Chapter 1

General Introduction
The research in this thesis focuses on the evaluation and implementation of personalized psychosocial interventions for people with dementia who live in the community and for their informal caregivers. Community-based care for dementia is often fragmented and not specifically tailored to the individual needs of people with dementia and their informal caregivers. Whereas over the last decade personalized care in the nursing home setting received increasing attention (Testad et al., 2014), this was not the case for the community care setting.

To better understand which subgroups benefit from which psychosocial interventions, we started our research by reviewing the literature on (possible) relationships between personal characteristics of our target group (people with dementia and informal caregivers) and (positive) outcomes of the described intervention. Subsequently we evaluated four different personalized care interventions. Three of them were aimed at the informal caregiver (provision of information on care and social services by a digital interactive social chart called DEM-DISC; Dementelcoach, a telephone support intervention; and case management in dementia), and one intervention was aimed at both formal and informal caregivers (an intervention to enhance the transfer of psychiatric care information regarding people with dementia with complex behavior problems to nursing home personnel).

Besides the efficacy of these interventions we investigated implementation issues as well. The results of these studies were used to create an ‘evidence-based implementation model and checklist’ to promote further implementation of individualized dementia care interventions in the community.

The general introduction below provides the outline and explains the context of this thesis in more detail.

General introduction

Incidence and impact of dementia

The number of people diagnosed with dementia will rise dramatically over the next decades. Worldwide it is estimated that 44.4 million people have dementia today and this number will increase to 135.5 million in 2050 (Alzheimer Disease International Report 2013). In the Netherlands, over 260,000 people are diagnosed with dementia, and this number will more than double in 2050 (Alzheimer Netherlands Report 2014). Dementia ranks very high when it comes to health care-related costs. More than 5% of the total health care budget in the Netherlands is spent on dementia, and dementia-related costs make up 24% of the total health care costs for psychiatric disorders (Meijer et al., 2014).
Approximately 70% of the people with dementia live at home (Black et al., 2013) and are taken care of by their informal caregiver, usually their spouse or another family member. Providing care for a person with dementia is stressful: 90% of informal caregivers are overburdened or run the risk of becoming overburdened (Alzheimer Netherlands Report 2013). Informal caregivers frequently suffer from high levels of strain, anxiety and depression (Schulz et al., 1995; Pot et al., 2000; Cooper et al., 2007; Brodaty et al., 2013). A high subjective burden in informal caregivers is one of the strongest predictors of institutionalization of people with dementia (Alzheimer Netherlands Report, 2013, Eska et al., 2013; Prince et al., 2013; Van der Lee et al., 2014).

The expected increase of people with dementia puts pressure on the available community and long term care services that aim to support them and their caregivers. As the amount of available care in the coming decades is not expected to rise at the same rate, people with dementia will become even more dependent on care delivered by informal caregivers i.e. their spouses, other family members, friends, neighbors and volunteers (Van der Roest et al., 2010). Over the years, the importance of supporting informal caregivers has become more apparent. Many different care interventions have been developed to support and provide information to carers, although not all have proven to be equally effective (Thompson et al., 2007).

More adequate support is necessary in order to help people with dementia and their informal caregivers who live in the community deal with dementia, to prevent informal caregivers from developing their own mental health problems, to improve the quality of life of both groups, and to prevent or delay institutionalization of the person with dementia.

**Psychosocial interventions in dementia**

Psychosocial interventions aim to improve the quality of life of people with dementia and informal caregivers, to minimize the impact of existing deficits, and, unlike pharmacological interventions, do not have physical side effects (Vasse et al., 2011). Psychosocial interventions can be directed at different targets, such as improving coping styles of people with dementia and informal caregivers, reducing mental health problems in informal caregivers, including depression and anxiety, reducing behavioral problems in people with dementia, improving cognitive functioning, improving social interaction and overall wellbeing, and reducing or delaying admission to a nursing home (Robinson et al., 2010). The benefits of psychosocial interventions to support people with dementia and informal caregivers both in the community and in nursing home care have been studied increasingly (Olazaran et al., 2010; Robinson et al., 2010; Dröes et al., 2010, 2011; Moniz-Cook et al., 2011). Examples of proven effective community-based psychosocial interventions are the Meeting Centers Support Program for people with dementia.
and their primary caregivers (Dröes et al., 2004), occupational therapy at home, including cognitive and behavioral interventions (Graff et al., 2009), cognitive behavioral therapy (Adams et al., 2005), reminiscence therapy (Moniz-Cook & Manthorpe, 2009), a biobehavioral home-based intervention (Gitlin et al., 2010) and family meetings (Zarit and Zarit, 2008; Mittelman et al., 1996). Despite the growing evidence on the effectiveness of psychosocial interventions, research in this area often deals with methodological difficulties, such as small study samples, the lack of a theoretical model to justify chosen outcome measures, lack of blinded measurements, using control groups that receive only minimal attention as comparison intervention, and non-replicable results (Olazarán et al., 2010). There is a need for higher quality RCTs to support the use of psychosocial interventions and strengthen the evidence in favor of these interventions. Overall, multi-component interventions that actively engage care recipients and are targeted at both the person with dementia and their caregiver promise the best outcomes (Mittelman et al., 2006; Smits et al., 2007). In addition, the most successful psychosocial interventions that are also associated with a delay in nursing home placement, are those that are flexible, provide sufficient variation in its content, are targeted at subjective burden, involve follow-up care and provide care opportunities for a long time period (Brodaty & Donkin, 2009).

