CHAPTER 1
Social Participation and Quality of Life in Dementia: an introduction to the thesis
CHAPTER 1

Introduction

This chapter is a general introduction aiming to set the scene of this thesis and to summarize the existing literature on the overarching theme of this thesis: promoting quality of life of people with dementia and their carers by enhancing their social participation. Firstly, dementia and the concepts ‘quality of life’ and ‘social participation’ are explained. Subsequently, the importance of social participation for people with dementia is clarified, as well as factors influencing the opportunities for people with dementia to remain involved in social activities. Then, a short overview will be given of psychosocial interventions that specifically focus on enhancing social participation in order to promote quality of life of people with dementia. In this overview of psychosocial interventions, also the significant role of informal carers and professionals in enhancing social participation and quality of life of people with dementia is described. Finally, the outline of the thesis will be explained, beginning with a brief description of the two interventions under study, followed by a description of the objectives and chapters.

Dementia: definition, prevalence and impact on those living with it

Subjects under study in this thesis are in the first place people with dementia. Dementia is a collective term for a range of underlying diseases that diminish the daily functioning of a person because of a variety of cognitive disorders. According to the diagnostic criteria of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), a distinction is made between major neurocognitive disorders (NCD) which incorporates the diagnosis of dementia as described in the 4th edition of the DSM, and mild neurocognitive disorders, including mild cognitive impairment (MCI) (DSM-5; American Psychiatric Association, 2013). According to the DSM-4, dementia is diagnosed when there are (1) memory problems (the reduced ability to process new information or to remember information that was learned earlier in life) and (2) one or more of the following cognitive disorders: (a) aphasia (language disturbance), (b) apraxia (impared ability to carry out motor activities despite intact motor function), (c) agnosia (failure to recognize or identify objects despite intact sensory function), and (d) impairments of the executive functions (e.g. planning, organizing, sequencing, abstracting). The cognitive disorders as described above interfere with the ability to function at work or in every-day activities and represent a significant decline from previous levels of functioning and performing, and they are not exclusively explained by a delirium (DSM-4; American Psychiatric Association, 2000). The most common type of dementia is Alzheimer’s disease, counting for approximately 60% of the dementia cases. Other types of dementia are, for example, vascular dementia, frontotemporal dementia, Lewy-body dementia, Parkinson dementia, or mixed forms (Scheltens, 2015).

Alzheimer’s Disease International estimated a worldwide prevalence of 46.8 million people with dementia in 2015 and expects that this number will almost double every 20 years, based on the assumption that the number of older people will grow (Alzheimer’s Disease International, 2015). However, these trends might not continue at the expected pace, especially in high-income
countries, since exposure to potential risk factors for dementia, such as unhealthy lifestyles and cardiovascular risk factors is changing (World Health Organization, 2016). The Dutch Alzheimer Association estimated the prevalence of dementia in the Netherlands in 2016 at 270,000, but there are also lower estimates (Alzheimer Nederland, 2016, Poos and Meijer, 2014).

Dementia is a progressive syndrome, greatly impacting the emotional and social life of people living with it and resulting in an increased dependency and need for assistance by informal carers and professional caregivers (De Boer et al. 2007; Clare, 2002: Steeman et al., 2006). This is, for example, illustrated by the prevalence rates of neuropsychiatric symptoms, which vary from 61 to 96 percent among community-dwelling people with dementia and 82 percent or more among nursing home residents with dementia (Borsje et al., 2015; Zuidema et al., 2007).

Informal carers play an important role in the care for community-dwelling people with dementia: on average they care for their relatives 20 hours a week for five years (Peeters et al., 2012). Although carers report positive experiences when caring for someone with dementia such as feeling useful (Tarlow et al., 2004), caring is often experienced as a burdensome task. This is reflected by the high onset and prevalence of depression and/or anxiety disorders (onset 52% within 24 months, Joling et al., 2015) and lower levels of subjective wellbeing compared to non-carers (Pinquart and Sorensen, 2003). In the Netherlands, a study among informal carers pointed out that 51 percent felt burdened, of which 10 percent were very burdened and 3% overburdened (Peeters et al., 2014). Over time, additional support of professional caregivers is often necessary, at home, in day care centres, or in residential care facilities. Currently, approximately two thirds of the people with dementia in the Netherlands live in the community, and one third lives in a care facility such as a nursing home (Meijer and Willeme, 2014). Both community-dwelling people with dementia and people with dementia living in nursing homes, as well as their (informal/ professional) carers, will be the subject of investigation in this thesis.

