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Effectiveness and efficiency of community
based occupational therapy for older
people with dementia and their caregivers

Maud Graff

Voor Jules en onze kinderen

Voor mama, papa en Ine

The studies presented in this thesis have been performed at the homes of the clients with dementia and their caregivers and at the departments of Occupational Therapy and Geriatrics of the University Medical Centre Nijmegen, the Alzheimercentre Nijmegen and the Centre for Quality of Care Research of the Radboud University Nijmegen.

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Effectiveness and efficiency of community based occupational therapy for older people with dementia and their caregivers

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

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Chapter 1

Introduction

Maud J. L. Graff

Dementia

Dementia is one of the three major diseases with regard to health care consumption¹⁻⁴ and is a major cause of disability and care burden in the elderly. Dementia is a chronic and degenerative disease that causes disorders of memory, behavioural problems, loss of initiative, loss of independent functioning in daily activities and loss of participation in social activities. These problems decrease the quality of life of patients and put pressure on both family relationships and friendships. Caregivers often experience feelings of helplessness, social isolation, and loss of autonomy.^{5,6} The world prevalence of dementia recently has been estimated at 24.3 million people. This is expected to double over the next 20 years.⁷ In 2002, in the Netherlands alone, nearly 1% of 65 year olds suffered from dementia. This percentage rose with increasing age to around 40 % in people aged 90 and over. Because of the increase in the number of very old people, the number of dementia patients and the number of caregivers and their related health care costs are supposed to increase substantially in the next five decades. In 2050 it is predicted that 2.2% of 65 years olds will suffer from dementia.⁸ In the Netherlands in 2002, 39% of the dementia patients needed continuous care, 38% of the dementia patients needed home care daily, 23% needed home care occasionally.⁹ Considering the substantial burden for persons with dementia, their caregivers and society it is important to implement new effective and efficient health care interventions that increase independence and well-being of dementia patients and decrease care giver burden resulting in a more efficient use of scarce health care resources.¹⁰

Effective treatments in dementia

Drugs are not yet very effective in reducing the symptoms of dementia. Although non-pharmacological strategies are generally more time-consuming than pharmacological therapy, these non-pharmacological interventions seem to reduce symptoms. A systematic review found non-pharmacological interventions to produce similar or larger effect sizes in dementia patients' behaviour than cholinesterase inhibitors, the currently available symptomatic drug treatment, but without any side effects.¹¹ As dementia is affecting multiple cognitive and non-cognitive domains, and often also affects nutrition, gait and other co-morbidities, as well as the health state of carers, treatments often consist of multiple components targeted to different outcomes. Selecting items out of these potential treatment options is needed. Such tailored interventions seem to increase the likelihood of success more effectively than general interventions.¹² Also multi-component caregiver interventions using

individualised support, information and training of skills were proven to be more effective.¹³⁻¹⁵ Such multi-component interventions are also called complex interventions which are defined as those interventions that include several components, which may act both independently and interdependently.^{16,17} Often, complex or multi-component interventions for older people and for caregivers, tailored to the individual priorities, are more effective than single component interventions.^{13-15,18} Community based occupational therapy for older people with dementia and their primary caregivers¹⁹⁻²² is such a multi-component intervention that is tailored to individual needs .

Previous studies have shown community based occupational therapy, given in the home, to improve the functional independence and autonomy of patients with dementia and to decrease their caregiver burden.^{23,24} However, a systematic review has shown these earlier studies²⁵ to be methodologically unsound and therefore insufficient evidence is found for the effectiveness of community based occupational therapy in older people with dementia and their caregivers.

Occupational therapy

Definition and history

The profession of occupational therapy (OT) was founded at the beginning of the previous century in the United States of America. The founders of the profession had different backgrounds i.e. physicians, architects, social workers, psychiatrists, teachers of arts and crafts or nurses. The occupational therapy profession was at first practiced in psychiatric hospitals and moved gradually to other settings such as rehabilitation centres, nursing homes and general hospitals. Within the Dutch health care system occupational therapy is a young profession, which was introduced after the Second World War. The first patients treated by Dutch occupational therapists were former soldiers admitted in nursing homes and rehabilitation centres who had to be trained for their come back in society and in former work places.^{26,27}

The definition of occupational therapy by the World Federation of Occupational Therapy (WFOT) is: occupational therapy is a profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation.²⁸ The Dutch definition of the aim of occupational therapy is: occupational therapy is

directed at the improvement of clients' participation in a meaningful daily life, which means participation in activities of daily living, work and leisure.²⁹

Occupational therapy assists people in developing the "skills for the job of living" necessary for independent and satisfying lives. Together with the client, the occupational therapist sets up a programme, to help the client improve abilities to carry out meaningful activities of daily living in the client's own environment, for instance dressing, doing grocery shopping, cooking, writing, typing, using the telephone, gardening, woodworking, etc. When skills cannot be developed or improved, occupational therapy offers creative solutions and resources for carrying out the person's daily activities by making use of environmental adaptations and by training family members and caregivers in coaching the client. Furthermore, occupational therapy is aimed at improving clients' participation in social activities. In terms of the International Classification of Functioning, Disability and Health (ICF) occupational therapy operates in all fields of the ICF but is focused at decreasing the disabilities and increasing the participation and health of their clients.

Occupational therapy practitioners are skilled professionals whose education includes the study of human growth and development with specific emphasis on the social, emotional, psychological and physiological effects of illness and injury.²⁸ The last decades occupational therapy has been the fastest growing profession-allied to medicine in the Netherlands. About 3000 occupational therapists are employed at this moment. In 2000, almost 79% of the occupational therapists worked in health or hospital services.³¹

Occupational therapists work in geriatrics, disabled person care, (child) rehabilitation, psychiatry, hospitals, health centres and other forms of institutional care (e.g. for mentally retarded patients), outpatient care and also in community health care. At the end of the year 1999 the minister of health decided that community based occupational therapy would be admitted in the public health assurance fund. This decision meant that on the 1st of January 2000 occupational therapy was also available in primary health care and became accessible for all the inhabitants of the Netherlands for ten visits at home per year. As a result the Netherlands counted 50 private occupational therapy practices in 2006 and about 100 private practices in 2007.³¹

Occupational therapy in dementia

In the past, occupational therapy in dementia was offered in institutions. However, two thirds of the patients with dementia are cared for at home by relatives with or without support from home care.⁸ From the moment occupational therapy could be offered at home, occupational therapy in

dementia was primarily directed at the patient and at his primary caregiver. The primary focus of community based occupational therapy in dementia is to improve patients' autonomy and abilities (or to enable patients) to perform meaningful daily activities in their own environment and hence promote their independence and social participation and to reduce caregiver burden, by increasing caregivers' competence and ability to handle the behavioural problems they encounter.^{19-25,28,32,33} Community based occupational therapy in dementia focuses on the empowering of the possibilities of individuals and proxies.²⁵ In community based occupational therapy older people with dementia are trained in making use of an adapted physical and social environment. Their caregivers are educated about the consequences of the dementia and are trained in supervision and problem solving by use of cognitive and behavioural interventions^{19-25,32}, to change their coping behaviors and reduce their burden of care. Both the clients with dementia and their caregivers are actively involved in the therapeutic process, and outcomes of therapy are diverse, client-driven and measured in terms of participation in activities of everyday life, competence or satisfaction derived from participation. This definition of community based occupational therapy is based on the definition of occupational therapy of the World Federation of Occupational Therapists (WFOT),²⁸ of the Canadian Association of Occupational Therapists (CAOT)³⁰, of consensus based definitions made for our occupational therapy program and guideline¹⁹⁻²² and on the definition as described in the Dutch Foundations of Occupational Therapy.²⁹

The relevance of occupational therapy in dementia is supported by findings that problems in initiative and in performing daily activities often are the reason for a decrease in quality of life in dementia patients^{25,34} and that information, emotional support and training of skills improved the quality of life of patients with dementia and their caregivers.³⁵ It is expected and hypothesized that patients' and caregivers' daily performance and quality of life can be improved and that caregiver burden can be decreased by occupational therapy.^{20,21,23-25,32} Research to the effectiveness and efficiency of community based occupational therapy for older people with dementia and their caregivers is needed to investigate this research question. Outcomes on daily functioning, caregiver burden and quality of life are increasingly being considered equally or even more clinically relevant than measures of cognitive outcome.³⁶

Client-centeredness in community based occupational therapy in dementia

Client-centred interventions are based on the needs, beliefs, norms and goals of the client (i.e. the patient or informal caregiver). The therapist's attitude is open and flexible and directed at collaboration with the client.^{37,38,42,44-48}

Family-centred interventions are based on the needs, beliefs, norms and goals of the family (i.e. the client and his or her family).^{24,32,37,39,40} Community based occupational therapy in dementia is based on a client and family centred perspective and is focused on the problems of the client with dementia in his social environment (family centred perspective) and on the individual problems of the caregiver as a client. In the Netherlands, there is a trend towards client and family centred interventions⁴⁰ of chronically ill patients. Recently a Dutch law on social support and assistance was accepted supporting also informal caregivers of chronically ill patients (WMO, 2006).⁴¹

Occupational therapists use client centred methods to support clients with dementia and their caregivers to determine their own needs and goals. It is the first step in the motivational process to get a person with dementia more active and motivated to perform meaningful daily activities and to get a primary caregiver conscious of his own needs and goals. Narrative methods, like story telling, are such client centred methods that are useful for clients with dementia and their caregivers.^{42,43} In these narrative methods, the occupational therapist together with the client analyses his or her life story to get insight in the beliefs, interests, norms, habits, roles, meanings of activities and situations, problems and goals of the client. The Occupational Performance History Interview (OPHI),^{45,46} is a narrative instrument that is used for the analysis of life stories of different categories of patients and is also useful for patients with mild to moderate dementia.¹⁹⁻²² The Ethnographic Interview⁴² is another useful client centred instrument to analyze the story of the informal caregiver.^{19-22,42} To analyze, prioritize and evaluate the problems to be worked on, the occupational therapist together with the client with dementia or with his informal caregiver uses the Canadian Occupational Performance Measure (COPM).⁴⁴ Based on the problems determined with the COPM, the occupational therapy goals are defined together with the client with dementia (client-centred goals), and together with the caregiver (client-centred goals) separately and accordingly with the client and his family together (family-centred goals). These family-centred goals are negotiated by the occupational therapist, patient and family to determine the final family-centred goals.¹⁹⁻²² This client- and family centred method of problem defining and goal setting is used to retain patients' and caregivers' motivation to perform

meaningful daily activities alone and together, and to retain and sustain autonomy for both clients.

The aim of the research project

The overall aim of this research project is to evaluate the effectiveness and cost-effectiveness of a client- and family-centred community based occupational therapy intervention for older people with dementia and their caregivers. The aim is primarily to determine what the effectiveness and cost-effectiveness is on the daily functioning of people with mild to moderate dementia and on their caregivers' burden. Secondly, the aim is to determine what its effectiveness is on the quality of life, mood and health status of these older people with dementia and their caregivers. Campbell & Campbell and colleagues^{16,17} described the UK's Medical Research Council's framework (MRC framework, www.mrc.ac.uk) for the design and evaluation of complex or multi-component interventions (figure 1). In this framework they advocate for a phased approach (including one preclinical and four clinical phases) in the development and evaluation of complex interventions. In this thesis and in an earlier project^{21,22} we carried out the process of development and evaluation of our OT method in highly similar steps.

The MRC framework for design and evaluation of complex interventions

The preclinical or theoretical phase aims at exploring relevant theories, developing and testing the intervention on eligibility and feasibility, and identifying potential effects and reasons for these supposed effects. Phase I is the phase of modelling, which is directed at the underlying components and mechanism in relation to predicted outcome. In phase II, the phase of the exploratory trial, the information gathered in phase I is used to develop and test the optimal intervention and study design on feasibility. Phase III is the phase of the definitive randomised controlled trial. In this phase this randomised controlled trial is conducted in a methodological sound manner. Phase IV is the phase of long term implementation in which is determined what the conditions of effective and long term implementation will be.

This phased framework for the design and evaluation of complex interventions can be used in a flexible way but emphasizes pilots and implementation studies before conducting a randomised controlled trial. Therefore, the preclinical phase and phase I and II can be seen as a part of a larger interactive activity before conducting a randomised controlled trial.^{16,17}

Outline of this thesis' route to evidence based occupational therapy in dementia

This project evaluates the complex and multi-component intervention of community based occupational therapy in older people with dementia and their primary caregivers (figure 1) based on the theoretical Model of Human Occupation of Kielhofner.^{46,47}

Theoretical phase, development and testing the OT-in dementia-guideline

In this project, the preclinical phase¹⁶ was performed in which the content of our community based occupational therapy intervention for older people with cognitive impairments and their primary caregivers was developed using not only the theoretical model of Kielhofner, but also comprehensive literature review, and a consensus process according to the method of effective guideline development.^{21-22,48} Consensus was reached with a national and international panel of experienced occupational therapists, teachers and researchers in occupational therapy. In this phase, no randomised controlled trials of sufficient methodological rigor were found that proved the effectiveness of our intervention. Therefore the guideline we developed^{19,20} was a theory- and consensus based guideline, extensively described in an occupational therapy program with a manual and workbook, and was a first step to evidence based community based occupational therapy in older patients with dementia and their caregivers. We accordingly performed in this phase a study to test the feasibility of our intervention^{21,22} in an occupational therapists' evaluation of the quality and usefulness of the guideline,^{21,22} adherence to the guideline and an evaluation of patients' and caregivers' opinions about the quality and eligibility of the intervention received. The guideline is not presented in a paper in this thesis, because of its length, but formed the essential base of this community based occupational therapy intervention for older people with dementia and their caregivers. The guideline and the development and testing of the guideline is described earlier in two papers in the Dutch Journal of Occupational Therapy^{20,21} and in a report for the Board of Higher Education and for the Dutch Ministry of Education.²² (figure 1, phase I)

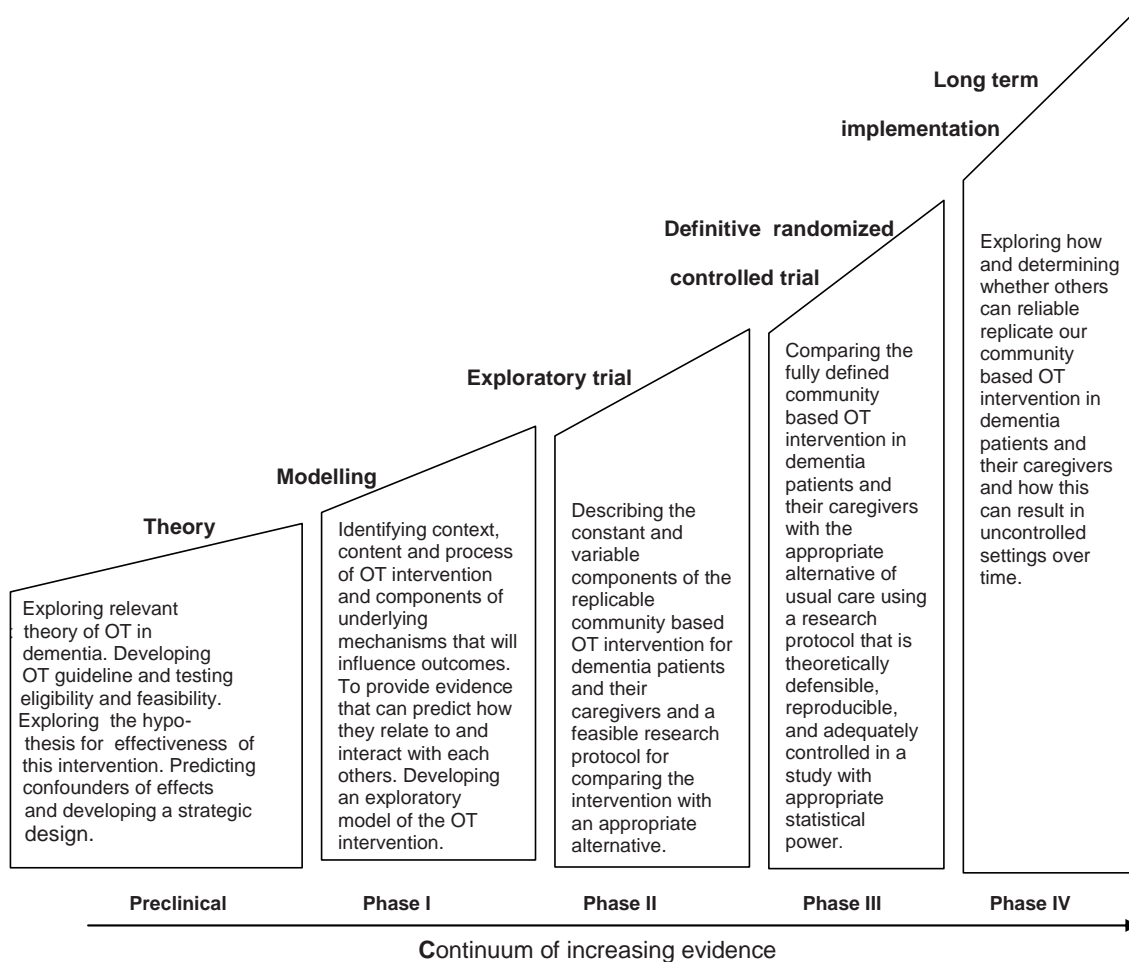


Figure 1: The evaluation of the complex community based occupational therapy (OT) intervention for people with dementia and their caregivers placed in the MRC framework and continuum of increasing evidence of Campbell (et al., 2000)

Modelling phase

We described modelling of the intervention by a case study analysis (Chapter 2). Our aim of this case study is to identify the context, contents and process of providing and receiving occupational therapy at home in dementia patients and their caregivers and to develop a model explaining our intervention. In this study the underlying mechanisms of the prediction of outcomes are analyzed.

