General introduction

Dementia

Dementia is a chronic or progressive syndrome which affects the memory, thinking, behaviour and ability to function at work or during the usual daily activities. Dementia is one of the major causes of disability, dependency and care burden among older people worldwide and has an overwhelming impact on global public health. The number of people with dementia worldwide is expected to increase rapidly in the coming decades from the current 46 million to 131.5 million in 2050, due to the ageing population and increased life expectancy. Estimations for the Netherlands are an increase from the current 260,000 people with dementia to 660,000 in 2050. Dementia also has a huge economic impact. Today, the total estimated worldwide cost of dementia is USD 818 billion, increasing to a trillion dollars by 2018.

In the Netherlands, most people with dementia (estimated around 70-75%) live in their own homes in the community. Up to 75% of the care they receive is provided by spouses and adult children and occasionally by neighbours and friends. Providing care for a person living with dementia over a longer period of time has serious health consequences for informal caregivers. Informal caregivers of people living with dementia suffer from high levels of psychological distress, with an estimated 23% of informal caregivers having a high risk of meeting the diagnostic criteria for depression. Therefore, the impact of dementia is overwhelming not only for the people living with dementia and the wider society, but also for their informal caregivers.

Psychosocial interventions

There is thus far no cure for dementia. Therefore, it is essential that people with dementia and their informal caregivers learn how to cope with the consequences of the disease which are influenced by an interaction of the individual’s neurological impairment, personality, biography, physical health, and physical and social environmental factors. There is a great need for psychosocial interventions reducing functional impairments and meeting the care needs of people with dementia living in the community and their informal caregivers.

Over the two decades, many developments have taken place within the psychosocial care for people with dementia. At the end of the 20th and the beginning of the 21st century, in the Netherlands and other Western European countries, psychosocial intervention studies were mainly directed at people with dementia living in nursing homes. Day-care centres for people with dementia and social support groups for caregivers appeared and increasingly also alternative services like meeting centres or Alzheimer Cafes. In

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a. These estimations are provided by Alzheimer Nederland (AN) in March 2016, made by the Dutch organisation for applied nature science research (TNO), and based on Ott et al. (1996), Perenboom et al. (1996) and Van Duin & Stoeldraijer (2012).
spite of this, informal caregivers’ needs for support often remained unmet; they had
difficulties finding the appropriate services because of excessively fragmented care.\textsuperscript{17,18} A survey of community-dwelling people with dementia and their informal caregivers showed that the reasons for these unmet needs are a lack of knowledge about the existing service offer, barriers to use services and insufficient access to services.\textsuperscript{19}

Deinstitutionalisation and the need for support of people with dementia and their informal caregivers living in the community
In the last decade, the proportion of people with dementia living in residential care has begun to decline in Western European countries, consistent with policy initiatives to provide care at home where possible in the face of growing numbers of people living with dementia.\textsuperscript{2,20} There is an increasing tendency wherein people with dementia are remaining at home as long as possible.\textsuperscript{2} The focus on deinstitutionalisation and at the same time on the improvement of the well-being of both the person with dementia and the informal caregiver, has resulted in the development of dyadic services: combining support of people with dementia \textit{and} their informal caregivers living in the community.\textsuperscript{2,21}

Dyadic interventions
Dyadic or so-called combined interventions have the potential to reduce the perceived frequency and severity of behavioural and psychological symptoms of dementia as well as caregivers’ perceived stress, and the delay of the admission to long-term care facilities.\textsuperscript{22-27}

Dyadic interventions that simultaneously address care issues for people with dementia and informal caregivers, offer several advantages. First, involving both the person living with dementia and the informal caregiver creates an opportunity to discuss difficult topics with them together that would not be discussed otherwise. An independent professional can create a familiar environment in which topics such as dealing with emotional issues, such as coping with the illness and future care planning (e.g. driving or household chores) can be discussed. Second, skills for coping with dementia-related challenging behaviours, such as communication skills, can be more consistently and rigorously applied when both the person with dementia and the caregiver are involved. It enables the observation of their interaction and the provision of concrete feedback. Third, dyadic interventions implemented at home could be more effective because they can be better aligned with the personal daily routines of the dyad in accordance with their needs, habits and preferences that may otherwise be more easily overlooked.

Dyadic, multicomponent interventions
To be able to adequately support people with dementia living at home and their informal caregivers, dyadic interventions with an active component directed at the person with dementia and a caregiver support component seems promising. Such multicomponent interventions, which includes several components, may act both independently (on out-
comes of people with dementia and their caregivers) and interdependently (for example on the quality of the relationship between both) and has found to be more effective than a single component intervention by targeting different outcomes. For example, in the Netherlands, a community-based intervention with occupational therapy including cognitive and behavioural interventions enabled people with dementia to participate in meaningful activities of daily living (ADL) and helped caregivers to support them in these activities, thereby reducing caregiver burden.

