdening the primary informal carer is a problem to them as well. Secondary informal carers tend to focus more on preparing for the future by anticipating decisions that may become relevant in the future.

As brothers, we are more or less on the same wavelength, although I notice that my brother, well, he lives opposite my father, so well, he comes by my father's much more often than I do. He is there almost every day, depending on the situation. And well, I have said before, wouldn't it be better if he went to another place. I am in favour of a better situation for him. But my brother is more like: let him be. It's okay as it is. – Son of a man with dementia living alone, care network 19

All the care network members – the people with dementia and their informal and professional carers – value the autonomy and independence of the person with dementia.

[Interviewer: How did you like it in the sheltered home?] It was okay, but still, you're not your own boss, are you? You're like a child. They pamper you, and if you are not well, they will do everything to make it go away. They pat you on the back, but you're not your own boss anymore. [Interviewer: And you would like to be?] Yes, of course. I would give as much for it as the entire proceeds from the collection for this or that. – Woman with dementia, care network 2

The perspectives on how to preserve autonomy differ between care network members. The need of people with dementia for independence may result in a refusal of professional care, but informal carers and professionals see precisely that professional care as the means of preserving independent living in the long run.

He talks about it as a chain of surrendering. It's getting worse and worse. That's how he sees it. Well I understand that's how it feels to him, it apparently does. But, I think he would be better off if he would accept more care and look at the possibilities. Then again, his energy seems to be gone. Stick to what you have, and don't give in, because it only gets worse. I think that if he would accept care in good time, he could have more instead of less. – Son of a man with dementia living alone, care network 19

Professionals and secondary informal carers do not curb independence lightly. However, the perspective of safety risks, given the functional decline of the person with dementia and the possible overburdening of the primary informal carer, is a serious matter to them.

We are considering whether or not to put his medication in a safe, so that he cannot get it himself, so that only we [home care] have the key. Only that's quite a rigorous step. So, we will try again for a while, until it gets too risky. – Case manager of a man with dementia living alone, care network 8

The challenges for care network members are: to share and listen to each other's perspectives of the situation; to acknowledge the deterioration of the person with dementia; and, to find common grounds about what problems require decision-making and how to shape decision-making. The challenge for professionals is to establish trust in the care network so that care network members feel free to share their views.

Longstanding relationships and positions in the care network

Care network members, more or less knowingly, influence each other via their mutual positions and relationships when they discuss and implement decisions. They often have longstanding relationships based on their particular roles (e.g., spouse, daughter, or case manager). Professionals especially mention the importance of trustful relationships for making decisions. However, longstanding or trustful relationships may also hamper an open dialogue about decisions, such as when care network members are afraid of hurting each other's feelings.

Now, it's not nice of me to say it. Because I have a very good father and I am his only child. To say, as hard as nails, "Dad, you have to stay here [in the care home], you cannot go home. – Daughter of a man with dementia, care network 4

Longstanding relationships and positions that influence decision-making consist of the unspoken rules about who has a say and the strategies that care network members use for pushing through decisions.

My daughter is wide awake, you know. So when she suggests something I'll usually think 'Oh well, you're quite right. – Man with dementia, care network 8

For example, my brother didn't want her to bicycle any more. And I felt, now, just let her enjoy bicycling. She'll get there OK.... [Interviewer: How did you solve that?] Well, by avoiding it, just not talking about it. That's the easy way. I heard from my sister-in-law that my brother really didn't want mum to bicycle. I just said, "Well I don't mind. She can cycle if she wants to." And, I would say that to my mother too. My mother said to me, "Your brother won't let me bicycle." Then I said, "No, he says that, but if you think you can do it, I'll let you bicycle." My brother knew what I had said to our mother. But, he just left it alone... You know each other very well, don't you? – Daughter of a woman with dementia, care network 2

The positions of professionals are relevant too. People with dementia and their informal carers sometimes tend to rely on the expertise of the professional, given their specific role and put their own ideas aside.

Living at home and living where she is now [in the nursing home], there should be something in between. Well, they [the case manager and the nursing home staff] all advised it, so I assume that that is well, uh... Well, I don't know how that works. I assume that they have looked into it. – Niece of a woman with dementia, care network 17

[Interviewer: What did you think of that? That the home care nurses suggested that personal alarm?] Good. They are quite right. I don't know what kind of things exist and all. But then they come up with this. Well, I think that's fine. – Man with dementia, care network 8

The challenge for the professional facilitating shared decision-making is to elicit the perspectives of the different care networks despite the existing communication patterns and positions in the care network. It is a challenge for professionals and informal carers to stand up for the person with dementia if necessary.

The challenge of exchanging information within the care network

Exchanging information involves care networks members sharing knowledge, information, thoughts, and ideas about the decision in question. This information-exchange is often difficult to follow for the person with dementia. They rely on their informal carers for comprehending what the decisions are about.

Spouse: For me it's more easy to oversee the consequences. That's much more difficult for her: to list all the ins and outs, to weigh the pros and cons against each other, and then to reach a decision. At least, that is how I feel it. That I keep trying to explain her again and again how things are and what choices we have. And, that is how we reach decisions. Woman with dementia: "I can't anticipate so well, and what will be possible, and he can do it all so much better. Interviewer: And how is that for you? Woman with dementia: Well, pleasant. That's why I say, if he wouldn't be there, it would be a disaster. – Interview with a woman with dementia and her spouse, care network 9

Given that multiple participants are involved in the decision-making, an adequate information exchange is extra complicated. The challenge is for all participants to contribute their perspectives. The fact that not every participant is present when decisions are discussed hinders the process. Sometimes participants who are not present want to provide background information that they feel is relevant. For example, the daughters of the woman with dementia in care network 21 felt the need to stand up for their mother by explaining their perspectives about the relationship of their parents.

My sister and I went to talk with [the case manager]. My mother absolutely did not trust this lady....So, at least we informed this lady, and also told her the whole history of my parents. Because, although I feel [my father] is now really trying his best, he had previously been a really lousy husband. – Daughter of a woman with dementia, care network 21

In some situations, organisational barriers hinder adequate information exchange between the professional carers.

Because she only has an indication for support [and not for treatment], the [contact with relatives and other professional carers] is really minimal. Only if there are special circumstances, will I first contact the daughter, and if there is really a dramatic decline, or really a big problem, then of course I will alert the [case manager]. With someone with an indication for treatment, you will keep in touch more. – Daycare employee, care network 5

Providing adequate information for people with dementia and their carers is a challenge to professionals. Care network members have differing information needs and preferences for the timing of the information provision. Some want to be well-informed about everything from the beginning to get a grip on the situation, whereas others are reluctant to learn about anything related to the dementia because the information is too confronting for them.

My brother has a book. I say I don't want to read it; I'll see what happens to me. – Partner of man with dementia, care network 17

These information needs can change over time, which makes it necessary for professionals to continue monitoring the information needs of care network members. The final challenge in exchanging information about the decision is that care networks members, professionals as well as people with dementia and their informal carers, often have little information about alternative options.

Weighing conflicting perspectives and interests

When deciding together about the situation of the person with dementia, care network members need to weigh the perspectives and the interests of all the participants. Considerations of care network members vary depending on the perspectives and interests of the care network members. They include respecting the identity and personality of the person with dementia, striving for well-being, considering the levels of functioning of the person with dementia, safety issues, carer burden, and the quality of relationships between the person with dementia and the informal carer, as well as practical and financial issues. Depending on the perspectives of care network members, certain interests may be dominant in considering the situation and possible solutions.

[Interviewer: So, you were kind of surprised, because the test results were quite good, but still you had to stay here in the nursing home.] Then it comes to my wife. They say to me: 'Your wife can't take care of you'. But, my wife doesn't have to take care of me. I dress myself, I undress myself. If I get home I can help. Clean a bit. I did it all. She never complained. Only, she is afraid that I will fall and she doesn't get me on my feet again. Of course, that can happen. But, you can get help then. – Man with dementia, care network 4

It is important that someone keeps an eye on her, at least checking several times a week. And I do say this. But well, her interest is meeting new people. So there are different interests, depending on the perspective. It's important to the

daughter that her mother can live in her home safely. She lives far away and is worried. – Case manager of a woman with dementia, care network 5

The different perspectives and interests of care network members sometimes cause dilemmas that need to be resolved by deliberation.

It would be less of a problem for me if she were to live in a care home, that's true of course. But it must be good for her. As long as she is not up to it, I don't know, I feel that I cannot force it upon her. I feel I should allow her freedom. – Daughter of a woman with dementia, care network 5

The participants feel that the process of deliberating potentially conflicting perspectives and interests is shared when they have a sense of working together in making decisions. This requires that care network members at least have an idea about what the others think about a given decision.

And we have always said: 'Whatever you decide. We're behind you'. But we are so interwoven with each other that we really can't just make such a difficult decision alone, that we all just want to consult one another about how or what. – Daughter of a woman with dementia, care network 6

The challenge for care network members is to share considerations about the decision, overcome dilemmas, and reach consensus about what to do and when.

Discussion

Our results suggest that the care networks of people with dementia encounter two challenges when making decisions together: (1) adapting to a situation of diminishing independence of the person with dementia, and (2) tensions in network interactions. These challenges relate to social health and to the essential elements of shared decision-making.

Our results relate to the essential elements of shared decision-making as described by Stacey et al. (2010), but seem to be influenced by the dementia process. The first essential element is recognizing that there is a decision to be made. Our theme of tensions in network interactions highlights the complexity of this element in the context of dementia care networks, as people with dementia, their informal carers and professionals, may express different ideas about what constitutes a problem for which decision-making is relevant here and now. Informal carers' roles are overlooked

in many shared-decision-making models (Stacey et al., 2010). Epstein and Gramling (2013) have pointed out that shared decision-making for complex problems has specific characteristics. In complex situations such as the ones that dementia creates, it is necessary to consider the multiple perspectives, including those of the informal carers, to attune decisions to the patient's characteristics. A shared attentional focus can help promote effective decision-making in complex situations with multiple participants, who often highlight different facets of the situation. This means that professionals who want to facilitate shared decision-making in dementia care networks need to work together with all relevant participants towards a shared view of the situation and the problem that needs addressing now.

The second and third essential elements include exchanging information and deliberating about options (Stacey et al., 2010). Our theme of adapting to a situation of diminishing independence of the person with dementia illustrates that it is precisely the capacities necessary for exchanging information and deliberation about options that diminish over time in people with dementia. Taking the involvement of people with dementia seriously means that professionals and informal carers need to gradually accommodate to the changing capacities of the person with dementia, allowing them to contribute to decision-making according to their capabilities. They do this by helping people with dementia getting an overview of the situation and the options, by limiting the amounts of information, and by providing information at shorter notice. This declining control over the decision-making contrasts with the perspective of shared decision-making in other chronic contexts, such as diabetes management, where shared decision-making aims at patients' growing control over the disease (Montori et al., 2006). Our results show that over time deliberating about decisions can become stressful to people with dementia. However, they can contribute to the decision-making in ways that go beyond deliberating, for instance by expressing their desires, their emotions, and body language (Boyle, 2014). Acknowledging and taking into account these expressions can help professionals and informal carers in the later stages of the dementia to attune decisions to the preferences of the person with dementia.

Finally, also the elements of expressing values and preferences and making and implementing decisions are challenging in the context of dementia care networks. People with dementia are well able to express their values and preferences (Feinberg and Whitlatch, 2001). However, decisions have consequences for both people with dementia and their informal carers. People with dementia and their informal carers may have different preferences and interests. Professionals who want to facilitate shared decision-making in the context of dementia care networks should thus try and find

a balance between the preferences and interests of people with dementia and their informal carers.

The challenges concerning shared decision-making in dementia care networks relate to all three dimensions of social health (Huber et al., 2011): (1) the capacity to fulfil one's potential and obligations, (2) the ability to manage one's life with some degree of independence despite a disease, and (3) the ability to participate in social activities. Social health implies a dynamic balance between a person's capacities and limitations and his or her social environment. Looking at dementia from the perspective of social health puts the focus on the remaining capacities of people with dementia and the possibilities of compensating for disabilities (Vernooij-Dassen and Jeon, 2016).

As to the theme of adapting to a situation of diminishing independence of the person with dementia, an important prerequisite for supporting the remaining capacity of people with dementia is that their networks must allow them a role in the decision-making. Care network members can either include or marginalize people with dementia in making decisions (Entwistle and Watt, 2006; Hamann et al., 2011; Smebye et al., 2012; Boyle, 2014). When informal carers are confronted with diminishing capacities, they tend to exclude people with dementia from decision-making too early on (Miller et al., 2014). Our results show that even in the mild stages of the dementia, people are only moderately involved in decisions. The decisions in dementia care networks often concern the decreasing independence of the person with dementia and their diminishing control over their lives. Shared decision-making in dementia aims to preserve the autonomy of the person with dementia for as long as possible (Livingston et al., 2010; Samsi and Manthorpe, 2013) and professionals need to advocate the decision-making role of the person with dementia. This means being aware of any marginalisation of people with dementia and helping them participate in ways that strengthen their remaining capacities, such as expressing values and communicating experiences and feelings (Peisah et al., 2013).

Professionals can also build on the remaining capacity of people with dementia by anticipating future decisions. The difficulty here is that participants' preferences in anticipating future decisions differ. Pressuring people with dementia and their families into making decisions before they are ready to make them can cause family conflict and carer stress (St-Amant et al., 2014). However, not anticipating future decisions limits the choice of options and the opportunity for the person with dementia to be included in the decision-making (Wolfs et al., 2012). This results in a negative impact on the social health of the person with dementia. Professionals must therefore balance the idea of anticipating future decisions with the preferences of the participants, who

want to focus on living well in the present. Introducing change slowly is relevant here (Livingston et al., 2010). It allows people with dementia and their informal carers to adjust to having to make certain decisions, which provides them with an opportunity to manage their own lives while the dementia progresses.

As to the theme of tensions in network interactions, the progressive dementia demands changes in patients' and informal carers' roles (Samsi and Manthorpe, 2013). Over time the informal carer's role in the decision-making increases, which means that people with dementia may not be the ones actually making the decisions. This is not necessarily problematic if the interacting participants take into account the expressed desires, emotions and body language of the person with dementia, thereby reaching decisions that are meaningful to him or her and attuned to his or her values and experiences (Peisah et al., 2013; Boyle, 2014). Such decisions may restore the social health of people with dementia with respect to managing their lives and remaining socially active (Vernooij-Dassen and Jeon, 2016).

Finally the social health of people with dementia impacts the way the shared decision-making evolves. If people with dementia have invested in good-quality relationships, and have built supportive networks over the course of their lives, their decision-making may be more easily facilitated. In contrast, poor family relationships, loss of social contacts, and disturbed social behaviour caused by the dementia hinder shared decision-making processes. Longstanding family relationships influence how making decisions is shared in dementia care networks (Samsi and Manthorpe, 2013; St-Amant et al., 2014; Su et al., 2014). Positions in families and unspoken expectations in family circles affect who has a say (St-Amant et al., 2014; Su et al., 2014) and therefore whose perspective will gain the most weight.

Limitations and strengths

This study has some limitations: first, it is based on self-report, not on observing decision-making situations such as consultation with professionals, people with dementia, and their informal carers. Second, we included only people with dementia who had at least one informal carer: those without informal carers may present different or additional experiences. Third, this study involves only people with dementia who can participate in interviews. Although we reached a wide variety of dementia care networks, the person with dementia who can no longer participate in interviews likely experiences decision-making differently. This study also has strengths: the first is its multi-perspective approach describing each case from five perspectives, which provides rich data from 113 care network members. The second strength is its thorough analytical process involving a multidisciplinary research team.

Conclusion

The challenges found in the actual process of shared decision-making in dementia care networks relate to all dimensions of social health. In shared decision-making, informal carers can compensate for limitations in cognitive abilities, while strengthening the remaining capacities of the person with dementia and allowing the person with dementia to fulfil his or her role in decision-making. When decision-making aligns with the needs and wishes of people with dementia, they can manage their lives as independently as possible and remain socially active. The challenges described have consequences for a model of shared decision-making in dementia care networks. Such a model requires flexibility regarding changes in the capabilities and roles of the care network members, which preserves the autonomy of the person with dementia. It requires professionals advocating the involvement of people with dementia by helping them participate in ways that strengthen their remaining capacities, such as expressing values and communicating experiences and feelings. Finally, it requires professionals to work with care networks towards a shared view about what constitutes a problem in the situation.

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CHAPTER 4

RECOGNIZING DECISION NEEDS: FIRST STEP FOR COLLABORATIVE DELIBERATION IN DEMENTIA CARE NETWORKS

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Abstract

Objective: This study describes the process elements of decision-making for dementia, in order to enrich a model to facilitate shared decision-making for professionals working with people with dementia and their informal carers.

Methods: We performed a qualitative study based on secondary analysis of 113 interviews from 23 care networks consisting of people with dementia, their informal carers and professionals. Findings were compared to an existing model of collaborative deliberation.

Results: We made an enhancement to the existing collaborative deliberation model, to include: (1) constructive network engagement, (2) recognizing the need for a decision, (3) defining what to decide on, (4) developing alternatives, (5) constructing preferences through deliberation and trying out alternatives, (6) multiple preference integration, and (7) evaluating decision-making.

Conclusion: In describing the process elements of decision-making in dementia, this empirical study proposes a modification of the model of collaborative deliberation for the context of dementia care. The adaptation highlights the special attention needed to recognize and define what to decide on, try out alternatives, and handle conflicting interests and preferences.

Practice implications: Professionals should be attentive to mark the start of the decision-making process and work with participants towards a shared view on the pressing matters at hand.

Introduction

Shared decision-making aims to reach decisions that reflect what is important in patients' lives (Elwyn et al., 2012; Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). Through this process, knowledge about health care options is exchanged and patients are facilitated to express their values and develop informed preferences. As shared decision-making models focus mainly on the patient - health professional dyad (Stacey et al., 2010), they are less suitable in the context of decision-making for dementia, where decisions are made in care networks. Care networks are networks including a patient, and a mixture of often multiple informal carers and professionals who collaborate to care for this particular person (Jacobs, van Tilburg, Groenewegen, & Broese van Groenou, 2016). Few publications address the nature of interactions among networks of clients, informal carers and health professionals when making decisions (J. Dalton, 2005; Quinn, Clare, McGuinness, & Woods, 2012). The evidence till now indicates that professionals tend to overlook the possible role of the informal carers in decision-making; their role is often not discussed by professionals and they are not facilitated to contribute their unique perspectives (Boehemer et al., 2014). Shared decision-making involving multiple participants is not self-evident for dementia care professionals.

Reaching shared decision-making in the context of dementia is even more difficult because people with dementia experience increasing difficulties in making decisions due to cognitive decline (Samsi & Manthorpe, 2013). They want to be involved in decisions about their lives as long as possible, but realize that over time they will increasingly have to rely on their Informal carers (Fetherstonhaugh, Tarzia, & Nay, 2013; Hamann et al., 2011; Samsi & Manthorpe, 2013). In addition, informal carers experience difficulties in deciding for their loved one. This is partly because it involves balancing their own interests with those of the person with dementia (Boyle, 2013; Smebye, Kirkevold, & Engedal, 2012), as decisions have implications for them both (J. M. Dalton, 2003; Peckham, Williams, & Neysmith, 2014). Decision-making in the context of dementia should thus be considered a relational process, in which the interdependency between people with dementia and their carers is evident (Smebye et al., 2012). Professionals who want to facilitate shared decision-making must address both the person with dementia and informal carers.

The theoretical model of collaborative deliberation may be helpful when facilitating shared decision-making with multiple participants (Elwyn et al., 2014). This model describes deliberation and collaboration as the main processes for reaching decisions in accordance with the preferences of participants. Deliberation is the process whereby participants cooperate to consider and explicate alternatives and develop their personal and mutual preferences. Collaboration encompasses multiple participants

working together to move towards a certain course of action. Rather than focussing on reaching consensus, collaboration emphasizes the process of working together in reaching decisions. This model may offer professionals a tool when practicing shared decision-making in dementia care networks. However, we do not know whether the model matches the empirical context of decision-making in dementia where cognitive deterioration hinders the decision-making.

Our research questions are:

1. What are the process elements of decision-making in dementia care networks?
2. How can the model of collaborative deliberation be enriched in order to facilitate shared decision-making in dementia care networks?

Methods

Design

This study involves a secondary analysis of data gathered for a large longitudinal study on decision-making in dementia care networks (Groen - van de Ven, Smits, Span, et al., 2016; Groen - van de Ven, Smits, Oldewarris, et al., 2016). For this study we interviewed people with dementia, their informal carers, and the professionals involved. Data were analysed using content analysis. The resulting categories were compared to the model of collaborative deliberation (Elwyn et al., 2014).

Setting

This study followed the care networks of people with dementia in the Netherlands, both those living independently and those admitted to a nursing home. People with dementia and their informal carers were interviewed at their homes or in the nursing home. Professional carers were interviewed at their workplaces.

Participant selection

In the original study (Groen - van de Ven, Smits, Span, et al., 2016) we purposefully selected care networks of people with dementia, consisting of the person with dementia, two informal carers, and two professional carers. We sampled for maximum variation regarding the characteristics of the person with dementia (gender, socio-economic status and stage of dementia) and type of informal carer (spouses, children, other relatives or friends). We recruited care networks via: (1) health care organisations, (2) Alzheimer cafés, and (3) the website of the Dutch Alzheimer's Society. The inclusion criteria were: a diagnosis of any form of dementia, the ability to participate in an interview, and the availability of at least one informal carer.

We reached out to 30 care networks, of which 25 consented to participate. Refusals of care networks were due to the expected burden on carers or people with dementia. Two care networks were excluded because the person with dementia did not meet the inclusion criteria. The remaining 23 care networks included two care networks with only one informal carer who was willing to participate, resulting in 113 interviews in total. Table 1 lists the characteristics of the care networks.