The exploratory phase

This phase is described in chapter 3 with a preliminary evaluation of pilot changes on patients' and caregivers' outcomes in a small (n=12 patients with dementia and caregivers) and uncontrolled study with measurements before and after occupational therapy intervention and an evaluation of the feasibility of the measurement instruments with regard to sensitivity for change (Figure 1, phase II).

Randomized controlled trial-phase

Because the outcomes of the exploratory trial were based on the results of the case study analysis, and because they confirmed the hypothesis and showed their feasibility and sensitivity to change, the next (golden) step to evidence based occupational therapy in people with dementia and their caregivers is conducted: a randomised controlled trial on the effects of this community based occupational therapy intervention on the daily functioning and quality of life of dementia patients, and on the sense of competence and quality of life of their primary caregivers (Chapter 4, 5) (figure 1, phase III). Noting that a systematic review confirmed the evidence on the effectiveness of community based occupational therapy in dementia patients and their caregivers (Steultjens et al., 2004), we had firm ground to perform the next step to evidence based occupational therapy in dementia and thus we carried out a cost effectiveness study to evaluate the efficiency of this occupational therapy intervention from a societal perspective alongside our prospective randomized clinical trial (Chapter 6). This thesis ends up with a general discussion, in which these studies of the continuum of increasing evidence (figure 1), their context and the continuum itself are discussed (Chapter 7).

Implementation phase

In future, but not part of this thesis, the implementation of this community based occupational therapy intervention in dementia, will be performed and evaluated (figure I, phase IV). However, in the discussion part of the thesis (Chapter 7) we discuss the implementation of this community based occupational therapy intervention for older people with dementia and their caregivers, by describing the possible chances and threats of this future implementation and end this thesis with recommendations for clinical practice and for future studies.

Terminology

In this thesis different kinds of terminology are used because the chapters were published in different journals (medical, social or occupational therapy journals). Therefore, different terms were used for people with dementia. We used terms such as patients with dementia, clients with dementia and individuals with dementia. With all these terms the same group of older people with dementia is meant. With the terms informal caregivers, primary caregivers and caregivers, also the same people (partners, family members, neighbours or friends) are meant that deliver informal care to older people with dementia. The terms community based occupational therapy, community occupational therapy, occupational therapy at home or occupational therapy in primary health care, include all the same occupational therapy that is delivered at the homes of older people with dementia, as described in our studies. Cost-effectiveness and efficiency are concepts that are used for the same understanding.

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Chapter 2

How can occupational therapy improve the daily performance and communication of an older patient with dementia and his primary caregiver?

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ABSTRACT

Objective: to enhance insight into the process of occupational therapy (OT) and the changes after OT, in an older patient with mild dementia and his primary caregiver.

Design and setting: case study: content analysis of an OT patient record.

Intervention: System-based OT at home using a guideline focusing on both patient's performance in daily activities and caregiver's cognition on patient behavior and caregiver role and focusing on adaptation of physical environment.

Measures: Triangulation of results of qualitative content analysis and quantitative description using the following measures:

Brief Cognitive Rating Scale (BCRS), Assessment of Motor and Process Skills (AMPS), Interview of Deterioration in Daily Activities in Dementia (IDDD), Canadian Occupational Performance Measurement (COPM), Dementia Quality of Life Instrument (DQOL), Sense of Competence Scale (SCQ) and the Mastery Scale.

Results: The global categories derived from content analysis were: daily performance and communication. The specific categories were the patient with dementia, his or her caregiver and the occupational therapist. Important themes derived from content analysis were: patient's capacity for pleasure, autonomy and appreciation in performing daily activities and caregiver's competence. Patient's changes reported after OT: more initiative, autonomy and pleasure in performing daily activities, increase of quality of life; caregiver's changes reported after OT: improved communication and supervision skills, changed cognition on patient behavior and caregiver role, improved sense of competence. The quantitative results showed an improved daily performance (e.g. initiative, motor and process skills, need for assistance) and quality of life of the patient and improved sense of competence, quality of life and mastery of the situation of the caregiver after OT intervention. Thus the results of the qualitative content analysis were supported by the quantitative results.

Additionally, based on the results of the content analysis an exploratory and system-based model has been developed connecting OT diagnosis and OT treatment at home for patients with dementia and their primary caregivers.

Conclusion: This case study provides information on how occupational therapy can improve the daily performance, communication, sense of competence and quality of life of an older patient with dementia and his or her primary caregiver. A combination of education, setting feasible goals, using adaptations in physical environment, training compensatory skills, training

supervision skills, and changing dysfunctional cognitions on patient behaviour and caregiver role seemed to be successful. A randomized controlled trial must provide information on the effects of OT at home for older patients with dementia and their primary caregivers.

Keywords activities of daily living; autonomy; caregiver burden; cognition on caregiver role; coping; education; occupational therapy; quality of life

Introduction

Dementia is characterized by cognitive, functional, and behavioural deficits that ultimately result in the inability to care for oneself.¹ The daily functioning of patients with dementia is dependent on the quality of care received at home.²

Informal, unpaid care provided by family or friends, with one individual designated as the primary caregiver, is the most common long-term care provided to these patients.³⁻⁷ Occupational therapy (OT) is expected to be of value in dementia care because of the enormous challenges in daily performance and decrease of quality of life that dementia brings to patients living with dementia and for their caregivers. OT is supposed to be effective through facilitating the personal capacities of the older persons with dementia, changing the cognition on patient behaviour and caregiver role, enhancing the supervision skills of the caregivers, and taking advantage of any opportunities that an (adapted) physical environment may offer.⁸⁻¹⁰ In a pilot study^{8,9} it was found that OT seemed to improve the daily performance of elderly people with dementia and the sense of competence of their informal caregivers. The intervention used was a comprehensive, home-environmental and system-based OT intervention according to an OT guideline.^{10,11} There are some other studies¹²⁻¹⁵ that also reported improved functional independence and decrease of caregiver burden following a home environment OT intervention. However, these studies had insufficient methodological rigour.¹⁶ In conclusion, very little is known about the effects and the process of successfully providing and receiving OT at home for patients with dementia and their primary caregivers. In the Netherlands, OT is most usually found in a hospital, in rehabilitation or nursing home settings. Recently, OT at home for community dwelling patients with dementia is more usual and seems to be more effective. The aim of this case study analysis was to get insight into the content, context and process of OT at home and to study the possible effects and conditions for success of OT at home for older patients with dementia and their caregivers. An occupational therapist's patient record offered the unique opportunity to do an in-depth study and the quantitative measurements before and after this OT intervention

gave the possibility to compare both results and to search for supporting information.

The specific aims of this study were:

1. To enhance insight into the context, content and process of providing and receiving occupational therapy at home in the case of an older patient with dementia and his primary caregiver;
2. To ascertain the themes of OT intervention in this case study;
3. To study the changes after OT at home in the case of an older patient with dementia and his primary caregiver;
4. To ascertain the conditions for success in this case and to present these conditions in an exploratory model of OT at home for older patients with dementia and their primary caregivers.

Methods

Occupational therapy

In general, the aim of OT at home for older patients with dementia is to increase or maintain their functional independency in performing daily activities, their social participation and their quality of life.¹⁶ The process consists of analysing patients' interests, habits, and capacities; teaching and training compensatory strategies; and using adaptations in physical and social environments. OT also aims to analyse and improve the sense of competence and mastery skills of their primary caregivers during the supervision of the daily activities of the patients with dementia, by teaching practical skills and communication strategies.

Furthermore, OT aims to change caregiver cognition on patient behaviour and caregiver role by teaching primary caregivers more effective coping strategies for dealing with the behaviour of the patient and the burden of care. This OT intervention is based on a guideline of OT at home^{9,10,11,17}. Methods, assessments and strategies available to the occupational therapist are described in this guideline. The guideline applies the Model of Human Occupation¹⁸ to the practice of task analysis and explores the impact on an individual patient and his caregiver through observation and through patient and caregiver narrative. It is system-based and clientcentred, so that individual treatment goals are set with both the patient with dementia and with his or her primary caregivers. This OT guideline is the first system-based guideline directed at OT at home and at the patient with dementia and the patient's primary caregiver together.

Data collection

Subject selection: the subjects described in this case study were selected from a group of patients and primary caregivers who were followed in a quantitative study and were measured before and after OT intervention. All patients included in that study had mild to severe dementia, were living at home, had an informal primary caregiver, were not diagnosed with severe Behavioural or Psychological Symptoms in Dementia (BPSD), were well motivated towards OT intervention, and were being treated according to an OT guideline.^{10,11,17} For this case study evaluation, the occupational therapist was asked to choose retrospectively one case of OT at home of an older patient with dementia and the patient's primary caregiver that was an example of common occupational therapy practice. Accordingly, the case selected was that of Richard, an older patient with mild dementia and Anne, his wife and primary caregiver.

Design and setting: This content analysis of this case study was based on a patient record containing detailed descriptions of the context, the treatment process, and its outcomes on the patient and his primary caregiver, written by an occupational therapist. The record consisted of observational data, instructions, advices and detailed narrative data of the in-depth interviews of the occupational therapist with the older person with dementia and his primary caregiver. In addition, quantitative data, collected by an independent research assistant (M.T.), were used to describe characteristics of Richard and Anne at the start (Tables 1 and 2) and end of the OT intervention (Tables 1 and 2). These data reflect values concerning Richard's cognitive functioning; level of dementia; daily performance (performance, initiative and need for assistance in (Instrumental) Activities of Daily Living (ADL)/(IADL)), satisfaction with the daily performance, quality of life and depression (including psychological well-being); and concerning Anne's sense of competence, mastery of the situation, quality of life and depression (including psychological well-being). Validated instruments were used to assess patient's and caregiver's condition (see Tables 1 and 2).

Data analysis

Qualitative research methods were most appropriate in this case, as most of the questions addressed required a detailed investigation of the OT intervention process¹⁹ and the aim is to improve understanding of the context in which behaviours take place.²⁰ Therefore, the method of qualitative analysis used was that of the systematic comparison of situations or events²¹⁻²³ and the grounded theory.^{22,24,25} According to this method, six stages in describing

the case could be identified. First, an independent researcher (M.G.) was asked to distinguish global categories in the qualitative data of the patient record. Second, these global categories were subdivided into specific categories and themes. Third, this analysis was repeated independently by a second independent researcher (M.V-D). Fourth, consensus was reached between the two researchers. Fifth, the two researchers analysed and described the case study on the basis of these categories and themes. Sixth, the description of this final case study was checked by the occupational therapist, the author of the record (J.Z.) (member check). Reflection and analysis of the data in the patient record was alternated in a cyclical process by the two researchers. The case study was divided into three phases: (1) the situation before the start of the occupational therapy intervention (using the quantitative baseline data, assessed by the research assistant MT); (2) the process of providing and receiving OT (using the qualitative data of the patient record); (3) the situation at the end of the occupational therapy intervention (using the qualitative and the quantitative data of the second measurement, after five weeks and 10 sessions OT intervention, assessed by the research assistant MT). Quantitative data were used to study the changes in patient's and caregiver's characteristics after OT intervention and are presented in Tables 1 and 2.

The description and qualitative analysis of the data of the diagnostic phase were based on the patient record of the occupational therapist concerning her observations of the skills in daily performance and the communication between the patient and his wife. The description and analysis was also based on the narrative interviews with the patient and his primary caregiver.

Reliability: we made use of triangulation of the results^{19,26,27} to ascertain reliability and credibility by following the three phases mentioned above, by following the six stages of the qualitative method used and by use of an independent researcher and reliable quantitative measurement instrument. Validity of the themes was studied by comparing the themes of this case study analysis with the themes of the Model of Human Occupation (MOHO)¹⁸ and other relevant literature findings. Validity of the results after OT intervention was investigated by triangulation of the results found in the qualitative content analysis and the quantitative results of the patient's and caregiver characteristics after OT intervention. The names of the patient and caregiver were changed to ensure anonymity.

Context: The case Richard and his wife Anne

Richard was a 71-year-old man who lived with his wife Anne in a detached bungalow. Richard had been a carpenter until he was 54 years old. He then stopped working because of hip problems. The physical environment in their house was adapted and made safe for Richard. Their house had good accessibility. Richard walked with a stick and cycled independently. Since reaching the age of 69 he has suffered from Parkinson's disease. A year ago, a geriatrician from the memory clinic of the Radboud University Nijmegen Medical Centre diagnosed mild dementia with subcortical features.

Richard's social environment included many friends and three children who lived out of town. Richard's interests had been singing in a choir and woodwork, but he was no longer able to practice these two activities. He hoped that he and his wife would be able to live in their house as long as possible. Anne, his wife, was 68 years old. In the past, she was a housewife. She was afraid to leave Richard on his own, because of his cognitive impairments. Anne expressed an overall sense of fatigue, because she felt she had a heavy burden of care.

Results

First, the situation before OT intervention was described based on the quantitative assessments of patient and caregiver characteristics before OT intervention (see Tables 1 and 2). Second, the OT intervention period, comprising the phase of OT diagnostics and the phase of OT treatment, was described. The two global categories identified from the patient record by the two independent researchers were the two problem areas on which the OT was focused. These were: (1) *daily performance* and (2) *communication*.

These two global categories were subdivided into more specific categories and themes. Three specific subcategories were identified, based on the participants involved in this therapeutic setting: *the older person with dementia*; *the primary caregiver*; and *the occupational therapist*. The main result of this qualitative analysis was the identification of the themes as described in the text of this case study and presented in Table 4. These were the specific problems on which the OT was focused. As a result of this case study evaluation, an exploratory system-based model connecting OT diagnosis and intervention at home for older patients with dementia and their primary caregivers was created (Table 4). Third, the situation directly after OT intervention was assessed by using validated measures of patients and caregivers characteristics (Tables 1 and 2). Accordingly, changes in daily

performance, sense of competence, mastery and quality of life of the patient and his caregiver after OT intervention were described (Tables 1 and 2).

Situation before OT intervention

As can be seen in Table 1, Richard's diagnosis was just mild dementia; his dementia was of a sub-cortical type. According to the Assessment of Motor and Process Skills (AMPS), his motor skills were below the level of independent living at home and he had many problems in performing daily activities because of his limited process skills (AMPS process). In ADL and IADL activities he showed variability in initiative (IDDD initiative) and in many activities he needed assistance (IDDD performance). Richard's wife Anne had a moderate sense of competence (Table 2). Neither Richard nor Anne had any hearing or vision impairments.

Table 1: Characteristics of patient Richard before and after OT intervention and range of the measurement instruments

Characteristics	Range	Before OT (T0)	After OT (T1)
MMSE	0-30 (24 and lower is possibility of dementia)	24	-
BCRS	0 – 56 (9-24 = mild dementia; 25-40 = moderate dementia)	24	27
AMPS motor	-3 – 4 (cut off point = 2.0)	-0.2	0.5
AMPS process	-3 – 4 (cut off point = 1.0)	0.3	1.3
IDDD initiative	0 – 36	13	23
IDDD performance	0 - 44	17	11
DQOL A (enjoy)	5-25	12	16
DQOL C (overall)	1-5	4	5
COPM performance	1-10	5.3	7.0
COPM satisfaction	1-10	5.7	8.6
CSD	0-38	8	2

MMSE= Mini Mental State Examination (Folstein et al., 1975)²⁸; cognitive functioning; BCRS: Brief Cognitive Rating Scale (Muskens, 1993; Reisberg, 1983)²⁹⁻³⁰; cognitive functioning and level of dementia; AMPS: Assessment of Motor and Process Skills (Fisher, 2001)³¹; motor and process skills in daily activities; IDDD: Interview of Deterioration in Daily activities in Dementia (Teunisse, 1997)³²; IDDD initiative and IDDD performance: initiative and need for assistance in daily activities; DQOL = Dementia Quality of Life Instrument (Brod, 1999, Dutch version Bosboom & Jonkers, 2000/2001)^{33,34}; COPM = Canadian Occupational Performance Measurement (Law, Baptiste, Carswell, McColl, Palatajko & Pollock, 1994, 1998, Dutch version Duijn, Niezen, Verkerk, Vermeeren, 1998)³⁵⁻³⁷; COPM performance= self perception in occupational performance ; COPM satisfaction = satisfaction with occupational performance; CSD = Cornell Scale for Depression (Alexopoulos, 1988; Dutch version Droës, 1993)³⁸⁻³⁹; depression.