A dyadic multicomponent intervention with physical exercise and support
Several studies have shown the beneficial impact of physical exercise on cognitive functioning and mood in older people without cognitive impairment. Studies indicate that physical exercise can counteract the molecular changes that underlie the progressive loss of hippocampal function in advanced age and dementia. The benefits of physical activity might increase over the life course and physical activity is suggested to slow down the dementia process.

While the general belief is growing that physical exercise may benefit people with dementia and their informal caregivers, there are only a few physical exercise programmes specifically designed to meet the needs of people with dementia who are living in the community. So far, they show mixed results on cognitive functioning, behaviour and psychological symptoms of people with dementia. However, good quality Randomised Controlled Trials (RCTs) are lacking.

A home-based intervention combining physical exercise and a pleasant activities training
Given the increase of the number of people with dementia worldwide, the importance of dyadic multicomponent interventions, and the expectations regarding the benefits of physical exercise, this study focused on a dyadic multicomponent intervention with a physical exercise component for people with dementia living in the community and their informal caregivers. At the time of the start of this study, an intervention combining physical exercise training for people with dementia and a behavioural management training including stimulating pleasant activities for their caregivers, was found to be effective in the US. Research in the US showed that this multicomponent dyadic intervention significantly improved physical health and reduced depression in people with dementia. This intervention might also have potential for other countries outside the US. From an efficiency point of view, it is worthwhile to adopt an intervention programme already developed and found to be effective in another country. Although the effects on informal caregiver’s health were not studied in the study of Teri et al. (2003), the intervention might also have the potential to reduce caregivers’ psychological

b. In this thesis, we use the term ‘home-based intervention’. By this, we mean interventions for people with dementia living at home independently in the community, thus not in a care home.
distress as has been found in previous research on dyadic and/or multicomponent interventions.\textsuperscript{40,41}

The aim of this thesis and the research questions

The overall aim of this research project was to study the effects of a home-based physical exercise and support intervention on the functioning and health of people with dementia living in the community and on the psychological distress of their informal caregivers. This home-based physical exercise and support intervention was based on an adapted and expanded version of an intervention developed by Teri (2003) in the US. The following research questions were investigated:

1. \textit{What are the effects of dyadic psychosocial interventions on functioning and health of people living with dementia in the community and on psychological distress of their informal caregivers in previous research?}

2. \textit{What is the quality of the execution of our study and what is the feasibility of a home-based physical exercise and support intervention?}
   2a. \textit{What is the quality of the success rate of recruitment and the quality of the study population?}
   2b. \textit{What is the quality of the execution of the intervention and what are the experiences of the participants with the intervention?}
   2c. \textit{What is the quality of the data collection process?}

3. \textit{What are the effects of a home-based physical exercise and support intervention on the functioning and health of people with dementia living in the community?}
   3a. \textit{What are the effects of a home-based physical exercise and support intervention on mood, behaviour and physical health of people with dementia?}
   3b. \textit{What are the effects of a home-based physical exercise and support intervention on the cognitive functioning of people with dementia?}

4. \textit{What are the effects of a home-based physical exercise and support intervention on the psychological distress of informal caregivers who care for people with dementia living in the community?}

Research methods

To answer the first research question, we conducted a systematic review. To answer
the second research question a process evaluation was performed using both the data of a RCT and an additional qualitative study with in-depth interviews. In addition, the data of the RCT were used to answer the third and fourth research question.

Outline of the thesis
The first research question on the effects of dyadic psychosocial interventions for people living with dementia in the community and their informal caregivers in earlier research is answered in Chapter 2. This chapter concerns a systematic review of the effects of dyadic multicomponent psychosocial interventions on psychosocial outcomes, improving mental health or well-being, of people with dementia living in the community and their informal caregivers.

In Chapter 3, the study protocol of the Randomised Controlled Trial (RCT) on the effects the home-based physical exercise and support intervention is described.

Chapter 4 answers the second research question on the quality of the execution of our study and the feasibility of the home-based physical exercise and support intervention. It contains a process evaluation of the home-based exercise and support programme for people with dementia living in the community and their informal caregivers. It provides information about the quality of the study population, the execution of both intervention components (exercise and support) and the experiences of the participants with these intervention components, and the process of the acquisition of data.

The two research questions on the effects of the home-based physical exercise and support intervention on the outcomes of people living with dementia and their informal caregivers are answered in chapters 5 to 7. Chapter 5 describes the effects of the intervention on mood, behaviour and physical health of people with dementia. Chapter 6 focuses on the effects of the intervention on the cognitive functioning of people with dementia. Chapter 7 describes the effects of the intervention on the psychological distress of caregivers.

Chapter 8, which is the general discussion of this thesis, reflects on the study and its results. The strengths and limitations of the study and the intervention are discussed and the implications of this study for clinical practice, policy and future research are described.
References