**Personalized care/tailored care support**

Evidence on the effectiveness of psychosocial interventions suggests that interventions that are tailored to specific needs and characteristics of people with dementia and their informal caregivers are more beneficial than non-tailored interventions, and their use and development should therefore be promoted (Pinquart & Sörenson, 2006; Sörensen et al., 2006; Brodaty & Donkin, 2009; O’Connor et al., 2009). In recent decades the importance and benefits of personalized care are becoming evident for medicine in general. In this thesis personalized care will be discussed specifically in relation to dementia care.

Tailored care requires a systematic assessment of the needs and wishes of people with dementia and informal caregivers. Not every individual with dementia or caregiver benefits from the same care interventions. It is important to consider people in their context to see which intervention or type of care would meet their needs and also fits their context, setting and care demands. To better understand which specific persons may benefit more from certain interventions than others, we performed two explorative systematic reviews of psychosocial intervention studies. We investigated whether personal characteristics of people with dementia and of informal caregivers were associated with positive intervention outcomes. The results provide a rationale for selecting specific interventions for subgroups of people with dementia and caregivers and promote customized dementia care. This knowledge can help professional carers, such as physicians, practice nurses, case
managers and even policy makers to target psychosocial interventions at care recipients more efficiently.

Personalized care interventions are increasingly offered, and have been studied relatively frequently in the institutional setting (Sloane et al., 2004; Garland et al., 2007; Bharwani G, 2012; Testad et al., 2014), but have not been adequately integrated in community-based care (Ruggiano & Edvardsson, 2013). Fragmented dementia care, insufficient communication between care providers and the financing structure for dementia care do not facilitate the practice of community-based personalized care. Further efforts and research are needed to better implement personalized care initiatives for people with dementia and informal caregivers in their home (Gill et al., 2011; Robinson et al., 2010). From the care recipient perspective, people with dementia and informal caregivers also report that dementia care is fragmented and usually not individualized (Longley & Warner, 2002; Waldemar et al., 2007). This illustrates the need for more personalized care and support for people with dementia and their caregivers in the community, as well as for guidelines on how to effectively implement these interventions in actual practice. Personalized care is also recommended in the national dementia care guidelines which have been developed in several European countries (e.g. in the Netherlands: Dementia Care Standard; Alzheimer Netherlands & Vilans, 2012).

In this thesis, personalized psychosocial care interventions play a central role. We aimed to evaluate the surplus value, effectiveness and implementation feasibility of several personalized care interventions for people with dementia and their informal caregivers. These interventions were: provision of information by DEM-DISC, a digital interactive social chart; Dementelcoach, an individual telephone support intervention; case management in dementia; and an intervention to improve the transfer of psychiatric care information on people with dementia with complex behavior problems to the nursing home personnel.

**The personalized care interventions**

DEM-DISC is a digital interactive social chart system that provides general and personalized information about dementia healthcare services based on the needs of users (Dröes et al., 2005; Van der Roest et al., 2008). This ICT-tool was developed to promote self-management in informal caregivers of people with dementia and is aimed at helping them find the service they need. A prototype of DEM-DISC was studied in a pilot and it was shown to increase the caregiver’s sense of competence after two months of use (Van der Roest et al., 2010). There was also a decrease in the number of reported unmet needs and an increase in reported met needs. For the follow-up evaluation reported on in this thesis, we further developed DEM-DISC by including information on more relevant need areas and by improving the system’s ability to provide personalized advice to caregivers.
GENERAL INTRODUCTION

In the Dementelcoach study we evaluated an individual telephone support intervention that provides informal caregivers with emotional, social and informational support. The support provided by the coaches is tailored to the individual as the timing of telephone calls and the content of the conversations are adjusted to personal wishes/needs of informal caregivers. Caregivers are able to build a therapeutic relationship with their coach who provides the telephone support throughout the intervention.