Table 2: Characteristics of caregiver Anne before and after OT intervention and range of the measurement instruments

Characteristics caregiver	Range	Before OT (T0)	After OT (T1)
SCQ	27 – 135	96	118
DQOL A (enjoy)	5-25	19	22
DQOL C (overall)	1-5	4	5
Mastery Scale	5-25	10	5
Ces-D	0-60	9	5

SCQ= Sense of Competence Questionnaire (Vernooij-Dassen et. al., 1996, 1999)^{40,41,56} COPM = Canadian Occupational Performance Measurement (Law, Baptiste, Carswell, McColl, Palatajko & Pollock, 1994, 1998, Dutch version Duijn, Niezen, Verkerk, Vermeeren, 1998)³⁵⁻³⁷; DQOL = Dementia Quality of Life Instrument (Brod, 1999, Dutch version Bosboom & Jonkers, 2000/2001)^{33,34}; Mastery Scale (Smits, 1998)⁴²; Ces-D = Center for Epidemiologic Studies Depression Scales (Beekman et al., 1994; Radloff, 1977)^{43,44}: depression.

OT intervention period: OT diagnosis

Daily performance

Passive behaviour, loss of habits and structure, loss of pleasure in daily activities

According to his wife Anne, Richard had become passive, and had lost interest and took little pleasure in his previous activities.

Richard's daily performance problems became apparent by analysing his habits and interests. At home Richard always used to do the odd jobs and the gardening. But recently, he had given up his old habits, like gardening and preparing the vegetables, because Anne had taken over these activities.

His disabilities were apparent in a multi-faceted way, as the occupational therapist describes:

Richard wanted to prune the hedge. He had some special pruning shears that did not require much strength, but after a few minutes he asked his wife Anne how to use them. After she had explained them to him, he used the pruning shears in a strange way. When Anne demonstrated the correct use, he was able to prune the hedge, but he did so in a meaningless way or walked around aimlessly. When Richard stopped gardening, he seemed tired and disappointed.

Another activity to which Richard was accustomed was washing and preparing fresh vegetables from the garden. For Jane (the occupational therapist), he demonstrated how to prepare a leek. Despite his appearance of apathy, he showed pleasure in this activity and revealed that he could perform it without physical assistance, although his performance had no structure. But overall,

he seemed to be proud of the result and seemed happy to be acting on his own. Jane's observations were as follows:

Richard washed the leek. He was in a happy mood. He dropped water on the kitchen floor, and made a puddle that he didn't notice until he almost slipped on it. He was very slow. He couldn't find the right pan, or the salt. He asked his wife for help, but she was too busy, cleaning up the mess he had made and complaining. Her instructions from the occupational therapist had been not to take over the activity. After a while, he found the things he wanted by himself and he finished the task adequately. He stood throughout this activity, which lasted for over an hour! Afterwards, he was quite exhausted, but proud he had finished the task. Anne was also tired and disappointed and irritated with him because of the mess he had made. She finally suggested that it would be better if he sat on a chair and let her prepare the vegetables.

Limited abilities, individual norms and goals

Anne was grateful that Richard had stopped the gardening activity, because she did not believe he was capable of performing these gardening tasks any more. She said she had given him the maximum guidance she could offer. She said she often felt powerless about knowing what to do and that was actually the reason for her irritation. She preferred to perform activities herself, because he worked so inefficiently and some activities were not safe.

The following examples illustrate the discrepancy in perception of the same situation, the difference between Anne's and Richard's norms and goals, and the influence of the difference on their daily performance and communication.

Individual norms and goals, Richard's loss of autonomy

Anne: He likes to help me in the kitchen and to do the gardening. He says he wants to do some activities by himself, but for me it is stressful to see him struggle. That's why I sometimes think that it would be better if I took over these activities myself. He is also no longer able to perform some of the other activities he used to like, such as going to the choir practices.

Loss of autonomy and roles of Anne

Anne: This is also difficult for me, because during that time I visited friends, which I liked very much. Since Richard has been home I

have lost a part of my freedom. Now, I can't work anymore, because he can't stay at home alone.

Communication

Denial and process of accepting the dementia

Richard's denial of the dementia and Anne's problems with adapting and accepting the dementia:

Anne: I have more problems with our situation than he has. Richard doesn't recognize his deficiencies, his driving problems for example. He can easily get lost and can't integrate all the stimuli needed to drive safely. But he still likes driving. I am in the process of adapting to his dementia and accepting it. But I feel guilty about things that happened in the past, because I didn't recognize the symptoms of his dementia. Now I know more about it, but handling the situation is still difficult.

Loss of appreciation

Anne had many problems with Richard's limitations in performing daily activities independently. Richard said he had a lot of problems with Anne's loss of appreciation for him.

Anne: He always used to vacuum the house but now he forgets to do some parts. I become irritated about it. I know that's my problem, because I am very particular and always work very fast. Although he has no problems with the situation, I do. The result of my reaction is that he feels helpless, has stopped vacuuming, and I have taken over the activity.

Anne's feelings of helplessness and decrease of sense of competence

Anne: I don't know how I can help him. I'm tired and I have back problems because of all the things I have to do myself at the moment. I am afraid for the future. But I hope we can make some arrangements that will allow us to stay together in this house as long as possible. We always used to help each other in the past, so we should be able to manage that now, as well.

The following section is a comparison made by the occupational therapist of Richard and Anne's reactions based on their individual feelings of helplessness, Anne's loss of appreciation, and Anne's role as a coach for Richard.

For example, Jane described Anne's reaction to Richard's need for help during the gardening activity as follows:

Anne explained the working of the shears verbally to him; she did it twice, until she saw that Richard seemed to have understood her information.

Richard's reaction was not what Anne had hoped for:

When Richard started working, it seemed he hadn't understood: he used the pruning shears in a strange way.

Anne's reaction was:

. . . she demonstrated the working of the shears.

Richard's reaction:

. . . he imitated the use of the shears correctly. But then he trimmed the hedge aimlessly. He trimmed some parts of the hedge over and over again. . . .

Anne's reaction showed her inability to stimulate Richard in this gardening activity:

. . . she got very irritated. She said to me (Jane): 'He'd better stop gardening'.

Richard's reaction:

After 15 minutes, Richard had to finish his gardening activity, because he was exhausted and he had pain in his hip. He was in a somber mood and grumbled a lot.

Anne's inability to stimulate Richard, their feelings of helplessness

Anne was aware of their communication problems, her irritated behaviour, and her inability to stimulate Richard into performing this activity. She also felt helpless. Anne said to the occupational therapist:

'I know, we get irritated with each other, but I don't know how to change this.'

Jane's conclusions about their daily performance and communication

The observation of the gardening and cooking activities was valuable for the occupational therapist Jane. According to her, Anne only saw his limited abilities. She said that Anne didn't see his other abilities, his pleasure in some activities, positive behaviours, or feelings. And that Richard didn't see his limitations because of his denial of the dementia, but he could still be very proud or disappointed. Jane indicated that this disappointment should be taken seriously. She noticed that Anne hadn't recognized Richard's disappointment and need for appreciation, because she was too taken up with her own norms and habits. Jane explained accordingly that Richard's goals should not be set too high; they should be adapted to Richard's level of endurance and physical abilities, and they should be safe. Richard needed more time and structure in his activities. She argued that if Anne were able to learn to supervise Richard, facilitate activities for him, and communicate in a more effective way, he ought to be able to perform these activities in a safer and more efficient manner. He would then derive pleasure, autonomy, and a feeling of competence from these activities instead of the present feelings of helplessness. Jane's analysis of the situation was that Anne needed more information about the consequences of dementia. She thought that Anne might perhaps learn to feel less guilty and set more feasible goals for Richard and for herself. She even thought that Anne could learn to modify her own norms periodically, appreciate Richard for what he did adequately, and set limits on the care she gave by setting aside more time for herself.

In Table 3, the results of the OT diagnostic and treatment phase are presented.

Table 3: Global and specific categories (bold) and themes of an older patient with dementia, the primary caregiver and the occupational therapist in OT diagnosis and treatment.

Patient	Primary caregiver	Occupational therapist
Daily performance Passive behavior	<ul style="list-style-type: none"> Feelings of helplessness 	Analysis of: <ul style="list-style-type: none"> cause of passive behavior and feeling of helplessness interesting but feasible activities Adapting: <ul style="list-style-type: none"> the home environment by structuring. Training: <ul style="list-style-type: none"> primary caregiver's supervision skills. patient's receptiveness towards assistance and adaptations in physical environment.
Loss of habits and structure in daily activities	<ul style="list-style-type: none"> Desire to maintain old habits and role as partner. Problems in accepting new role as coach and caregiver. 	Analysis of: <ul style="list-style-type: none"> previous and present habits, abilities and disabilities of patient and caregiver. Adapting: <ul style="list-style-type: none"> the home environment by structuring. Training: <ul style="list-style-type: none"> primary caregiver's supervision skills. patient's receptiveness towards assistance and adaptations in physical environment.
Loss of pleasure in daily activities	<ul style="list-style-type: none"> Inability to stimulate patient in performing daily activities 	Analysis: <ul style="list-style-type: none"> of previous and present interests or challenging activities and reasons for loss of interests/pleasure in activities. Adapting: <ul style="list-style-type: none"> Structuring the physical environment. Training: <ul style="list-style-type: none"> primary caregiver in setting feasible goals and in effective supervision skills.

Table 3: continued

Patient	Primary caregiver	Occupational therapist
Limited abilities	<ul style="list-style-type: none"> • High demands on the quality and deliverance of care • Decrease of psychological wellbeing (Loss of time for own activities, loss of social contacts and privacy). 	<p>Analysis of:</p> <ul style="list-style-type: none"> • abilities & disabilities of the patient and primary caregiver. • Adaptation of the physical environment. <p>Training:</p> <ul style="list-style-type: none"> • primary caregiver's supervision skills • patient's receptiveness towards assistance and adaptations in physical environment. <p>Guiding:</p> <ul style="list-style-type: none"> • caregiver through process of accepting patient's dementia. Guiding caregiver in setting limits to and finding solutions for the delivery of care.
Individual norms and goals	<ul style="list-style-type: none"> • Individual norms and goals 	<p>Analysis of:</p> <ul style="list-style-type: none"> • norms and goals of both individuals: similarities and differences. • abilities of patient and caregiver. <p>Training:</p> <ul style="list-style-type: none"> • primary caregiver in feasible goal setting for daily activities together with the patient. • primary caregiver's supervision skills.
Loss of autonomy	<ul style="list-style-type: none"> • Problems in dealing with the patient's changing behavior. • Loss of autonomy: inability to perform own activities 	<p>Analysis of:</p> <ul style="list-style-type: none"> • need for autonomy of patient and primary caregiver. <p>Adapting:</p> <ul style="list-style-type: none"> • the physical environment by structuring. <p>Training:</p> <ul style="list-style-type: none"> • primary caregiver to respect patient's autonomy. • patient to respect primary caregiver's autonomy. • primary caregiver to perform own activities by arranging practical solutions.

Table 3: continued

Patient	Primary caregiver	Occupational therapist
<p>Communication Denial and acceptance of the dementia process</p>	<ul style="list-style-type: none"> Problems with adapting to and accepting patient's dementia, feeling guilty 	<ul style="list-style-type: none"> primary caregiver to encourage and appreciate patient's abilities. primary caregiver to arrange outlined and feasible tasks or activities and to structure these by providing adaptations in physical environment. patient in using adaptations in physical environment. <p>Analysis of:</p> <ul style="list-style-type: none"> need for information about the consequences of the dementia process. <p>Informing:</p> <ul style="list-style-type: none"> patient and primary caregiver about these consequences. <p>Guiding:</p> <ul style="list-style-type: none"> Using counseling principals to guide the primary caregiver in finding more effective coping strategies. <p>Training:</p> <ul style="list-style-type: none"> Communication skills of primary caregiver.
<p>Loss of appreciation</p>	<ul style="list-style-type: none"> Problems in dealing with limited abilities and changed behavior of the patient 	<p>Analysis of:</p> <ul style="list-style-type: none"> expectations of the caregiver. needs for assistance and appreciation of the patient. <p>Informing:</p> <ul style="list-style-type: none"> primary caregiver about consequences of dementia disease. Using counseling principles to guide the primary caregiver in finding more effective coping strategies. <p>Training:</p> <ul style="list-style-type: none"> the primary caregiver to use more effective communication and supervision strategies.

Table 3: continued

Patient	Primary caregiver	Occupational therapist
	Feelings of helplessness and decrease of sense of competence	Analysis of: <ul style="list-style-type: none">the helplessness and sense of competence of caregiver Informing: <ul style="list-style-type: none">the primary caregiver about the (lack of) ability to care and the limitations of care deliverance Training: <ul style="list-style-type: none">effective supervision, communication and coping skills

OT goal setting phase

Goal setting with Richard and Anne

Jane stated that goal setting was difficult for Anne and Richard. The first goal came from Anne's suggestion that Jane should point out the opportunities Anne had to supervise Richard more adequately in the gardening activity, so that Richard could work more efficiently in an adapted, more relaxed style. In the event, Jane concluded that they would help each other if they were to try to find a way to do this activity together. She stated that Richard and Anne were well motivated to work towards this goal. Jane said that another goal that Richard suggested was for him to be able to start an activity and to be less passive. Accordingly, Jane described other OT goals

Anne suggested: for Richard to learn to use adaptations for fine motor tasks, like buttoning up his shirt; for Anne to learn to prepare and structure various ADL and IADL activities as well as make use of the right cues to supervise Richard; for Richard to learn how to use and handle his choir songbook; for Anne to learn to deal with Richard's cognitive problems caused by the dementia and improve communication between them. Jane stated that, at the beginning, both Richard and Anne wanted only advice and no training. They would then incorporate the advice into their activities themselves. They also wanted Jane to evaluate whether they had succeeded in achieving these goals. Jane reported that she had told them that they should set the priorities of these goals. They decided accordingly that the first goal they should concentrate on was improving

Richard's efficiency in the gardening activity, which meant more autonomy for Richard with the use of some cues from his wife.

OT treatment phase

In this phase, the process and results of OT treatment were described and analysed. This description and analysis was based on the global categories, or problem areas on which the OT was focused: the performance of daily activities and communication. These global categories were subdivided into specific categories: the components of the study. The most important results of this qualitative analysis were the themes, or concrete problems providing a focus for OT. These themes are described above and are presented in Tables 2 and 3.

Occupational therapy interventions on daily performance

Because Richard and Anne wanted only advice and were apprehensive about Jane's influence in their lives, Jane described how she began to advise the use of easy-to-use gardening aids.

Use of adaptations in physical environment

Jane described how she demonstrated how to incorporate some helpful aids and adaptations into the physical environment. For example, she demonstrated a kneel-sit-rest, a three-phase shears, and a pick-up instrument. Richard and Anne enjoyed trying these instruments together with the occupational therapist. Jane gave them the address and information of an organization that provides this type of advice and sells these and other tools for adapted gardening tasks.

Improving the skills of the older dementia patient and the primary caregiver

Jane described how she had given advice to Anne on how to structure the environment and the gardening activity in line with Richard's abilities, including how to put adaptations in place and how to communicate. She reported how Anne then prepared the gardening activity by placing strips of red tape in the garden to outline the part of the hedge Richard should work on for that day. They then made a schedule to limit how long he would work until the first rest period (say, 10 minutes). Jane encouraged him to use an alarm clock to remind him when it was time to rest. She explained that in this way he gained more of a sense of autonomy instead of just relying on Anne telling him that it

was time to rest. Anne then prepared tea for them, thereby allowing Richard to rest for a moment. Some user-friendly signs and instructions were placed on the shears (open and close, left and right hand, and so forth).

During the dressing activity, Jane described how Richard was receptive to the advice and training she gave him: how to use a big paper clip on his zipper, how to use a buttonhook for buttoning his shirt, or to use Velcro tape behind his buttons. Jane also told Richard and Anne about elastic shoelaces.

To cope with his songbook, Richard learned to use a rubber counting finger. She described how he also learned to look at the notes that Anne had placed on his music to mark the songs they would sing that evening and when they had finished a song. Richard trained himself to incorporate these adaptations and respond to the physical and social cues.