Table 1. Characteristics of the participants with dementia and the carers interviewed

Respondent characteristics		Care network numbers
Gender	8 Male	1, 4, 8, 10, 14, 17, 19, 23
	15 Female	2, 3, 5, 6, 7, 9, 11, 12, 13, 14, 15, 16, 18, 20, 21, 22
Age	80.4 Mean (6.6 SD)	
Dementia stage	5 Beginning	5, 8, 11, 19, 20
	16 Middle	1, 3, 6, 7, 9, 10, 12, 13, 14, 15, 16, 17, 18, 21, 22, 23
	1 Advanced	2
	1 Unknown	4
Marital status	13 Married	1, 4, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22, 23
	7 Widowed	2, 5, 8, 13, 15, 16, 19
	3 Single	3, 18, 20
Living arrangements	16 Community dwelling	5, 7, 8, 9, 10, 11, 12, 14, 14, 15, 16, 17, 19, 20, 21, 22
	5 Nursing home	2, 4, 6, 18, 23
	2 Home for the elderly	1, 3
Informal carers interviewed	11 Spouses	1, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22
	17 Children	1, 2, 4, 5, 6, 8, 9, 11, 14, 15, 17, 19, 21, 23
	5 Children-in-law	4, 12, 13, 15, 16
	10 Other family	3, 13, 18, 20, 22, 23
	1 Friend	5
Professionals interviewed	18 Case managers	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 15, 16, 17, 18, 19, 20, 22
	8 Daycare employees	5, 7, 11, 12, 14, 17, 20, 22
	7 Home care nurses	8, 13, 14, 15, 16, 19, 21
	7 Principal attendants nursing home	1, 2, 3, 4, 6, 18, 23
	3 Team leaders	6, 13, 21
	1 Creative therapist	10
	1 Domestic help	9

Data collection

Overall, 11 interviewers conducted the semi structured interviews. The topics included the decisions made, participants in decision-making, and communication about decisions (Table 2). The interviewers included the researchers and eight bachelor students (Nursing or Applied Gerontology) whom two researchers (LG and MS) trained in interviewing people with dementia. The interviews lasted 1 hour on average and were audio-recorded and transcribed verbatim.

Table 2. Interview topics for the different types of respondents

Subject	Topics and questions for PWD	Topics and questions for informal carers	Topics and questions for professional carers
General information	Age Former profession Ethnicity Gender Living accommodation (community dwelling, home for the elderly, or nursing home)	Gender Relationship with the PWD	Professional background Tasks related to the care of the PWD Type of organisation where professional works Team composition Involved in care for the PWD since when? Diagnosis of the PWD (by whom and what is it?) Professional assessment of the stage of dementia
Decisions	How are you? What has changed for you lately? What choices have you had to make because of these changes? What do you think about your decisions now?	How do you feel the PWD is doing at the moment? What has changed for PWD lately? What choices have you had to make because of these changes? What do you think about your decisions now?	What has changed for the PWD lately? What choices have you had to make because of these changes? What do you think about your decisions now?
Decision-making	What was the cause of the decision? What happened before the decision was made? Who was involved? What was your role in making this decision? What did you want? What made this important to you? What did others want? What made this important to them? What were the alternatives? How did you manage to reach a decision together? What information did you need to reach a decision?		

Data analysis

Our analysis consisted of three steps. First, we used content analysis to determine the process elements of decision-making in dementia care networks (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). For this secondary analysis, we used codes that had been developed in an earlier part of our study on decision-making in dementia care networks. These codes were developed by two researchers independently using the method of open coding (Corbin & Strauss, 1990), and formed the empirical basis of this study (Groen - van de Ven, Smits, Span, et al., 2016). Second, we clustered the codes into meaningful categories regarding the process elements of the decision-making. We did this by using the method of affinity diagramming. LG, CS, JJ, and MS worked together in a group session, using the predetermined steps of clustering, labelling, and defining categories (Johnson, Barach, & Vernooij-Dassen, 2012; Scupin, 1997). Third, we aligned our categories with the elements of the model of collaborative deliberation (Elwyn et al., 2014) and defined the necessary adaptations.

Ethical considerations

This study was approved by the local ethics committee of the Isala Klinieken (number: 10.11113). All persons provided informed consent before participating. Participants received oral and written information before consenting to participate. The interviewers stopped the interview in response to any verbal or nonverbal signs that the person with dementia did not want to continue the interview (Meulenbroek et al., 2010).

Results

Through our analysis we found four process elements of decision-making in dementia care networks: (1) Constructive network engagement, (2) Recognizing the need for a decision, (3) Defining what to decide about, and (4) Collaborating in deliberation and trying out alternatives to reach a course of action. These elements, though presented here as separate and sequential, are in practice blurred and partly overlapping. Participants may move forward and later revert to previous elements.

Constructive engagement

This element is a precondition for decision-making and covers the whole process of working collaboratively towards choosing a course of action. It includes engaging with all relevant care network members to involve them in decision-making. The sub-elements are: defining the participants, involving participants, and handling the nature of the interactions between participants.

Defining the issue

Case managers are identified as facilitators of the decision-making. Depending on the problem at stake and the participants of the care network, others such as informal carers, nurses or daycare employees may be involved. Care network members may be closely involved and present during consultations, or influence the decision-making alongside the formal consultations. Some couples choose not to involve their children in decision-making. In-laws are also sometimes excluded. As such, the decision-making participants may change depending on the care network and the particular decision at stake.

*[Interviewer: Were all your children involved in the decision to start daycare?]
No, well they may have talked about it between themselves, but it was [name of daughter] who went with me to the doctor. That was when I was angry with my husband again. – Care network 11, woman living with dementia.*

The couple has good contact with their children, but they say: ‘They have a life of their own. As long as we can manage ourselves, we will do that’. – Care network 9, case manager of a couple in which the woman is living with dementia.

Involving participants

Facilitating shared decision-making means involving people with dementia as well as their informal carers. To meaningfully involve people with dementia, they need support in overseeing what is relevant to their situation and to understand information about a number of alternatives. As their dementia progresses involvement will become too difficult or stressful for the person with dementia. This is carefully monitored by case managers, who will then support the informal carers by helping them to understand their new role and encouraging them to express their concerns and interests.

I can’t anticipate so well, and what will be possible, and he [spouse] can do it all so much better. [Interviewer: And how is that for you?] Well, pleasant. That’s why I say, if he wouldn’t be there, it would be a disaster. – Care network 9, woman living with dementia.

[The spouse] kept trying to explain everything to her. While, I sometimes had the idea that... at a given moment, the time had come, that explaining hurt her more than just doing things for her. – Care network 7, case manager of a woman living with dementia.

Handling the nature of the interactions between participants

Shared decision-making in the context of dementia means working together with couples or families, where individuals each have their own roles and where communication patterns have been developed over the years. Some families are used to discussing things openly, while in other families this is more difficult. Dementia complicates interactions in the network because role changes may become necessary. Professionals can operate strategically once they are aware of the interactions within the care network, and can thus navigate between the network members to find common grounds. For instance, they can function as a bridge between care network members who have difficulties in discussing their situation together.

There were quite a lot of relational issues. That is why we decided that I would see [her] alone first, and then her husband also alone. Before, we would be together. I had to explicitly promise her not to convey anything she told me to her husband. Well, that's how we did it. – Care network 11, case manager of a woman living with dementia.

I find it difficult to take the initiative. Because you take things away from him, you know? You are going to decide and do this and that. You don't want to do more than just mediate. But it becomes more and more you taking the lead about what he can and cannot do, kind of an executive role. – Care network 19, son of a man living with dementia.

Recognizing decision needs

This is a necessary element because of the gradual emergence of problems stemming from progressive decline and other changes in the care network. The changes result in an emerging realisation that the situation as it is can no longer be maintained. Participants may differ, however, in their level of recognition of problematic situations. The sub-elements are: decision-making triggers, raising a decision topic, and respecting the decision-making pace of participants.

Decision-making triggers

Decision-making triggers include the declining functioning of the person with dementia and other circumstances that generate the need to make decisions. Triggers may result from a particular event, such as the primary informal carer being hospitalized, or from a safety hazard regarding the person with dementia. However, a trigger can also mean a gradual change in views of the situation, which can sometimes make the start of decision-making blurred.

I went cycling with her once, and we may have cycled about 40 kilometres when she became tired and then everything went wrong. She began swinging and not riding on the right side of the road, and suddenly crossing the road. That's when I thought: 'Oh, this is going wrong'. Then I really saw it myself. – Care network 2, daughter of a woman living with dementia.

I used to think: 'Till my last breath [I will care for her]'. But then you are confronted with the effect of that. You have no future for yourself. This only gets worse. More care, more monitoring... And, what if it takes another five years? Or eight? How old will I be then? What's left for me? – Care network 7, spouse of a woman living with dementia.

Raising a decision topics

When a trigger for decision-making is experienced, someone in the care network needs to act upon it and initiate decision-making. Topics are raised by case managers or other professional carers, but also by informal carers. Problems experienced in the here and now, as well as topics expected to become a problem in the future are relevant. Most people with dementia do not raise topics for decision-making themselves. Exceptions to this in our study were two single women who were used to living their own lives and arranging things for themselves.

About five weeks ago I had a small cerebral infarction. That was the reason for me to consult with the case manager again. I said: 'What shall we do?' Because what if something happens again and my wife is left home alone? – Care network 21, spouse of a woman with dementia.

At a given moment she said 'I think you should put me on a list. That if you get ill, then I can go there [to a nursing home]'. Well, and then this woman came to talk to her, and she clearly stated to that woman: 'I cannot take care of myself anymore, so I should go and live in [name of nursing home]'. – Care network 18, sister of a woman with dementia.

Respecting the decision-making pace of the participants

Case managers want to prepare the care networks for future decisions. However, in doing so they must attune to the decision-making pace of the participants. Pushing is not effective and professionals need to act carefully by slowly introducing topics and proceeding in accordance with the reaction of care network members. The difficulty here is that the pace may vary among the different care network members.

I am not there to push them into all kinds of things that they may not want for the time being. No, you should wait for the right moment. – Care network 11, case manager of a couple in which the woman is living with dementia.

They leave that to you, you know? Whether you think it's time for a nursing home admission. It's your choice. Not like they don't care. No, it's simply your choice. They leave you in peace. Then [the care coordinator from the nursing home] said to me: 'I'll call you up every month'. I said: 'That's fine'. You know, they are looking at me too, right? How am I doing? Am I still keeping up with it? – Care network 6, spouse of a woman living with dementia.

Defining what to decide on

This element includes participants defining problems that require decisions now, and defining what they want to achieve in the situation of the person with dementia. Sub-elements involve: defining the decision topic and goal setting.

Defining the decision topic

Care network members may have different views about what constitutes a problem in the situation of the person with dementia. Some care networks experience conflict because of these differing views. This is especially apparent when people with dementia or their informal carers have trouble accepting the decline caused by dementia. Multiple problems may also be relevant simultaneously. To avoid miscommunication during decision-making, case managers must help the care network to develop a shared view of which decision topic needs to be discussed.

I relied especially on what the daughter said. That her mother called her a lot, especially at night. And [the person with dementia] also stated that she had been outside alone at night and had lost her way. Particularly the daughter played an important role on the whole in getting a clear idea about what was going on. – Care network 5, case manager of a woman living with dementia.

Well... actually she doesn't want any care, because she feels she can still do it herself. Acknowledging that she cannot do something is very hard for my mother. – Care network 9, daughter of a woman with dementia.

Goal setting

Goals relate to overarching values that care network members strive for when making decisions. Making decisions becomes easier when these overarching goals have been explicitly discussed. Professionals use goals that were set with the care network to

focus their conversations about particular decisions. Goals include the person with dementia remaining independent for as long as possible, the well-being of the person with dementia and the informal carer, and the safety of the person with dementia living at home alone or living in the nursing home.

A long-term care plan with long-term goals is important, because you can continually refer to that: 'We agreed all together that we would try for you to remain here in your own home as long as possible. That is what you want, right?' They will agree. Then you explain that some measures are necessary. – Care network 15, case manager of a woman with dementia.

I would rather not move from this house. We have lived her for so long. Selling the house... I don't like the sound of it. But they have said in [the daycare organisation] 'You don't have to do that. Don't worry, you can stay in your own home'. So that's what I want to try for as long as possible. – Care network 5, woman living with dementia.

Collaborating in deliberation and trying out alternatives to reach a course of action.

This element includes the process of developing alternatives, deliberating over them, and trying them out to reach a course of action that is suitable to the particular situation of the care network. Sub-elements include: developing alternatives, constructing preferences through deliberation and trying out alternatives, balancing conflicting preferences and interests, and evaluating the decision. As these sub-elements were seen both simultaneously and alternately in the interviews with the care networks, they have been combined into one element.

Developing alternatives

The problems that care networks experience are intertwined with their specific situation, and consequently no standard alternatives are readily available. Finding out what the alternatives are implies deliberation as well as trying out alternatives through trial and error and observing what works well. Informal carers sometimes have difficulties to develop ideas about possible solutions and therefore rely on professional carers for information about the alternatives. Unfortunately, professionals themselves are not always aware of all the alternatives or are reluctant to provide information about alternatives that go beyond their own organisation.

It took us quite some time to figure out what to do with her. Now she likes it a lot. She helps with cooking here at [name of the ward]. Preparing the food.. involving her in that, potatoes, vegetables, cleaning. She likes it all. She likes doing that

a lot. – Care network 3, principle attendant of a woman with dementia living in a nursing home.

If the alternative is outside your organisation, that's a pity of course. Preferably you'd see her with your organisation for the whole trajectory. But those are choices they make themselves. You provide options, but at some point the possibilities for your organisation stop. – Care network 22, principal attendant of a woman living with dementia.

Constructing preferences through deliberation and trying out alternatives

Deliberation and weighing alternatives is quite difficult for people with dementia. What they say is not always congruent with their behaviour, which makes it difficult for others to attune to their preferences. For this reason, trying out alternatives and observing the reactions of the person with dementia is incorporated into the deliberation process in order to reach conclusions about the suitability of alternatives. In this way, emotions are relevant cues to interpret the preferences of the person with dementia. The process of deliberating upon considerations and developing preferences is full of emotion because of the confrontation with the declining functioning of the person with dementia. Informal carers may experience feelings of guilt about having to relinquish care to others, or fear for the safety of the person with dementia. It is important to acknowledge these emotions during the deliberations.

Saying and doing is not quite alike with her. Like the issue of privacy. That's very important to her. So you would expect her to retire in her own room. But she is actually the person who is the most often in the joint living room. – Care network 3, principal attendant of a woman living with dementia in a nursing home.

What happens is that other issues rise to the surface too: 'You want me out of the home'. On occasion we have talked about daycare or a care farm or something. Well, then I have to explain endlessly why this may not only be good for her, but also for me. To keep up. – Care network 9, spouse of a woman living with dementia

Balancing conflicting preferences and interests

People with dementia and their informal carers sometimes have different considerations and preferences based on their different perspectives and interests. Primary informal carers tend to conform to the preferences of people with dementia, while secondary informal carers seem to have less difficulty in contesting their preferences. For professionals who want to facilitate shared decision-making in care networks, this

means balancing the potentially conflicting preferences of people with dementia and their informal carers. Depending on the situation, professionals assert the preferences of the individual least heard. Making decisions takes time and it is sometimes difficult to reach consensus given the differences in perspectives and interests. When consensus is hard to reach, decisions are sometimes postponed or accepted as temporary, with the explicit understanding that they will be reviewed and may be reversed later.

My brother comes over much more ...almost daily... to check dad. Well, I have said...wouldn't it be better...if he moved to another setting? I would want to take action and settle for him to be somewhere else. But my brother is like...: 'Let him be. It's okay like this'. Care network 19, son of a man living with dementia.

When he says no [to extending daycare by an extra day] it will become very difficult. Often it won't happen then. We will simply wait another while and try again later. – Care network 14, daycare employee of a man living with dementia.

Evaluating the decision-making

Evaluating decisions is seen by professionals as a way of continuing the consensus on courses of action, and if necessary making adjustments to these actions to align with the changing preferences of participants. Evaluations look at both the content and the timing of the decision. It is important to take into account that people with dementia may need some time to adjust to changes. This means that evaluations should not be planned too soon after the implementation of a decision. Evaluating decisions includes deliberating as well as observing the person with dementia, with respect to well-being, satisfaction and sense of ease. These observations provide more information for the evaluation of the decision than the verbal contributions of the person with dementia alone.

[The person with dementia] agreed to try and see how it went. If he or his wife didn't like it, we could reverse it. We agreed to try it out for six weeks. – Care network 1, principal attendant of a man living with dementia.

When she was just living here, the family had the idea that she didn't find it to her liking with us [in the nursing home]. She kept saying she didn't like it here. Of course, that's bothersome. But, we saw her laughing, or enjoying activities. We thought we could gather that from what we saw. We observed that in some ways she is nevertheless enjoying herself. – Care network 6, Head of the department of a nursing home housing a woman living with dementia.

Enriching the model of collaborative deliberation to support professionals in facilitating shared decision-making in dementia care networks.

The model of collaborative deliberation consists of five elements (Elwyn et al., 2014): (1) Constructive engagement, (2) Recognizing alternatives, (3) Comparative learning, (4) Preferences construction and elicitation, and (5) Preference integration. The model seems helpful in structuring the process of shared decision-making in dementia care networks. Nevertheless, some process elements are lacking.

Constructive engagement in the context of dementia means involving all relevant participants in the decision-making, thereby handling the interactions between them by aligning to longstanding spousal and family relationships. This implies that the professional builds constructive relationships with and within the network of the person with dementia. Before proceeding to the next element of recognizing alternatives, two elements are necessary in the context of dementia that are not described in the model of collaborative deliberation.

First, there is a need to mark the start of the decision-making, because of the progressive character of the dementia, which implies an ever changing situation. This implies an emergent realisation that the situation as it is can no longer be maintained. As the multiple participants involved may differ in their level of recognition of the need for a decision, it is necessary to reach agreement within the network that decision-making is required. Second, the multiple participants involved may have various ideas about what constitutes a problem in the situation of the person with dementia and about what they want to achieve. This makes it necessary to explicitly define what to decide about, before moving on to deliberating about the alternatives.

Recognizing alternatives in the context of dementia implies a process of negotiating in order to develop the alternatives. Alternatives are often not readily available, but are intertwined with the particular situation of the care network. The next element of the model of collaborative deliberation is comparative learning, which implies comparing the alternatives that are recognized in the earlier stage of the decision-making. For people with dementia it is often difficult to compare alternatives based on verbal deliberation alone. Trying out alternatives is an important way of finding out the pros and cons and to develop their preferences. The emotions and behaviours of people with dementia during these try-out periods may be used by informal carers and professionals to interpret their preferences. As such, comparative learning and preference construction are linked processes in the context of dementia, and both are supported by people with dementia trying out alternatives. The last element in the model of collaborative deliberation, preference integration, is complicated in the context of

dementia by the fact that people with dementia and their informal carers have different perspectives, preferences and interests. This means that preference integration includes balancing the potentially conflicting interests and preferences of the person with dementia and the informal carers into a course of action.

The model of collaborative deliberation does not include evaluation of the decision made. However, in the context of dementia evaluating seems to be relevant for adapting the course of action if necessary. Besides this, by looking back at the process of reaching decisions, care networks may learn for future decision-making situations.

Based on our empirical findings, we enrich the model of collaborative deliberation for the context of dementia care by highlighting the special attention needed to recognize and define what to decide on. Moreover, we address the roles of the multiple participants involved in the decision-making. Additionally, we clarify that alternatives need to be developed with the participants. Besides, we add trying out as part of the work needed to construct preferences. Finally, we explain the need for evaluating the decision-making. The enriched model of collaborative deliberation consists of the following elements: 1) Constructive network engagement; 2) Recognizing the need for a decision; 3) Defining the problem; 4) Developing alternatives; 5) Constructing preferences through deliberation and trying out alternatives; 6) Multiple preferences integration; 7) Evaluating decision-making. Table 3 compares the existing model to the enriched model of collaborative deliberation in dementia care networks, that was based on the empirical elements of our study.

Discussion

Three elements are essential for collaborative deliberation in the context of dementia care networks. First, preparatory work is needed before care networks can actually start deliberating about possible alternatives to deal with a certain problem. This includes recognizing the need for decision-making and defining the decision at stake. Problems are often recognized at first by informal carers, but they may find it difficult to initiate discussions about them. Professionals could help informal carers to do this by making it a regular part of the consultation to discuss the concerns of all participants involved. Multiple views on what is experienced as a problem often exist, since care network members tend to focus on different aspects of the situation (Epstein & Gramling, 2013). Wolfs et al. (2012) described how decision-making in dementia starts by identifying the individual needs of people with dementia and their informal carers, based on experienced problems that are likely to differ. These different views of participants are a potential cause of miscommunication during decision-making and

Table 3. The enriched model of collaborative deliberation in dementia care networks compared to the original model of collaborative deliberation (Elwyn et al, 2014)

Elements in the model of collaborative deliberation (Elwyn et al, 2014)	The enriched model of collaborative deliberation in dementia care networks	The empirical basis for the adaptations to the model
<i>Constructive engagement</i> takes place when interactions between participants are characterized by curiosity, respect, and empathy.	<p><i>Constructive network engagement</i> includes involving the network of the person with dementia and aligning to the nature of the longstanding family or spousal relationships in the network.</p> <p><i>Recognizing the need for a decision</i> is an additional element to the model. It includes negotiating with the network about emerging decision topics, arising from the differences between participants in terms of recognizing problems.</p> <p><i>Defining what to decide on</i> is an additional element to the model. It includes explicating decision topics and the related goals, and choosing which problem needs to be addressed now.</p>	<p><i>Constructive network engagement</i></p> <ul style="list-style-type: none"> • Defining decision-making participants • Involving participants • Handling the interactions between participants. <p><i>Recognizing the need for a decision</i></p> <ul style="list-style-type: none"> • Decision-making triggers • Raising a decision topic • Respecting different decision-making paces. <p><i>Defining what to decide on</i></p> <ul style="list-style-type: none"> • Defining the decision topic • Goal setting. <p><i>Collaborating in deliberation and trying out alternatives to reach a course of action.</i></p> <ul style="list-style-type: none"> • Developing alternatives.
<i>Recognizing alternatives</i> takes place when interactions between participants recognize the existence of relevant, alternative potential courses of action.	<i>Developing alternatives</i> includes developing alternatives together with the network, often by trial and error. Care networks usually perceive a lack of readily available alternatives. Alternatives therefore depend on the possibilities and knowledge of the care network.	