Quality of life

In the last decades, there has been a growing interest in healthcare research on quality of life and wellbeing, instead of a narrow focus on solely physical health outcomes. Nowadays, quality of life has become an important outcome measure in research into chronic diseases, including dementia research. Different dementia-specific measures for quality of life have been developed (Schölzel-Dorenbos et al., 2007), based on different conceptualizations (Ettema et al., 2005). Most of the dementia-specific measures focus on multiple domains of quality of life, which have also been reported as important by people with dementia, such as health, physical functioning, mood, social relations, affect, self-esteem, enjoyment of activities, and finances (Drões et al., 2006, Ettema et al., 2005). Hoe et al. (2009) found that fewer unmet needs were associated with a higher quality of life among people with dementia living in care homes. Behavioural or neuropsychiatric problems in people with dementia are correlated with a reduced quality of life of both people with dementia and their informal carers (Beerens et al., 2013; Karttunen et al., 2011; Van der Lee et al. 2015). On the other hand, a high sense of
competence in caring for a relative with dementia appears to diminish the experienced burden and distress caused by neuropsychiatric symptoms (Feast et al., 2016; Van der Lee et al., 2015), whereas a reduced burden/distress predicts a better quality of life among carers (Abdollahpour et al., 2015).

Another approach to defining quality of life is derived from research among chronically ill patients, naming the ‘ability to adapt to the consequences of the disease’ as a quality of life-related outcome (Dröes, 1991; Dröes and van Tilburg, 1998; Dröes et al., 2011; Ettema, 2007). The recently proposed change of the static WHO definition of health into a more dynamic definition, in which health is characterized by the ability to adapt to (chronic) diseases (Huber et al., 2011), is in line with this vision.

In this thesis, different measures, based on either self-report or proxy-report, of quality of life and quality of life-related outcomes (including behavioural symptoms, needs, positive and negative behaviour, and mood of people with dementia, and feelings of competence, needs, and burden of carers) are used. These measures are also presented in the theoretical framework at the end of this Introduction.

**Defining social participation**

Participating in social activities is important for human beings, both for their personal wellbeing and societal functioning. This is confirmed by multiple studies among older adults (Adams et al., 2011) and people with dementia (Nyman and Szymczynska, 2016). Several studies also found that social participation is associated with better quality of life, and reduced morbidity and mortality among the elderly (Dahan-Oliel et al., 2008). In the proposed new definition of health by Huber et al. (2011), social health is included as one of the three main domains of health (next to physical and mental health). The authors mention the participation in social activities as one of the dimensions of ‘social health’. Although researchers seem to agree that ‘social participation’ is important for healthy ageing, a common definition of this construct is lacking. According to Sorensen et al. (2008), social participation is a broad concept that involves taking part in formal and informal relationships. Ways in which someone can participate socially are: the use of media (e.g. television and Internet), being among others (e.g. shopping), contact with family, friends, neighbors, joining in meaningful activities, clubs or religious communities or volunteer work (Dahan-Oliel et al., 2008; Levasseur et al., 2010; Broese- van Groenou and van Tilburg, 2012). Levasseur et al. (2010) reviewed the literature on definitions of social participation and related concepts such as social engagement or community involvement of the elderly and concludes that the 43 definitions found mostly focus on who socially participates, how (involvement or engagement), in what kind of activities (e.g. social activities or recreational activities), and where (in which environment). Some definitions define also with whom (e.g. a group), when (e.g. regular), and why (e.g. satisfaction) someone socially participates. Based on this literature study, Levasseur et al. (2010) define social participation as ‘a person’s involvement in activities that provide interaction with others in society or the community’. They also distinguish levels of participation by differentiating between social
activities based on 1) the level of involvement of the individual with others, and 2) the goals of these activities (see Figure 1 for the different levels of participation). With this taxonomy, ‘social participation’ (level 3 to 6) is distinguished from the concepts ‘participation’ (levels 1 to 6) and ‘social engagement’. Since the introduction of the thought of the Big Society (in Dutch: participatiesamenleving) in the Netherlands (Rijksoverheid, 2013), ‘participation’ is often associated with a narrower definition, namely the degree to which people contribute to the society by volunteering or paid work. In this thesis, the term social participation of people with dementia is used according to Levasseur’s broader definition as ‘People with dementia’s involvement in activities that provide interaction with others in society or the community.’