Jane described how Anne prepared the dressing activity by laying out Richard's clothes in the right sequence. Accordingly, Jane taught Richard to train himself first to look around for cues and aids and then try to figure out and solve problems before asking his wife for help. In order to obtain more autonomy and control over his life, Jane taught Richard to use his diary for date identification or daily plan clarification if he couldn't remember it himself. She also taught him to incorporate behaviour modification techniques that allowed for an increase in Anne's autonomy, such as refraining from asking Anne incessant questions while he was sitting and resting in a chair.

Occupational therapy interventions concerning communication

Giving more information about the consequences of the dementia

The occupational therapy intervention was also directed towards improving the communication skills of the primary caregiver by giving more information regarding the consequences of the dementia, teaching some principles about counselling, and by collaborating with the primary caregiver in order to find the right solution for some practical situations.

Jane described how she and Anne discussed ways of communicating with Richard. Anne said:

I always wanted him to finish tasks more quickly and more correctly than was possible. If things didn't go the way I wanted, I became very irritated.

Jane said that she understood Anne's problem and gave her some verbal and written information about the consequences of dementia and the resulting disabilities in Richard's performance of daily activities. And she related how

they then discussed how to deal with these consequences. Jane said that she responded to Anne as follows:

Richard felt proud of his gardening and cooking tasks, so you ought to reinforce his idea that he can produce good results. Activities should be broken down into component parts, because of his deficits in paying attention and his physical condition. For Richard, it doesn't matter if the activity is not completed today. He is satisfied if he only does one part effectively. If something needs to be done quickly, you can divide the activity so that you can do one part and he can do another. Otherwise, you can do this activity for him now and he can do another activity later for you, or together with you.

Jane reported that Anne replied:

Yes, I understand. I need to learn to set smaller goals, to use a slower pace, and to concentrate on Richard's happiness and pleasure in activities instead of just how the garden looks.

Training Anne's supervision skills

Jane explained how she had analysed the situation and advised Anne that it was her role to supervise Richard in getting more control over his life by facilitating an increased level of independence during gardening, cooking, and dressing tasks. Jane described how she structured the tasks before and during the activity and placed adaptations in the environment. She explained that it was important for Anne to motivate him, and show appreciation of what he could accomplish, rather than take over an activity that he could do with help. Anne was advised to give her instructions to Richard in a clear and concise manner along with visual cues and a demonstration if needed. Jane also advised Anne to call the leader of the choir each week to find out what songs they would sing at the choir practice and in what sequence. Then, Jane showed Anne how to make a note for him in his songbook and how to place the rubber fingers on the corresponding papers. Jane taught Anne how she could help Richard structure the days of the week and remember the planned dates by writing them down in the diary. Jane taught them that together they could structure the week and days by deciding on a time each day that Richard would work in the garden, help with the cooking, when they would visit friends, and so forth. Jane said that every morning and evening Anne should remind Richard to use the diary so that he could take more control of his life.

Setting limits to the care

Jane described how she told Anne that it was important that she should feel free carry out her own activities as well.

Because Richard could undertake more daily activities by himself, he would become more tired and would need more rest during the day. In that free time Anne could execute her own activities, like visiting neighbours or friends. Jane thought that if this strategy were successful, Anne would no longer be provoked into becoming irritated about his passive behaviour.

Anne said:

Perhaps I can arrange for us to go away for a weekend with one of the children, to have a different environment from time to time. We would both feel free for a little while. Perhaps he could make an appointment for a weekly visit to one of his friends. During that time, I could do a course.

The patient's and primary caregiver's evaluation of the process and results of OT

Jane said that Richard and Anne were very positive about the process of the occupational therapy intervention. Jane described how, following her suggestions, Anne structured the activity and made preparations before Richard embarked on dressing himself. And that they now knew about shops and organizations where they could get the aids and adaptations that they could buy for the dressing and gardening activities.

Jane also described how they used the diary and made plans together every morning and that they planned to continue to do so in future. Jane reported that Anne's evaluation of these modifications was that they helped Richard feel less unsure and have more control over his daily life. In addition, Anne felt herself to be less dominant. She concluded that Anne was still reading the written OT tips and printed information regarding coping with the everyday consequences of the dementia, and that this helped Anne keep control over her emotions. Jane observed that they now cooked together and Richard did the gardening each day, that Richard was also showing more initiative, and that Anne was more patient. Jane concluded that Anne was very positive in her attitude towards Richard. She observed that Richard showed increased initiative and tried first to figure things out for himself before asking her for help. And that Richard also worked more efficiently in a more comfortable and safe way as a result of the adaptations in the environment. She said that he

did not take up as much of Anne's energy as he did before and was more satisfied with his daily performance. Jane concluded that as a result Anne felt more free and positive towards Richard as well as more inclined to have a good conversation with him. Jane reported that Anne and Richard said that their quality of life had improved and Anne said she felt less tired and less guilty during the day. Overall, Anne felt more competent and less burdened, because she could offer Richard effective assistance. Moreover, she said that their communication had improved.

Occupational therapist's evaluation of the process and results of occupational therapy

Jane was also satisfied with the process and results of the therapy. She reported that Anne and Richard were kind and wellmotivated people, although they had shown some resistance to the therapy at the beginning. She estimated that at that moment all the occupational therapy goals had been reached. All the advice she had given had been taken on board. Jane also noted that Anne and Richard had asked her for more guidance and training during the treatment phase, that they had began to implement the advice in their daily lives, and hopefully they would continue to do so, as they had planned. Jane asserted in her descriptions that this goal would still be difficult for Anne and Richard, since they had old habits that would not be easy to change. Jane concluded that Richard and Anne had however seen what the result of these changes meant for them both and this improvement ought to provide enough motivation for them to continue their new behaviours.

In Table 4 an exploratory OT model is presented that connects the OT diagnosis themes with the OT treatment themes of this OT intervention at home for patients with dementia and their primary caregivers, based on the in-depth analysis of this case study evaluation.

Table 4: Model of OT diagnosis and treatment at home for older patients with dementia and their primary caregivers

OT diagnosis	OT treatment
<p>Daily performance</p> <p>Problems:</p> <p>A. Passive behavior</p> <p>B. Loss of habits and structure in daily Activities</p> <p>C. Loss of pleasure in daily activities</p> <p>D. Limited abilities</p> <p>E. Individual norms and goals</p> <p>F. Loss of autonomy</p>	<p>Daily performance</p> <p>Teaching patient and/or primary caregiver to:</p> <ol style="list-style-type: none"> 1. Choose challenging and interesting daily activities. 2. Provide and use structure in activities. 3. Provide and use adaptations in physical environment. 4. Enable patient's performance of challenging and interesting daily activities by using effective supervision skills. 5. Set feasible goals 6. Provide and use supervision during performance in daily activities 7. Provide and use adaptations in physical environment 8. Set feasible goals 9. Deal with the consequences of dementia and 10. Respect and use patient's abilities and primary caregiver's needs. 11. Set limits to the care
<p>Communication</p> <p>Problems:</p> <p>G. Denial or acceptance of the dementia process</p> <p>H. Loss of appreciation</p> <p>I. Feelings of helplessness and decrease of sense of competence or caregiver burden</p>	<p>Communication</p> <p>Teaching primary caregiver to:</p> <ol style="list-style-type: none"> 1. Deal with the consequences of dementia by using effective coping strategies 2. Respect the patient's autonomy and appreciate achievements 3. Encourage acknowledgement of (lack of) ability to care and set limitations on the delivery of care 4. Make use of effective supervision, Communication, and coping skills

Situation after OT intervention

As can be seen in Tables 1 and 2, patient's and caregiver's characteristics changed in the presumed direction after OT intervention in this case study. The results of the quantitative measurements support the changes described by the case study analysis. Interestingly, despite decrease in cognitive functioning (higher BCRS-score), in Richard's case, his skills in performing daily activities improved (higher AMPS motor and process scores), his initiative increased (higher IDDD initiative score) and his need for assistance decreased (lower IDDD performance score). He reported improved quality of life (higher DQOL enjoy and overall) and was more satisfied with his daily performance (COPM satisfaction). His wife Anne presented an increase in her sense of competence (higher SCQ score) and a better mastery of the situation (lower score on Mastery Scale). Additionally, her quality of life was a little increased (higher DQOL enjoy and overall) as well. These results confirm the positive changes in patient's and caregiver's characteristics that were also found by the qualitative case study analysis after the OT intervention.

Discussion and conclusion

Daily performance and communication were found in this case-study evaluation to be the global categories in the process of providing and receiving OT at home. They are central in OT diagnosis and treatment. The dominant themes in daily performance were the patient's loss of habits and structure in daily activities, passive behaviour, loss of pleasure or interest in activities, and limited abilities. The central themes for the patient and his primary caregiver together were the individual norms and goals and the loss of autonomy. The dominating communication themes of the patient were denial of the dementia and loss of appreciation. The primary caregiver's communication themes were problems with accepting the dementia process, feelings of helplessness, and decrease of sense of competence, or caregiver burden. Table 3 presents the themes that were the concrete problems on which OT was focused in this case study. The dominant themes in daily performance of the patient and the sense of competence theme of the caregiver, were consistent with the OT problems evaluated in our pilot study⁹ and in the literature. Other themes, such as loss of appreciation, denial and acceptance of the dementia, and individual norms and goals of the patient and caregiver were problems first evaluated in this case study, but were consistent with the OT guideline.^{10,11}

Since there was no system-based model connecting OT diagnosis and treatment at home directed at both the patient and caregiver, the results of this

case study were used to build an exploratory OT model (Table 4), connecting OT diagnosis themes with OT treatment themes for both community dwelling patients with dementia and their primary caregivers. However, more cases need to be analysed to test this exploratory systembased model of OT at home for patient with dementia and their caregivers.

The occupational therapy intervention in this case study was based on the system-based OT guideline.^{9-11,17} According to this client-centred guideline, goal setting is considered to be very important, is tailor-made and directed at both the patient and the primary caregiver. The focus of the guideline is on client empowerment rather than professional control. Prior studies have demonstrated that client-centred and tailor-made approaches directed to patients and their primary caregivers were appropriate in the case of dementia.^{45,46}

The reliability of the results of this case study analysis was studied by using triangulation^{19,26,27} of the results. The results of the qualitative content analysis were compared to the quantitative results and these were highly consistent. Daily performance themes changed positively in the content analysis and these themes were improved after OT intervention according to the quantitative results. The outcome of this case study of improved daily performance following OT intervention for patients with dementia was consistent with the outcomes of OT programmes in which individual environmental adaptations were used (such as visual or auditory signs and memory or safety aids).⁴⁷⁻⁵¹ Improved daily performance was also found in occupational therapy programmes in which intervention was directed towards the relatively well-preserved functions (such as motor skills and procedural memory) of older patients with dementia.⁴⁵ However, dementia can lead to disabilities in learning skills and poorer performance of daily activities. The older patient with dementia in this case study had a mild, but quite moderate dementia.

This result indicates that the learning ability of this patient was limited. The outcomes of this case study were therefore quite remarkable, because it was usually supposed that learning ability was a condition for the patient to participate successfully in an OT intervention. In our pilot study^{8,9} it was also found that OT seemed to improve the daily performance of elderly people with dementia and the sense of competence of their informal caregivers. The intervention used was a comprehensive, home-environmental and system-based OT intervention according to the OT guideline.^{10,11}

There are some other studies^{12,13-15} that also reported improved daily performance and decrease of caregiver burden following a home environmental OT intervention.

However, these studies had insufficient methodological rigour.¹⁶ Further data of the effect of OT intervention for elderly people with other types and more severe forms of dementia is needed.

Considering this case study, it can be supposed that patients with mild to moderate dementia with the right cues in physical and social environment, as with this case of Richard, are able to perform more independently than should be expected based on their relatively high MMSE score and despite cognitive decline. This could be the explanation for the improvement of the daily performance; for example more initiative, structure, autonomy and better skills in performing daily activities of the patient with dementia in this case study after OT intervention, despite his limited learning abilities and decrease in cognitive functioning (higher BCRS score).

In the content analysis of this case study, the changes after OT intervention in the supervision skills, the sense of competence, communication, coping skills of this primary caregiver of an elderly person with dementia were also positive. These findings are consistent with the results of the quantitative measurements after OT intervention. These measurements determined an improved sense of competence and better mastery of the situation after OT intervention. An improved sense of competence in primary caregivers and a delay in the institutionalization of elderly people with dementia has been found in the literature regarding interventions that consisted of tailor-made support for primary caregivers of patients with.⁵² It was also found that training programmes, in which primary caregivers learn how to deal with elderly persons with dementia, offer a potential avenue of caregiver support.^{3,6,53-55}

The first limitation of this study was that this was a single-patient case study. Based on these results, it could not be proven that occupational therapy really improved either the daily performance of elderly people with dementia or the sense of competence of their primary caregivers.

The second limitation is that other behavioural disturbances not occurring in this case study may be themes of intervention as well.

The third limitation of this case study was the possible selection bias by the occupational therapist, who may have selected this case history because of the positive outcome. Further cases are needed to learn more about the process of providing and receiving OT. Meanwhile, this case describes how OT can be used successfully. In a pilot study⁹, encouraging results were found regarding the improvement of the daily performance of elderly people with

dementia and the sense of competence of their primary caregivers. A randomized clinical trial is needed to investigate the question of OT effectiveness.

Conclusion

This qualitative content analysis enabled the description of the aspects of daily performance and communication interactions within the context of the physical and social environment and the construction of an exploratory system-based model connecting OT diagnosis and OT intervention for older patients with dementia and their primary caregivers. Furthermore, the observations that were described here, gave insight into the perception of the participants during the process of providing and receiving OT. The themes extracted from this study offered new insights into the conditions that were important for an older person with dementia and his primary caregiver to receive OT.

One important result of this case study was the conclusion that, despite the limited learning conditions and cognitive decline of the older patient with dementia, the daily performance and quality of life of this patient improved after OT intervention. Another important result was the improvement in sense of competence and quality of life of the primary caregiver of this patient with dementia after OT intervention. This OT intervention might therefore prove to be of great value, because of the enormous problems in daily performance and the decrease in the quality of life that dementia causes for patients suffering from this disease and for their caregivers.

Practical implications

This case describes how OT can be used successfully for a geriatric patient with dementia and the primary caregiver. For occupational therapists, this study makes explicit the problems on which OT was focused. It makes explicit the content of OT diagnosis and OT treatment in this case and gives information additional to the OT guideline.^{10,11}

Furthermore, the study gives some insights into what the perceptions of geriatric patients with dementia and their primary caregivers were during the process of providing and receiving OT. These insights are important for occupational therapists and for other health care workers involved in the care of elderly patients with dementia in multi-disciplinary care settings such as hospitals, nursing homes, or community care. Moreover, healthcare workers can acquire some insight into the daily performance and communication of elderly patients with dementia and their primary caregivers. The study provides

a description of the conditions that were important for an older person with dementia and his primary caregiver to receive OT and what accordingly was the content of the OT intervention. This information might well be important for geriatricians, general practitioners, and other medical practitioners who refer patients with dementia to occupational therapy.

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Chapter 3

Occupational Therapy at Home for Older Individuals With Mild to Moderate Cognitive Impairments and Their Primary Caregivers: A Pilot Study

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Abstract

The objective of this pilot study was to explore the effects of occupational therapy on the performance of daily activities by older individuals with cognitive impairments and on the sense of competence of their primary caregivers. The design was a single group design. Older individuals with cognitive impairments and their primary caregivers were assessed prior to the first occupational therapy visit in hospital and after 5 weeks of occupational therapy at home.

Participants were older individuals (n = 12) with mild to moderate cognitive impairments live at home and their primary caregivers (n = 12). These older clients with cognitive impairments and their primary caregivers received an occupational therapy intervention in hospital and at home after discharge in accordance with an occupational therapy guideline. This guideline is client-centered and makes use of collaborative, psychosocial, and environmental approaches. The main outcome measures were older clients' motor and process skills, initiative, need for assistance, self-perception in occupational performance, and satisfaction with this performance in daily activities and primary caregivers' sense of competence. The results of this study indicated that older clients' motor and process skills and self-perception in occupational performance improved and that they needed less help. The sense of competence of their primary caregivers also improved. This study provides preliminary evidence for the effectiveness of occupational therapy in older individuals with cognitive impairments and their primary caregivers, which should be tested in a randomized, controlled trial.

Introduction

Older individuals with mild to moderate cognitive impairments who live in the community depend on the quality of care received at home.¹ Problems in performing daily activities are cited as reasons for a decrease in their quality of life.² The burden of care for such older individuals falls mainly on relatives already struggling with the adjustment and loss that cognitive problems, especially dementia, bring.³

Occupational therapy provides clients with opportunities to perform in their own environment in an optimal way such meaningful daily activities as self-care, work, and leisure.⁴ Occupational therapy is also targeted at the clients' primary caregivers by offering practical and emotional training and support. The primary caregivers of older individuals with cognitive impairments are therefore also occupational therapy clients. Better performance of daily activities by older individuals with cognitive impairments should improve not only their quality of life, but also the quality of life of their primary caregivers.