Table 3. The enriched model of collaborative deliberation in dementia care networks compared to the original model of collaborative deliberation (Elwyn et al, 2014) (continued)

Elements in the model of collaborative deliberation (Elwyn et al, 2014)	The enriched model of collaborative deliberation in dementia care networks	The empirical basis for the adaptations to the model
<i>Comparative learning</i> takes place when interactions between participants compare alternative courses of action	<i>Constructing preferences through deliberation and trying out alternatives</i> means combining and alternating deliberation and trying out alternatives to find what suits best. The emotions and behaviours of people with dementia may be used by informal carers and professionals to interpret their preferences.	<ul style="list-style-type: none">• Constructing preferences through deliberation and trying out alternatives.
<i>Preference construction and elicitation</i> takes place when interactions between participants consider, construct, and elicit preferences in relation to alternatives courses of action		
<i>Preference integration</i> takes place when interactions between participants integrate individual preferences in determining the subsequent courses of action	<i>Multiple preferences integration</i> means balancing the potentially conflicting interests and preferences of the person with dementia and the informal carers into a course of action.	<ul style="list-style-type: none">• Balancing conflicting preferences and interests.
	<i>Evaluating decision-making</i> is about looking back at decisions made and modifying decisions if necessary. It is also important to evaluate the process of reaching decisions in order to learn for future decision-making situations.	<ul style="list-style-type: none">• Evaluating decision-making.

it is recommended to discuss them and reach agreement about which problem needs to be addressed now.

Second, deliberation includes rational discussion as well as trying out alternatives, expressing emotions and observing the behaviour of the person with dementia. This is important for two reasons. First, contributing to decision-making by observing emotions and trying out alternatives allows for an inclusive way of involving people with dementia throughout the course of their dementia. It recognizes the potential agency of people with dementia as a first step in supporting their decision-making role (Boyle,

2014). It helps to understand what people with dementia prefer in a certain situation, without always requiring them to be cognitively involved. Carefully monitoring the emotions of people with dementia and allowing them to experience certain alternatives supports their capabilities and provides them with the opportunity to engage in decision-making in a meaningful and less burdensome way (Entwistle & Watt, 2013; Peisah, Sorinmade, Mitchell, & Hertogh, 2013). Second, in the complex context of dementia care networks, the evidence about the pros and cons of different alternatives is often unclear and depends on the particular context of the person and his or her informal carers (Epstein & Gramling, 2013). Through a process of trial and error new alternatives may become clear, which are then compared through processes of deliberation and trying out alternatives. Because the alternatives are not clear upfront, it is the participants who must decide together when enough alternatives have been considered, deliberated upon and tried out (Epstein, 2013).

Third, collaborative deliberation in the context of dementia care networks inevitably includes conflict between care network members given their different perspectives on the situation and their different interests concerning the decision-making outcome. Quinn et al. (2012) have described how triads of people with dementia, their spouses and nurses must constantly negotiate the balance between their own needs and the views of the others involved. In this context, coalitions may be formed between participants to reach solutions for certain problems (J. Dalton, 2005; Quinn et al., 2012). Professionals should be aware of these coalition strategies, because they may involve overruling the perspectives of either the person with dementia or the informal carer. As a result, collaborative deliberation in dementia care networks may often include some form of struggle in order to reach compromises, and in some cases consensus may not be reached.

Strengths and limitations

The strength of this study lies in its reliance on empirical data stemming from a rigorous approach leading to rich data from multiple perspectives (Koehly, Ashida, Shafer, & Ludden, 2015). This study nevertheless has several limitations. First, we used secondary analysis of interview data about decision-making. This means we did not gather data with the model of collaborative deliberation as a basis, and we did not ask on questions about elements of collaborative deliberation. Second, this study is based on interviews about decision-making processes, and not on observations of actual decision-making encounters. The reported behaviours of the professionals may be an overestimation. The fact that we gained information from multiple perspectives may have counterbalanced this limitation.

Conclusion

This empirical study has helped to validate and enrich the model of collaborative deliberation for dementia care networks. It is a useful model for structuring the often blurry decision-making process regarding dementia. Special attention is needed, however, for the preparatory steps of decision-making, for trying out alternatives, and for handling conflicting interests and preferences.

Practice implications

Professionals who want to facilitate shared decision-making in dementia care should be aware that they need to involve both the person with dementia and the informal carers. They should be attentive to the preparatory steps of decision-making and start by working with all participants towards achieving a shared view about the problem requiring decision-making. They can include people with dementia in the deliberation process by allowing them to try out alternatives instead of merely relying on rational discussions about alternatives. Behaviours and emotions of the person with dementia serve as indications of preferences during this process. Finally, they should be aware of the potentially conflicting perspectives of people with dementia and their informal carers when working towards a course of action, and stress the perspectives of those participants least heard.

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CHAPTER 5

INVOLVEMENT OF PEOPLE WITH DEMENTIA IN MAKING DECISIONS ABOUT THEIR LIVES: A QUALITATIVE STUDY THAT APPRAISES SHARED DECISION-MAKING CONCERNING DAYCARE

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Abstract

Objective To explore how people with dementia, their informal caregivers, and their professionals participate in decision-making about daycare and to develop a typology of participation trajectories.

Design A qualitative study with a prospective, multi-perspective design, based on 244 semi-structured interviews, conducted during three interview rounds over the course of a year. Analysis by means of content analysis and typology construction.

Setting Community settings and nursing homes in the Netherlands

Participants Nineteen people with dementia, 36 of their informal caregivers, and 38 of their professionals (including nurses, daycare employees, and case managers).

Results The participants' responses related to three critical points in the decision-making trajectory about daycare: (1) the initial positive or negative expectations of daycare; (2) negotiation about trying out daycare by promoting, resisting, or attuning to others; and (3) trying daycare, which resulted in positive or negative reactions from people with dementia, and led to a decision. The ways in which care networks proceeded through these three critical points resulted in a typology of participation trajectories, including: (1) working together positively towards daycare, (2) bringing conflicting perspectives together towards trying daycare, and (3) not reaching commitment to try daycare.

Conclusion Shared decision-making with people with dementia is possible and requires an adapted process of decision-making. Our results show that initial preferences based on information alone may change when people with dementia experience daycare. It is important to have a try-out period so that people with dementia can experience daycare without having to decide whether to continue it. Whereas shared decision-making in general aims at moving from initial preferences to informed preferences, professionals should focus more on moving from initial preferences to experienced preferences for people with dementia. Professionals can play a crucial role in facilitating the possibilities for a try-out period.

Introduction

Daycare is an important source of support for people with dementia who want to live at home for as long as possible (Brataas, Bjugan, Wille, & Hellzen, 2010; Robinson et al., 2012). It is a regular form of care for community-dwelling people with dementia in various countries worldwide (Brataas et al., 2010; Contador et al., 2013; de Jong & Boersma, 2009; Mavall & Malmberg, 2007; Robinson et al., 2012). It aims to stimulate the person with dementia and relieve the burden on caregivers (de Jong & Boersma, 2009; Mavall & Malmberg, 2007). As such, daycare may be helpful in delaying institutionalization. Deciding about daycare may be complex, since it is often the first source of support outside the home – a time when people with dementia and their caregivers are not yet used to discussing support options with professionals. The subject of daycare arises when people with dementia increasingly have to rely on others to complete cognitive tasks, have difficulties with structuring the day, but are still aware of and able to express their wishes (Robinson et al., 2012). It is often a time when care becomes burdensome for informal caregivers. It is important to involve people with dementia in these decisions, since involvement contributes to the well-being and quality of life of both the people with dementia and their informal caregivers (Fetherstonhaugh, Tarzia, & Nay, 2013; Menne, Tucke, Whitlatch, & Friss Feinberg, 2008).

Shared decision-making is the preferred way of reaching decisions with patients (Elwyn, Edwards, Gwyn, & Grol, 1999; Elwyn et al., 2012; Stiggelbout et al., 2012). It is a method whereby professionals help patients choose health care options by exchanging information and evidence about options, as well as discussing the patient's values in order to elicit his or her preferences. However, although shared decision-making is recommended, it is not common practice yet in dementia care (Miller, Whitlatch, & Lyons, 2014). Decision-making in the context of dementia is complex, dynamic, time-consuming, and full of emotions (Wolfs et al., 2012). Complex decision-making situations are characterized by insufficient clinical evidence, lack of clearly defined goals and options, and preferences that are contextual, provisional, and conditional (Epstein & Gramling, 2013). In dementia care networks multiple participants contribute to decision-making over long periods of time. Professionals who facilitate shared decision-making must therefore combine all the participants' perspectives. Moreover, shared decision-making in dementia care networks may be challenged by tensions in the interactions between the participants, and the need to adapt to the diminishing independence of the person with dementia (Groen - van de Ven, Smits, Span, et al., 2016).

Diminishing independence also influences the roles of people with dementias in the decision-making. Decision-making is often described as a solely cognitive task,

which makes it difficult for people with dementia (Moye & Marson, 2007). However, research has pointed out that they are able to state consistent choices and preferences (Feinberg & Whitlatch, 2001; Karel, Gurrera, Hicken, & Moye, 2010; Whitlatch & Menne, 2009). Moreover, decision-making involves more than mere analytical thinking, since preferences and their underlying care values are also shaped by emotions and social interactions (Entwistle & Watt, 2006; Entwistle, Carter, Cribb, & McCaffery, 2010; Epstein, 2013). Emotions and social interactions continue to be present during the course of the dementia trajectory, making it possible to include people with dementia even when the dementia progresses. For instance, informal caregivers and people with dementia deciding together gives patients a chance to maintain a role in decision-making by using their extant capacities (Boyle, 2013; Smebye, Kirkevold, & Engedal, 2012). Professionals who want to involve people with dementia in decision-making should also encourage informal caregivers to play a role. However, the informal caregivers have their own interests in the decisions, which means that shared decision-making includes weighing up the different perspectives and interests present (Groen - van de Ven, Smits, Span, et al., 2016). In addition, informal caregivers can influence the level of involvement of the person with dementia on the basis of their own judgments of the person's decision-making capacities (Boyle, 2013; Hamann et al., 2011; Smebye et al., 2012). This takes place at the risk of marginalising the person with dementia (Boyle, 2013; Hamann et al., 2011; Smebye et al., 2012). Professionals are challenged to involve informal caregivers in decision-making, elicit their perspectives and interests, and at the same time take the preferences of persons with dementia into account. There is a lack of evidence about how people with dementia, their informal caregivers, and their professionals participate in the different stages of the decision-making. The decision about daycare is of particular interest because it is a complex decision where the interests of both the person with dementia and the informal caregivers are at stake.

This study had two objectives: first, to explore how people with dementia, their informal caregivers, and their professionals participate in decision-making about daycare and second, to develop a typology of participation trajectories to get a clearer understanding about the way care networks proceed through the decision-making process collaboratively. This information is for professionals who support people with dementia and their informal caregivers in making decisions about health and well-being. Furthermore, the results of this study add to the debate on social health and citizenship of people with dementia, and help move forward the shared decision-making research about people with dementia.

Methods

Design

We used a qualitative, prospective, multi-perspective design to gain in-depth insight into the experiences of participating in decision-making about daycare from the perspectives of people with dementia, their informal caregivers, and their professionals. The participants were interviewed three times over the course of a year. This study is part of a research program about shared decision-making in dementia care networks (Groen - van de Ven, Smits, Oldewarris, et al., 2016).

Setting

Community-living and institutionalized people with dementia in the Netherlands in the early and moderate stages of dementia who made a decision about daycare in the Netherlands. Daycare is a common form of support for community living people with dementia. However, several institutions in the Netherlands provide daycare services for institutionalized people with dementia as part of their daily support. Our participants included mainly community living people with dementia as well as several people with dementia who lived in institutions.

Participants

We purposively selected care networks of people with dementia: networks consisting of a person with dementia, two of his or her informal caregivers, and two professional caregivers (Coyne, 1997). We aimed for maximum variation regarding the characteristics of the person with dementia (gender, socio-economic status, and stage of dementia) and the types of informal caregivers (spouses, adult children, other relatives, and friends). We used three recruitment routes: (1) health care organizations for people with dementia, (2) a local meeting for informal caregivers and people with dementia, and (3) the website of the Dutch Alzheimer's Society. The inclusion criteria were: a diagnosis of any form of dementia, the ability to participate in an interview, and the availability of at least one informal caregiver. The exclusion criteria were: no confirmed diagnosis of dementia and the inability of the person with dementia to participate in an interview. We aimed to include 20 to 30 care networks in order to reach data saturation (Creswell, 1998).

Data collection

We interviewed the individual participants of the care networks at 6-month intervals, between July 2010 and July 2012. Twenty-two interviewers had been trained to conduct the semi-structured interviews using an interview guide. The interviewers included three researchers from the research team (LG, MS and another researcher), and

students studying for bachelor degrees (in nursing, speech therapy, or applied gerontology). The researchers (LG, and MS) trained the students in qualitative interviewing and interviewing people with dementia. The same interviewer interviewed all the care network members in a given interview round. The interviews lasted 1 hour on average, and they were audiotaped. The interview guides for the three rounds contained similar topics: the changes that had occurred, the decisions that were made, what had happened before these decisions, who was involved, and how people had experienced the decision-making. Interviews were conducted at the home or workplace of the respondent. We stressed the importance of interviewing the participants alone to avoid influence from others (Nygård, 2006). However, in three care networks the person with dementia was willing to participate only in the presence of the informal caregiver.

Data analysis

The interviews were transcribed verbatim and analyzed with Atlas.ti software. To reach our two study objectives, we used a two-step approach that combined a content analysis (Elo & Kyngas, 2008) with a methodology of type construction (Kluge, 2000). We used constant comparison in both steps (Corbin & Strauss, 1990).

Step 1: Content analysis (objective 1)

The content analysis aimed at developing categories and themes related to the participation of people with dementia, their informal carers, and their professionals in the decision-making about daycare. This started with open coding of the individual interviews of each care network in the three interview rounds, which meant reading the interview transcripts and labelling the relevant fragments. Codes were thus constructed on the basis of: the information of the five perspectives in each care network, and the three interview rounds (Kendall et al., 2009; Murray et al., 2009). After the open coding, we developed categories by grouping codes into meaningful clusters related to the participation in the decision-making about daycare. The categories were then grouped into meaningful clusters representing the themes of the participation in the decision-making about daycare (Corbin & Strauss, 1990).

Step 2: Typology construction (objective 2)

To develop our typology of the participation trajectories, we used a method for developing empirically grounded typologies, which consists of the following components (Kluge, 2000): (1) development of the relevant analysing dimensions and properties, (2) grouping the cases and analysis of the empirical regularities, (3) analysis of meaningful relationships and type construction and (4) characterization of the constructed types. For the first component, we developed our dimensions and properties from the themes and categories elicited in the content analysis in step 1. For the second component, we

made matrices displaying the dimensions and properties for each member of a care network. For the third component, we made comparisons within and between the care networks to construct the types. Since our focus was on how care networks proceeded through the decision-making process collaboratively, our typology was based on the differences in the combination of the properties of different care network members within each care network. Thus, by comparing within and between care networks, we were able to group care networks that had similar combinations of properties between the care network members. This resulted in three types of participation trajectories that were then described on the basis of their properties (component 4). LG prepared the components of the typology construction and discussed these with her supervisors (MV and CS) which led to the final version of the typology.

Constant comparison

Constant comparison was at the heart of our qualitative analysis in all steps. Constant comparison implies comparing newly analysed data with emerging ideas about the research question (Corbin & Strauss, 1990). In our analysis, we used comparisons at different levels: within individual interviews, between individual interviews within a care network, between interviews of different types of respondents, between interview rounds for a given care network, and between care networks (Boeije, 2002).

Ethical considerations

The Isala Clinics' ethical board approved this study (number 10.11113). Respondents received written information about the study beforehand. Because of the vulnerability of people with dementia as research subjects, participation in the study required the consent of both the person with dementia and his or her primary informal caregiver. We treated the participants' consent, especially that of the people with dementia, as a process (Murphy, Jordan, Hunter, Cooney, & Casey, 2015), and remained alert to signs indicating that the participant wanted to stop the interview (Meulenbroek et al., 2010). We did not share interview information with other network participants (Kendall et al., 2009). This study was supported by the Regional Attention and Action for Knowledge circulation (RAAK) program of the Foundation Innovation Alliance (SIA—Stichting Innovatie Alliantie) with funding from the Ministry of Education, Culture, and Science (project number PRO-1-014). The funder had no role in the study design, data collection, analyses, and interpretation of the data, nor in the writing of the article or the decision to submit it for publication. All researchers had access to all the data.

Results

Respondent characteristics

Twenty-five of the 30 care networks we contacted, agreed to participate. The reason given by the five who declined to participate was caregiver burden. We excluded two care networks: one because the person with dementia was unable to participate in the interview at that time, and the other because the diagnosis had been reset to mild cognitive impairment during the study. Our total study consisted of 23 care networks.

Table 1. Characteristics of the care networks in the study

Respondent characteristics		Care network numbers
Gender	6 Male	1, 8, 10, 14, 17, 19
	13 Female	5, 6, 7, 9, 11, 12, 13, 14, 15, 16, 18, 20, 21, 22
Age	80.5 (7,48 SD)	
Dementia stage ¹	5 Initial stage	5, 8, 11, 19, 20
	14 Middle stage	1, 6, 7, 9, 10, 12, 13, 14, 15, 16, 17, 18, 21, 22
Marital status	11 Married	1, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22
	6 Widowed	5, 8, 13, 15, 16, 19
	2 Single	18, 20
Living arrangements	16 Community dwelling	5, 7, 8, 9, 10, 11, 12, 14, 14, 15, 16, 17, 19, 20, 21, 22
	2 Nursing home	6, 18
	1 Home for the elderly	1
Informal caregivers interviewed	11 Spouse	1, 6, 7, 9, 10, 11, 12, 14, 17, 21, 22
	13 Daughter /Son	1, 5, 6, 8, 9, 11, 14, 15, 17, 19, 21
	4 Daughter- / Son-in-law	12, 15, 16
	7 Other family	13, 18, 20, 22
Professionals interviewed	1 Friends	5
	15 Case manager/care coordinator	1, 5, 7, 8, 9, 10, 11, 12, 15, 16, 17, 18, 19, 20, 22
	8 Day-care employee	5, 7, 11, 12, 14, 17, 20, 22
	7 Home care nurse	8, 13, 14, 15, 16, 19, 21
	3 Principal attendant nursing home	1, 6, 18
	3 Team leader/ head of the department	6, 13, 21
	1 Creative therapist	10
	1 Domestic help	9

¹ The stage of the dementia was based on the professional expertise of the case manager or other professional interviewed

This paper focuses on the 19 care networks in the study that discussed the issue of daycare in the interviews. Table 1 provides an overview of the characteristics of the 19 care networks. For an overview of all care networks, see Groen - van de Ven, Smits, Oldewarris, et al. (2016). Two of 19 care networks had only one informal caregiver each who could be interviewed, which left 93 respondents altogether for the analysis of this paper. The professional caregivers involved included case managers, home care nurses, daycare employees, and a psychotherapist. Two care networks opted out after the first interview round because of the burden of the study. We have used the information from the first interview rounds for these networks. One or more interviews in nine of the care networks could not be conducted during the second or third round because of circumstances such as holidays, moving house, or a change of the professionals involved. In total, we used 244 interviews in the analysis. We reached the intended variation in our sample with respect to gender, stage of dementia and type of informal caregivers. However, we reached mainly people with dementia with a mid level socio-economic status, and we reached only a few with low or high socio-economic status. We did reach data saturation regarding our study topic, since the last interviews did not provide new codes and themes (Fusch & Ness, 2015).

Results for objective 1: themes related to taking part in decision-making about daycare

We found three themes regarding participation in the decision-making: (1) initial expectations of daycare, (2) negotiating about trying daycare, and (3) trying daycare. Table 2 describes the themes with the related categories and codes on which they are based.

Theme 1: Initial expectations of daycare

This theme includes care network members starting to discuss and consider daycare for the person with dementia. The categories in this theme are: (1) initiating decision-making, (2) positive expectations, and (3) negative expectations. The care network members' initial expectations of daycare are critical for continuing the decision-making, because they have an impact on how the negotiation about trying daycare proceeds.

Initiating decision-making about daycare

Decision-making about daycare was initiated when one of the care network members started an exchange about the idea of daycare with one or more other care network members. It is notable that people with dementia and their spouses were not the ones to initiate conversations about daycare. Adult children were often the ones who initiated the conversations. They wanted to prevent overburdening of the spouse.

Table 2 Themes, categories, and codes for participation in decision-making about daycare

Themes	Categories	Codes
Initial expectations about daycare	Initiating decision-making about daycare	Anticipating
		Taking initiatives
	Positive expectations about daycare	Arguments in favour of daycare Preferences for daycare
	Negative expectations about daycare	Negative associations with daycare Arguments against daycare Dislike of daycare
Negotiating about trying daycare	Participating in conversations about daycare	Conversations about daycare Contributing to discussions about daycare Informing oneself about daycare Level of open communication
		Promoting daycare
		Offering daycare services Encouraging daycare Repeatedly discussing daycare
		Resisting daycare
	Resisting daycare	Rejecting daycare Being ambivalent about daycare Postponing daycare
		Attuning to others
		Listening to others Attuning to the person with dementia Weighing different perspectives
		Working together to try out daycare
	Working together to try out daycare	Resigning Giving in Trying daycare Supporting daycare
		Positive reactions of people with dementia towards daycare
		Positive experiences Positive feelings Positive behaviour
		Negative reactions of people with dementia towards daycare
		Negative experiences Negative behaviour
Trying daycare	Deciding about daycare	Determining Arranging daycare

“I did raise the issue with my mother before: ‘Wouldn’t it be good for him to go to the daycare centre so that you can catch your breath’ – Daughter of a man with dementia, care network 1

The professionals also initiated discussions with couples about daycare. When no spouse was present, the adult children (or other relatives), and the professionals initiated discussions about daycare.

“The daycare is a result of the daughters-in-law telling us that there was one day in the week when actually no one came by and then he used to call sometimes to say that he was feeling alone, and then they thought: ‘Well, we might try daycare. Well, I suggested that and discussed it with them.’ – Case manager of a woman with dementia living alone, care network 16

Positive expectations of daycare

Children and other relatives, as well as health care professionals, were in favour of daycare for the person with dementia. The only exception to this is care network 8 where the daughter had positive expectations towards daycare, but the son followed the negative expectations of his father. The people with dementia and their spouses were the participants who did not always have positive expectations of daycare. Positive ideas and expectations about daycare related to concerns about the deterioration of the person with dementia, well-being issues such as loneliness of the person with dementia, caregiver burden, and conflicts between spouses that made daycare necessary.