Figure 1. Proposed taxonomy of social activities based on 1) levels of involvement of the individual with others, and 2) goals of these activities according to Levasseur et al. (2010).

Social participation and quality of life of people with dementia

People with dementia’s need for social participation and the benefits for their quality of life

Dementia does not take away the need for social relations. A literature review on subjective needs of community-dwelling people with dementia pointed out that social contact is one of their main needs as well as one of the most frequently experienced unmet needs (Van der Roest et al., 2007). Besides social contact, people with dementia also reported on the need to maintain or regain self-esteem and to be able to enjoy activities. According to the previous mentioned definition of social participation, both the need for social contact and the need to enjoy activities, can be seen as a need for ‘social participation’. This thesis addresses the importance of enhancing social participation as a means to promote the quality of life of people with dementia. The importance of social participation for quality of life has previously
been described by Cahill and Diaz-Ponce (2011) who studied the quality of life of 61 people in different stages of dementia living in nursing homes. Social contact appeared to be one of the four aspects that were most important for their quality of life, especially contact with family. In a qualitative study among 32 people with dementia in residential settings, Moyle et al. (2011) also found that family (visits), establishing relationships, and engaging in meaningful activities were important for people with dementia's quality of life (see also Dröes et al., 2006). A literature review on occupational therapy interventions for people with dementia to improve their quality of life demonstrated promising results when they participated in leisure time activities that involved social interaction (Lett et al., 2011).

The ‘use it or lose it’ theory states that maintaining intellectual engagement through participation in everyday activities buffers individuals against cognitive decline in later life. This theory is still not fully proven because many study designs fail to prove causality. However a cohort study among elderly showed that a poor or limited social network is associated with increased risk of developing dementia (Fratiglioni et al., 2000). Smits et al. (1995) found a positive association between social participation (memberships in clubs) and cognitive functioning among elderly aged 55-89. A review of the literature on social participation in the elderly pointed out that higher levels of participation in different types of leisure activities is associated with better functional skills, well-being, health-related quality of life, and survival (Dahan-Oliel et al., 2008). Although these studies were not performed among people with dementia, there is no reason to expect that this positive relation between social participation on the one hand and cognitive and functional skills and wellbeing on the other hand does not apply to people with dementia. It may also be the case that people with dementia cognitively, functionally and mentally benefit from social participation, thus experiencing a better quality of life.

The ability and problems of people with dementia to remain involved in social activities

Although dementia is a progressive disease, people remain able to connect to others in one way or another. The degree to which someone makes connections with other people and takes part in social activities depends on many factors including (1) personal characteristics, such as age and preferences, (2) dementia-related problems and how someone copes with dementia, (3) the social environment, (4) living situation of the person, as well as (5) societal aspects such as the availability of supportive community services (van Haeften-van Dijk and Boersma, 2015). These factors will be explained below.

Firstly, personal interests will obviously influence the way in which someone with dementia participates in social life, and which activities he or she prefers to undertake. Since dementia often occurs in later life, age-related problems such as reduced mobility can negatively influence the ability to undertake social activities (Dahan-Oliel et al., 2008). Better performance of activities of daily living (ADL) is positively related to social participation of people with dementia (Sorensen et al., 2008). Elderly people with pain, hearing loss or visual impairments tend to be less socially involved (Cohen-Mansfield et al., 2011).
Secondly, the disease and how someone copes with dementia influences social participation. In the early stages of dementia, people are able to take more initiatives for social contact, whereas when the disease progresses, the ability to socially participate independently decreases (Branelly, 2011). Dementia often leads to disorientation in place, making people anxious to leave their home. Problems with recognizing people also impede social contacts (Holst and Hallberg, 2003). People with dementia also experience difficulties with abstract thinking or they forget what someone told earlier, which hinders conversations:

“I withdraw because I don’t feel involved in what they’re talking about.” (Holst and Hallberg, 2003, p.362)

“In my present condition there are times when I feel normal. At other times I cannot follow what is going on around me; as the conversation whips too fast from person to person and before I have processed one comment, the thread has moved to another person or another topic, and I am left isolated from the action- alone in a crowd” (Basting, 2003, p. 93)

Problems with simple actions (apraxia) such as pouring a cup of coffee can cause feelings of uncertainty and may lead to withdrawal from social situations. People with dementia may also have neuropsychiatric symptoms such as agitation/aggression, depression, suspiciousness, and apathy. These symptoms obviously negatively affect social relations and peoples’ own initiative to join in (social) activities. For instance, de Vugt et al. (2003) showed that apathy is associated with a deterioration of people with dementias’ marital relationship. Based on a literature review, Van der Lee et al. (2014) found, that carer burden was highly determined by neuropsychiatric symptoms. It is therefore not surprising that such symptoms are a common reason for institutionalization of the person with dementia (Gaugler et al., 2009). A third reason for reduced social contact, explicitly mentioned by people with dementia, is the way in which family, friends and others treat them. In several studies, people with dementia indicate that they are treated differently by their relatives since suffering with dementia and that they feel excluded or that their opinion was not asked sufficiently in decision-making about care. A person with dementia appreciated that someone did provide information about the disease (Harman and Clare, 2006, p.496):

“It helped because he was the only person who seemed to tell me the truth, that was what I wanted”

When the disease progresses, people with dementia become more and more dependent on the initiative of their relatives, friends and carers for social contact. Fourthly, the living situation is a factor that influences social participation of people with dementia. For example, people living with a spouse tend to join more social activities than people living alone (Dahan-Oliel et al., 2008).
The extent to which people with dementia are able to socially participate also depends on societal factors. In many communities, dementia is surrounded by stigma which makes it more difficult to actively participate in social activities (Burgener et al., 2015). A study in the UK showed that GP’s perceive that dementia is surrounded by stigma caused by the general assumption that it is difficult, or even impossible, to have reciprocal interpersonal contact with someone with dementia and that people with dementia fail to contribute to or are a burden to society (Gove et al., 2016). Besides, the availability of community services, like transportation services and accessibility of, for example, psychogeriatric day care centres, influence the ability of people with dementia to participate in social activities.

Need for support of people with dementia to remain involved in social activities
Given the fact that social participation is important for the quality of life and health of people with dementia, and that their capabilities to remain socially involved decrease with the progression of the disease, adequate support to help people with dementia to remain socially involved is necessary. This need for support is also underlined by a study in the UK in which 62 percent of community-dwelling people with dementia living alone indicated that they felt lonely (Alzheimers’ Society UK, 2013). Of the respondents, 70 percent stopped doing activities they used to do due to a lack of self-confidence, and nearly 50 percent only went out once a week or less to do things in their local area.

Interventions to improve social participation and quality of life of people with dementia
In the last decades, many psychosocial interventions for people with dementia and their carers have been developed (Van ‘t Leven et al., 2013). These psychosocial interventions can be classified as interventions promoting social health as defined by Huber et al. (2011), that is interventions promoting (1) the capacity of people with dementia to fulfil their potential and obligations, (2) their ability to self-manage despite the disease, and/or (3) participation in social activities.

This thesis focuses on the latter category: interventions with a specific focus on enhancing participation in social activities. Several psychosocial interventions aimed at enhancing social participation of people with dementia have been developed, and they can be roughly categorised as (1) interventions focused on community-dwelling people with dementia and their informal carers, (2) interventions specifically developed for people with dementia in residential care settings, and (3) interventions aimed at a dementia friendly society. These categories will be further explained and some interventions that proved effective will be described.