Training programs in which primary caregivers learn how to deal with older individuals with dementia offer a potential avenue of caregiver support.^{3,5-7} Practical and emotional support has been found to strengthen the sense of competence of the primary caregivers of older individuals with dementia.⁸

A literature search of publications dating from 1985 revealed no randomized, controlled trials, or other controlled studies, of the effectiveness of community based occupational therapy on the performance of daily activities by older individuals with cognitive impairments, or on the sense of competence of their primary caregivers. A few articles regarding occupational therapy interventions were found concerning methods of diagnosis, goal setting, and occupational therapy treatment for older individuals with cognitive impairments.^{5,6,9-14,44} Some studies reported positive experiences using environmental adaptations for older individuals with cognitive impairments and their caregivers.^{10,11,15,16,17}

In contrast, many intervention studies directed at the improvement of the sense of competence of informal or formal caregivers of older individuals with dementia were found.^{8,18-22} Flexible and individualized support programs for primary caregivers of older individuals with dementia were reportedly most effective.⁸

Because no standards or guidelines had as yet been established, a guideline was developed for the occupational therapy diagnostics and treatment of older individuals with mild to moderate cognitive impairments and their primary caregivers.²³ The developmental process of this guideline was evidence-based and drew on extended literature searches, the consultation of

independent experts, and several quality audits based on the consensus of a national panel of experts. The final guideline was tested accordingly in terms of quality and usefulness by a panel of experts and three independent occupational therapists who treated 20 older individuals with cognitive impairments and their primary caregivers.²⁴

The methods, assessments, and strategies the occupational therapist could use were described in this guideline. It was based on two client-centered models: the Model of Human Occupation,^{25,26} and the Canadian Model of Occupational Performance.²⁷⁻³¹ The central features of this occupational therapy guideline were the life stories and the needs of people with cognitive impairments and their primary caregivers. In all phases of the guideline, client-centered assessments and strategies were used. The occupational therapy intervention according to this guideline gave flexible, individualized support to older individuals with cognitive impairments and their caregivers (Appendix).

The aim of this pilot study was to explore the effects of an occupational therapy intervention on the performance of daily activities by older individuals with mild to moderate cognitive impairments and on the sense of competence of their primary caregivers. It was hypothesized that occupational therapy improves the skills and initiative of older individuals with non-moderate cognitive impairments, decreases their need for assistance, and improves the sense of competence of their primary caregivers.

Methods

Participants

Between February and August 1998, 12 eligible older individuals and their primary caregivers from the Department of Geriatrics of the University Medical Center of Nijmegen, The Netherlands, were included in this study. Participants were older individuals with mild to moderate cognitive impairments who were to be discharged to their homes or a residential home. These residential homes were institutions where many elderly people live together. Each had an individual room, a little kitchen, and a bathroom, but they had their meals and undertook some activities together, and they could call on some assistance in activities of daily living.

The first screening of cognitive impairments was based on the clinical judgment of a geriatrician using the *DSM-IV* criteria for dementia, the outcomes of the Cambridge Cognitive Screening Test,³² and the Mini-Mental State Examination.³³ Mild to moderate cognitive impairments was defined as a Mini-Mental State Examination score between 10 and 24^{33,34} and a Cambridge Cognitive Screening Test score of less than 79 or 80.

Accordingly, these older individuals were referred for participation in the research project. First, the older individuals and their primary caregivers were asked to give informed consent for participation in this study. If they both agreed, a more explicit assessment of the level of cognitive impairments was used: the Brief Cognitive Rating Scale (BCRS).^{35,50} The older individuals with cognitive impairments were divided into two groups according to the BCRS criteria for the severity of dementia: very mild to moderate cognitive impairments (a BCRS score of 9 to 24) or moderate to severe cognitive impairments (a BCRS score of 25 to 40).

All older individuals with cognitive impairments had an informal primary caregiver available. The primary caregivers were informal caregivers (e.g., partner, child, or friend) who were caring for the older individuals at home, had frequent contact with them, and were able to supervise their daily activities. If two caregivers were available, the person who was most involved and visited the older individual most frequently was designated the primary caregiver.

Older individuals with cognitive impairments who had depression or moderate psychiatric disorders, or who should be admitted to a nursing home, were excluded. Reasons for terminating participation in the project included moderate psychological or somatic problems, admission to a nursing home, or the absence of occupational therapy goals.

Twenty older individuals with cognitive impairments and their primary caregivers had been included in the study at baseline (T0). Only 12 older individuals with cognitive impairments and their primary caregivers could be observed during the whole study. Reasons for the other eight older individuals to terminate participation in the project between T0 and T1 were admission to a nursing home (n = 2); moderate illness (n = 2); delay of easurement through illness resulting in death (n = 1); and no occupational therapy goals (n = 2). In the eighth case, the primary caregiver was overstressed and therefore unable to participate in the study (n = 1). Eventually, only 12 of 20 older individuals with cognitive impairments could be observed during the whole study period.

Two-thirds (n = 8) of the older individuals had very mild to mild cognitive impairments as assessed with the BCRS; one-third of them (n = 4) had moderate cognitive impairments. Dementia was present in 10 of the older individuals, one patient had cognitive impairments resulting from a stroke, and one patient had cognitive impairments resulting from Parkinson's disease. The average age of the participants was 79.9 years (range, 69 to 88 years). The average age of the primary caregivers was 56.6 years (range, 49 to 78 years). Eight of the older individuals with cognitive impairments were women and four were men. Nine of the primary caregivers were women and three were men.

The relationships of the primary caregivers (n = 12) to the older individuals with cognitive impairments were partners (n = 3), daughters (n = 5), daughters-in-law (n = 3), and son (n = 1).

Instruments

The Assessment of Motor and Process Skills (AMPS)³⁶ was used to assess skills in performing daily activities. The AMPS is a valid, reliable observational assessment that is sensitive to change over time, if the researcher is trained in the use of the AMPS assessment. It comprises 12 items of “motor skills” and 20 items of “process skills.” The skills must be observed in two of 56 standardized daily activities, chosen by the patient. Scores are linked to a continuous scale of ability in motor or process functioning and are calibrated for the raters’ severity of scoring. Scores above the cut-off point in motor skills (2.0) or in process skills (1.0) indicate that older individuals with cognitive impairments are able to function independently in the community. Higher scores signify better functioning.³⁶

The Interview of Deterioration of Daily Activities in Dementia (IDDD)² was used to assess the initiative and need for assistance in performing daily activities by interviewing the primary caregiver. This assessment is valid and reliable,^{2,37} and is sensitive to change during 6 months.^{2,37} The internal consistency of the IDDD is good; the test–retest reliability is 0.89 for IDDD initiative and 0.93 for IDDD performance.^{2,37} It includes nine questions on “initiative” (IDDD initiative) and 11 questions on “need for assistance in performing daily activities” (IDDD performance), each rated on a 5-point scale. The theoretical range of the IDDD initiative scale is from 0 to 36; a lower score on this instrument indicates less initiative in performing daily activities. The IDDD performance scale has a theoretical range of 0 to 44; a low score on this instrument indicates that the patient needs little help in performing daily activities and a high score indicates that a lot of help is needed. At interview, primary caregivers were asked to score initiative and need for assistance in 11 different daily activities during the previous week.

The Sense of Competence Questionnaire^{38,39} was used to assess the primary caregivers’ sense of competence by interview. This assessment instrument is valid, reliable, and sensitive to change.^{38,39} The reliability coefficient of the Sense of Competence Scale is 0.79. It contains 27 items, each rated on a 4-point scale; the theoretical range of the scores is from 27 to 135. Higher scores indicate a greater sense of competence and better functioning.

The level of cognitive impairments of the group of older individuals was assessed by the BCRS,^{35,50} which is valid, reliable, and sensitive to change over time.^{35,50} The BCRS is a cognitive behavior scale enabling the categorization of older individuals with cognitive impairments into different stages of cognitive impairments^{35,50}: mild, mild to moderate, moderate to moderately moderate, and moderate. The scale comprises eight observation items, each with a score from 1 to 7, to be totaled to form an overall score. An overall score between 8 and 24 indicates mild cognitive impairments and a score between 25 and 40 signifies moderate to moderately moderate cognitive impairments.

The Canadian Occupational Performance Measurement (COPM)^{29,30} was used to assess the self-perception in occupational performance and satisfaction with this performance of the client and the primary caregiver. The reliability of the COPM in older individuals with cognitive impairments is good.^{29,30} The COPM performance and satisfaction scales were scored by report marks by older individuals with cognitive impairments and their primary caregivers ranging from 1 to 10 on five occupational therapy problems. Client pairs were seen together as a family system and thus specified their five most important problems together. The COPM score used is the mean of these scores for the five self-perceived problems in performing daily activities. A higher COPM performance score indicates that the clients rated their occupational performance at a higher level, and a higher COPM satisfaction score means that the clients were more satisfied with their performance in daily activities. If older individuals with cognitive impairments had problems in scoring the items because of their cognitive impairments, their primary caregivers helped them make their own judgments; they themselves gave the report marks.

Occupational Therapy Intervention

The previously mentioned occupational therapy guideline for older individuals with cognitive impairments²³ was used. The contents of this guideline were based on the client-centered principles of the Model of Human Occupation^{25,26} and the Canadian Model of Occupational Performance (CAOT),²⁷⁻³¹ In accordance with these client-centered models, the self-perception of clients with respect to their needs, interests, beliefs, habits, roles, skills, and disabilities, and the physical, social, and cultural environment, were explored and became the focus of this occupational therapy intervention. The clients in this intervention included both the older individuals with cognitive impairments and their primary caregivers.

The key aim of this guideline was to optimize the daily performance of older individuals with mild to moderate cognitive impairments and their primary caregivers. The former and recent needs, interests, beliefs, habits, and roles of the older individual with cognitive impairments were explored with a client-centered narrative interview, the Occupational Performance History Interview-II.^{40,41} These aspects of the primary caregiver were also explored by means of the Ethnographic Interview.^{42,43} If it was not mentioned informally, the occupational therapist also gathered additional information about the burden and coping strategies and the opportunities of the primary caregiver.

Subsequently, using the information gathered in both interviews, an inventory was made of the problems of the older person with cognitive impairments and the primary caregiver in performing daily activities.^{29,30} In this problem inventory, the most important problems in the daily activities of both clients and their self-perception of and satisfaction with their own performance of these activities were evaluated. The therapy goals were defined by the older individuals with cognitive impairments and their primary caregivers together, based on the outcomes on the COPM form. A collaborative and client-centered treatment approach was used.

Treatment was given in their personal environment at home or, where appropriate, in a residential home, with the older person with cognitive impairments and the primary caregiver together.

The occupational therapy intervention was also based on an environmental and psychosocial approach, as described in the occupational therapy models (the Model of Human Occupation and the Canadian Model of Occupational Performance). The treatment was arranged to meet the needs of older individuals in their personal environment. Typically, aspects of the environment (physical, social, and cultural) form the context of the occupational therapy intervention and play an important part in the way the intervention takes place. The features and opportunities afforded by the environment differ for each client and each situation. Compensatory strategies and strategies to adapt the physical and social environment are described in the guideline to improve the skills of the older individuals with cognitive impairments. The principles of the collaborative learning of the primary caregiver, the older person, and the occupational therapist are also described to improve the skills and sense of competence of the primary caregivers in guiding the older person with cognitive impairments.

Further strategies used included education, problem solving, training in effective coping strategies, and practical and emotional support in how to deal with these cognitive problems of their relatives (Appendix).

The subjects received the occupational therapy intervention twice a week for 2 weeks in the hospital and twice a week for 5 weeks at home. After discharge, the same occupational therapist visited the older individuals and their primary caregivers in their homes or in the residential homes. There was a maximum of ten home occupational therapy visits.

Procedure

The research design of this pilot study was a single group pretest–posttest design. The subjects were assessed two times, at T0 and T1. T0 was at baseline, before the start of 2 weeks of occupational therapy intervention in the hospital, and T1 was after 5 weeks of occupational therapy at home. The assessment period (from T0 to T1) amounted to 7 weeks.

Participants were assessed for approximately 1½ hours at each measurement session by an independent researcher. This researcher was blind with respect to the focus and content of the occupational therapy treatment. The researcher was also blind to the clients' specific purposes and the problems on which the clients and occupational therapists worked together during the occupational therapy intervention.

Primary outcome variables of this study were skills in performing daily activities, assessed by the AMPS; initiative and need for assistance in performing daily activities, assessed by the IDDD; and primary caregivers' sense of competence, assessed by the Sense of Competence Questionnaire. The researcher was trained in the use of the AMPS assessment.

Secondary outcome variables were the level of cognitive impairments, assessed by the BCRS, and self-perception in occupational performance and satisfaction with this performance of the patient and primary caregiver, measured by the COPM.

Caregivers were interviewed by telephone for approximately 30 minutes at each measurement session.

Data Analysis

Changes between T0 and T1 were computed for all of the variables. These changes were tested for their significance by means of the nonparametric Wilcoxon signed rank test.

Results

Characteristics at Baseline

The table presents the characteristics of the older individuals with cognitive impairments and their primary caregivers at baseline (T0). These are the baseline scores on the primary and secondary outcome measures. The primary outcome variables at baseline showed that the median of the scores on AMPS motor skills was 1.1 for motor functioning in daily activities. This score lay far below the point of independent functioning (cut-off score = 2.0). Only five older individuals with cognitive impairments had a score equal to or above this cut-off score. The lowest score was -0.4 and the highest was 3.5. The median of the scores on AMPS process skills was 0.7, which was also below the point of independent functioning (cut-off score = 1.0). In addition, only five older individuals with cognitive impairments had scores equal to or above this cut-off point. The lowest score was -0.6 and the highest score was 1.9.

Another primary outcome variable, IDDD performance in daily activities, had a median of 26.5. The lowest score was 13 and the highest score was 44 (theoretical range, 0 to 44). The median of the scores for IDDD initiative was 18.0. The lowest score was 0 and the highest score was 29 (theoretical range, 0 to 36). The median of the scores on the primary outcome measure for the caregivers, sense of competence, was 77.5. The lowest score was 57 and the highest score was 111 (theoretical range, 27 to 135).

The secondary outcome measure, COPM performance in daily activities, had a median of 5.9. The lowest score was 1.0 and the highest score was 7.5 (theoretical range, 0 to 10). The median of the scores for COPM satisfaction with own performance was 5.9. The lowest score was 1.6 and the highest score was 7.0 (theoretical range, 0 to 10).

Effects on the Outcome Variables

The main purpose of this study was to describe and assess the effects of the occupational therapy intervention on the primary and secondary outcome variables. The important changes for this study between T0 and T1 were analyzed. The medians at T0 and T1 are presented in the table. Changes in the outcome variables and the significance of these changes (p value) were computed by the Wilcoxon signed rank test (Table 1).

Table 1: Effects of Occupational Therapy on the Outcome Measures (T1 to T0) of Older Individuals With Cognitive Impairments (n = 12) and Their Primary Caregivers' (n=12)

Outcome measures	Theoretical ranges	Minimum - maximum scores (T0)	Median (T0)	Median (T1)	Improved (n) (T1-T0)	Wilcoxon Signed Ranks Test (Z-score)	P
AMPS motor	-3 to 4	-0.4 to 3.5	1.1	1.8	9	-2,449	.014
AMPS process	-3 to 4	-0.6 to 1.9	0.7	1.9	11	-2,828	.005
IDDD performance	0 to 44	13 to 44	26.5	18.5	9	-2,139	.032
IDDD initiative	0 to 36	0 to 29	18.0	21.5	7	-1,388	.165
COPM performance	0 to 10	1.0 to 7.5	5.9	7.0	10	-2,609	.009
COPM satisfaction	0 to 10	1.6 to 7.0	5.9	7.2	12	-3,064	.002
BCRS score	8 to 56	13 to 37	23.5	24.0	5	-0,852	.394
Sense of competence Questionnaire	27 to 135	57 to 111	77.5	91.0	8	-2,296	.022

T0 = baseline, before 2 weeks of occupational therapy in hospital; T1 = after 5 weeks of occupational therapy at home; AMPS motor skills = motor skills as assessed by the Assessment of Motor and Process Skills; AMPS process skills = process skills as assessed by the Assessment of Motor and Process Skills; IDDD performance = the need for assistance in performing daily activities as assessed by the Interview of Deterioration of Daily activities in Dementia; IDDD initiative = initiative in performing daily activities as assessed by the Interview of Deterioration of Daily Activities in Dementia; COPM performance = self-perception in occupational performance as assessed by the Canadian Occupational Performance Measurement; COPM satisfaction = satisfaction with occupational performance as assessed by the Canadian Occupational Performance Measurement; BCRS = Brief Cognitive Rating Scale.