“We talked about daycare, partly because the spouse mentioned he couldn’t cope at home with his wife. Because of the tensions between them. And partly it was because we thought: ‘This woman should have something to do now and then, she just sits there at home.’ Well, and that combination, it just adds up to, that means daycare.” – Case manager of a woman with dementia, care network

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Negative expectations of daycare

The people with dementia and their spouses sometimes had negative ideas and expectations of daycare. They related to the idea that the person with dementia was not yet affected enough to need daycare; that daycare would not be useful or suitable, possibly because the person with dementia did not like being in groups; and that daycare would limit the autonomy of the person with dementia. Negative feelings

associated with daycare included: mistrust; being or feeling abandoned; fear, anger, grief, and shame due to loss of functioning; and guilt about putting someone away.

“I think she is far too good to go to daycare, then she would rapidly worsen. Because then she wouldn’t be activated anymore. And now her brother comes by for a walk with her, or he drops in once in a while, or people come over for me, or she will go along with me, just for companionship.” – Spouse of a woman with dementia, care network 22.

Theme 2: Negotiating about trying daycare

This theme involves care network members working towards getting the person with dementia to try daycare. The theme includes: (1) participating in conversations about daycare, (2) promoting daycare, (3) resisting daycare, and (4) attuning to others. The negotiation about trying daycare forms a critical point in the decision-making process. Depending on how the negotiation proceeded, the person with dementia might or might not move towards trying daycare.

Participating in conversations about daycare

Conversations about daycare occurred at different times, and places, as well as in different forms, such as face-to-face, by phone, or e-mail. The interviews from different rounds showed that the issue was often discussed multiple times before a decision was reached. In four care networks, the person with dementia was deliberately not involved in some of these conversations. Openly discussing daycare was seen as too confronting, or care network members were afraid that it would result in resistance of the person with dementia to daycare.

“[The woman with dementia] is not present herself at this meeting of course. Because you want to protect your client. Because matters may come up that the client doesn’t judge the same way. You discuss the more heated issues, so to speak. The results will be submitted to her afterwards, because she has to be up to date at a certain point about the changes that are going to come.” – Daycare employee of a woman with dementia, care network 22

In most situations, the conversations focused on whether or not daycare was acceptable, without really exploring the alternatives. The available or perceived options for daycare were often limited, especially for those who did not feel comfortable in groups.

Promoting daycare

Care network members in favour tried to promote daycare to the person with dementia and the spouse by encouraging them to try it. They did this by talking positively about daycare, adjusting their phrasing to what was acceptable to the person with dementia, repeatedly proposing the issue, and looking for support from other care network members who had an influence on the person with dementia.

“The doctor did encourage me to go to the daycare here. And, I must say, up until now it has turned out to be better than expected.” – Woman with dementia, care network 5

“Well, it wasn’t during the first consultation, that she said: ‘Yes, that daycare, that’s what we’ll do’. Before that, it was more like ‘[Let’s] think about it a little more’. I think that after two or three consultations she gave her approval to arrange the daycare.” – Case manager of a woman with dementia, care network 11

Resisting daycare

People with dementia, and the spouses too in some cases, tended to resist the efforts of others to get them to try daycare. They did this by rejecting daycare and by protesting or showing negative emotions when daycare was discussed. Another way of resisting included expressing doubts about daycare. The people with dementia and their spouses would also resist daycare by postponing or delaying discussions about it. In several care networks, reaching a decision about daycare was postponed and the issue came up in different interview rounds.

“You really feel a bit pushed aside, you know, in the beginning. That made me fight in the beginning. I didn’t want that.” – Woman with dementia, care network 11

“We decided that we would visit a care farm, one that I had already seen before. She said that she agreed. But well, she finds excuses not to go every time.” – Spouse of a woman with dementia, care network 9

Attuning to others

Attuning was necessary for reaching common ground, given the different perspectives and interests of the participants. Attuning included listening to the ideas and advice of others and weighing different perspectives. The people with dementia tended to stick to their own standpoints, with other care network members attuning to their preferences. A commonly used phrase was, “You cannot force someone to accept daycare.” Children were more likely to go against the wishes of the person with dementia;

however, those with decision-making responsibilities for a parent living alone were cautious about overruling the person with dementia. Attuning is illustrated by the following quotation, where the activity coach had a different point of view than the informal carer, but tried to attune to her point of view.

“The spouse indeed really puts [the person with dementia] in the centre. I believe she talks about things with [the person with dementia], how she sees them. With daycare too. She asked whether [the person with dementia] really wanted to go there. Rightly of course. I mean, as long as it’s possible it is very important that the client is the first one to express what she wants.” – Activity coach of a woman with dementia, care network 22

Theme 3 Trying daycare

This theme is about people with dementia trying and experiencing daycare as part of reaching a decision about it. It includes the categories of: (1) working together to try daycare, (2) positive reactions of people with dementia to daycare, (3) negative reactions of people with dementia to daycare, and (4) deciding about daycare. Trying daycare is a critical point in the decision-making because continuing or discontinuing daycare depends on the reactions of the person with dementia. Therefore, this is another phase in the decision-making where people with dementia have an important say.

Working together to try daycare

Arranging a try-out was often still part of the process of encouraging the person with dementia to use daycare. Their children and home care nurses were eager to make the try-out as easy as possible so that the person with dementia would not hesitate. They did this by visiting the daycare centre together, bringing the person to the daycare, or by making sure that the person was ready to go when the bus to the daycare arrived. In this way, the transport of people with dementia to the daycare facility was not only a practical solution, but also part of encouragement to use daycare.

The first days that she went there [to the daycare centre] I tried to take time for her. That I would be there to help her shower and dress and to stay until the taxi arrived. And after a few days she actually thought it was great [to go there].” – Home care nurse of a woman with dementia, care network 12

A try-out took place once the person with dementia had consented to it. Only in cases where there was risk of overburdening and the spouses had started to relinquish some of their care would the person with dementia perhaps be forced to try daycare.

“My mother-in-law always said: ‘I won’t go to daycare’. But well, there comes a time when they can no longer make that kind of decision themselves. At least, the care became too burdensome for my father-in-law.” – Daughter-in-law of a woman with dementia, care network 12

Positive reactions of people with dementia to daycare

For care network members, the person with dementia’s reactions to daycare, once he or she had tried it out, were very important. Positive reactions included positive experiences, such as liking daycare or enjoying the activities; positive feelings, such as relief, happiness, and trust; and positive behaviour towards daycare.

“She goes with pleasure [to daycare]. She makes sure that she is downstairs on time. This morning I overslept a bit. Well, she had everything all ready. She had set the table, because ‘Yes, I have to be on time!’” – Spouse of a woman with dementia, care network 22

When people with dementia reacted positively to daycare, it helped the spouse and children decide about daycare. Positive reactions reinforce the decision about daycare. Further, informal carers showed reactions based on their own experiences with the person with dementia visiting daycare. Positive reactions of informal carers related to feelings of relief and having a sense of control of the situation.

Negative reactions of people with dementia to daycare

Negative reactions to daycare included negative experiences, such as disliking daycare or being dissatisfied, and negative behaviour such as complaining, not participating in the activities, or walking away. Care network members took negative reactions seriously. Daycare would be stopped, or discussions about reducing daycare would be initiated.

“It seems as if he enjoys it all, only if you speak to him about it, he says: ‘What am I doing here? Why am I here? Why can’t I be with my wife?’ I do take that back to the care coordinator every time. In the sense of, ‘Can we do something about that?’ We discussed the idea of him staying home one day a week.” – Principal attendant of man with dementia, care network 1

However, care network members also found it is important to give time to the person with dementia to adjust to daycare, as the reactions of people with dementia about daycare might shift over time from negative to positive.

“We warned her [laughs]. Try it first. If you don’t feel like going, you quit. So, just try, because, if you really think it’s terrible, all right, then no! We’ll quit. Well, it took several months before she found her niche.” – Daughter of a woman with dementia, care network 11

Sometimes negative reactions were overruled by informal carers who were overburdened.

“[Interviewer: Did she consent to extend the daycare to three days a week?] Well, not really consent. She was against it until the day it started. She didn’t want to go another day. But, well, in the end, you can’t really do anything else. Because the care becomes too much.” – Daughter-in-law of a woman with dementia, care network 12

Deciding about daycare

Once daycare had been tried the care network members explicitly or implicitly reached a decision. The reactions of the person with dementia were important cues for the informal carers and professionals involved in reaching this decision.

“She signed her care plan last week and she has said that she feels comfortable here and that she enjoys coming here. And I believe that. Sometimes you see that clients say one thing here and at home it’s a different story. That they are not motivated at all. But, with her, I think she is really motivated and enjoys coming here.” – Day-care employee of a woman with dementia, care network 5

“Meanwhile, she went to the daycare, but she didn’t like it because everyone was asleep according to her. [Both the interviewer and respondent laughed]. She was like: ‘That dead place, I don’t fancy that’. So, well, she made the choice herself. We showed her what it was like, she has been there twice, and the third time she was like: ‘I won’t go there anymore’. That was her choice, and there must have been someone trying to convince her otherwise, but no was no.” – Case manager of a woman with dementia, care network 16

The whole process of deciding about daycare could start over once the situation of the person with dementia changed because of a decline in functioning or when the informal carer relinquished care. Follow-up decisions included extending or reducing daycare, and changing between groups.

Results objective 2: Types of participation trajectories

The themes and categories elicited for objective 1 functioned as the dimensions and properties for constructing our typology. Table 3 displays them. We distinguished three different types of participation trajectories on the basis of the manifestation of the dimensions and properties in our care networks: (1) working together positively towards daycare, (2) bringing conflicting perspectives together to facilitate trying daycare, and (3) not reaching a commitment to try daycare. Table 4 displays the different types of participation trajectories.

Table 3 Criteria for the construction of the types of participation trajectories

Dimensions (themes)	Properties (categories)	Manifestations of the properties in the care networks
Initial expectations towards day-care (theme 1)	Positive (category 1.2)	All care network members positive
	Negative (category 1.3)	Conflicting perspectives of participants*
Negotiation about day-care (theme 2)	Promoting day-care (category 2.2)	Promoting dominant, no resistance
	Resisting day-care (category 2.3)	Resisting dominant, promoting participants attuning to the resisting participants
	Attuning to others (category 2.4)	Promoting dominant, resisting participants attuning to the promoting participants
Try-out of day-care (theme 3)	Yes (category 3.1)	Yes
	No (category 3.1)	No
Experiences with day-care (theme 3)	Positive experiences (category 3.2)	Positive experiences
	Negative experiences (category 3.3)	Negative experiences
	Mixed experiences (both positive and negative)	Mixed experiences

*Purely negative expectations are never seen, since the initiator of the decision-making about day-care has positive expectations.

Type 1: Working together positively towards daycare

This type of participation trajectory consists of situations that were characterized by congruent positive expectations about daycare within the care network. There was no resistance to the idea of trying daycare in these situations, and once it has been tried out, the person with dementia and the informal caregivers experienced the daycare as

positive. In these situations, the decision to reach daycare was easy and things were promptly arranged without much discussion.

“It all went very fast...that she could go there [to the daycare]. And, at first she said: ‘I’ll just try it first, and then we’ll see.’ But, she found it terrific from the first day.” – Daughter of a woman with dementia, care network 5

Type 2: Bringing conflicting perspectives together towards trying daycare,

This trajectory type is characterized by conflicting perspectives of the care network members about trying daycare. The person with dementia, and some of the spouses are negative about trying it, whereas other care network members are positive. Sometimes there are multiple conversations or attempts to take the person with dementia to try daycare. Care network members take the time to think things over as long as they feel this is safe for the person with dementia, and doable for the informal carers.

“The way he is now, he is not wandering or anything, you know? I think he’s very lonely, but he says he is doing fine. I ask him all the time: ‘How are you doing? Don’t you want more?’ Then he says: ‘No, I’m fine.’ Well, then I may feel he is lonely, and think he needs more activities, but if he keeps saying he doesn’t want that, then you have to let it go. I had difficulties with that at first. But, my husband says it too: ‘Let it go. You can’t force it.’ ” – Daughter of a man with dementia, care network 8

It is notable that the professionals seldom discussed alternatives to daycare. Therefore, the choice was either accepting or not accepting daycare. Continuing daycare after the try-out depends on the reactions to daycare of the person with dementia. Positive and mixed experiences lead to a continuation of daycare, whereas negative experiences imply that daycare stops.

“And wonder of wonders, she began to like it [daycare], and gradually she recovered physically, which made her a lot clearer. You could see that. She was more approachable. She became a totally different lady.” – Case manager of a woman with dementia, care network 11

“Daycare is something she absolutely does not want. We even went to the daycare one afternoon with her and she experienced it all. But, she definitely does not want it.” – Team leader for nurses of the home care organisation of a woman with dementia, care network 21

Table 4. Types of participation trajectories of the decision-making about daycare

Trajectory type	Initial expectations	Negotiation about daycare	Daycare try-out	Experiences with daycare
(1) Working together positively towards daycare	All participants have positive expectations	Promoting daycare	yes	Positive
(2) Bringing conflicting perspectives together towards trying daycare	Person with dementia has negative expectations and sometimes the spouse does too, while other participants are positive	Professionals and informal carers (adult children) promote daycare. The person with dementia resists daycare or has no clear role in the negotiation. The spouse or other primary informal carers are ambivalent towards daycare. They tend to align with the person with dementia or resist daycare themselves. After multiple conversations about daycare, the person with dementia and the informal carers are willing to support trying daycare	Yes	Positive, negative or, mixed
(3) No commitment to try daycare	Person with dementia negative, the informal carers are negative or have no clear expectations about daycare, professionals are positive	The professionals in these situations promote daycare, while the person with dementia resists. The informal carers either resist as well or align with the person with dementia. Daycare does not suit the person with dementia because he or she dislikes groups or does not like being away from home. Professionals eventually accept that the person with dementia does not want to try daycare	No	No

Note:

Care networks of type 1: 5, 7, 13, 17

Care networks of type 2: 1, 6, 8, 9, 11, 12, 14, 16, 18, 19, 20, 21, 22

Care networks of type 3: 10, 15

Type 3: Not reaching a commitment to try daycare

This type of participation trajectory is characterized by the person with dementia being part of a small network and resisting daycare. The secondary informal caregivers in these care networks did not have a clear role in the decision-making. The primary

informal caregivers were either negative or had no clear role. The initiative for discussing daycare came from the professionals. They tended to have multiple conversations about daycare in which they tried to encourage the person with dementia and primary informal caregiver to try daycare. However, these discussions did not lead to trying daycare. Then, finally the professionals accepted the fact that daycare was not suitable in this situation. The professionals did not discuss alternatives to daycare, even if the informal caregivers came up with alternatives themselves. These care networks decided to manage the situation as best as they could, without day-care.

“In the past I tried to guide her to a form of daycare. Because then she wouldn’t have to have this private care, because she would be taken care of for a few hours. She could get a meal there, she could go to the hairdresser and the physiotherapy. But, she wouldn’t go outside for all the tea in China. So, at a given moment, you reconcile to the situation, and you accept that.” – Case manager of a woman with dementia, care network 15.

“They [community services] keep suggesting that he should first try daycare in a group. That he should undergo daycare here at [name of a nursing home]. Well, the misery is that he doesn’t hear anything in a great hall full of people like that. And then the sort of things they do there. Old Dutch activities, that’s wasted on him. I mean, he is a musician with absolute pitch. That singing with all those different voices hurts his ears. [...] And, he doesn’t stand up for himself in groups. He gets more depressed and at home he complains. But, then they said to me, ‘You can just try it for a month and if it doesn’t work, he will get another indication [for one-to-one care]’. I said: ‘So, he and I must be worn out for a month? It’s pure fraud. You know in advance he can’t do it. I refuse to lie about it.’” – Spouse of a man with dementia, care network 10.

Discussion

We explored how people with dementia and their informal and professional carers participate in decision-making about daycare. Three themes representing the critical points of the participation in the decision-making about daycare emerged: (1) the initial positive or negative expectations of daycare; (2) negotiating about trying daycare by promoting, resisting, or attuning to others; and (3) trying daycare, resulting in positive or negative reactions from people with dementia, and leading to a decision about daycare. The ways in which care networks proceeded through these three critical points resulted in a typology of participation trajectories, including: (1) working

positively together towards daycare, (2) bringing conflicting perspectives together towards trying daycare, and (3) not reaching commitment to try daycare.

Taken together, the results of our study make several important contributions to the current theory and understanding of the practice of shared decision-making. We believe four elements should be incorporated in a theoretical model of shared decision-making for people with dementia: (1) shared decision-making in dementia should aim at moving from initial to experienced preferences, (2) non-verbal contributions should be acknowledged as factors in the decision-making along with the verbal expressions of people with dementia, (3) the important roles of both primary and secondary informal caregivers need to be acknowledged as both are important for reaching necessary compromises, and (4) professionals should work together with people with dementia and their informal caregivers to find tailor-made alternatives to daycare if necessary. We explain each of these elements in the following paragraphs.

First, the findings demonstrate that a try-out period is an essential element of the decision-making for people with dementia. For people with dementia it is often quite difficult to forecast their preferences on the basis of factual information about options (Entwistle & Watt, 2006). Our results show that initial preferences based on information alone may change when people with dementia experience daycare. A try-out period is important for them so that they can experience daycare without having to decide whether they want to continue it (Epstein & Gramling, 2013). Whereas shared decision-making in general aims at moving from initial preferences to informed preferences professionals should focus more at moving from initial preferences to experienced preferences for people with dementia.

Second, the findings suggest that people with dementia exercise considerable influence with their preferences and reactions to daycare. During the three critical points of the decision-making about day-care they provide arguments and standpoints about daycare that are taken seriously by the other participants. They stand for their preferences and are not easily persuaded to act contrary to those preferences. In addition to their verbal expressions about day-care, the people with dementia's emotions and behaviours during the daycare try-out serve as important cues for their preferences. In this way, they influence the decision-making pace as well as the direction of the decision. This is in line with Boyle's findings (2014) that people with dementia who lack deliberative capacity exercise agency in other non-verbal ways. Focusing solely on the cognitive contributions to decision-making ignores the other contributions of the person with dementia and does not fit in with the ways in which the various participants mutually influence each other. Professionals who want to facilitate shared

decision-making with people need to acknowledge the non-verbal contributions of emotions and reactions as factors in decision-making.

Third, the types of decision-trajectories show the important role of informal caregivers in bringing together conflicting perspectives. The various participants have distinct perspectives, so that reaching a decision about daycare means negotiating these different points of view by promoting and resisting daycare, and by attuning to each other's views. Adult children or professionals are the ones who initiate decision-making about daycare. People with dementia, and sometimes their spouses as well, tend to start off with negative expectations of daycare. They resist daycare. Their children are often more positive from the beginning and tend to promote daycare. Their perspectives are more in line with those of the professionals involved. This is in line with the work of Clemmensen, Busted, Soborg, and Bruun (2016) who found differences between the 'protective relative' and the 'decisive relative'. The protective relative usually lives with the person with dementia and tends to protect the relationship with the person, conceal carer burden, and resist change. The decisive relative tends to initiate decision-making, articulate the problems, and addresses the carer burden of the protective relative. Our results seem to indicate that including the perspectives of carers with a decisive role may be crucial in initiating decision-making and in reaching compromises. Only 20% of shared decision-making models recognize informal caregivers as relevant participants for shared decision-making (Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). Their roles are often incorporated in the patient role without explicating their specific contributions to the decision-making. An exception to this is the interprofessional shared decision-making model (IP-SDM) of Légaré et al. (2014). Our study exemplifies that the perspectives of informal caregivers are different from those of the patient, and that the perspectives of the different informal caregivers involved also vary.

Fourth, our results indicate that the decision about daycare is often presented as a yes-or-no decision by professionals. Alternatives to daycare are seldom discussed. This is especially troublesome for those people with dementia who dislike groups, or who do not prefer the activities at the daycare centre. Since daycare is not only aimed at the person with dementia, but also at relieving carer burden (Mavall & Malmberg, 2007; Robinson et al., 2012), it seems important to at least consider alternative options. Such options may not be readily available. In complex situations such as the ones dementia creates, shared decision-making requires professionals to engage in conversations with their patients that go beyond merely informing them about the options they know of. Rather, they should have open conversations that allow all the participants to consider new information, perspectives, and options (Epstein & Gramling, 2013;

Epstein & Street, 2011). This might result in “third ways” that the professional had not yet thought about. The difficulty is that professionals may have their own interests in the daycare decision as well, on the basis of the organisation of the health care in their region (St-Amant et al., 2014). This might be part of the reason why professionals do not always take the alternatives as presented by the informal carers into consideration.

Strengths and limitations

This is the first study to explore the participation of different participants in the decision-making about daycare in dementia. The decision about daycare is an important one, since it often marks the point time in which people with dementia engage in professionals care on a regular basis. Our study includes the perspectives of people with dementia, their informal carers, and the professionals involved. As such, it provides rich stories about participation in the decision-making regarding daycare (Kendall et al., 2009). The perspectives of people with dementia themselves are often neglected in research (Murphy et al., 2015).

This study also has several limitations. First, there were various interviewers, some of whom were undergraduate students. This may have led to variation in the quality of the interview data between interview rounds. All the interviewers were trained, and received feedback on their interview style after each interview, but there were still differences in the extent to which they persisted in asking questions. To minimize the effect of different interviewers, we made sure that the interviews of each care network in a given interview round were conducted by one interviewer. Second, this study involves people with dementia who were able to participate in an interview and who had informal carers present. Cases in which the person with dementia cannot communicate and cases without informal caregivers could likely present different or additional experiences. Third, our findings are limited by the fact that they represent the Dutch context and focus at shared decision-making about day-care. However, we believe our findings may be transferable to shared decision-making for people with dementia outside the Netherlands and for other decision topics. Nevertheless, certain elements should be taken into account to assure that the situation is similar to our context (Krefting, 1991). These include: (1) people with dementia are seen as partners in the decision-making, (2) informal caregivers are involved in the decision-making, and (2) it is possible to try out options before reaching a decision.