Interventions focused on people with dementia and their informal carers
For the greater part of their illness people with dementia live in their own home. Because of the aging society and the increasing number of people with dementia, it is expected that the public
resources for professional dementia care will diminish. Therefore, a greater call on the support of the informal network, e.g. family, friends and neighbours, will be made. Although strong evidence is lacking due to failing study designs, combined support of people with dementia and their carers is expected to be more effective than single interventions for either the person with dementia or the carer (Smits et al., 2007; Van ‘t Leven et al., 2013). The reasoning behind this is that there is a mutual influence between, for example, behaviour of people with dementia and caregiver management strategies and it may be therefore more effective when support for both is given by the same care provider (van ‘t Leven et al., 2013). Examples of effective combined interventions with a specific focus on stimulating social integration of people with dementia and offering social support to carers are Adult Day Services Plus (Gitlin et al., 2006) and the Meeting Center Support Program (Dröes et al., 2004a; Dröes et al., 2004b). Both these support programs integrate adult day care and a support programme for carers, resulting in amongst others increased well-being and self-esteem and less depression and behavioural problems (specifically less inactivity and less unsocial behaviour) in people with dementia, and increased carer competence. Graff et al. (2007) developed and evaluated an occupational therapy intervention for community-dwelling people with dementia and their carers, with a specific focus on enhancing people with dementias’ ability to perform relevant daily activities and sustainment of their autonomy and social participation. This intervention proved to positively influence quality of life, mood and health status of the person with dementia and their carers. Bakker et al. (2011, 2013) found a 60% reduction of severity of behavioural problems in people with dementia and a 50% reduction in carer burden as a result of an integrated rehabilitation programme for people with dementia and their carers. This programme consisted amongst others of group sessions for life review, interpersonal therapy, psychotherapy, and family therapy.

Other interventions aim to strengthen the social system of people with dementia by educating informal carers about dementia and stimulating them to involve the social system (family, friends, neighbours etc.) of the person with dementia and to share care responsibilities with others. An example is the Home Environmental Skill Building-program resulting in reduced burden and increased wellbeing of carers (Gitlin et al., 2003).

Interventions developed for persons with dementia living in care settings
When people with dementia become more dependent on others, many of them will finally need professional care, either at home or in a residential care setting. New relationships have to be built, with other residents and with professional caregivers (Cahill and Diaz-Ponce, 2011). In the context of professional care facilities, several psychosocial interventions have been developed with the specific aim to enhance people with dementia’s involvement in activities that provide interaction with other residents and professional caregivers and to contribute in this way to the quality of life of people with dementia. Examples of these interventions are reminiscence group activities in which people with dementia are invited to talk about topics related to the past, and music and dance interventions which have been proved to positively influence social interaction, cognition, mood and behaviour (Guzmán-Garcia et al., 2013;
Reminiscence also increased staff knowledge about the participants of the reminiscence groups. The enriched opportunities programme of Brooker et al. (2011), in which a special staff member was appointed to organize a person-centred activity programme (including integration with the local community) for residents with dementia, improved quality of life and reduced depression of people with dementia. An intervention that has been proven effective in enhancing positive communication between people with dementia and professional caregivers in nursing homes, positive behaviour and mood of people with dementia is ‘snoezelen’, also referred to as multisensory stimulation (Van Weert et al., 2005; Van Weert et al., 2006).

Most of these interventions relate to the principles of person-centred care as described by Kitwood (1997). In person-centred care the personhood, individual capabilities and perspective of the person with dementia are the starting point of care, while caregivers are also aware of their own personhood and behaviour and how this influences the relationship with the person they care for. There is evidence that a better quality of the relationship between professional caregivers and patients has positive effects on behavioural symptoms and satisfaction in people with dementia as well as on the burden and job satisfaction of professional caregivers (Nolan et al., 2008; Van Weert et al., 2006).

Interventions aiming at a dementia friendly society
Engaging in social life and participating in meaningful activities has proven to be an important wish of people with dementia (Cahill and Diaz-Ponce, 2011; Clare, 2002, Van der Roest et al., 2007). However, this would be much easier when our society would be more dementia friendly, e.g. when it would enable people with dementia to participate in leisure and cultural activities. To achieve this, physical adjustments to neighbourhoods such as clear sign-postings are necessary for people with dementia to help them to orientate themselves. General awareness about dementia is necessary in order to reduce stigma and to make people understanding toward people with dementia (Gove et al., 2016; Van Haeften-van Dijk and Boersma, 2015).