As noted in the table, scores for AMPS motor skills increased for 9 subjects and scores for AMPS process skills increased for 11 subjects between T0 and T1. The scores for IDDD performance improved for 9 subjects and the scores for IDDD initiative improved for 7 subjects, indicating a decrease in their need for assistance and an increase in using their own initiative. COPM performance scores increased for 10 subjects (from 5.9 to 7.0) and COPM satisfaction scores increased (from 5.9 to 7.2) in all 12 subjects. Cognitive impairment scores (BCRS score) improved or decreased for 5 subjects, increased for 3 subjects, and remained the same for 4 subjects. The scores on the Sense of Competence Scale improved for 8 of the 12 primary caregivers.

Between T0 and T1, almost all of the outcome measures of the older individuals with cognitive impairments improved significantly. AMPS motor ($p = .014$) and process ($p = .005$) skills improved significantly and the need for assistance (IDDD performance, $p = .032$) decreased significantly. The sense of competence (the primary outcome measure for the primary caregivers) showed a significant improvement ($p = .022$). Significant improvements were

also noted for two secondary outcome variables of the older individuals with cognitive impairments: self-perception in occupational performance (COPM performance) and satisfaction with this performance (COPM satisfaction). On the other hand, no significant changes in the initiative or the cognitive impairment scores of the older individuals with cognitive impairments were found.

Discussion

Positive changes were found following the occupational therapy intervention for almost all of the primary outcome measures. The motor and process skills of the older individuals with cognitive impairments increased, their need for assistance in performing daily activities decreased, and the sense of competence of the primary caregivers also increased. The levels of initiative and the levels of cognitive impairments (BCRS) did not change. Patients' and caregivers' most important aims (patients' improvement of skills, a decrease in dependence in performing daily activities, and the primary caregivers' goal of increased sense of competence in guiding the patient when performing daily activities) were reached by occupational therapy.

These findings were in accordance with the effects of occupational therapy on stroke patients.⁴⁵ An explanation might be the focus of occupational therapy on the disability level, directed at the improvement of skills in performing daily activities rather than on the impairment level, such as the improvement of cognitive functions.^{4,45} Furthermore, these findings are consistent with those of Teunisse² indicating that, although cognitive functioning would decrease with the progression of dementia, the level of dysfunction in daily activities did not decrease in the same way. In dementia, the process of the loss of skills in performing complex activities (e.g., the independent activities of daily living we measured in the AMPS assessment) starts much earlier than the loss of skills in performing self-care activities. As a result, opportunities to improve skills in performing daily activities remain.

Performance in daily activities depends not only on a person and that person's abilities (e.g., cognitive abilities), but also on the interaction between the person, that person's environment, and the demands made by the specific task or.^{25,28,46} It is possible that a client may learn to perform adequately in a structured way in an adapted environment, despite having cognitive impairments. The opportunities of adapting the environment and adapting the tasks or activities to the abilities of the person are therefore important factors in improving a client's daily performance.

The positive effects of this study may also be explained by the client-centeredness of the program, aiming at the main problems experienced by older individuals with cognitive impairments and their primary caregivers (behavioral changes and the decline in the performance of the daily activities of older individuals with dementia and the burden of care on their primary caregivers).² The flexibility and the individual goals of the method used may have contributed to the positive effects on the caregivers' sense of competence.^{8,47-49}

Conclusion

The results of this pilot study support the capacity of the measures used to detect changes in the primary and secondary outcome variables during 7 weeks (2 weeks of occupational therapy in hospital and 5 weeks of occupational therapy at home). The extent of the increase in the scores on the sense of competence was encouraging, because the scores were already fairly high at baseline. Thus, these instruments appeared to be capable of measuring the outcomes of occupational therapy.

The positive results of this study should be interpreted with care, because of the small size of the group of older individuals with cognitive impairments and primary caregivers investigated.

Although all consecutive older individuals with cognitive impairments were selected for this study, the small number of older individuals with cognitive impairments limits the possibility of generalizing our results. Furthermore, because of the uncontrolled nature of the study, the possible influence on the outcomes of other caregiver interventions or medication cannot be ruled out.

Nevertheless, positive changes were found after occupational therapy intervention on almost all of the primary outcome measures. The motor and process skills of older individuals with cognitive impairments increased, their need for assistance decreased, and the primary caregivers' sense of competence also increased. These changes are encouraging and provide pointers for the design of a randomized, controlled clinical trial on the effectiveness of occupational therapy at home for older individuals with cognitive impairments and their primary caregivers.

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APPENDIX

Guideline of Occupational Therapy (OT) Intervention for Older Individuals With Cognitive Impairments and Their Primary Caregivers

Phase of OT Diagnostics

- 1a. Explore former and recent interests, habits, roles, and daily performance of the older individual with cognitive impairments by interview (OPHI and COPM-I).
- 1b. If not possible, use the VQ to obtain the older individual's motivation in performing daily activities (VQ).
- 1c. Make inventory of the older individual's problems in performing daily activities from the primary caregiver's point of view (Ethnographic Interview and COPM-I).
- 1d. Make inventory of the burden and coping strategies of the primary caregiver by interview. (Ethnographic Interview).
- 1e. Gather information about the opportunities for adaptations in the physical and social environment (Environment Checklist).
2. Observe the older individual's skills and interests in performing daily activities without the use of adaptations in the physical or social environment (AMPS or Checklist of Skills, VQ).
- 3a. Describe the self-reported problems of the older individual and the primary caregiver as their stories (Diagnostics Registration Form).
- 3b. Describe your findings as an occupational therapist based on observations and interviews with the older individual and the primary caregiver (Diagnostics Registration Form).
4. Formulate an occupational therapy diagnosis (Diagnostics Registration Form).
5. Choose the best treatment strategy option, or a combination of two options, for this older individual and the primary caregiver (see Phase of OT Treatment) (Diagnostics Registration Form).

Phase of Goal Setting and Treatment Plan

- 1a. Let the older individual and the primary caregiver evaluate the patient's recent performance of daily activities and their satisfaction with this performance and the problems of the primary caregiver (COPM-II).
- 1b. Set realistic goals together with the older individual and the primary caregiver (Goal Settings Form).

Phase of OT Treatment

Choose one or two of the treatment options:

1. Improvement of the older individual's skills by training and rehabilitation (Rehabilitation strategies).
2. Improvement of the older individual's skills through:
 - a. Compensational strategies: Older individuals with cognitive impairments learn to use internal and external compensatory strategies (e.g., visual, verbal, or auditory memory aids or the use of backward or forward chaining strategy).
 - b. Adaptations in the physical environment: Older individuals with cognitive impairments learn to use adaptations in the physical environment (e.g., reorganization of cupboard contents or signs) and social environment (e.g., instructions and support from the primary caregiver).
 - c. Adaptations in the social environment: Older individuals with cognitive impairments learn to deal with instructions and guidance from their primary caregivers and primary caregivers learn to use instructions and support strategies for the older individuals.
3. Improvement of the primary caregiver's skills by means of coping strategies and practical aids: Primary caregivers learn to deal with the older individuals with cognitive impairments and find effective coping styles and problem-solving methods.

Note: OT assessments used are indicated in parenthesis. OPHI = Occupational Performance Life History Interview; VQ = Volitional Questionnaire; COPM-I = Canadian Occupational Performance Measurement, Part I; COPM-II = Canadian Occupational Performance Measurement, Part II; AMPS = Assessment of Motor and Process Skills.

Chapter 4

Community based occupational therapy for patients with dementia and their care givers: a randomized controlled trial

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Abstract

Objective To determine the effectiveness of community based occupational therapy on daily functioning of patients with dementia and the sense of competence of their care givers.

Design Single blind randomised controlled trial. Assessors were blinded for treatment allocation.

Setting Memory clinic and day clinic of a geriatrics department and participants' homes.

Participants 135 patients aged ≥ 65 with mild to moderate dementia living in the community and their primary care givers.

Interventions 10 sessions of occupational therapy over five weeks, including cognitive and behavioural interventions, to train patients in the use of aids to compensate for cognitive decline and care givers in coping behaviours and supervision.

Main outcome measures Patients' daily functioning assessed with the assessment of motor and process skills (AMPS) and the performance scale of the interview of deterioration in daily activities in dementia (IDDD). Care giver burden assessed with the sense of competence questionnaire (SCQ). Participants were evaluated at baseline, six weeks, and three months.

Results Scores improved significantly relative to baseline in patients and care givers in the intervention group compared with the controls (differences were 1.5 (95% confidence interval 1.3 to 1.7) for the process scale; -11.7 (-13.6 to -9.7) for the performance scale; and (11.0; 9.2 to 12.8) for the competence scale). This improvement was still significant at three months.

The number needed to treat to reach a clinically relevant improvement in motor and process skills score was 1.3 (1.2 to 1.4) at six weeks. Effect sizes were 2.5, 2.3, and 1.2, respectively, at six weeks and 2.7, 2.4, and 0.8, respectively, at 12 weeks.

Conclusions Occupational therapy improved patients' daily functioning and reduced the burden on the care giver, despite the patients' limited learning ability. Effects were still present at 12 weeks, which justifies implementation of this intervention.

Trial registration Clinical Trials NCT00295152.

Introduction

Dementia has far reaching consequences for patients and their primary care givers and is currently a major driver of costs in health care and social systems in developed countries.¹ Major problems are the losses in independence, initiative, and participation in social activities, decreasing the quality of life of patients and putting pressure on both family relationships and friendships. Care givers often experience feelings of helplessness, social isolation, and loss of autonomy.²⁻⁴ Unfortunately, drugs are not yet effective in improving the symptoms of dementia, and non-pharmacological strategies are generally more time consuming and not widely available. A systematic review found non-pharmacological interventions to produce effect sizes in behaviour similar or larger to those seen with cholinesterase inhibitors, the currently available drug treatment, but without any side effects.⁵ Occupational therapy is also said to be effective in dementia.⁶⁻⁹ The primary focus of such a therapy is to improve patients' ability to perform activities of daily living and hence promote independence and participation in social activities^{4 7 9} and to reduce the burden on the care giver by increasing their sense of competence and ability to handle the behavioural problems they encounter.^{4 6-10} These outcomes are increasingly being considered equally or even more clinically relevant than measures of cognitive outcome.¹¹

Earlier studies have shown community based occupational therapy given in the home can improve the functional independence of patients with dementia and decrease the burden on the care giver.⁶⁻⁹ We considered that community based occupational therapy in dementia would improve patients' daily functioning and care givers' sense of competence. As a systematic review questioned the methods of these earlier studies¹² we conducted a randomised controlled trial to study the effects of community based occupational therapy on the daily functioning of patients with dementia and on the sense of competence among their primary care givers.

Methods

Participants

From April 2001 to January 2005, we recruited 135 people from the memory clinic and the day clinic of a department of geriatrics. Patients were included if they were aged ≥ 65 , had been diagnosed with mild to moderate dementia, were living in the community, and had a primary care giver who cared for them at least once a week. The diagnosis of dementia was based on criteria from the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV)*.¹³ Severity of dementia was determined with the Brief Cognitive Rating

Scale (BCRS),¹⁴ with a score of 9-24 indicating mild dementia and a score of 25-40 indicating moderate dementia.

We excluded patients with a score > 12 on the Geriatric Depression Scale (GDS, 30 items),¹⁵ severe behavioural or psychological symptoms in dementia (BPSD), and severe illnesses as judged by a geriatrician and those in whom occupational therapy goals could not be defined or who were not on stable treatment of a dementia drug (that is, less than three months on the same dose of a cholinesterase inhibitor or memantine). We also excluded care givers with severe illnesses.

The geriatrician gave all eligible patients and primary care givers written and verbal information, and the researcher explained the assessment instruments and gave examples. After being given the time needed to make a decision and if they wanted to take part, the patient and care giver signed the informed consent form in a second meeting with the researcher.

Randomisation and procedures

Patients were randomly assigned by blocked randomisation (block size 4) to the intervention (10 sessions of occupational therapy at home over five weeks) or control group (no occupational therapy), which was stratified by level of dementia (mild or moderate). A statistician not involved in the study carried out randomisation. Concealed envelopes were used to allocate the patients to either the occupational therapy or the control group and these envelopes were opened by an independent secretary. In this single blind randomised controlled trial, patients and care givers were aware of the treatment assigned. The assessors (MT or MJLG) were blinded to group allocation. Patients and care givers were asked before each assessment not to inform the assessors about the intervention.

To check the success or failure of the blinding after each measurement the assessors were asked if they had been told or knew for sure to which group each patient had been allocated.

The total study period per patient was 12 weeks from the moment of inclusion. The control group received occupational therapy after completion of the study (12 weeks later).

Participants left the study period if they started another possibly effective treatment, were admitted to a nursing home, home for the elderly, or hospital, withdrew, or died. We carried out a process analysis evaluating the steps of the occupational therapy that were followed in each case.

Intervention

The study intervention was developed in a consensus process and was implemented by experienced occupational therapists who had been trained (for about 80 hours) and were experienced (for at least 240 hours) in delivering treatment according to a client centred occupational therapy guideline for patients with dementia.^{9 16} Treatment consisted of 10 one hour sessions held over five weeks and focused on both patients and their primary care givers. In the first four sessions of diagnostics and goal defining, patients and primary care givers learnt to choose and prioritise meaningful activities they wanted to improve. To this end, the occupational therapist used three narrative interview instruments: the Occupational Performance History Interview, second version (OPHI-II)¹⁷ directed at the patient; the ethnographic interview¹⁸ for the primary care giver; and the Canadian Occupational Performance Measure (COPM)¹⁹ for both patient and primary care giver. The occupational therapist evaluated the possibilities for modifying patients' homes and environment and observed patients' ability to perform relevant daily activities and to use compensatory and environmental strategies. Compensatory strategies are used to adapt activities of daily living to the disabilities of patients, and environmental strategies are used to adapt the patients' environment to their cognitive disabilities. Therapists also observed primary care givers' supervision skills.

In the remaining six sessions, patients were taught to optimise these compensatory and environmental strategies to improve their performance of daily activities. Primary care givers were trained, by means of cognitive and behavioural interventions, to use effective supervision, problem solving, and coping strategies to sustain the patients' and their own autonomy and social participation.

The total time spent for the intervention, including the time spent for treatment at home (10 hours), narrative analysis, reports, and multidisciplinary briefing, was about 18 hours per patient and care giver together. Detailed description of the intervention has been published elsewhere.⁴

Outcome assessments and measures

We assessed patients and their primary care givers at baseline before the intervention and six weeks (effect measurement) and 12 weeks (follow-up measurement) later. Our primary outcome measure for patients was daily functioning assessed with the process scale of the Assessment of Motor and Process Skills (AMPS),²⁰ in which scores range from -3 to 4 (higher scores indicate better process skills), and with the performance scale of the Interview of Deterioration in Daily activities in Dementia (IDDD),²¹ in which scores range

from 0 to 44 (lower scores indicate less need for assistance). The outcome for primary care givers was sense of competence assessed with the Sense of Competence Questionnaire (SCQ),²² in which scores ranged from 27 to 135 (higher scores denote greater sense of competence).

We collected information on the age, sex, and educational level of the patient and care giver at baseline. In patients we assessed co-morbidity (Cumulative Illness Rating Scale for Geriatrics, CIRS-G²³), depressive mood (Geriatric Depression Scale, GDS), 30 items¹⁵), cognition (Mini-Mental State Examination, MMSE²⁴), and behaviour (Revised Memory and Behavioural Problems Checklist, RMBPC^{21 25}). We also assessed the relationship between care givers and patients and depression in patients (Cornell Scale for Depression, CSD) and care givers (Center for Epidemiologic Studies Depression scale, CES-D²⁶).