A rapidly growing care profession in the Netherlands and abroad is case management for dementia care (Peeters et al., 2012; Somme et al., 2012; MacAdam, 2008). Case managers function as coordinators of care for people with dementia and informal caregivers and they connect them with available psychosocial care interventions based on individual needs of care recipients. Case management is thus considered a type of personalized care. Case managers can be involved in the diagnostic process and also provide emotional and social support. In the Netherlands, two case management models have emerged. In a process evaluation that was part of a larger evaluation study into case management (The Compas study; MacNeil-Vroomen et al., 2012), facilitators and barriers to the implementation of these two models were investigated in order to identify which model is easier to implement and more suited to provide personalized care.

Last, in the CAVIA study we evaluated follow-up visits at the nursing home conducted by community psychiatric nurses from a Mental Health care service after the institutionalization of a person with dementia with complex behavioral problems who was formerly treated by this Mental Health care service. The goal of the follow-up visit was to improve the transfer of information about a client, that is relevant to personalized care, to the nursing home setting by the community psychiatric nurse who had been involved in a client’s situation prior to admission. It was hypothesized that providing nursing home carers with information on how to deal with behavioral problems of this client and their biographical information would improve the transfer of a client to the nursing home.

A common factor for the psychosocial interventions we studied is that they are all targeted at individual needs and personal characteristics of people with dementia and informal caregivers and that they are offered in people’s own living environment. This makes the interventions easily accessible for a large group of informal caregivers and people with dementia. The applicability of the interventions covers the period from before diagnosis until institutionalization and focuses on providing continuity of care throughout this period.

The systematic literature reviews revealed certain characteristics of people with dementia and informal caregivers that were considered relevant when offering personalized care to this target group. In the development of the Dementelcoach
and DEM-DISC intervention study designs, as well as in the analysis of the results, these characteristics were taken into account.

**Implementation of interventions**

Successful implementation of personalized psychosocial interventions is essential for them to find their way into daily practice. Grol & Wensing (2013) define implementation as: “*a planned process and systematic introduction of innovations and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functioning of organizations or in the health care structure*”. In other words, to integrate new care interventions into the daily practice of health care.

Implementation research contributes to the identification of effective strategies that can be used to accomplish this implementation. A process evaluation can be conducted to gain insight into different stages of implementation (Grol & Wensing, 2013; Hulscher et al., 2003). Process evaluations are an essential contribution to research focused on the evaluation of new care initiatives. They can be used to describe the content of the intervention, to help explain factors that may have influenced intervention outcomes, and to describe experiences of the target group with the intervention (Leontjevas et al., 2012; Vernooij-Dassen et al., 2014). Thus, they can provide information about success and failure factors and can be used to adapt an intervention, identify future implementation strategies or change previous ineffective implementation strategies.

Various models are available to structure active implementation, such as the Implementation of Change model (Grol & Wensing, 2013), the Intervention Mapping framework (Bartholomew et al., 2001), the MIDI framework (TNO Report, 2012) and the RE-AIM model (Glasgow et al., 1999; 2001). In our studies into personalized care interventions we used the Theoretical model of adaptive implementation (See Figure 1; Dröes et al., 2003, Meiland et al., 2004) to trace facilitators and barriers to the implementation of these interventions. This model was constructed as a framework to help structure the research on implementation of the Meeting Centers Support Program for people with dementia and their carers. It was based on previous work by Nies (1994), who developed a systematic guideline for the implementation of care innovations. The Theoretical model is based on the principles of adaptive implementation, and for the implementation of innovative care interventions this method is preferred to programmed implementation (Boekholdt & Pepels, 1994). The implementation process for innovative care interventions is often complex and requires for instance, adaptation to different regional characteristics or care providers (Meiland et al., 2005). The Theoretical model of adaptive implementation describes external conditions (characteristics of the intervention, operational constraints, personal and financial resources, organizational conditions) that can influence implementation, at the start
of the process as well as during the consecutive phases (preparation, execution and continuation phase). Furthermore, in each of these phases the model differentiates between influencing factors on different levels: micro level (professional carers and care recipients), meso level (collaboration between care providers/organizations) and macro level (legal and financial framework). The model was used to shape the interviews with stakeholders involved in the implementation of the various personalized care interventions we studied. As such it helped us gain detailed insight into the implementation processes. In addition, the model was used to structure the qualitative data analysis, more specifically the creation and categorization of key words that were assigned to extracts of the transcripts of the interviews.