An example of an intervention to reduce stigma and increase social integration is a choir consisting of students and elderly with dementia and their carer, which resulted in reduced social isolation of people with dementia, and students getting more understanding and a more positive attitude towards people with dementia (Harris and Caporella, 2014). Other examples are the Dutch initiative DemenTalent in which people with dementia are enabled to socially contribute by doing voluntary work (www.dementalent.nl), and an initiative in the US in which people with dementia become mentors of teenagers in high school (George and Whitehouse, 2010). Although evidence on the effects of a dementia-friendly society on quality of life of people with dementia is not available yet, these initiatives show that people with dementia can still have meaningful roles in the society.
Successful implementation crucial for effective interventions

In the last decennia, research on psychosocial interventions in dementia care focused mainly on the effects and benefits for people with dementia. Less attention was given to implementation, although the effectiveness of interventions strongly depends on whether the intervention is implemented effectively (Boersma et al., 2015; Vernooij-Dassen and Moniz-Cook, 2014). In this thesis, implementation is defined as ‘the process of preparation, introduction, execution and continuation of a new intervention or work approach in an organization’. Successful implementation is not a matter of course, and therefore more insight is needed into which factors facilitate or impede this process. Facilitators and barriers can be found at different stages of the implementation process and on different levels (the level of the patient, the individual professional and the team, the level of the health care organisation and the level of the wider environment (Grol and Grimshaw, 2003; Meiland et al., 2004). Literature on successful implementation strategies of psychosocial interventions in dementia care is scarce (Burgio et al., 2001; Meiland et al., 2005; Boersma et al., 2015). Insight in factors that influence the implementation of interventions in dementia care during effect studies will not only help better interpretation of the study findings, but will also contribute to successful dissemination of effective interventions (Vernooij-Dassen and Moniz-Cook, 2014). For this reason, an important part of this thesis is to study facilitating and impeding factors of implementation of the interventions under study.

Outline of this thesis

Although several psychosocial interventions aimed at enhancing social participation of people with dementia have shown positive effects on quality of life, the evidence is still scarce. In order to contribute to this field of study, this thesis reports on the evaluation of two interventions that aim to improve quality of life of people with dementia by enhancing their social participation. In order to evaluate if these interventions were implemented and executed according to plan and which factors influenced the implementation, process evaluations were performed. In the following section the two interventions under study will be explained.

Interventions under study

The first intervention focused on people with dementia and their informal carers. It concerned the transition of six nursing home-based (NH) day cares to community (CO) day care with the possibility of informal carer support. The NH day cares were transitioned to community day cares according to the proven effective Meeting Centres Support Programme (MCSP) model (Dröes et al., 2000; Dröes et al., 2004a, 2004b). The aim of this new model of day care is to support community-dwelling people with dementia to remain socially integrated and to live at home with an optimal quality of life for as long as possible. Therefore, both the person with dementia and the informal carer receive support in adapting to, and coping with, the functional, emotional and social consequences of dementia in their life. We expected that,
compared to the traditional day care offered in nursing homes, the socially integrated support of CO day care in the community would have added value to the quality of life of people with dementia as well as to quality of life-related outcomes such as needs and behaviour problems, and would also contribute to the quality of life, needs, and burden of their carers. In addition we expected that the socially integrated and person-centred approach of CO day care would contribute to both user and staff satisfaction.