Future directions

Our results contribute to the social health of people with dementia by appreciating their potential to participate in decision-making, and by acknowledging the roles of informal caregivers for people with dementia to manage their own lives (Vernooij-Dassen

& Jeon, 2016). Future research could strengthen these insights by exploring how the remaining capacities of people with dementia with respect to decision-making can effectively be included in the decision-making. Besides this, our study excluded the perspectives of people with dementia without informal caregivers. Research about shared decision-making for people with dementia who lack the support of informal carers could reveal how they reach decisions together with their professionals, thereby contributing to their social health.

Conclusion

Our results show that shared decision-making with people with dementia is possible and requires an adapted process of decision-making. The attention should shift from merely deliberating about daycare to trying it in order to move from initial expectations of daycare to experienced preferences. Doing this allows people with dementia to have an impact on the decision-making. The other participants usually honour the preferences based on experiences with daycare. While shared decision-making in general aims at moving from initial preferences to informed preferences, professionals should focus more on moving from initial preferences to experienced preferences for people with dementia.

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CHAPTER 6

GENERAL DISCUSSION



Good-quality care for people with dementia includes valuing them, treating them as individuals, and exploring the care situation through their perspectives (Brooker, 2003). Shared decision-making includes these elements and should be the norm for professional care. However, it is seldom used in practice. This leads to suboptimal care for people with dementia. Professionals who want to use shared decision-making feel unprepared to do so because the existing shared decision-making models do not fit the complex situation of people with dementia. This thesis contributes to the scientific knowledge about shared decision-making – by describing the decision-making in the care networks of people with dementia and comparing the actual shared decision-making in this context to the existing theories about shared decision-making.

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

1. What are the decisions and related key events in the trajectories of the care networks that include the people with dementia, and their informal and formal carers?
2. What are the challenges of shared decision-making for people with dementia, their informal carers, and their professionals?
3. What are the process elements of decision-making in dementia care networks?
4. How can these elements enrich the model of collaborative deliberation in order to facilitate shared decision-making in dementia care networks?
5. What types of participation trajectories can be distinguished in the decision-making about daycare?

Main findings and conclusions

In answer to research question 1, we found that care networks of people with dementia encounter decisions related to managing daily life, arranging support, community living, and preparing for the future (**Chapter 2**). These findings show that decisions relate not only to the disease as such, but to living one's life with the dementia, which includes daily issues and living in society. We describe eight key events along the dementia trajectory that require multiple decisions. The key events vary from concerns before the diagnosis, the diagnosis, the inactivity of the person with dementia, and safety incidents at the beginning of the dementia, to 24-hr monitoring, hospitalisation, and nursing home admission in the more advanced stage of the dementia. Our study is unique in indicating both the key events and the types of decisions related to certain key events along the decision trajectory. For instance, the inactivity of the person with dementia is a key event that generates decisions about managing daily life, such as grocery shopping, daily activities, or daycare. There are also decisions to be made about arranging health care and support, such as volunteer or home care. Knowing what types of decisions are relevant to the key events can help professionals

contribute to advance care planning and shared decision-making. We found that these key events and the related decisions differ for people with dementia living with their carer and those living alone. The emphasis for those living alone is on safety issues; and for those living with an informal carer, on carer burden. The decisions of people with dementia living with an informal carer show more variety than the decisions of those living alone. They include issues of well-being that do not occur for those living alone such as, taking trips together. Moreover, the decision-making role of the people with dementia, and especially those living alone, was often at stake when key events occurred. This implies that professionals should be extra watchful to include the perspectives of people with dementia regarding key events, especially for those living alone. We conclude that individual differences in decision content and sequence may affect shared decision-making and advance care planning.

In answer to research question 2, we found two major challenges related to shared decision-making that care networks of people with dementia encounter: (1) adapting to a situation of diminishing independence, and (2) tensions in network interactions that result from the participants' differing perspectives and interests (**Chapter 3**). These challenges relate to the essential elements of shared decision-making and to social health, which is the dynamic balance between a person's capacities and limitations and his or her social environment. Our findings suggest that shared decision-making in the context of dementia should look beyond the expected verbal and rational contributions of the participants. Further, all the relevant participants, including secondary informal carers, should be involved in order to reach decisions that really matter to the people with dementia. Given that informal carers themselves have an interest in the decisions, professionals should find a balance between the perspectives and interests of both the people with dementia and their informal carers. When informal carers and professionals can give the person with dementia a role in the decision-making and move towards decisions that are meaningful to him or her, this may contribute to the person's social health. We concluded that professionals should help people with dementia participate in ways that strengthen their remaining capacities, and that the perspectives of all participants should be involved.

In answer to research question 3, we enriched the model of collaborative deliberation, which is an existing model that facilitates shared decision-making. Our findings suggest that collaborative deliberation in dementia care networks should be extended with two elements: (1) recognising the need for a decision, and (2) defining what must be decided (**Chapter 4**). The different views of the participants are often a potential cause of miscommunication during decision-making, and we recommend to discussing the views to reach agreement about what problem needs to be addressed now.

Furthermore, deliberation includes not only rational discussion, but also trying out options, expressing emotions, and observing the behaviour of the person with dementia. These elements contribute to a more inclusive way of involving people with dementia throughout the dementia trajectory. Moreover, a process of trial and error may make new options become clear, which can then be compared. Shared decision-making in the context of dementia care networks inevitably includes conflict between care network members, given their different perspectives and their different interests in the decision-making outcome. We conclude that professionals should mark the start of the decision-making process and work with participants towards a shared view of the pressing matters at hand.

In answer to research question 4, we have described how care network members participate in decision-making about daycare. Deciding about daycare may be complex, since it is often the first source of support outside the home – a time when people with dementia and their carers are not yet used to discussing support options with professionals. We found that three critical points emerge in the participation in the decision-making about daycare: (1) the initial positive or negative expectations towards daycare, (2) negotiating about trying daycare, and (3) trying daycare (**Chapter 5**). We found that care networks differ in how they proceed through these critical points, and we constructed three types of participation trajectories. In care networks where all the members, including the person with dementia, start off with positive expectations of daycare, the participants work together towards daycare (type 1). In situations with conflicting perspectives about daycare, some care networks manage to bring the perspectives together towards a try-out of daycare. These care networks base the final decision about daycare on the experiences of the person with dementia (type 2). There are other care networks that do not reach commitment for a daycare try-out (type 3). In these care networks, the primary carers are negative about daycare, and the secondary informal carers do not contribute to the decision-making. We conclude that trying daycare is crucial for reaching decisions about it, and that secondary informal carers may have an important role in moving towards a try-out when primary informal carers and people with dementia have negative expectations about daycare.

Discussion on main findings

Our findings show that shared decision-making in the context of dementia care networks differs from other contexts with respect to the point of departure, the process, and the conditions

The point of departure for shared decision-making: balancing conflicting needs and preferences

Balancing the needs and preferences of people with dementia and their informal carers

The basic assumption of shared decision-making is that individual self-determination is important and should be facilitated where possible (Elwyn et al., 2012). Considering the circumstances of people with dementia, this assumption seems inadequate. People with dementia live their lives independently by virtue of the support they receive from their loved ones (Wimo et al., 2011; Winblad et al., 2016; World Health Organisation, 2012). Given the interconnectedness of their lives, the decisions that are made concern the informal carers as well as the people with dementia (Chrisp, Tabberer, & Thomas, 2013). The findings presented in this thesis show that people with dementia and their informal carers have different perspectives and interests (**Chapters 3 and 4**), so that decisions are not made solely for the people with dementia. Rather, the decisions should be about balancing the needs of the person with dementia and the informal carers (Quinn, Clare, McGuinness, & Woods, 2012; Quinn, Clare, & Woods, 2013). Consequently, in most cases, conflict is an inevitable part of shared decision-making for people with dementia, which often requires compromising instead of working towards consensus.

Balancing autonomy and safety risks

Decision-making in the context of dementia aims at preserving the autonomy of the person with dementia (Livingston et al., 2010; Samsi & Manthorpe, 2013). Our study demonstrates that balancing independence and safety risks, is a central dilemma faced by their care networks when they try to preserve the autonomy of people with dementia (**Chapter 2**). Several studies about risk-taking and ethical issues in the context of dementia recognise this dilemma (Berry, Apesoa-Varano, & Gomez, 2015; Chrisp et al., 2013; Smebye, Kirkevold, & Engedal, 2016; Stevenson, McDowell, & Taylor, 2016). Research shows that people with dementia, their informal carers, and professionals have different perceptions and tolerances with respect to risk (Gilmour, Gibson, & Campbell, 2003; Stevenson et al., 2016). The issue of risk versus autonomy should be discussed in order to reach a shared understanding about the risks that the participants are willing to take.

The process of shared decision-making

The necessary preparatory work of defining the issue

In general, models of shared decision-making start by explaining to patients that they have a choice of different but equivalent options, after which the options are presented and discussed (Elwyn et al., 2012; Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). Preparatory work is necessary before options can be introduced in the care networks of people with dementia (**Chapters 3 and 4**). This is due to the different perspectives of the various participants about what constitutes a problem. The complex problems in dementia are often multifaceted, and various problems may be presented together (Epstein & Gramling, 2013; Milte et al., 2013; Wolfs et al., 2012). Additionally, participants may differ in their timing and level of acknowledging problems related to the progressive decline of the dementia (**Chapter 4**). This requires problem recognition and problem definition before care networks can start to deliberate the options (**Chapter 4**). Problem recognition includes negotiating with the care network about emerging decision topics, which participants may or may not acknowledge as problematic. Problem definition includes explicating decision topics and the related goals, and determining which problem needs to be addressed now.

Developing options: the need for tailor-made solutions

Shared decision-making models start from the position that the options are clear up front and need to be presented by the professional (Elwyn et al., 2012; Stacey et al., 2010). In dementia care networks the problems are intertwined with the specific situation, and consequently standard options may not match the problems (**Chapter 4**). Rather, options need to be explored as an integral part of the decision-making (Epstein & Gramling, 2013; Wolfs et al., 2012). This process is complicated, time-consuming, and continuously changing. People with dementia and their informal carers, and even their professionals, are only partly aware of the possible options or tend to focus too much on familiar options (St-Amant et al., 2014; Whitlatch, 2008; Wolffs, de Vugt, Verkaaik, Verkade, & Verhey, 2010). This may be the reason why our findings show that a limited number and types of options are often discussed, while alternatives are not explored (**Chapter 5**). Finding alternatives that really suit the situation at hand requires exploring the particulars of the situation from multiple perspectives (Epstein & Gramling, 2013).

Deliberation and trying options as ways of moving towards a decision

Deliberation in shared decision-making generally aims at sharing evidence-based information and discussing the pros and cons of various options (Elwyn et al., 2014; Entwistle & Watt, 2006; Hargraves, LeBlanc, Shah, & Montori, 2016). The aim of this pro-

cess is to help patients move towards informed preferences. Our findings demonstrate that deliberation in the decision-making of care networks of people with dementia includes not only exchanging information, but also trying options (**Chapters 4 and 5**). It is difficult for most patients to predict how they will feel when a certain option is implemented, which makes trying options important for reaching decisions that really suit the preferences of the person with dementia and the informal carers. Our findings show that initial preferences based on information alone may change once people with dementia have experienced the options.

The conditions for shared decision-making: inclusive involvement, and the right timing

Use the diversity of the perspectives of the care network members

Many studies about decision-making in the context of dementia describe the involvement of informal carers in the decision-making as problematic. Their roles are often presented as overruling the perspectives of people with dementia, so that decisions are made on the basis of the informal carers' perspectives alone, while the people with dementia are excluded from the decision-making too early (Boyle, 2013; Fetherstonhaugh, Rayner, & Tarzia, 2016; Samsi & Manthorpe, 2013; Smebye, Kirkevold, & Engedal, 2012; Taghizadeh Larsson & Österholm, 2014; Tyrell, Genin, & Myslinski, 2006; Whitlatch & Menne, 2009; Wolfs et al., 2012). Therefore, Miller, Whitlatch, and Lyons (2014) argue that shared decision-making in dementia should focus on the type and degree of involvement of the person with dementia in the decision-making. Our study reveals that the contributions of both people with dementia and their informal carers are necessary for reaching decisions that really matter (**Chapter 3**).

First, including multiple perspectives is necessary to develop alternatives to the standard options. This means that professionals should engage with people with dementia and their informal carers in conversations that go beyond merely informing them about options they know of by explicitly inviting people with dementia and their informal carers to contribute their ideas too (**Chapter 5**). It can be quite difficult for people with dementia and their informal carers to suggest options themselves, given the perceived power imbalance within professional-lay consultations (Joseph-Williams, Elwyn, & Edwards, 2014). Professionals must explain to them why it is necessary to include all the ideas to find solutions that fit. Because the options are not clear up front, it is the participants who must decide together when enough alternatives have been considered, deliberated upon and tried out (Epstein, 2013).

Second, shared decision-making in dementia care networks includes reaching compromises to meet the different needs and interests of the participants. Especially secondary informal carers, who are involved at a greater distance, seem to have an important role here (**Chapter 5**). Our findings highlight the fact that the perspectives and roles of primary and secondary informal carers differ (**Chapter 5**). Whereas secondary informal carers are the ones who initiate the decision-making and are positive towards change, the primary informal carers are often more accordant to the person with dementia and tend to resist change. Clemmensen, Busted, Soborg, and Bruun (2016) confirm these different roles of primary and secondary informal carers: they found differences between the ‘protective relative’ and the ‘decisive relative’. The protective relative usually lives with the person with dementia and tends to protect the relationship with the person, conceal carer burden, and resist change. The decisive relative tends to initiate decision-making, articulate the problems, and address the carer burden of the protective relative. Our results seem to indicate that including the perspectives of secondary informal carers with a decisive role may be crucial in initiating decision-making and in reaching compromises (**Chapter 5**). Even though including families in the decision-making may increase the length of the decision-making conversations (Milte et al., 2013) and may be complicated by the longstanding patterns of communication of the families (**Chapter 3**), it is necessary for reaching decisions in the complex situation of people with dementia.

Moving beyond the verbal and rational deliberation

Shared decision-making models tend to focus on deliberation as a verbal and rational dialogue about different options (Elwyn et al., 2014; Entwistle & Watt, 2006; Hargraves et al., 2016). Wolfs et al. (2012) pointed out that decision-making in dementia is often overwhelmed by emotions, and that rationality constitutes only a small part of decision-making. Our findings confirm this. However, while Wolfs et al. (2012) state that people with dementia have a minor role in decision-making, our findings suggest that they exercise considerable influence with their reactions and the way they express themselves (**Chapter 5**). Even though it can be difficult for people with dementia to rationally consider a set of options and to reach decisions, they can direct decisions about their lives by expressing their aspirations, values, emotions, and their body language (Boyle, 2014). Therefore, focusing solely on the cognitive contributions to decision-making overlooks other valuable and important contributions of the person with dementia and does not take into account all the ways that people with dementia influence the decision-making (**Chapter 5**). Shared decision-making in dementia care networks should be about finding ways of involving people with dementia in decision-making such that their strengths are addressed, since even with little cognitive capacity people with dementia can have an impact on the decisions about their

lives (Boyle, 2014; Epstein, 2013; Peisah, Sorinmade, Mitchell, & Hertogh, 2013). This requires flexibility regarding the changing capabilities of people with dementia, to preserve their autonomy (**Chapter 3**) as well as acknowledging non-verbal contributions, such as emotions and behaviours as factors in decision-making (**Chapter 5**). Using the full range of experience, including thinking, acting, feeling and relating to each other is necessary to reach decisions that have logical, emotional and practical meaning to the participants (Epstein, 2013; Hargraves et al., 2016). This can only be realised in care networks with a trusting partnership of the people with dementia, their informal carers, and the professionals.

Timely discussion of issues in accordance with the preferences of the care network members

Many daily decisions in the care networks of people with dementia are about reducing the independence of the person with dementia (**Chapters 2 and 3**). Discussing issues in a timely fashion is important to preserve the autonomy of people with dementia, because the decision-making role of the person with dementia is threatened by many key events (Chapter 2). The participants' preferences in anticipating future decisions differ, which causes difficulties. The resistance of people with dementia to making decisions that require changes (**Chapter 5**) is likely to be related to their difficulty in accepting their progressive decline (Livingston et al., 2010; Wolfs et al., 2012). Pressuring people with dementia and their families into making decisions before they are ready can cause family conflict and carer stress (St-Amant et al., 2014). However, not anticipating future decisions limits the choice of options and the opportunity for the person with dementia to be included in the decision-making (Wolfs et al., 2012). Professionals must introduce change slowly to balance the idea of anticipating future decisions with the preferences of the participants who want to focus on living well in the present (Dickinson et al., 2013; Livingston et al., 2010).

Theoretical considerations

Towards a conceptual model of shared decision-making in dementia care networks

Shared decision-making is often defined as the process of professionals and patients working together towards informed preferences regarding health care options that are based on the best available evidence and the patient's values (Elwyn et al., 2012; Joosten et al., 2008; Stiggelbout et al., 2012). As described in the general introduction of this thesis, the current debate about shared decision-making emphasises the need for a broader conceptualisation that (1) assumes an on-going partnership of patients and professionals in the decision-making (Elwyn et al., 2014; V. A. Entwistle, Carter,

Cribb, & McCaffery, 2010; Epstein & Gramling, 2013; Hargraves et al., 2016; Morant et al., 2015); (2) realises that evidence-based information alone is too limited as a basis for reaching decisions (Berger, 2015; Epstein & Gramling, 2013; Greenhalgh, Howick, & Maskrey, 2014; Hargraves et al., 2016); and, (3) acknowledges family members as partners in shared decision-making (Elwyn et al., 2014; Morant et al., 2015). Our findings may sharpen this debate, as they illustrate the complexity of shared decision-making in partnership with patients and family members in a situation where evidence based-information is scarce. This complexity consists of the divergent and sometimes conflicting interests in the decision-making of patients and families, the multiplicity of problems that may require decision-making, the lack of readily available options, the need of timely discussion of the issues, and the differences in decision-making capacities of the participants. Our results emphasise the need of a shared decision-making model that includes the diversity of the participants' perspectives, a model that moves beyond verbal deliberation to include trying out the options, and emotions as elements of the decision-making. Whereas shared decision-making in general aims at moving from initial preferences to informed preferences, professionals should focus more on moving from initial preferences to experienced preferences for people with dementia.

Our findings enable us to develop a model of shared decision-making that reflects the context of care networks of people with dementia (Figure 1). Such shared decision-making takes the needs and preferences of both the person with dementia and the informal carers as point of departure, and it aims at achieving a balance between autonomy and safety. When this balance is threatened, participants recognise the issues that require decision-making. Such issues can be anticipated and dealt with to prevent any imbalance of autonomy and safety. Once decision needs are recognised, a process begins with the preparatory work of the participants defining the issue together. Then the participants develop multiple options, deliberate about these options, and try them out to reach a decision. There are several conditions that determine whether people with dementia and their informal carers experiences this process as shared. The first condition is that professionals must include the diversity of the participants' perspectives. The second condition is that professionals must move beyond the rational and verbal elements of the decision-making and accept other elements, such as emotions and actions, as relevant contributions to the decision-making. They should constantly search for inclusive ways of involving the perspectives of the person with dementia in the decision-making. It is necessary to discuss issues in time, but in accordance with the preferences of the participants, so that they are ready to take the next steps in the decision-making.

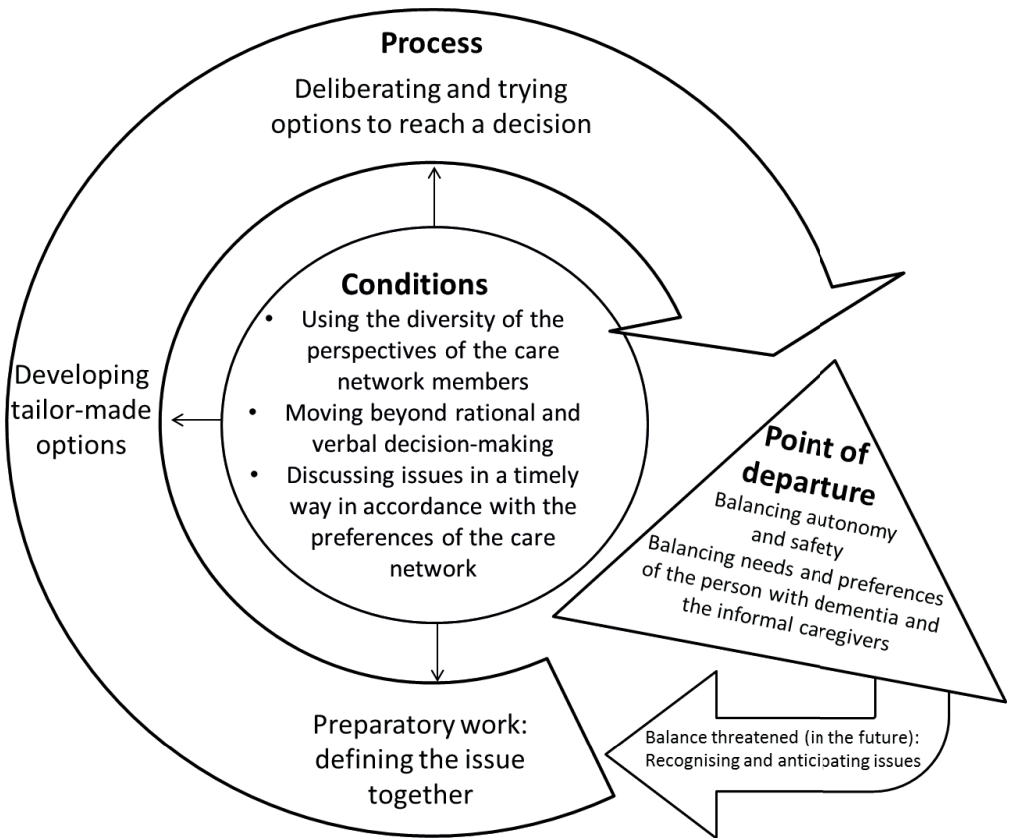


Figure 1. A conceptual model of shared decision-making in dementia care networks

Shared decision-making and social health

Social health refers to the dynamic balance between opportunities and limitations of patients affected by social and environmental challenges (Huber et al., 2011; Vernooij-Dassen & Jeon, 2016). It has several dimensions, including the capacity to fulfil one's potential and social obligations and the ability to manage one's life with some degree of independence. Our findings show that others sometimes limit people with dementia in their abilities to participate in the decision-making. However, we also show that shared decision-making can enhance the social health of people with dementia. The shared decision-making model as presented in this thesis relates to social health in several ways. First, the starting point is the balance in the needs of the person with dementia and the informal carers. People with dementia depend on the support of informal carers to manage their lives in accordance with their preferences. Second, our model of shared decision-making incorporates several elements that aim at including

people with dementia in the decision-making in ways that strengthen their remaining capacities. For instance, the model encourages professionals to discuss issues in a timely fashion, and to move beyond rational and verbal deliberation about options. Applied in this way, shared decision-making may help people with dementia reach decisions that resonate with the way they want to live their lives and support them in managing their lives independently.