**Figure 1.** Theoretical model of adaptive implementation based on Dröes et al., 2003; Meiland et al., 2004

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<td>Characteristics of the innovation</td>
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<th>IMPLEMENTATION PROCESS</th>
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<td><em>Meso level</em> (collaboration between organizations)</td>
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<td><em>Macro level</em> (law and financial regulations)</td>
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<th><strong>Continuation phase</strong></th>
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The process evaluations we conducted in the studies to evaluate the implementation of DEM-DISC and the follow-up visit after nursing home admission of people with dementia with complex behavioral problems were intended to gain insight into the feasibility of future large-scale implementation of these interventions in practice. The process evaluation regarding the implementation of the two existing case management models in dementia was intended to determine which of these models was implemented more successfully and why, by providing insight into facilitating and impeding factors.
The research conducted in this thesis not only helps to identify facilitators and barriers to the implementation of different care interventions, but also contains information about which specific factors contribute to the implementation of personalized care in particular. These factors were synthesized into a new evidence based model to promote the implementation and development of personalized psychosocial care interventions for people with dementia and informal caregivers. The theoretical model of adaptive implementation was used as a generic framework to construct the evidence-based implementation model and checklist for personalized dementia care in the community.

Contents of thesis

This thesis focuses on the benefits and implementation of personalized care interventions for people with dementia living in the community and for their informal caregivers. The first part of the thesis investigates if psychosocial intervention outcomes are possibly related to personal characteristics of people with dementia and informal caregivers. The second part of the thesis focuses on psychosocial interventions that aim to provide personalized dementia care, tailored to individual needs of people with dementia and informal caregivers. Both intervention effects and facilitators and barriers to the implementation of these interventions are investigated. Based on the study results an evidence-based implementation model is proposed in the final part of the thesis. The model describes essential factors for the development and implementation of personalized psychosocial care interventions for people with dementia and informal caregivers in the community setting.

The research questions of this thesis were:

1. *Are specific characteristics of people with dementia and informal caregivers related to positive outcomes of individual psychosocial interventions?*

2. *What are the benefits of four tailored psychosocial care interventions for people with dementia and their caregivers, i.e. digital information provision by DEM-DISC, telephone support by Dementelcoach, case management, and follow-up visits by a community psychiatric nurse after institutionalization of people with complex behavior problems, and which facilitating and impeding factors influence the implementation of these interventions?*

3. *Which factors are essential for developing and implementing personalized care interventions for people with dementia and their caregivers?*
Chapter 2 and 3 present an overview of the existing literature that provides insight into the relationships between personal characteristics of people with dementia and informal caregivers and positive outcomes of interventions that they received. We describe results on several outcome categories and make a distinction between community-based and institution-based interventions.

Chapter 4 describes the results of a randomized controlled trial that investigates the added value of the use of DEM-DISC on care needs of people with dementia and informal caregivers who receive case management. Usefulness and user friendliness of DEM-DISC were also investigated among informal caregivers and case managers who had access to DEM-DISC. Future implementation issues are described as well.

Chapter 5 focuses on the results of the controlled pre-test post-test study into the effects of Dementelcoach, an individual telephone coaching intervention for informal caregivers of community-dwelling people with dementia that provides emotional, social and practical support.

Chapter 6 reports on the process evaluation of the implementation of two case management models in the Netherlands. A qualitative case study design was used; semi-structured interviews were conducted with stakeholders regarding the execution phase and continuation phase of the implementation process.

Chapter 7 describes the results of an explorative pilot study that aimed to improve the transfer of people with dementia with complex behavioral problems to the nursing home. A community psychiatric nurse visited the nursing home to transfer important care information about the new resident to the responsible nursing home caregiver. Semi-structured interviews were conducted with participants in the intervention (i.e. community psychiatric nurses, family caregivers and nursing home caregivers) and with key stakeholders to identify facilitators and barriers to the future implementation of this intervention.

Chapter 8 presents a model and checklist for the implementation of personalized dementia care that is based on the evidence and knowledge obtained in the conducted studies as described in the previous chapters of this thesis. The model presents essential factors to be considered when developing or implementing personalized psychosocial care interventions in dementia.
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