Statistical analysis

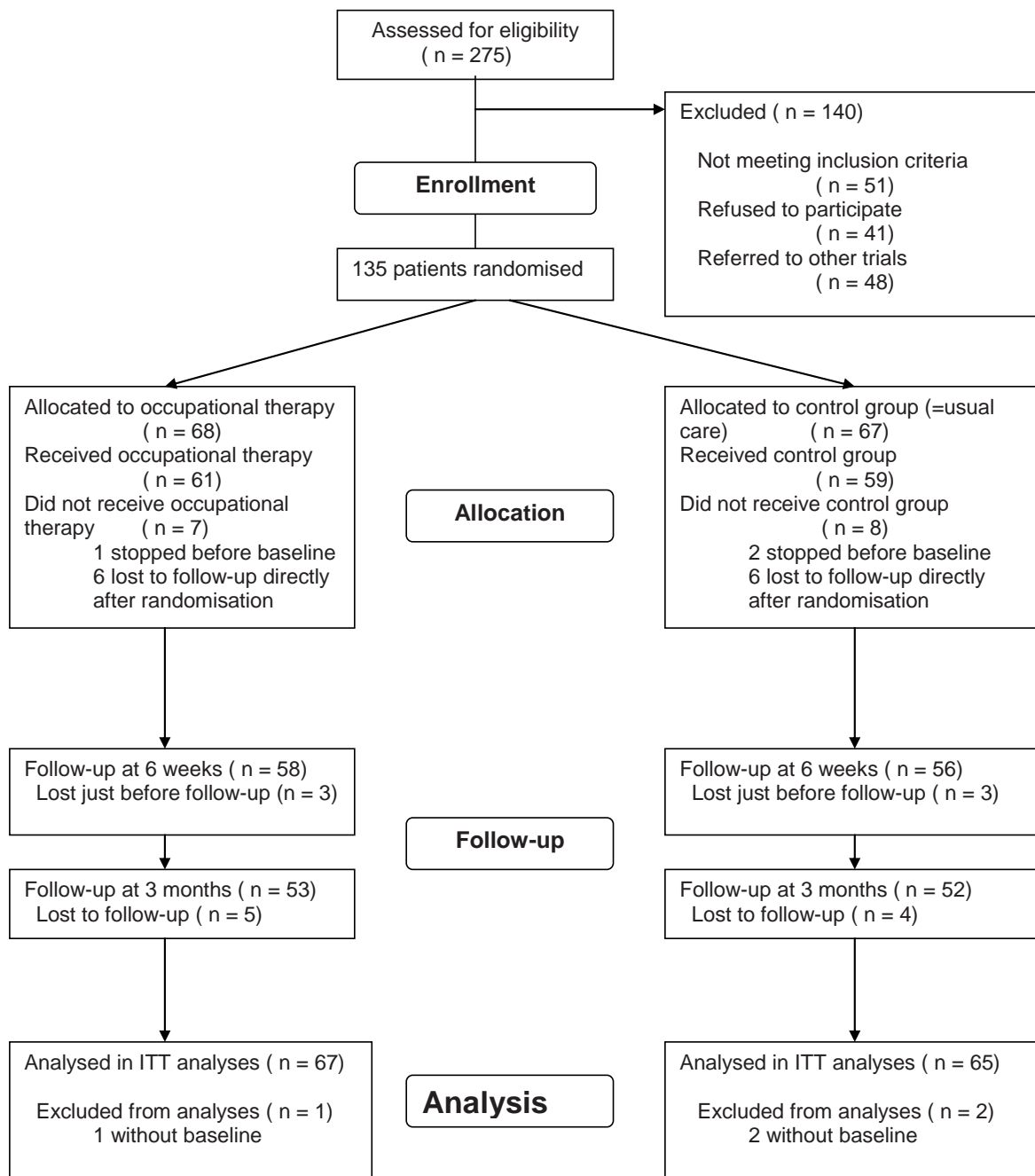
We used analyses of covariance of the primary outcome measures (process scale, performance score, and competence at six weeks) to determine the main effects based on an intention to treat analysis of all available data, applying the last observation carried forward method for dropouts. Treatment differences between baseline and six weeks were computed by analysis of covariance, with age, sex, relation to patient, other care givers, and baseline scores on the comorbidity, depression, cognition, and behaviour scales and the outcome variable as covariates. We carried out secondary analyses on the primary outcome measures at 12 weeks (conditional analysis: only in case of positive effects at six weeks).

The study was powered to detect a clinically relevant difference in change over time of 0.5 points on the process scale between the two groups, 20% improvement on the performance scale, and a 5 point difference on the competence scale, with a power of 80% on the basis of one sided testing, a standard deviation of 0.8 on the process scale, and $n \geq 100$. The power calculation was based on earlier data⁹ and on the minimal clinically relevant differences in the primary outcomes as defined in the measurement guideline for the process scale, which describes 0.5 points as clinically relevant,²⁰ and the measurement guideline for the performance interview.²¹ We used one sided tests in this power calculation because we previously found highly significant improvements after occupational therapy at $p < 5\%$.⁹ For ease of comparability we have presented two sided test results throughout, with $p < 0.05$ as significant. We computed the proportion of patients and care givers who achieved a clinically relevant improvement for each of the primary

outcome measures and calculated the numbers needed to treat with 95% confidence intervals for each of these outcome measures separately and for all three together. We also carried out per protocol analyses. The treatment effect sizes were computed as $d' = \Delta E / \text{SDr}$ (ΔE = adjusted treatment effect, SDr = residual standard deviation).

Results

We evaluated 275 consecutive patients diagnosed with dementia and living in the community for eligibility (fig 1). Of the 135 patients randomised, three (one in intervention group, two in the control group) stopped the trial immediately after randomisation because they did not want to continue and they did not receive the study intervention. Six patients in the intervention group (three admitted to hospital, one to a nursing home, one to a residential home, and one started other treatments that influenced cognition and behaviour) and six patients in the control group (one died, one admitted to hospital, one to a residential home, two withdrew themselves, and one primary care giver died) stopped the trial immediately after baseline data were recorded. Three patients in the intervention group (one admitted to a nursing home, one to hospital, one withdrawal) and three patients in the control group (one admitted to a nursing home, two did not complete assessments) dropped out just before the six week assessment. At six weeks the per protocol analyses included 114 patients.



ITT = Intention-to-treat.

Figure 1 Flow of participants through the trial

The baseline characteristics of patients and care givers were well matched between the two groups. We corrected for age differences (mean ages were lower by 2.0 (patients) and 4.7 (care givers) years in the control group) in the analysis of covariance (table 1).

Table 1. Baseline characteristics of patients and care givers

	Occupational therapy (n = 68)	Control (n= 67)
Mean (SD) age (years):		
Patient	79.1 (6.2)	77.1 (6.3)
Primary caregiver	66.0 (15.3)	61.3 (15.4)
Sex (M/F)		
Patient	29/39	31/36
Primary caregiver	22/46	18/49
Relation caregiver to patient		
Partner	41	38
Daughter	22	21
Other	5	8
Mean (SD) scores on assessment scales:		
Mini-Mental State	19.0 (5.7)	19.0 (4.0)
CIRSG	10.7 (3.5)	11.6 (4.3)
GDS-30	6.9 (3.0)	7.5 (3.0)
RMBPC frequency	5.6 (5.3)	5.0 (6.0)
AMPS-motor	1.0 (1.1)	1.1 (1.0)
AMPS-process	0.2 (0.8)	0.3 (0.8)
IDDD-performance	23.5 (7.9)	24.5 (8.7)
Cornell Depression Scale	8.3 (6.2)	8.1 (4.6)
Brief Cognitive Rating Scale	27.3 (5.1)	27.1 (4.2)
Sense of competence	89.7 (14.9)	90.4 (13.6)
CES-D	11.7 (8.3)	11.4 (7.2)

CIRSG= Cumulative Illness Rating Scale for Geriatrics; GDS-30 = Geriatric Depression Scale 30 items; RMBPC = Revised Memory and Behavioural Problems Checklist; AMPS = Assessment of Motor and Process Skills (higher scores indicate better skills); IDDD= Interview of Deterioration in Daily activities in Dementia (lower scores indicate less need for help); BCRS = Brief Cognitive Rating Scale; CES-D = Center for Epidemiologic Studies Depression Scale.

Outcomes at six weeks

There were significant differences between the groups on all primary outcome variables at six weeks. Patients who received occupational therapy functioned significantly better in daily life than those who did not (for intervention v control, mean process scores were 1.2 (SD 0.7) v 0.2 (SD 0.8), fig 2), and mean performance interview scores were 14.4 (SD 6.1) v 25.3 (SD 8.6), fig 3).

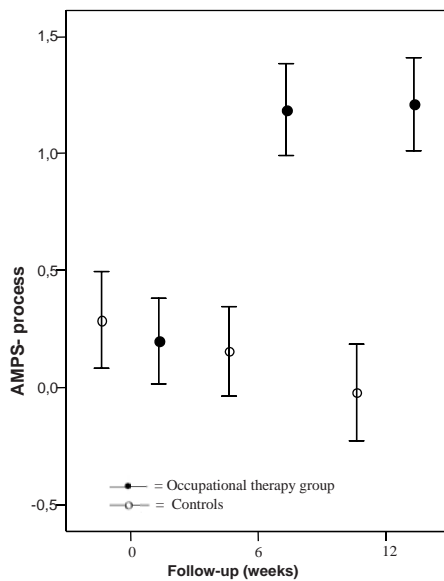


Figure 2: Mean (95% confidence interval) scores on assessment of motor and process skills (AMPS) at baseline, six and 12 weeks in intervention and control groups.

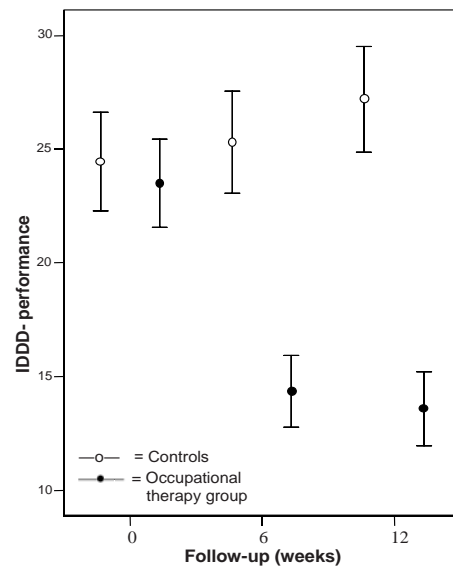


Figure 3: Mean (95% confidence interval) scores IDDD-performance at baseline, six and 12 weeks follow-up in intervention and control groups.

The difference between the groups was significant 1.5 (95% confidence interval 1.3 to 1.7) for the process scale; and -11.7 (-13.6 to -9.7) for the performance interview; table 2). Primary care givers who received occupational therapy felt significantly more competent than those who did not (mean competence score 104.6 (SD 13.4) v 88.4 (SD 13.7), fig 4). The difference in competence scores was significant (11.0, 9.2 to 12.8; table 2).

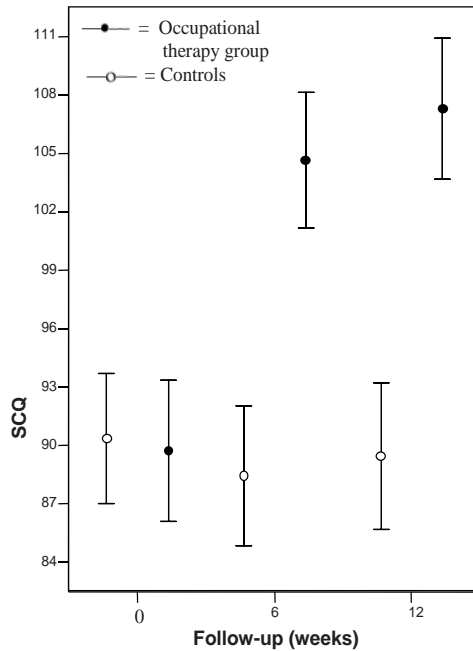


Figure 4: Mean (95% confidence interval) sense of competence (SCQ) scores in caregivers at baseline, six and 12 weeks in intervention and control groups.

Overall, 84% in the intervention group and 9% in the control group achieved a clinically relevant improvement on the process outcome, the figures being 78% v 12% for the performance interview. For the care givers 58% and 18% had a clinically relevant improvement in sense of competence. For all three outcomes together 47% in the intervention group and 2% in the control group achieved a clinically relevant difference. The number needed to treat was 1.3 (1.2 to 1.4) for the process outcome, 1.5 (1.4 to 1.6) for the performance outcome, and 2.5 (2.3 to 2.7) for competence outcome (table 2). The number needed to treat for all three primary outcomes together was 2.2 (2.1 to 2.3). The effect sizes at six weeks were 2.5, 2.3, and 1.2, respectively (table 2). The per protocol analyses at six weeks showed effect sizes of 3.2, 2.3, and 1.2, respectively. In 82% of the cases blinding was successful, and in 18% (n = 21) the assessors knew the treatment allocation.

Table 2: Outcomes in patients with dementia and caregivers in intention to treat population at six weeks

	AMPS- process	IDDD- performance	SCQ competence
Occupational therapy group			
Observed mean (SD) score	1.2 (0.7)	14.4 (6.1)	104.6 (13.4)
Clinically relevant improvement	84%	78%	58%
Control group			
Observed mean (SD) score	0.2 (0.8)	25.3 (8.6)	88.4 (13.7)
Clinically relevant improvement	9%	12%	18%
Occupational therapy v control group			
covariate adjusted treatment difference (95% CI)	1.5 (1.3 to 1.7)	-11.7 (-13.6 to - 9.7)	11.0 (9.2 to 12.8)
Difference in clinically relevant Improvement	75%	66%	40%
Number needed to treat (95% CI)	1.3 (1.2 to 1.4)	1.5 (1.4 to1.6)	2.5 (2.3 to 2.7)
Statistics			
<i>p</i> value	< 0.0001	< 0.0001	< 0.0001
Effect size	2.5	2.3	1.2

AMPS = Assessment of Motor and Process Skills (higher scores indicate better skills);
 IDDD= Interview of Deterioration in Daily activities in Dementia (lower scores indicate less need for help);
 SCQ = Sense of Competence Questionnaire (higher scores indicate better competence)

Outcomes at 12 weeks

At 12 weeks, 53/68 (78%) patients in the intervention group and 52/67 (78%) in the control group remained in the study (fig 1). The daily functioning of patients who had received occupational therapy was still much better than that in the control group: for the intervention v the control group the mean process score was 1.2 (SD 0.8) v -0.02 (SD 0.7) and the mean performance interview score was 13.6 (SD 6.0) v 27.2 (SD 8.9) (figs 2 and 3). Analysis of covariance of the intention to treat population (n = 132) showed that the difference in groups at 12 weeks compared with baseline was significant for the process scores (1.6, 1.3 to 1.8; table 3) and the performance interview (-13.6, -15.8 to -11.3; table 3). Care givers' sense of competence was significantly better at 12 weeks than at baseline (mean 107.3 (SD 13.6) v 89.4 (SD 14.4); fig 4), the difference between the groups being significant (9.6, 4.7 to 14.5; table 3).

Table 3: Outcomes in patients with dementia and care givers in intention to treat population at 12 weeks

	AMPS process	IDDD performance	SCQ competence
Occupational therapy group			
Observed mean (SD)	1.2 (0.8)	13.6 (6.0)	107.3 (13.6)
Clinically relevant improvement	75%	82%	48%
Control group			
Observed mean (SD)	0.0 (0.7)	27.2 (8.9)	89.4 (14.4)
Clinically relevant improvement	9%	10%	24%
Occupational therapy v control group			
Covariate adjusted treatment difference (95% CI)	1.6 (1.3 to 1.8)	-13.6 (-15.8 to -11.3)	9.6 (4.7 to 14.5)
Difference in clinically relevant improvement	66%	72%	24%
Number needed to treat (95% CI)	1.5 (1.4 to 1.6)	1.4 (1.3 to 1.5)	4.2 (4.0 to 4.4)
Statistics			
<i>p</i> value	<0.0001	<0.0001	<0.0001
Effect size	2.7	2.4	0.8

AMPS=assessment of motor and process skills (higher scores indicate better skills); IDDD=interview of deterioration in daily activities in dementia (lower scores indicate less need for help); SCQ=sense of competence questionnaire (higher scores indicate greater competence).

The proportion of patients still having a clinically relevant improvement at 12 weeks for the process and the performance interview outcomes were 75% and 82% in the intervention group and 9% and 10% in controls. Nearly half (48%) of the care givers in the intervention group still felt more competent to care compared with 24% in the control group. A clinically relevant difference was reached on all three outcome measures in 37% of the intervention group and 2% of the control group. The number needed to treat was 1.5 (1.4 to 1.6) for the process outcome, 1.4 (1.3 to 1.5) for the performance outcome, and 4.2 (4.0 to 4.4) for the competence outcome (table 3). For all three outcomes

together the number needed to treat was 2.8 (2.7 to 2.9). The effect sizes at 12 weeks were 2.7, 2.4, and 0.8, respectively (table 3). The per protocol analyses at 12 weeks showed effect sizes of 2.3, 2.4, and 0.8, respectively. In 20% of the cases (n = 21) the assessors knew the treatment allocation. No adverse events were reported in intervention or control group.

Discussion

In this randomized controlled trial we found evidence that 10 sessions of community based occupational therapy, given over five weeks, improves the daily functioning of patients with dementia and diminishes the burden of care on their primary care givers.