Methodological considerations

In this section we reflect on some methodological issues in addition to the discussion of the methods in the previous chapters.

The value of a prospective, qualitative, multi-perspective design

We chose a prospective, qualitative, multi-perspective design because it would yield rich information and insights that could not have been elicited from quantitative data (Kendall et al., 2009; Murray et al., 2009). Most multiperspective studies include dyads or triads, including only the primary informal carer as source of information. Koehly, Ashida, Shafer, and Ludden (2015) have demonstrated the added value of including multiple informal carers in dementia research, which leads to more comprehensive results. The added value of including two informal carers per patient in our study was that we could distinguish the different roles and views that primary and secondary informal carers have in decision-making. This would have been overlooked if we had only included the primary informal carer.

We tracked each care network for 12 months by interviewing them three times at 6-month intervals. This approach enabled us to go beyond a simple content analysis, by exploring the changing experiences and perspectives of the care network members regarding the decision-making (Murray et al., 2009). We were able to give an in-depth description of the decision trajectories in our care network, by eliciting the chronology of the decisions in each care network and combining this information with thorough content analysis. We also elicited the critical points in the participation trajectories about daycare by using a method of typology construction that included the differences in how the care networks discussed daycare issues in subsequent interview rounds.

Our prospective design had some drawbacks. First, we expected a follow-up period of 12 months to be long enough to make changes in the situation of the person with dementia visible. There were differences between care networks in the number and type of decisions made during the study. This related to the nature of the dementia, and

the vulnerability of the care network (Vroomen, Bosmans, van Hout, & De Rooij, 2013). It meant that the density of information differed between the care networks. A longer follow-up period might have brought in more information for the care networks that were in a rather stable year in the dementia trajectories. Second, the data from the first interview round were partly based on retrospective information. We had a large and changing team of interviewers, some of whom were undergraduate students. This may have led to variation in the quality of the interview data between interview rounds. All the interviewers were trained, and they received feedback about their interview style after each interview, but there were still differences in the extent to which they persisted in asking questions. To minimise the effect of having different interviewers, we made sure that the interviews of each care network in a given interview round were conducted by one and the same interviewer.

Diversity of the sample

We purposefully selected our care networks (Coyne, 1997), and aimed at maximum variation in the characteristics of people with dementia (with regard to gender, socio-economic status, type and stage of dementia, and living arrangements) and type of informal carers, (spouses, children, other relatives, and friends). We succeeded in reaching both men and women with varied stages and types of dementia. Our sample consisted of both community-dwelling people with dementia and others residing in a nursing home or home for the elderly. However, we mainly reached people in the beginning or intermediate stage of dementia, most of whom had spouses and children as informal carers. We excluded people with dementia who could not participate in an interview at the start of the study because the perspectives of the decision-making of people with dementia themselves were essential for answering our research questions. Consequently, we had no participants who were in the end-of-life stage, or who were unable to communicate. Such situations are likely to present different or additional information. Besides people who could not participate in an interview, we also excluded people with dementia who had no informal carers present. We did this because we were interested in how people with dementia interacted with their informal carers and professionals during the decision-making. It is likely that the experiences with shared decision-making differ when no informal carers are involved.

Credibility and transferability of findings

Two common key principles of credibility in qualitative research are systematicity and transparency (Meyrick, 2006). The principle of systematicity refers to the use of a consistent approach to data collection and analysis during the research (Meyrick, 2006). Several elements of our approach contributed to the systematicity of our study: (1) we used source triangulation, and throughout our analysis we consistently

checked our findings from the different perspectives of our care networks; (2) our analysis was the work of a multidisciplinary team consisting of researchers from different fields including health sciences, psychology, gerontology, sociology, medicine, and nursing science; (3) we used multiple analytical approaches to analyse our data including content analysis, timeline research, and typology construction; and, (4) we applied constant comparison throughout all steps of the analysis. A limitation of our approach is that our data are based on self-reporting, not on observations of actual decision-making encounters. The reported behaviours of the professionals may be an overestimation. The fact that we gained information from multiple perspectives may have counterbalanced this limitation.

Transparency means that researchers openly discuss all relevant research processes. We tried to establish this by describing our sampling strategy, the topics and procedures for our data collection, each step in the analysis, and the list of characteristics of the respondents whom we reached. We illustrated how we realised our findings by providing charts of codes, categories, themes, and quotes that underpin our description of the themes. Transparency is necessary for the transferability of study results. Our findings may be transferable to other contexts where shared decision-making is about complex problems and involves multiple participants with an interest in the decisions. When practitioners or researchers want to transfer our findings, they should judge to what extent their decision-making context is similar to that of the care networks of people with dementia (Krefing, 1991). We believe that certain elements should be taken into account when our findings transferred. These elements are: (1) continuous changes over the course of time, (2) progressive decline, which means that the independence of the patient is at stake and the decision-making is intertwined with dealing with loss, and (3) the potentially conflicting interests between patients and informal carers.

Context

Our findings should be considered in the context of the Dutch care system which may differ from other countries in care and residential arrangements. Dutch dementia care is provided in three settings: (1) general care for acute and chronic diseases, (2) mental health care, and (3) long-term institutionalised care, including sheltered homes and nursing homes (Minkman, Ligthart, & Huijsman, 2009). During our study, the continuity of Dutch dementia community care was reinforced by the use of case management programmes all over the country. Most of our community-dwelling respondents, and some of our respondents residing in institutions, were supported by case managers. Case managers are the first contacts for support for people with dementia and their informal carers in the dementia trajectory (Peeters, Pot, de Lange, Spreeuwenberg, &

Francke, 2016; Verkade et al., 2010). Their responsibilities are to provide information, support and counselling, as well as to coordinate the care provided by multiple professionals. Case managers know their clients well, and they are considered the main professionals involved in the decision-making for people with dementia. Although different forms of case management have been implemented worldwide (van Mierlo, Meiland, van Hout, & Dröes, 2014), in regions without case management, the decision-making may be more fragmented. It should be mentioned that the continuation of case management programmes in the Netherlands is currently uncertain. The com-

Table 1. Recommendations

Recommendations
for practice:
<ul style="list-style-type: none">• Methodically, but flexibly, work through the shared decision-making by defining the issue with the participants, develop options, and let the participants try them out• Use the diversity of participants' perspectives to reach decisions that really matter to people with dementia and their informal carers• Remain open to ways of including the perspectives of people with dementia in the decision-making
for education:
<ul style="list-style-type: none">• Include complex shared decision-making in educational curricula• Help students distinguish between situations that require a focus on information exchange about given options and situations that require a focus on working with clients and informal carers to achieve tailor-made options• Use the training material that has been developed on the basis of the findings of this thesis (Groen - van de Ven, 2017b)
for research:
<ul style="list-style-type: none">• Identify the effects of and conditions for using the stepwise approach to shared decision-making in reaching a balance of the needs and preferences of patients and their informal carers.• Explore the characteristics of the interactions between professionals, patients, and families during professional encounters• Modify our model of shared decision-making to fit the context of people with dementia who lack the support of informal carers• Explore the remaining capacities of people with dementia in contributing to the decision-making
for policy making:
<ul style="list-style-type: none">• Include shared decision-making as part of care policies in the context of dementia care• Make sure that people with dementia have a permanently assigned professional who is responsible for guiding the decision-making over the course of the dementia (case management).• Reconsider the communication with families via one contact person.

munity nurse with a generalist background is now being promoted to act as a case manager in the care of frail clients in the community.

Implications for practice, education, research, and policy

On the basis of the findings described in this thesis, we make the following recommendations for practice, education, research, and policy making (Table 1):

Recommendations for practice

We have several recommendations for professionals working with people with dementia and their informal carers when they are making decisions about issues of health and well-being. First, we recommend that they use the proposed steps of shared decision-making and methodically work through the decision-making by defining the issue, developing the options and, where possible, enabling participants to try out options (Groen - van de Ven, Jukema, De Lange, Coppoolse, & Smits, 2017; Groen - van de Ven, Smits, et al., 2017). Special attention is needed for defining the issue, as different participants may have different ideas about what issues should be addressed. An unclearly defined issue is likely to lead to miscommunication and friction in the subsequent steps of shared decision-making. To help professionals use the steps we developed a card (Appendix 1) with suggestions for questions to ask and points requiring attention for each step (Groen - van de Ven, 2017a). Second, professionals should use the diversity of the participants' perspectives, including those of the secondary informal carers, to reach decisions that really matter to people with dementia and their informal carers. Secondary informal carers may be more decisive because of their specific roles in the situation of a person with dementia (Clemmensen et al., 2016). Third, professionals need to remain open to ways of including the perspectives of people with dementia in the decision-making over time. When possible, people with dementia should be included in consultations or decision-making. This means that professionals must adjust their conversations to the tempo and comprehension of people with dementia. However, it is known that people with dementia are likely to be excluded from the decision-making too early (Miller et al., 2014). Professionals should be aware of any marginalisation of people with dementia and help them participate in ways that strengthen their remaining capacities. They can do this by encouraging people with dementia to try options out, and they can include their experiences and emotions as indications of their preferences. In this way, the perspectives of people with dementia should at all times be included in the decision-making without them necessarily always having to be present during consultations.

Recommendations for education

Education for professionals in care and welfare about shared decision-making relies mainly on the traditional model with its focus on exchanging evidence-based information. A new profile for nursing education has recently been introduced in the Netherlands, the 'Bachelor Nursing 2020' (Stuurgroep Bachelor of Nursing 2020, 2015), which is structured along the lines of the well-known CanMEDS Physician Competency Framework (Frankel, 2005). This profile explicitly names the competency of shared decision-making, which is defined as 'systematically deliberating with the care recipient and his or her informal carers about nursing care, and explicitly weighing the different knowledge sources and values of the care recipient.' This definition of shared decision-making reflects the traditional focus on rationally weighing information to reach decisions for an individual patient. While this view of shared decision-making may be relevant to some situations, many nurses encounter vulnerable older patients with complex, multifaceted problems whose lives are intertwined with those of their informal carers. For such situations, the traditional model of shared decision-making remains inadequate. We therefore recommend including a model of shared decision-making for complex situations in the educational profile – a model such as the one developed in this study. Students should learn to distinguish between situations that require a focus on information exchange and preference elicitation (the traditional shared decision-making) and complex situations that require a focus on working with clients and informal carers towards tailor-made options. On the basis of our findings, we developed a training course for shared decision-making in complex situations, which is structured around the steps presented in this thesis (Groen - van de Ven, 2017b). We recommend that students and professionals be trained in using the steps of shared decision-making in complex situations.

Recommendations for future research

The findings presented in this thesis give some directions for future research. First, this thesis presents a model of shared decision-making for people with dementia and their informal carers. On the basis of these findings, we have developed a step-wise approach, tools, and a training course for professionals. Future research could focus on the effects of using the step-wise approach and tools for reaching a balance of the needs and preferences of patients and their informal carers. Second, our findings highlight the importance of including multiple participants in shared decision-making. However, there is little evidence about how shared decision-making consultations with clients and patients work in practice (Laidsaar-Powell, Butow, Bu, Fisher, & Juraskove, 2016; Laidsaar-Powell, Butow, Fisher, & Juraskove, 2017). Therefore, we recommend explorative research that involves observations of consultations of professionals working with clients and families towards shared decisions. More research is necessary to

study shared decision-making for people with dementia who lack the support of informal carers. Research exploring the remaining capacities of people with dementia with respect to decision-making could help professionals and informal carers in effectively including their perspectives in the decision-making.

Recommendations for policy making

This thesis shows that shared decision-making is feasible. Shared decision-making should be part of the policies for good-quality care for people with dementia. Furthermore, the findings of this thesis highlight several elements that are necessary for shared decision-making to succeed. First, shared decision-making in the context of dementia requires a prolonged partnership between the professional and the informal network that is based on trust and on the fact that the participants know each other (Hargraves et al., 2016; Montori, Gafni, & Charles, 2006). People with dementia and their informal carers are faced with many decisions over the course of the dementia. This means that care networks can learn how to reach decisions together in time, which highlights the importance of having a regular contact for shared decision-making. When this PhD project started in 2010, the case manager functioned as this regular contact for most people with dementia. Currently, the funding of case management is under pressure, and in many regions of the country the continuity of case management is insecure (Francke & Peeters, 2015). Therefore, our first recommendation for policy makers is to ensure that people with dementia have a professional who is permanently responsible for guiding the decision-making over the course of the dementia. Such a professional should be a dementia expert and be able to prepare care networks for issues arising in the future. Our second recommendation is related to the communication between health care organisations and families. Many organisations try to structure their communication with families by appointing a single contact within the family, usually the primary informal carer, who is responsible for communicating information from the health care organisation to the other family members. Such a policy, although seemingly practical, may obstruct shared decision-making because it prevents other informal carers from being involved in consultations in which decisions are made. The health-care team may miss relevant information that secondary informal carers provide, which differs from the information given by primary informal carers.

Concluding remarks

This thesis illustrates how challenging shared decision-making in dementia care networks is, but shows that it is feasible. An inclusive approach to shared decision-making for people with dementia acknowledges that they, and their multiple informal carers have differing views and interests that need to be included in reaching decisions. Such

an approach starts with reaching a shared view on the pressing matters at hand, and it incorporates option try-outs and emotions as important ways of exploring alternatives and eliciting preferences. An inclusive approach involves timely discussions that include weighing autonomy versus risk in order to reach a shared understanding about the risks that participants are willing to take.

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Appendix 1

Front of the card with shared decision-making steps:

Hoe pak ik gezamenlijke besluitvorming aan?



Versie: April 2017

Stappen	Gespreksleidraad
De kwestie bespreken Wat is er aan de hand? Uitkomst: Eenduidige visie op het probleem dat wordt aangepakt.	<ul style="list-style-type: none"> • Wat is op dit moment belangrijk voor u? • Waarover maakt u zich zorgen? • Wat zien we samen als probleem dat moet worden aangepakt? • Waar wilt u naartoe werken bij dit probleem? • Spelen er meerdere problemen tegelijk? • Wat pakken we nu aan, wat kan eventueel later?
De mogelijkheden bespreken Wat zijn de mogelijkheden? Uitkomst: Helderheid over wat de keuzemogelijkheden (opties) zijn.	<ul style="list-style-type: none"> • Welke mogelijkheden ziet u zelf? • Wat heeft u zelf al geprobeerd? • Wat werkte daarbij wel en niet? • Wilt u dat ik u vertel over mogelijkheden die ik zie?
Achterhalen van voor- en nadelen Wat zijn na bespreken en uitproberen de voor- en nadelen van de verschillende opties? Uitkomst: De ervaren voor – en nadelen per opties op een rij.	<p>Loop iedere keuzemogelijkheid langs:</p> <ul style="list-style-type: none"> • Waarom zou dit een goede keuzemogelijkheid kunnen zijn? • Welke twijfels heeft u bij deze keuzemogelijkheid? • Wat zou deze keuzemogelijkheid opleveren/kosten? • Wat heeft u nog nodig om de voor – en nadelen van deze keuzemogelijkheid te kennen? • Wilt u dat ik mijn ervaringen met deze keuzemogelijkheden bij anderen met u deel? • Geef ruimte aan de cliënt om verschillende mogelijke oplossingen uit te proberen om te ervaren wat de voor- en nadelen ervan zijn.
De voorkeuren bespreken Wat zijn de voorkeuren van de verschillende betrokkenen? Uitkomst: Helderheid over ieders voorkeur.	<ul style="list-style-type: none"> • Welke voor- en nadelen vindt u het belangrijkst? • Hoe is dit voor andere betrokkenen? • Welke keuzemogelijkheid heeft uw voorkeur en waarom? • Komen onze voorkeuren overeen of niet? • Hoe reageerde de persoon met dementie op het uitproberen van verschillende mogelijkheden?

Stappen	Gespreksleidraad
De beslissing nemen Wat gaan we doen en wanneer, rekening houdend met ieders belangen?	Als voorkeuren overeen komen: <ul style="list-style-type: none"> • Wat moeten we concreet gaan doen? • Wie gaat wat doen en wanneer? Als voorkeuren niet overeenkomen: <ul style="list-style-type: none"> • Waar liggen overeenkomsten en verschillen? • Wat kan een compromis zijn? • Wie gaat wat doen en wanneer?
Uitkomst: Overeenstemming over wie, wat, wanneer gaat doen	
Terugkijken Hoe is het gegaan?	Terugkijken op de beslissing: <ul style="list-style-type: none"> • Hoe tevreden bent u met hoe het nu gaat? • Wat moet eventueel anders? Terugkijken op de besluitvorming: <ul style="list-style-type: none"> • Hoe kijkt u terug op het komen tot deze beslissing? • Wat hebben we geleerd van het samen beslissen in deze situatie? • Wat gaan we de volgende keer weer zo doen? Wat niet?
Uitkomst: Helderheid over wat wél werkte en wat niet en wat zo nodig moet worden aangepast.	

Voor contact en informatie over gezamenlijke besluitvorming in complexe situaties:

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Reverse side of the card with shared decision-making steps

Waar moet ik op letten?

Versie: april 2017



Stappen	Aandachtspunten
De kwestie bespreken Wat is er aan de hand? Uitkomst: Eenduidige visie op het probleem dat wordt aangepakt	<ul style="list-style-type: none"> • De zorgen van <u>alle</u> betrokkenen verhelderen • Iedere betrokkene komt aan het woord • Verschillen in visie verhelderen • Op zoek naar de vraag achter de vraag • Prioriteren van problemen die spelen
De mogelijkheden bespreken Wat zijn de mogelijkheden? Uitkomst: Helderheid over wat de keuzemogelijkheden (opties) zijn.	<ul style="list-style-type: none"> • Eerst ruimte voor ideeën van cliënt en diens netwerk zelf • Dan pas je eigen ideeën over mogelijke oplossingen • Bewustzijn van mogelijkheden die je al had uitgesloten. Kunnen die echt niet? Denken buiten bestaande kaders • Let op! Laat geen voorkeur doorschemeren
Achterhalen van voor – en nadelen Wat zijn na bespreken en uitproberen de voor- en nadelen van de verschillende opties? Uitkomst: De ervaren voor – en nadelen per optie op een rij.	<ul style="list-style-type: none"> • Eerst de overwegingen van cliënt en het netwerk zelf • Iedere betrokkene komt aan het woord • Nagaan wat belangrijk is voor de netwerkleden • Uitproberen kan helpen om voor – en nadelen te ontdekken • Ervaringskennis van andere cliënten (anoniem) of professionele ervaring kun je delen • Let op! Nog geen keuzemogelijkheden kiezen of afstrepen • Let op! Uitproberen is ook echt uitproberen, er wordt een tijd afgesproken waarop de ingezette acties worden geëvalueerd. Er is dan nog een weg terug.
De voorkeuren bespreken Wat zijn de voorkeuren van de verschillende betrokkenen? Uitkomst: Helderheid over ieders voorkeur.	<ul style="list-style-type: none"> • Prioriteren van overwegingen • Iedere betrokkenen komt aan het woord • Zo nodig helpen bij het vormen of verwoorden van voorkeuren • Aandacht hebben voor conflicterende waarden of belangen en dit neutraal benoemen
De beslissing nemen Wat gaan we doen en wanneer, rekening houdend met ieders belangen? Uitkomst: Overeenstemming over wie, wat, wanneer gaat doen	<ul style="list-style-type: none"> • Aandacht voor de timing van acties, zijn betrokkenen er aan toe? • Bouw voldoende tijd in om tot overeenstemming te komen. Plan zo nodig een tweede gesprek. • Aandacht voor verschillen in posities en belangen in het netwerk • Ondersteun de cliënt zo nodig om diens stem te laten horen.

Stappen	Aandachtspunten
Terugkijken Hoe is het gegaan? Uitkomst: Helderheid over wat wél werkte en wat niet en wat zo nodig moet worden aangepast.	<ul style="list-style-type: none"> • Aandacht voor de uitkomst van de beslissing • Aandacht voor het proces van beslissen • Reflecteren op de manier van samenwerken tijdens de besluitvorming • Expliciet aandacht voor het leren samen beslissen

Voor contact en informatie over gezamenlijke besluitvorming in complexe situaties:

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SUMMARY
SAMENVATTING
DANKWOORD
CURRICULUM VITAE
PUBLICATIELIJST



Summary

This thesis provides insight into how shared decision-making proceeds within care networks of people with dementia. These insights are based on three waves of interviews with people with dementia, their informal carers, and professionals in a qualitative, prospective, multi-perspective study. This study is part of a larger research programme, Shared decision-making in care networks of people with dementia, which also included the development of an online support tool for shared decision-making (the Decide Guide).

Chapter 1 elaborates on the background and aims of this PhD study. Dementia is one of the ten most burdensome conditions. The number of people with dementia is expected to increase worldwide from 46.8 million in 2015 to 131.5 million people in 2050. However, the accuracy of the estimated prevalence of dementia for high-income countries is currently being debated. Notwithstanding the uncertainty about the predicted rises in incidence and prevalence, dementia has a great impact on current and future care worldwide.

Good-quality care for a person with dementia requires close collaboration of the informal and professional carers, which is achieved in the care networks consisting of the person with dementia and multiple carers. Informal care, is a crucial part of the care networks. Multiple informal carers may share care tasks and responsibilities for the person with dementia, but typically one or two of them, the primary carers, take up most of the care. They are often supported by secondary informal carers with supplementary caregiving roles. In time, informal care is often no longer enough and professional care also becomes necessary. A range of professionals based in health-care, social care, daycare, housing, transport, and leisure may support people with dementia and their informal carers over the course of the dementia. Case management is often presented as a way of working towards well-organised and coordinated care.