The second intervention was developed for persons with dementia in residential care settings. It concerns the so-called Veder Method. This method is applied in a group activity ('living room theatre activity') in which theatrical stimuli are used in combination with the person-centred care methods Reminiscence (Woods et al., 2005), Validation Therapy (Feil, 1992), and Neuro-Linguistic Programming (Bandler and Grinder, 1975). The Veder Method aims to enhance participation of people with dementia by stimulating social interaction. Moreover, the living room theatre activities give people with dementia the opportunity to join in a meaningful activity together with others. By activating the (intact) long-term memory, the living room theatre activities aim to restore engagement in the present and to enhance the sense of personal identity and self-esteem of people with dementia. Professional caregivers are trained to offer a living room theatre activity according to the Veder Method and to better communicate with people with dementia, thus achieving reciprocity in the relation with persons with dementia. It was expected that, compared to a traditional reminiscence activity, the integration of these person-centred care methods in a living room theatre activity would have added value on the quality of life of people with dementia and on several quality of life-related outcomes: behaviour and mood.

Objectives of this thesis
The main objectives of the research reported on in this thesis were to get insight into facilitators and barriers for implementation of these two psychosocial interventions promoting social participation of people with dementia in the community and the nursing home, and to study the effect of these interventions on certain aspects of quality of life of people with dementia. Additionally, the effects of CO day care on user satisfaction, (aspects) of quality of life of informal carers and job satisfaction of professional caregivers were evaluated.

Central research questions were:
(1) What are facilitators and barriers for (a) the transition of nursing home-based day care for people with dementia to community day care with carer support, and (b) the implementation of living room theatre activities according to the Veder Method in nursing homes?
(2) What are the benefits of (a) CO day care with carer support compared to NH based day care and (b) living room theatre activities compared to a traditional reminiscence intervention with regard to needs, behaviour, mood and quality of life of people with dementia?
Secondary questions were:

(3) Does CO day care with carer support, compared to nursing home-based day care, add value with regard to needs, care burden and quality of life of informal carers?

(4) Are people with dementia and their carers using CO day care with carer support more satisfied than people with dementia and carers using nursing home-based day care, and has staff of CO day care with carer support a higher work satisfaction than staff of nursing home-based day care?

Theoretical framework

Figure 2 summarizes the theoretical framework of the conducted research. This research concerned the evaluation of the implementation and exploration of the effects of two psychosocial interventions for people with dementia and their carers in the community setting on the one hand and the residential setting on the other hand. Both interventions are characterized by a main focus on enhancing social participation of people with dementia in order to promote their quality of life and to contribute to the quality of life of their informal carers and job satisfaction and work experience of their professional caregivers.

Abbreviations: NH day care = nursing home-based day care, CO day care = community day care with carer support, PwD = people with dementia, QoL = quality of life.

Figure 2. Theoretical framework of this thesis.
Structure and chapters of this thesis

This thesis consists of two parts. Part 1 (Chapters 2 to 5) describes the implementation and effect studies on the transition of nursing home-based day care to community day care with carers support. Part 2 (Chapters 6 and 7) describes the implementation and effects of living room theatre activities in psychogeriatric nursing home wards.

In Chapter 2 the process evaluation of the transition of six nursing home-based day care centres for people with dementia into socially integrated community day care centres is presented. This study aimed to answer research question 1a and resulted in a description of factors that facilitate or impede this transition process. Chapter 3 reports on the study into the effects of socially integrated community day care compared to nursing home-based day care on needs, behaviour, mood and quality of life of people with dementia (research question 2a). Chapter 4 reports on the study that was conducted to explore if community day care, compared to nursing home-based day care, has beneficial effects on the needs, emotional burden and quality of life of informal carers (research question 3). In Chapter 5 the benefits of community day care for people with dementia, compared to nursing home-based day care are evaluated with regard to user satisfaction and job satisfaction of staff (research question 4). In Chapter 6 the implementation of living room theatre activities for people with dementia on nursing home wards is evaluated and facilitators and barriers for implementation are described (research question 1b). Chapter 7 reports on the study into the possible added value of living room theatre activities, compared to reminiscence group activities, with regard to behaviour, mood and quality of life of people with dementia (research question 2b).

Finally, Chapter 8 provides a general discussion of this thesis, addressing the main findings, methodological issues, as well as implications for practice and policy and recommendations for further research.1

1 Chapter 2 through 7 of this thesis are based on articles that are published in, or submitted to, peer-reviewed scientific journals. This implies that parts of the chapters overlap, especially the information given in the introductions and method sections. These chapters can be read independently of each other.
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