People with dementia and their informal carers make many decisions during the course of the dementia. Decision-making in dementia requires teamwork – it includes the person with dementia, the informal carers, and often multiple professionals. The roles of people with dementia in the decision-making diminish over time, which makes it important to anticipate future decisions and roles. People with dementia want to be involved in the decision-making about their lives for as long as possible. Unfortunately, they are often not involved, not even in the early stages of the dementia. Shared decision-making could be helpful to professionals who want to support the involvement of people with dementia in the decision-making.

Shared decision-making can be defined as the process of professionals and patients working together towards informed preferences for health care options, on the basis of the best available evidence and the patient's values. The essential elements are: defining or explaining the problem, clarifying the fact that patients have a choice (equipoise), presenting options, exchanging knowledge about the pros and cons of the options, checking for understanding, expressing values and preferences, making or deferring the decision, implementing the decision, and arranging follow-up. There is a growing body of knowledge about the effects of shared decision-making with respect to patients' knowledge about options, their feelings of being informed, decisional certainty, and the active role of patients in the decision-making. The recent debate about broadening the conceptualisation of shared decision-making discusses issues that are relevant to care networks of people with dementia: (1) the necessity of building trusting relationships with mutual respect in which participants feel safe having dialogues about what really matters, (2) the recognition that a focus on exchanging evidence-based information alone is too limiting for working out what is best for a given patient, and (3) the realisation that family members are important in shared decision-making.

Shared decision-making is seldom used in the context of dementia. People with dementia are thus excluded from participation in decisions about their own lives. This may lead to suboptimal care. Furthermore, this exclusion ignores their potential as decision-makers. Professionals who want to use shared decision-making feel unprepared to do so. There is a lack of evidence about what constitutes shared decision-making in the context of dementia, what models are relevant, and how professionals can facilitate shared decision-making. This thesis contributes to the knowledge about how shared decision-making proceeds. The overall aim of this PhD study is to gain insight into how shared decision-making takes place in care networks of people with dementia.

Chapter 2 provides insight into the decision trajectories of people with dementia. This chapter is based on the analysis of 285 interviews with 113 purposefully selected respondents. These interviews took place in three waves between July 2010 and July 2012. The respondents belonged to 23 care networks and consisted of 23 people in beginning to advanced stages of dementia, 44 of their informal carers, and 46 of their professional carers. They were interviewed three times at 6-month intervals, so that the interviews for a care network were completed in 12 months. We used an approach of multi-layered qualitative analysis consisting of content analysis, timeline methods, and constant comparison. We found four decision themes in our content analysis: managing daily life, arranging support, community living, and preparing for the future. Our timeline analysis provided eight key events along the dementia trajectory where

multiple decisions are at stake. They start with concerns before the diagnosis of dementia, the diagnosis, the inactivity of the person with dementia, and safety incidents at the beginning stage of the dementia. For more advanced dementia they include 24-hr monitoring, hospitalisation, nursing home admission, and switching between wards. We found that the decisions and key events of people with dementia living alone and those living with a carer differ. These findings show that decisions in dementia relate not only to the disease as such, but to living with the dementia. The individual differences in decision content and sequence may affect shared decision-making and advance care planning. Knowing the key events and related decisions can help professionals and informal carers prepare for the decisions ahead. The professional who facilitates shared decision-making along the trajectory should be aware that the role of the person with dementia is often at stake. In facilitating care networks of people with dementia living alone, the professional should be aware that safety issues may overrule issues about the quality of life of the person with dementia.

Chapter 3 describes the challenges of shared decision-making encountered by care networks of people with dementia. This chapter is based on the content analysis of the first round of interviews with our 113 purposefully selected respondents. The interview guide addressed the decision topics, and the contributions of the different participants to the decision-making. We elicited two themes relating to the challenges of shared decision-making. The first theme, adapting to a situation of diminishing independence, relates to the continuous changes in the situation that care networks of people with dementia are confronted with. Because of the progressive decline of people with dementia, there is a shift in decision-making roles with informal carers taking over more decision-making responsibility. The progressive changes in the situation make it necessary to anticipate future issues. The second theme, tensions in network interactions, relates to the different perspectives and interests of the multiple participants involved in the decision-making. This requires reaching agreement about what to decide about by exchanging information in the care network. We concluded that the challenges of shared decision-making relate to all dimensions of social health. These insights have implications for a model of shared decision-making in dementia care networks. Such a model requires flexibility regarding changing capabilities to preserve the autonomy of the person with dementia. It requires working towards a shared view about what constitutes a problem in the situation. It asks for professionals to advocate for the involvement of people with dementia by helping them participate in ways that strengthen their remaining capacities.

Chapter 4 describes the process elements of decision-making for dementia, in order to enrich the model of collaborative deliberation to facilitate shared decision-making for

care networks of people with dementia. Our qualitative study is based on the secondary analysis of the 113 interviews of the first interview wave with our 23 care networks. Our analysis consisted of three steps. First, we used content analysis to determine the process elements of decision-making in dementia care networks. For this secondary analysis, we used codes that had been developed in our study of decision-making in dementia care networks (Chapter 2). Second, we clustered the codes into meaningful categories regarding the process elements of the decision-making. We did this by using the method of affinity diagramming. Third, we aligned our categories with the elements of the model of collaborative deliberation and defined the necessary adaptations to the model. We enhanced the existing collaborative deliberation model of Elwyn et al. (2014) to include: (1) constructive network engagement, (2) recognising the need for a decision, (3) defining what should be decided, (4) developing alternatives, (5) constructing preferences by deliberation and trying out alternatives, (6) integrating multiple preferences, and (7) evaluating decision-making. We concluded that the adaptations to the model highlight the special attention needed to recognise and define what is to be decided, to try out alternatives, and to handle conflicting interests and preferences. This means that professionals supporting people with dementia and their informal carers should mark the start of the decision-making process and work with participants towards a shared view on the pressing matters at hand.

Chapter 5 explores how people with dementia, their informal carers, and their professionals participate in decision-making about daycare, and describes a typology of participation trajectories. This chapter is based on the analysis of the three interview waves of the 19 care networks in our overall sample that made a decision about daycare (244 interviews). The participants consisted of 19 people with dementia, 36 of their informal carers, and 38 of their professionals (including nurses, daycare employees, and case managers). We used a two-step approach to our analyses, which combined content analysis with a methodology of type construction. The participants' responses related to three critical points in the decision-making trajectory about daycare: (1) the initial positive or negative expectations of daycare; (2) negotiation about trying out daycare by promoting, resisting, or attuning to others; and (3) trying daycare, which resulted in positive or negative reactions from the people with dementia and led to a decision. The ways in which care networks proceeded through these three critical points resulted in a typology of participation trajectories, including: (1) working together positively towards daycare, (2) bringing conflicting perspectives together towards trying daycare, and (3) not reaching commitment to try daycare. Our results show the importance of a trial period, so that people with dementia can experience daycare without having to decide whether to continue it. Our findings show that initial preferences based on information alone may change when people with dementia

experience daycare. We concluded that, whereas shared decision-making in general aims at moving from initial preferences to informed preferences, professionals should focus more on moving from initial preferences to experienced preferences. Preferences of people with dementia may change once they have tried out daycare. Secondary informal carers have an important role in moving towards experienced preferences because their participation may help in moving towards a try-out of daycare.

Chapter 6 summarizes the main findings and conclusions of the study and discusses the theoretical and methodological considerations. Further, this chapter provides recommendations for practice, education, future research, and policy making. Our findings show that shared decision-making in the context of dementia care networks differs from other health care contexts with respect to: (1) the point of departure for shared decision-making, (2) the process of shared decision-making, and (3) the conditions for shared decision-making. The basic assumption of shared decision-making in general is that individual self-determination is important and should be facilitated where possible. This point of departure seems inadequate for people with dementia, and the decisions concern people with dementia as well as the informal carers. People with dementia and their informal carers have different perspectives and interests, so that the decisions are about balancing the needs of the person with dementia and the informal carers. A central dilemma for the participants of shared decision-making in dementia contexts is about balancing the independence of the person with dementia against safety risks.

The process of shared decision-making in dementia care networks differs from other healthcare contexts. First, preparatory work is necessary. The issues concerned must be recognised and defined before a decision can be deliberated. Second, the problems in the care networks of people with dementia are intertwined with their specific situation, so that standard options may not match these problems. Professionals should engage people with dementia and their informal carers in conversations that explicitly invite them to contribute their ideas in order to develop tailor-made options. Third, deliberation in the decision-making of dementia care networks includes not only exchanging information, but also expressing emotions, trying options, and observing the behaviour of the person with dementia. Using the full range of experience, including thinking, acting, feeling and relating to each other, facilitates the involvement of people with dementia, and is necessary for reaching decisions that have meaning to all the participants.

Our findings highlight the specific conditions for successfully making shared decisions in dementia care networks. First, it is important for professionals to use the diversity

of the perspectives of the participants. Our findings show that primary and secondary informal carers often have conflicting perspectives, but including them all helps reach meaningful decisions. Second, professionals should move beyond verbal deliberation about options, and find ways of including people with dementia at the level of their remaining capacities. For instance, people with dementia should be encouraged to try out options, and their emotions and behaviours should be considered as indications of their preferences. Third, it is important to discuss issues in a timely way. Our findings, taken as a whole, help us develop a model of shared decision-making that fits the context of the care networks of people with dementia. Such shared decision-making takes the needs and preferences of both the person with dementia and the informal carers as a point of departure toward achieving a balance of autonomy and safety. The shared decision-making model as presented relates to social health in two ways. First, it includes the social environment of people with dementia in the decision-making. Second, it incorporates several elements that aim at including people with dementia in the decision-making in ways that strengthen their remaining capacities.

We consider the prospective, qualitative, multi-perspective design to be a strength in our study. However, there are some drawbacks to our study. Several elements of our approach contributed to the systematicity of our study: (1) we used source triangulation, (2) our analysis was the work of a multidisciplinary team consisting of researchers from different fields, (3) we analysed our data in multiple analytical approaches, and (4) we applied constant comparison throughout all the steps of the analysis. First, the follow-up period of 12 months was too short to monitor major changes in some care networks. Second, we needed a large interview team to conduct all the interviews. We purposefully selected our care networks. However, we reached mainly people in the beginning or intermediate stage of dementia, whose informal carers were spouses. We had no participants in our sample in the end stage of the dementia or who did not have informal carers. Our findings should be considered in the context of the Dutch care system, which may differ in the care and living arrangements compared to other countries.

We can make several recommendations on the basis of our findings. We recommend that professionals methodically apply shared decision-making by including the participants in defining the issue, and developing options. The participants should be given the opportunity to try options. The professionals should use the diversity of the perspectives of participants and remain open to ways of including people with dementia. We recommend including complex shared decision-making in educational curricula and helping students distinguish between situations that require a focus on information exchange and situations that include complex problems. We recom-

mend future research that will identify the effects of using the stepwise approach to shared decision-making described in this thesis. This research should explore the characteristics of the interactions between professionals, patients, and families during professional encounters, as well as the remaining capacities of people with dementia in contributing to the decision-making. We recommend that policy makers guarantee that people with dementia be assigned a professionals who is permanently responsible for guiding the decision-making over the course of the dementia, and that policy makers reconsider the one-contact policy of many health care organisations.

Samenvatting

Dit proefschrift geeft inzicht in hoe gezamenlijke besluitvorming verloopt in zorgnetwerken van mensen met dementie. Een zorgnetwerk vatten we in deze studie op als de persoon met dementie omringt door diens mantelzorgers en professionele hulpverleners. Dit proefschrift is gebaseerd op een kwalitatieve, prospectieve, multi-perspectief studie bestaande uit drie interviewrondes met mensen met dementie, hun mantelzorgers en hun professionele zorgverleners. De studie maakt deel uit van een groter onderzoeksprogramma, 'Gezamenlijke besluitvorming in zorgnetwerken van ouderen met dementie'. Binnen dit onderzoeksprogramma werd tevens een online beslisshulp ontwikkeld om gezamenlijke besluitvorming te ondersteunen (de BeslisGids) en een competentieprofiel voor professionals.

In **hoofdstuk 1** wordt ingegaan op de achtergrond en de doelstellingen van deze promotiestudie. Dementie behoort tot de top tien van aandoeningen met de hoogste ziektebelasting. De verwachting is dat het aantal mensen met dementie wereldwijd zal stijgen van 46,8 miljoen in 2015 naar 131,5 miljoen in 2050. Hierbij moet worden aangemerkt dat de juistheid van deze schatting van de prevalentie momenteel ter discussie staat voor landen met een hoog gemiddeld inkomen. Hoe dan ook is duidelijk dat dementie wereldwijd een grote impact heeft op de gezondheidszorg van nu en in de toekomst.

Goede zorg voor mensen met dementie vraagt om een nauwe samenwerking tussen mantelzorgers en professionele zorgverleners. Deze krijgt vorm in zorgnetwerken bestaande uit de persoon met dementie, hun mantelzorgers en diverse professionele en vrijwillige zorgverleners. Een belangrijk deel van de zorg wordt verleend door mantelzorgers. Verschillende mantelzorgers kunnen taken en verantwoordelijkheden delen, maar over het algemeen nemen één of twee van hen, de primaire mantelzorgers, de meeste zorg op zich. Zij worden vaak ondersteund door secundaire mantelzorgers die aanvullende zorgrollen vervullen. Na verloop van tijd is mantelzorg vaak niet meer voldoende en is professionele hulp nodig. Diverse professionals op het gebied van zorg, welzijn, huisvesting, vervoer en dagbesteding kunnen mensen met dementie en hun naasten ondersteunen gedurende het verloop van de dementie. Om de zorg goed te organiseren en coördineren, wordt vaak casemanagement ingezet.

Mensen met dementie en hun mantelzorgers nemen veel beslissingen naarmate de dementia vordert. Uit onderzoek blijkt dat mensen met dementie zo lang mogelijk betrokken willen blijven in beslissingen over hun leven. Helaas worden ze vaak buitengesloten, ook in het vroege stadium van dementie. Besluitvorming bij dementie vraagt om teamwork tussen personen met dementie, hun mantelzorgers en professionals.

De besliscapaciteiten van de persoon met dementie nemen af in de loop van de tijd, waardoor het van belang is om tijdig te anticiperen op toekomstige beslissingen. Gezamenlijke besluitvorming kan professionals mogelijk helpen om de betrokkenheid van mensen met dementie in de besluitvorming te ondersteunen.

Gezamenlijke besluitvorming kan worden gedefinieerd als een proces waarbij professionals en patiënten samenwerken om te komen tot geïnformeerde voorkeuren voor behandelopties op basis van het best beschikbare bewijs en de waarden van de patiënt. Essentiële onderdelen van dit proces zijn: het definiëren en uitleggen van het probleem, duidelijk maken aan de patiënt dat deze een keuze heeft (equipoise), opties presenteren, informatie uitwisselen over de voor- en nadelen van de opties, nagaan of de informatie begrepen is, waarden en voorkeuren bespreken, een beslissing nemen of deze uitstellen, de beslissing uitvoeren en nazorg regelen. Er is steeds meer kennis over de effecten van gezamenlijke besluitvorming op de kennis van patiënten, het gevoel geïnformeerd te zijn, de ervaren zekerheid over de gemaakte keuze en de actieve rol van de patiënt in de besluitvorming. In het recente wetenschappelijke debat wordt gepleit voor een verbreding van het concept gezamenlijke besluitvorming. Hierbij komen onderwerpen aan bod die ook relevant zijn voor zorgnetwerken van mensen met dementie, namelijk: (1) het belang van een vertrouwensrelatie met wederzijds respect, waarin deelnemers zich veilig voelen om de dialoog aan te gaan over wat er echt toe doet, (2) het besef dat de focus op het uitwisselen van alleen evidence based informatie te beperkt is om uit te vinden wat het beste is voor een bepaalde patiënt en (3) de erkenning van het belang van familieleden binnen gezamenlijke besluitvorming.

Mensen met dementie worden vaak buitengesloten bij beslissingen over hun eigen leven. Dit kan leiden tot suboptimale zorg. Bovendien worden hiermee hun competenties als besluitvormer genegeerd. Professionals ervaren handelingsverlegenheid in het faciliteren van gezamenlijke besluitvorming. Ze missen kennis over wat gezamenlijke besluitvorming inhoudt in de context van dementie, welke modellen relevant zijn en hoe zij gezamenlijke besluitvorming kunnen ondersteunen. Het doel van deze promotiestudie is om inzicht te verkrijgen in hoe gezamenlijke besluitvorming verloopt in zorgnetwerken van mensen met dementie.

In **hoofdstuk 2** wordt inzicht gegeven in de beslissingen die mensen met dementie in de loop van het dementietraject nemen. Dit hoofdstuk is gebaseerd op de analyse van 285 interviews met 113 doelbewust geselecteerde respondenten. De respondenten behoorden tot 23 zorgnetwerken van mensen met dementie bestaande uit 23 mensen met beginnende tot gevorderde dementie, 44 van hun mantelzorgers en 46 van hun professionele zorgverleners. Zij werden drie keer geïnterviewd met tussenpozen van

een half jaar. De interviews werden afgenomen in de periode juli 2010 tot en met juli 2012. We gebruikten een combinatie van verschillende kwalitatieve analysetechnieken bestaande uit inhoudsanalyse en tijdlijnanalyse. De inhoudsanalyse leverde vier inhoudelijke beslisthema's op: (1) het omgaan met het dagelijks leven, (2) het regelen van ondersteuning, (3) het leven in de samenleving en (4) zich voorbereiden op de toekomst. Onze tijdlijnanalyses gaven zicht op acht sleutelmomenten in de loop van het dementietraject waarop meerdere beslissingen tegelijk aan de orde waren. In het beginstadium van dementie betreffen de sleutelmomenten de periode van zorgen om de persoon nog voordat de diagnose dementie is gesteld, de diagnose, passiviteit van de persoon met dementie, en incidenten op het gebied van veiligheid. In de meer gevorderde stadia van dementie zijn de situatie waarin 24-uurs monitoring nodig blijkt, ziekenhuisopname, opname in een verpleeghuis en het verhuizen naar een andere afdeling sleutelmomenten. We zagen dat de beslissingen en sleutelmomenten verschilden voor mensen met dementie die alleen woonden ten opzichten van zij die samenwoonden met hun mantelzorger. Deze bevindingen laten zien dat de beslissingen niet alleen te maken hebben met het hebben van dementie, maar zeker ook met het leven met dementie. De individuele verschillen in inhoud en volgorde van beslissingen hebben mogelijk invloed op gezamenlijke besluitvorming en proactieve zorgplanning (advance care planning). Kennis over de sleutelmomenten en hieraan gerelateerde beslissingen kan professionals en mantelzorgers helpen in het voorbereiden op beslissingen in de toekomst. Voor professionals die gezamenlijke besluitvorming faciliteren is het van belang te weten dat de rol die de persoon met dementie heeft in de besluitvorming onder druk staat tijdens de sleutelmomenten. Daarnaast lijken, in het bijzonder bij mensen met dementie die alleen wonen, veiligheidskwesties de kwaliteit van leven van mensen met dementie te overheersen.

In **hoofdstuk 3** wordt beschreven voor welke uitdagingen de zorgnetwerken van mensen met dementie komen te staan als zij vorm willen geven aan gezamenlijke besluitvorming. Dit hoofdstuk is gebaseerd op inhoudsanalyse van de eerste ronde van interviews met 113 doelbewust geselecteerde respondenten. De topiclijst die we gebruikten ging in op de onderwerpen waarover beslissingen werden genomen en de bijdragen van de verschillende deelnemers aan de besluitvorming. Onze analyses onthulden twee thema's die de uitdagingen van gezamenlijke besluitvorming in deze context weergeven. Het eerste thema, het aanpassen aan een situatie van afnemende zelfstandigheid, houdt verband met de continue veranderingen in de situatie waarmee zorgnetwerken van mensen met dementie worden geconfronteerd. Vanwege het progressieve beloop van de dementie ontstaat er een verschuiving in beslisrollen waarbij mantelzorgers steeds meer verantwoordelijkheid voor de besluitvorming op zich nemen. De progressieve verandering in de situatie maakt het bovendien nodig om

te anticiperen op toekomstige beslissingen. Het tweede thema, spanningen in de interacties tussen netwerkleden, heeft betrekking op de verschillende perspectieven en belangen van de diverse betrokkenen in de besluitvorming. Dit vraagt om het bereiken van overeenstemming over welke onderwerpen om besluitvorming vragen. Hiervoor is het nodig om informatie uit te wisselen in het zorgnetwerk. We concludeerden dat de vastgestelde uitdagingen een relatie hebben met alle dimensies van sociale gezondheid, uit het concept positieve gezondheid van Huber: (1) voldoen aan sociale verplichtingen door het eigen potentieel te benutten, (2) het eigen leven vormgeven met een zekere mate van onafhankelijkheid ondanks ziekte, (3) de mogelijkheid om te participeren in sociale activiteiten. De inzichten uit onze studie zijn van belang voor het ontwikkelen van een wetenschappelijk model van gezamenlijke besluitvorming in de context van dementie. Een dergelijk model moet flexibel omgaan met de veranderende capaciteiten van de persoon met dementie om diens autonomie te bewaren. Verder is het nodig om toe te werken naar een gezamenlijke visie in het zorgnetwerk op wat het probleem is waarvoor besluitvorming nodig is. Ten slotte zouden professionals de betrokkenheid van de persoon met dementie moeten ondersteunen door hen te helpen om deel te nemen aan de besluitvorming op een manier die hun vermogens versterkt.

In **hoofdstuk 4** beschrijven we de elementen van het besluitvormingsproces bij dementie om daarmee het theoretische model van collaborative deliberation (Elwyn et al. 2014) te verrijken. Dit doen we met het doel om professionals te ondersteunen in gezamenlijke besluitvorming met mensen met dementie en hun naasten. Deze kwalitatieve studie is gebaseerd op de secundaire analyse van de 113 interviews uit de eerste ronde interviews met de 23 deelnemende zorgnetwerken van deze promotiestudie. Onze analyse bestond uit drie stappen. Eerst gebruikte we inhoudsanalyse om de elementen vast te stellen van het besluitvormingsproces in de zorgnetwerken van mensen met dementie. Voor deze secundaire analyse maakten we gebruik van codes die we ontwikkelden in onze studie naar besluitvorming in zorgnetwerken van mensen met dementie (hoofdstuk 3). Daarna clusterden we de codes in betekenisvolle categorieën wat betreft de proceselementen van de besluitvorming. Hiervoor gebruikten we de methode van Affinity Diagramming. Ten slotte vergeleken we de ontwikkelde categorieën met de elementen uit het model van collaborative deliberation en beschreven op basis daarvan welke aanpassingen nodig zijn om dit model passend te maken voor de context van dementie. Op die manier breidden we het bestaande model van collaborative deliberation uit tot een model dat de volgende elementen omvat: (1) constructieve betrokkenheid binnen het netwerk, (2) het herkennen van de noodzaak tot besluitvorming, (3) vaststellen waarover besloten moet worden, (4) het ontwikkelen van alternatieven, (5) voorkeuren ontwikkelen door overleg en het

uitproberen van alternatieven, (6) het integreren van verschillende voorkeuren en (7) het evalueren van de besluitvorming. De aanpassingen aan het model benadrukken de speciale aandacht die nodig is voor het herkennen en vaststellen van onderwerpen die om besluitvorming vragen, het uitproberen van alternatieven en het omgaan met conflicterende belangen en voorkeuren in het zorgnetwerk. Dit betekent dat professionals die mensen met dementie en hun naasten ondersteunen de start van de besluitvorming duidelijk moeten markeren en samen met de betrokkenen moeten toewerken naar een gezamenlijke visie op de meest urgente onderwerpen.

In **hoofdstuk 5** onderzoeken we hoe mensen met dementie, hun mantelzorgers en hulpverleners participeren in besluitvorming over een specifieke kwestie, namelijk dagopvang. Dagopvang is een belangrijke bron van ondersteuning voor veel mensen met dementie. Het is bovendien vaak één van de eerste beslissingen waarbij de persoon met dementie buitenshuis zorg ontvangt. Dit hoofdstuk is gebaseerd op de analyse van de drie interviewronden met de 19 zorgnetwerken in onze steekproef waarbinnen sprake was van een beslissing over dagopvang (244 interviews in totaal). De deelnemers bestonden uit 19 personen met dementie, 36 van hun mantelzorgers en 38 van hun professionals (waaronder verpleegkundigen, medewerkers van de dagopvang en casemanagers). De analyses bestonden uit twee stappen waarbij we inhoudsanalyse combineerden met een methode voor typologieconstructie. Onze analyses laten zien dat het beslistraject rond dagopvang drie kritische momenten kent: (1) de positieve of negatieve verwachtingen van dagopvang vooraf, (2) het onderhandelen over het uitproberen van dagopvang door het promoten of afwijzen van dagopvang en het afstemmen op elkaar en (3) het uitproberen van dagopvang wat resulteert in positieve of negatieve reacties van de persoon met dementie die leiden tot een beslissing over dagopvang. De wijze waarop zorgnetwerken deze drie kritische momenten in het beslistraject doorlopen, levert drie typen participatietrajecten op: (1) positief samenwerken richting dagopvang, (2) conflicterende perspectieven samenbrengen om te komen tot het uitproberen van dagopvang en (3) geen steun bereiken voor het uitproberen van dagopvang. Onze resultaten laten het belang zien van een proefperiode waarin dagopvang kan worden uitgeprobeerd zodat personen met dementie kunnen ervaren wat dagopvang inhoudt zonder er al definitief over te hoeven beslissen. De bevindingen maken verder duidelijk dat aanvankelijke voorkeuren op basis van alleen informatie kunnen veranderen wanneer personen met dementie dagopvang hebben uitgeprobeerd. Op basis hiervan trekken we de conclusie dat waar gezamenlijke besluitvorming in het algemeen zich richt op het ontwikkelen van geïnformeerde voorkeuren, het in de context van dementie belangrijk is toe te werken naar 'ervaren voorkeuren'. Mantelzorgers wat meer op afstand (secundaire mantelzorgers)

hebben hierin een belangrijke rol omdat hun betrokkenheid in de besluitvorming kan helpen in het toewerken naar een proefperiode van dagopvang.

In **hoofdstuk 6** vatten we de belangrijkste bevindingen en conclusies van deze promotiestudie samen en bespreken we de theoretische en methodologische overwegingen. Verder doen we in dit hoofdstuk aanbevelingen voor praktijk, onderwijs, vervolgonderzoek en beleid. Onze bevindingen laten zien dat gezamenlijke besluitvorming in de context van zorgnetwerken van mensen met dementie mogelijk is. Zij verschilt van andere situaties in de gezondheidszorg wat betreft uitgangspunt, proces en randvoorwaarden. Het uitgangspunt van gezamenlijke besluitvorming in het algemeen is dat individuele zelfbeschikking belangrijk is en waar mogelijk ondersteund moet worden. Dit uitgangspunt lijkt ontoereikend in de context van dementie omdat beslissingen consequenties hebben voor zowel de persoon met dementie als diens mantelzorgers. Hierdoor gaat het om het afwegen van de behoeften van zowel personen met dementie als hun mantelzorgers. Een centraal dilemma hierbij is het afwegen van de zelfstandigheid en onafhankelijkheid van de persoon met dementie ten opzichte van veiligheidsrisico's.

Het proces van gezamenlijke besluitvorming in zorgnetwerken van mensen met dementie verschilt in drie opzichten van andere situaties in de gezondheidszorg. Ten eerste is voorbereidend werk nodig. De onderwerpen die om besluitvorming vragen moeten worden herkend en gedefinieerd voordat er over opties gesproken kan worden. Ten tweede zijn de problemen waar zorgnetwerken mee te maken krijgen, verweven met de specifieke situatie van de persoon met dementie waardoor er geen standaardopties beschikbaar zijn om de ervaren problemen het hoofd te bieden. Professionals zouden daarom mensen met dementie en hun mantelzorgers expliciet moeten uitnodigen om hun ideeën te delen over het omgaan met de situatie om zo te komen tot oplossingen op maat. Ten derde gaat het bij het overwegen van opties niet alleen om het uitwisselen van informatie, maar ook om emoties, het uitproberen van opties en het observeren van het gedrag van de persoon met dementie. Om tot betekenisvolle beslissingen te komen voor alle betrokkenen, is het nodig de volle breedte aan ervaringen van de betrokkenen mee te nemen. Dat wil zeggen denken, maar ook handelen, voelen en de relaties met anderen.

Onze bevindingen laten enkele specifieke randvoorwaarden zien voor succesvolle gezamenlijke besluitvorming in zorgnetwerken van ouderen met dementie. Ten eerste is het van belang dat professionals gebruik maken van de diversiteit aan perspectieven van de verschillende betrokkenen. Onze resultaten maken duidelijk dat primaire en secundaire mantelzorgers vaak conflicterende perspectieven hebben, maar dat het

betrekken van beiden helpt in het bereiken van betekenisvolle beslissingen voor de persoon met dementie. Ten tweede zouden professionals verder moeten gaan dan het alleen verbaal bespreken van opties. Zij zouden moeten zoeken naar manieren om mensen met dementie te betrekken in de besluitvorming op een manier die aansluit bij hun resterende vermogens. Bijvoorbeeld door mensen met dementie aan te moedigen om opties uit te proberen waarbij hun emoties en gedrag als indicaties kunnen worden beschouwd voor hun voorkeuren wanneer het voor hen moeilijk is deze te verwoorden. Ten derde is het van belang om onderwerpen tijdig te bespreken.

Onze bevindingen helpen ons om een model te ontwikkelen van gezamenlijke besluitvorming dat aansluit op de specifieke context van zorgnetwerken van mensen met dementie. Dit model van gezamenlijke besluitvorming neemt de behoeften en voorkeuren van zowel mensen met dementie als hun mantelzorgers als uitgangspunt en is gericht op het bereiken van de balans tussen enerzijds autonomie en anderzijds veiligheid van de persoon met dementie. Het gepresenteerde model houdt op twee manieren verband met het begrip sociale gezondheid (Huber). Ten eerste omdat het ontwikkelde model expliciet de sociale omgeving van de persoon met dementie onderdeel maakt van de besluitvorming. Ten tweede omdat het model verschillende elementen bevat die bedoeld zijn om mensen met dementie in de besluitvorming te betrekken op een manier die hun resterende vermogens aanspreekt.

Wij zien het kwalitatieve, prospectieve, multi-perspectief design als de kracht van dit promotieonderzoek. Verschillende elementen in onze aanpak droegen bij aan het systematische karakter van onze studie: (1) het gebruik van bronnentriangulatie, (2) een multidisciplinair onderzoeksteam, (3) een variatie van analysetechnieken en (4) constante vergelijking gedurende alle stappen in de analyse. Ons onderzoek kent ook beperkingen. Ten eerste bleek de follow-up periode van 12 maanden in sommige zorgnetwerken te kort om grote veranderingen waar te nemen. Ten tweede hadden we een groot interviewteam nodig om alle interviews af te nemen. We selecteerden onze zorgnetwerken doelbewust. Desondanks bereikten we met name mensen in het begin- of middenstadium van dementie van wie de partner de primaire mantelzorger was. We hadden geen respondenten in het eindstadium van dementie of die geen mantelzorg kregen. Onze bevindingen moeten verder gezien worden in het licht van het Nederlandse zorgsysteem, wat kan verschillen van andere landen wat betreft zorg en ondersteuning aan mensen met dementie.

Naar aanleiding van onze bevindingen doen we verschillende aanbevelingen. We bevelen professionals aan de stappen van gezamenlijke besluitvorming te gebruiken zoals beschreven in dit proefschrift. Personen met dementie en hun mantelzorgers zouden

betrokken moeten worden bij het vaststellen van het probleem en bij het ontwikkelen van mogelijke oplossingen. Personen met dementie zouden hierbij de mogelijkheid moeten krijgen om waar mogelijk opties uit te proberen alvorens hierover een beslissing te nemen. Emoties en gedrag kunnen worden meegenomen in de besluitvorming als signalen voor de voorkeuren van een persoon met dementie. Professionals zouden gebruik moeten maken van de diversiteit aan perspectieven van de verschillende betrokkenen en open blijven staan voor manieren om de persoon met dementie op passende wijze te betrekken in de besluitvorming. We raden opleidingen in zorg en welzijn aan om gezamenlijke besluitvorming op te nemen in het curriculum en om studenten te leren onderscheid te maken tussen situaties die vragen om een uitwisseling van evidence based informatie en situaties waarbij complexe problemen vanuit de ervaringen van de betrokkenen verkend moeten worden. Vervolgonderzoek kan zich richten op wat de effecten zijn van de stapsgewijze aanpak van gezamenlijke besluitvorming zoals beschreven in dit proefschrift. Hierbij zou aandacht kunnen worden geschonken aan de interacties tussen de verschillende betrokkenen professionals, cliënten en families, gedurende consulten. Ook is nader onderzoek gewenst naar de resterende vermogens van mensen met dementie om bij te dragen aan gezamenlijke besluitvorming. We adviseren beleidsmakers om ervoor te waken dat mensen met dementie een vaste professional hebben die verantwoordelijk is voor het begeleiden van de besluitvorming gedurende het hele dementietraject. Daarnaast raden we aan om het één contactpersonen beleid te heroverwegen, gezien het belang van het betrekken van meerdere familieleden om te komen tot betekenisvolle besluiten voor de persoon met dementie.

Dankwoord

*it's always just that little bit more
That doesn't get you what you're looking for
But gets you where you need to go*

Uit: Candles van het album Out of the Game, Rufus Wainwright (2012)

Aan de never-ending story die promoveren heet, komt dan toch een einde. Heel veel mensen hebben mij in de loop van deze zeven jaar gevraagd: “Hoe hou je dat toch vol?” Mijn antwoord was dan zoiets als: “Gewoon maar doorgaan”. Maar, dat is natuurlijk een veel te simpel antwoord. Ik kon alleen doorgaan dankzij de medewerking, hulp en ondersteuning van heel veel mensen, die ik hier graag wil bedanken.

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Myrra, je bent de grand dame van het onderzoek naar psychosociale interventies bij dementie. Wat een eer om jou als promotor te mogen hebben. Jouw focus op de wederkerigheid van mensen met dementie en op wat ze wél kunnen, is enorm inspirerend. Je wilde absoluut niet een promotie op afstand en zorgde voor regelmatige overleggen in Nijmegen of Zwolle. Het was heel goed om elkaar af en toe te zien, naast het telefoon – en mailcontact. Als promotor heb je me uitgedaagd om tot het uiterste van mijn kunnen te gaan. Je waakte daarbij altijd over de rigor van het onderzoek en eiste constante kwaliteit. Ik moet toegeven, het was best wel eens frustrerend als ik ergens lang en hard aan had gewerkt en jij er toch nog een slag overheen wilde hebben. Maar, de nieuwere versie was altijd beter. Ik ben heel trots op wat ik met jouw hulp heb kunnen laten zien.

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Mineur, bedankt voor jullie interesse om de opgedane inzichten een plaats te geven in het curriculum van de opleidingen Toegepaste Gerontologie, Verpleegkunde en Sociaal werk. Jullie weten het, ik denk graag met jullie mee en ben ook erg benieuwd naar hoe de lessen gaan uitpakken.

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Een promovenda moet af en toe ook ontspannen. Dat deed ik bij sportschool XLPRO tijdens de yoga en spinninglessen onder leiding van Esther en Dirk-Jan van Heijningen. Het was niet alleen een fysieke maar ook een mentale training ('Je bent er bijna, kom op, nu niet opgeven.'), want die promotie blijft altijd op de achtergrond aanwezig. Bij het laatste nummer van de spinningles deed ik vaak mijn ogen dicht en stelde me voor dat het de dag van de promotie was en zo fietste ik dan richting die felbegeerde bul. Dirk-Jan, nu begrijp je waarom ik juist dan met extra energie die trappers rond liet gaan. Ik ben heel benieuwd hoe die dag straks in het echt zal zijn. Naast de sportschool was daar natuurlijk de balletles om op de vrijdag alles even echt los te laten. Met Juf Maschenka en mijn vaste dansmaatjes Jeannette, Lucy, Marijke en Samantha zwierde ik het weekend in (al moet ik bekennen dat na de les de laptop vaak nog wel open ging).

Mijn studiemaatjes uit Maastricht, Alice, Dorien, Ilse, Petra en Yvonne. In ieder geval eens per jaar zien we elkaar ergens in het land. En natuurlijk kwam dan ook altijd die promotie ter sprake. Soms voelde het voor mij alsof er in dat jaar niets noemenswaardigs gebeurd was. Nog steeds geen publicatie. Dat feestje nog steeds niet dichterbij. Jullie verbaasden je soms over hoe het werkt in de onderzoekswereld en ik op mijn beurt verwonderde me over jullie verhalen vanuit het beleid en management van de zorg. Het leven ging niet altijd over rozen. Sommigen van jullie hebben veel voor de kiezen gekregen. Dat maakt het extra bijzonder als jullie er straks allemaal bij zijn om samen feest te vieren.

Pepijn en Susanne, jullie Mette kwam op maandag gezellig met ons mee vanuit school totdat onze buitenschoolse activiteiten een ander schema vereisten. Omgekeerd kunnen onze meiden altijd bij jullie terecht. Dat is ontzettend fijn en vertrouwd. Ik hoop dat we dat nog lang blijven doen. Sanne, Joris, Sonja en Remco mede door het ballet

van de meiden hebben we ontdekt dat het heel gezellig is om samen op pad te gaan met al die kinderen. Ik kijk uit naar het volgende uitje.

En dan mijn paranimfen. Jullie staan mij bij tijdens de verdediging. En dat geeft een gerust gevoel. Marijke, samen promoveerden we op het SDM-programma. Niemand kent de ins en outs van mijn onderzoek zoals jij. Altijd iemand hebben om mee te sparren, was een enorme luxe. We vulden elkaar met onze uiteenlopende kwaliteiten goed aan. Ik heb veel geleerd van hoe jij de dingen aanpakt, juist omdat dit soms zo anders is dan ik het zelf zou doen. Als een soort grote zus ging je me voor. In het begin deden we veel samen, maar al snel hadden onze trajecten ieder hun eigen inhoud, dynamiek en planning en haalde jij ruim voor mij de eindstreep. Inmiddels werk je (eindelijk) dichtbij huis in Sneek en zien we elkaar niet dagelijks meer. Maar, gelukkig sta je op 22 november naast me.

Julian, wij leerden elkaar kennen via de zwangerschapsgym. We zagen elkaar tijdens mijn verlof bijna dagelijks. En daarna was dat vaste prik op woensdag, tot ik verhuisde naar Zwolle. Eerlijk, en ik zou haast zeggen, Hollands direct, zeg je waar het op staat. Je vond het maar niks dat ik met die promotie zou starten terwijl ik net Eva had gekregen. Maar, naarmate het traject vorderde zag je dat het echt was wat bij me past, ook al moet je dan belachelijk veel overwerken. Je hebt me altijd gesteund met raad en daad. Het is veel waard om een vriendin te hebben die je zo nodig een spiegel voor durft te houden. En daarnaast kunnen we eindeloos kletsen en samen lachen en huilen. Ik mis het heel erg dat ik niet meer zomaar even bij je kan binnenlopen in Groningen. Fijn dat je dicht in de buurt bent op 22 november!

Ons pap en mam, jullie hebben me altijd gesteund in alles wat ik deed. Bij dit promotietraject vanaf het eerste sollicitatiegesprek. Oma reisde mee naar Zwolle om Eva bij zich te houden tijdens het gesprek. Met vijf weken oud had ze nog iedere drie uur borstvoeding nodig. Het was symbolisch voor de ingewikkelde spagaat die de combinatie van dit promotietraject met een jong gezin soms was. En voor de grote rol die jullie als (groot)ouders hierin speelden in de zorg voor de meiden. Opa Bergen, ook u stond voor ons klaar. U combineerde het oppassen met het op orde brengen van onze tuin. Als u bent langs geweest ziet die er altijd weer picobello uit. Dat is dubbel genieten. Sander, Bianca en Patrick, jullie vroegen vaak belangstellend naar hoe het er voor stond en zeiden hoe knap jullie het vonden dat ik het allemaal deed. Sander en Bianca, dat we Evi af en toe mochten lenen was heerlijk. Met zo'n kleintje in huis verdwijnt dat proefschrift voor even naar de achtergrond.

Lieve Milan, Veerle en Eva wat zijn jullie groot gegroeid in de tijd dat ik met dit proefschrift bezig was. Milan, ik vind het boffen dat ik zo'n prachtige jongen er zomaar bij heb gekregen. Als jij er bent, is het gezin pas echt compleet. Veerle en Eva, jullie zijn nu al zo groot dat jullie meeleven met de ups en downs van het promoveren en vragen hoe het gaat met het artikel. Ik hoop dat jullie alle drie net als ik gaan ontdekken waar je goed in bent en wat je heel graag doet.

Lieve Simon, jij stond er helemaal achter dat ik dit avontuur aanging terwijl we een jong gezin hadden en jij zelf al veel langer en sterker de ambitie had om te promoveren. Gelukkig werd jouw voorstel een aantal maanden later ook goedgekeurd en kon met je eigen promotietraject beginnen. Twee promovendi en twee kleine kinderen, het was best hectisch in huize Groen. Maar het leven valt nu eenmaal niet te plannen en kansen doen zich maar één keer voor. Iedere avond met de kinderen op bed, zaten we met de laptops tegenover elkaar aan tafel. Onze werkvrije donderdagavonden waren daarbij een uitkomst. Lieve lief, het waren tropenjaren en voor jou blijft het nog even door buffelen. Ik zal er voor je zijn. En dan als die promoties straks allebei klaar zijn en de rust weer terugkeert in huize Groen? Ja, dan..... bedenken we vast weer nieuwe plannen samen. Ik hou van je.

Curriculum vitae

Leontine Groen – van de Ven werd geboren op 3 december 1976 te Eindhoven. In 1994 rondde zij de HAVO af aan het Van Maerlantlyceum te Eindhoven. Daarna kreeg zij de kans om haar droomopleiding te volgen: de Vroedvrouwenschool in Kerkrade. Na twee jaar bleek dat dit beroep niet voor haar was weggelegd en keerde zij terug naar Eindhoven om in 1996 aan de Fontys Hogeschool te starten met de HBO-V. Met de propedeuse van deze studie op zak kreeg ze in 1997 toegang tot de studie Gezondheidswetenschappen aan de Universiteit Maastricht. Zij stond aan de wieg van de studievereniging van de destijds nieuwe studie Zorgwetenschappen. Haar afstudeeronderzoek ging over autonomie bij mensen met een hoge dwarslaesie. In 2001 behaalde Leontine haar bul en bleef aansluitend werken als projectmedewerker bij het iRv, Kenniscentrum voor Revalidatie en Handicap te Hoensbroek (inmiddels Vilans). Hier werd de kiem gelegd voor haar interesse in de eigen regie, participatie en inclusie van mensen met een beperking. In 2006 verruilde zij onderzoek voor onderwijs en begon als docent ethiek aan de opleiding verpleegkunde van Hogeschool Windesheim. Ze maakte er geen geheim van dat ze naast het onderwijs ook nog steeds ambities had als onderzoeker en toen het lectoraat Innoveren in de Ouderenzorg (inmiddels Innoveren met Ouderen) van Dr. Carolien Smits in 2008 startte, was zij er meteen bij. Zij combineerde haar docentschap met het doen van onderzoek tot zich in 2010 de kans voordeed om een promotietraject te beginnen op een onderwerp dat haar nauw aan het hart ligt. Van 2010 tot 2015 werkte zij als promovenda binnen het onderzoeksprogramma ‘Gezamenlijke besluitvorming in zorgnetwerken van ouderen met dementie’. Hierbinnen werkte zij samen met de afdeling IQ Healthcare van het Radboud UMC en het lectoraat Transitie in Zorg van Hogeschool Rotterdam. Vanaf 2011 was zij daarnaast gastdocent bij de post-HBO cursus Casemanagement Dementie. In 2015 nam ze naast haar werk als onderzoeker het docentschap weer op, nu als docent onderzoeksvaardigheden bij de opleiding Verpleegkunde en later ook bij de opleiding Toegepaste Gerontologie. Momenteel combineert Leontine onderzoek, onderwijs en nascholing van professionals vanuit haar thuisbasis, het lectoraat Innoveren met Ouderen.

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