The process skills and need for assistance in performing daily activities improved in patients, and their care givers felt more competent at six weeks (one week after completion of occupational therapy), and these beneficial effects remained so at 12 weeks (seven weeks after completion of the occupational therapy program). A similar positive effect of occupational therapy was reported earlier in stroke patients.²⁷ The improvement was also clinically relevant, meeting predefined criteria for clinical relevance and highly effective with low numbers needed to treat. At six weeks, the process outcome score of patients was higher than that associated with independent functioning (cut-off score of 1.0) and remained so at 12 weeks.

Moreover, the effect sizes of all primary outcomes were higher than those found in trials of drugs or other psychosocial interventions for people with dementia.⁵ We believe that the benefit was sustained because a component of the intervention was to train care givers in providing the supervision patients needed to sustain their performance of daily activities. The intervention also provided individualized support to care givers, which earlier studies have also shown to be effective.²⁸⁻³⁰

Strengths and weaknesses

Two earlier studies evaluated occupational therapy in patients with dementia^{6 7} but their methodological quality was poor.¹² A recent study by Gitlin et al had similar results on care giver outcome after a community based occupational therapy programme for patients with dementia and their primary care givers.⁸ The outcomes of our study were also expressed in effect sizes as recommended by Luijpen et al,⁵ which enables comparison with drug and non-drug interventions. Our design was based on a pilot study of the intervention protocol.⁹ The occupational therapy intervention was based on a guideline developed on the basis of consensus among a national panel of qualified and

experienced occupational therapists.^{4 16} We had a high follow-up rate at 12 weeks, possibly because our study was directly relevant to the daily lives of patients and their care givers. According to our process, all stages (diagnostics, goal defining, and treatment) of the intervention could be carried out.

A limitation of our study design is that, as with some other types of treatment, we could not carry out a double blind study because the patients and their care givers knew which therapy they received, nor was it possible to blind occupational therapists to treatments. We tried to maintain masked conditions for assessment, however, which succeeded for 80% of the cases.³¹ For this reason, we believe that our results are not greatly affected by observer bias. Another potential limitation is that our sample might not be representative of all patients with mild to moderate dementia in our health region as participants were recruited primarily from the outpatient clinics of the university hospital and not from other institutions or directly from general practices. We chose this recruitment strategy because we wanted to achieve uniformity in terms of screening and diagnosis to facilitate comparison with other national and international studies. The size of the effects is promising for implementation in other settings as well.

Because outcomes such as improvement in activities of daily living and sense of competence are associated with a decrease in need for assistance,²¹ we believe that, in the long term, occupational therapy will result in less dependence on social and healthcare resources and less need for institutionalisation.²⁹ The training in effective use of the intervention (at least 80 hours) and the intervention itself is quite comprehensive (time spent for treatment at home, narrative analysis, reports, and multidisciplinary briefing is about 18 hours per patient and care giver). We believe, however, that it is worth implementing in clinical practice because of its relevant effects and high efficacy, which makes it reasonable to expect cost effectiveness in clinical practice.

What is already known on this topic

Effective treatment for patients with dementia and their care givers should lead to improvement in activities of daily living and diminished burden on the care giver. Drugs are not effective in improving the symptoms of dementia and non-pharmacological strategies have similar or higher effect sizes and no side effects, but are generally more time consuming.

What this study adds

Ten sessions of community based occupational therapy over five weeks improved the daily functioning of patients with dementia, despite their limited learning abilities, and reduced the burden on their informal care givers.

The effect sizes of all primary outcomes were higher than those found in trials of drugs or other psychosocial interventions, and these effects were still present at three months

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Contributors: MJLG was the lead investigator, developed the study design, carried out data-acquisition, analysis, interpretations, and wrote the paper. MJMV-D, JD, MGMOR, and WHLH were responsible for design, project supervision, and writing. MGMOR was also involved in data acquisition and is guarantor. MT carried out data acquisition and was involved in preparing the study design and in writing the manuscript.

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Chapter 5

Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial

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Summary

Background Cure of dementia is not possible, but quality of life of patients and caregivers can be improved. Our aim is to investigate effects of community occupational therapy on dementia patients' and caregivers' quality of life, mood, health status and caregivers' sense of control over life.

Methods Community-dwelling patients aged 65 years or older, with mild-to-moderate dementia, and their informal caregivers (n=135 couples o patients with their caregivers) were randomly assigned to 10 sessions of occupational therapy over 5 weeks or no intervention. Cognitive and behavioural interventions were used to train patients in the use of aids to compensate for cognitive decline and caregivers in coping behaviours and supervision. Outcomes, measured at baseline, 6 weehs, and 12 weeks, were patients' and caregivers' quality of life (Dementia Quality of Life Instrument, Dqol), patients' mood (Cornell Scale for Depression, CSD), caregivers' mood (Center for Epidemiologic Studies Depression Scale, CES-D), patients' and caregivers' health status (General Health Questionnaire, GHQ-12), and caregivers' sense of control over life (Mastery Scale).

Results Improvement on patients' Dqol overall (0.8, 95% Confidence Interval [CI], 0.6 to 1.1, effect size 1.3) and caregivers' Dqol overall (0.7, 95% CI, 0.5 to 0.9, effect size 1.2) was significantly better in the intervention group as compared to controls. Scores on other outcome measures also improved significantly. This improvement was still significant at 12 weeks.

Conclusion Community occupational therapy should be advocated both for dementia patients and their caregivers, because it improves their mood, quality of life and health status and caregivers' sense of control over life. Effects were still present at follow-up.

Introduction

Occupational therapy is aimed at improving patients' ability to perform activities of daily living, promoting independence and participation in social activities, and reducing caregiver burden by increasing caregivers' sense of competence.¹⁻⁸

In occupational therapy, primary caregivers are educated about the consequences of the dementia and are trained by means of cognitive and behavioural interventions to sustain and improve patients' and their own autonomy, social participation, quality of life, and health status.

The relevance of occupational therapy is supported by findings that problems in daily functioning often are the reason for a decrease in quality of life in dementia patients^{9,10} and that information and emotional support improved the quality of life of patients and their caregivers.¹¹

In this study, we present the data of secondary outcome measures on quality of life measures, after having shown that OT at home improves patients' daily functioning and caregivers' sense of competence, which were the primary endpoints of our trial.³ Because of the highly positive outcomes, with effect sizes on patients' daily functioning measures of 2.3-2.6, and on sense of competence of 1.2, we hypothesize that occupational therapy also improves mood, quality of life, health status and sense of control over life of these patients and informal caregivers. This hypothesis was tested in the present study.

Methods

Patients

From April 2001 to January 2005 individuals were recruited from the Memory Clinic and the Day Clinic of the Department of Geriatrics of the University Medical Center, Nijmegen (UMCN), The Netherlands. Patients were included if they were aged 65 years old or older, had been diagnosed with mild-to-moderate dementia, were living in the community, and had a primary caregiver who cared for them at least once a week. The diagnosis of dementia was based on the *Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSMIV)* criteria.¹² Severity of dementia was determined with the *Brief Cognitive Rating Scale (BCRS)*¹³, with a score of 9–24 being indicative of mild dementia, and a score of 25–40 being indicative of moderate dementia. Patients with a score > 12 on the *Geriatric Depression Scale (GDS, 30 items)*¹⁴ were excluded from participation in the study, as were those with severe behavioural or psychological symptoms in dementia (BPSD) or with severe

illnesses as judged by a geriatrician, those in whom occupational therapy goals could not be defined after comprehensive goal setting by using eligible goal-setting instruments for occupational therapy goal setting (Occupational Performance History Interview [OPHI-II], Canadian Occupational Performance Measure [COPM])^{15,16} or those who were not on stable treatment of an antimentia drug (i.e. < 3 months on the same dose of a cholinesterase inhibitor or memantine). Caregivers with severe illnesses were also excluded. All eligible patients and primary caregivers received written and verbal information by the geriatrician, and explanation and examples of the assessment instruments by the researcher. Next, allowing patients and caregivers the time needed to make a decision, the informed consent form was signed (or not) in a second meeting with the researcher.

Procedures

Study design

Patients were randomly assigned by blocked randomisation (block size 4) to the intervention (10 sessions occupational therapy at home over 5 weeks) or to the control group (no occupational therapy), which was stratified by level of dementia (mild or moderate). A statistician not involved in the study carried out randomization. Concealed envelopes were used to allocate the patients to either the occupational therapy or the control group, and these envelopes were opened by an independent secretary. In this single-blind randomized controlled trial, patients and caregivers were aware of the treatment assigned. The assessors (MT or MG) were blinded to group allocation. Patients and caregivers were asked before each assessment not to inform the assessors about the intervention. After each measurement the success or failure of the blinding was checked in the assessors by the question: "Do you know to what group this patient was allocated?" The total study period per patient was 12 weeks from the moment of inclusion. The control group received occupational therapy after completion of the study (12 weeks later). Stop criteria during the study period were the start of another possibly effective treatment, admission to nursing home, home for the elderly, or hospital; withdrawal; or death. A process analysis was carried out evaluating the steps of the occupational therapy guideline that were followed in each case. The study protocol was approved by the medical ethics committee of the UMCN and was registered by the Protocol Registration System Clinical Trials.gov. no. NCT00295152.

Intervention

The study intervention was developed in a consensus process and was implemented by experienced occupational therapists, who had been trained (at least 80 hours) and were experienced (at least 240 hours) in delivering treatment according to this client-centred occupational therapy guideline for patients with dementia.^{1,2,17} Treatment consisted of 10 1-hour sessions held over 5 weeks and focused on both patients and their informal caregivers. In the first four sessions of diagnostics and goal defining, patients and informal caregivers learned to choose and prioritize meaningful activities they wanted to improve. To this end, the occupational therapist used three client-centred narrative interview instruments: the OPHI-II¹⁵ directed at the patient, the ethnographic interview¹⁸ for the primary caregiver, and the COPM¹⁶ for both patient and primary caregiver. The occupational therapist evaluated the possibilities of modifying patients' homes and environment and observed patients' ability to perform relevant daily activities and to use compensatory and environmental strategies. Compensatory strategies were used to adapt activities of daily living to the disabilities of patients, and environmental strategies were used to adapt the patients' environment to their cognitive disabilities. The informal caregivers' supervision skills were also observed.

In the remaining six treatment sessions, patients were taught to optimize these compensatory and environmental strategies to improve their performance of daily activities. Informal caregivers were trained, by means of cognitive and behavioural interventions, to use effective supervision, problem solving, and coping strategies to sustain patients' and their own autonomy and social participation. The total time spent for this occupational therapy intervention, including the time spent for treatment at home (10 hours), narrative analysis, reports and multidisciplinary briefing, was about 18 hours per patient and caregiver together. For a detailed description of the intervention, see Graff and colleagues.²

Outcome assessments

Patients and their informal caregivers were assessed at baseline before the intervention, and at 6 weeks (effect measurement), and at 12 weeks (follow-up measurement). Outcomes of this study were quality of life, health status and mood (of both the dementia patients and their caregivers), and caregivers' sense of control over life. Quality of life was assessed with the Dementia Quality of Life Instrument (Dqol)¹⁹⁻²¹ which is divided into three categories and six subscales: A) aesthetics (sum scores from 5-25); B) frequency of feelings: B1: positive affect (sum scores 5-30); B2: negative affect (sum scores 5-55);

B3: self esteem (sum scores 5-20); B4: feelings of belonging (sum scores 5-15); and C) overall quality of life (1-5) (higher scores on quality-of-life subscales indicate better quality of life, except for subscale B2). This quality-of-life assessment was performed on patients and caregivers separately, e.g. patients and caregivers were asked to rate their own quality of life. Health status was also assessed for the patients and primary caregivers with the General Health Questionnaire (GHQ-12),²² in which sum scores range from 0-36 (lower scores indicate a better health status). The mood of the patients, was assessed by interviewing their caregivers as proxies with the Cornell Scale for Depression (CSD),^{24,25} in which sum scores range from 0 to 38 (lower scores indicate less depressive characteristics), and mood of the caregivers was assessed with the Center for Epidemiologic Depression Scale (CES-D),^{26,27} in which sum scores range from 0 to 60 (lower scores indicate less depressive complaints). Caregivers' sense of control over life was assessed with the Mastery Scale²⁸ in which sum scores range from 5-25 (lower scores indicate a better sense of control over life).

Information on the age, sex, and educational level of the patient and caregiver was collected at baseline, as was information on patient comorbidity (assessed with the Cumulative Illness Rating Scale for Geriatrics, CIRS-G)²⁹, depressive mood (assessed with the GDS)¹⁴, cognition (assessed with the Mini-Mental State Examination, MMSE)³⁰, and behaviour (assessed with the Revised Memory and Behavioural Problems Checklist, RMBPC)^{9,31}, and caregiver relationship to the patient.

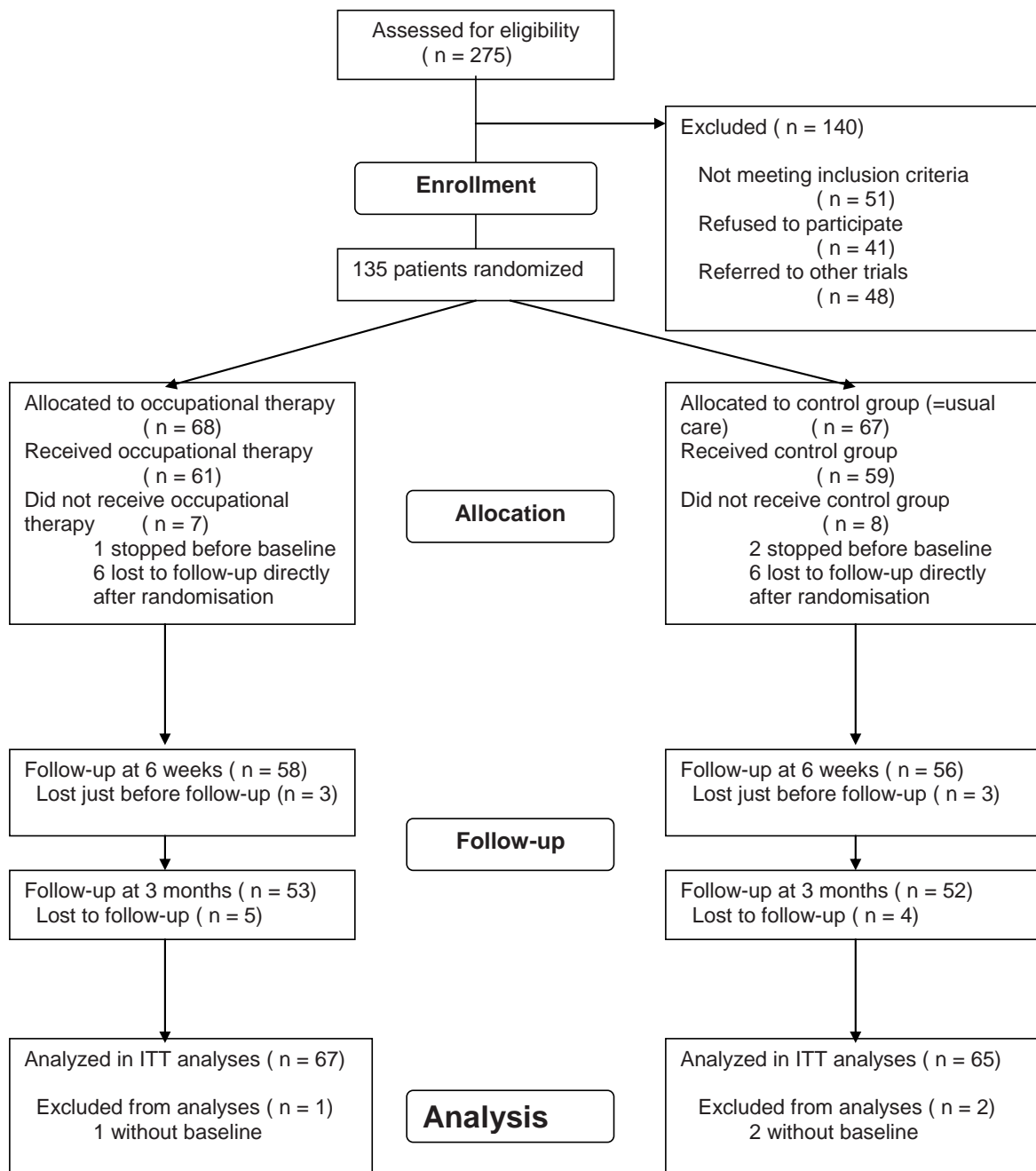
Statistical analysis

The primary effects of this study were determined by analyses of covariance of the outcome measures (Dqol-overall, GHQ-12, CSD, CES-D, and Mastery Scale at 6 weeks) based on an intention-to-treat analysis of all available data, applying the last observation carried forward method for dropouts. Treatment differences between baseline and 6 weeks were computed by analysis of covariance, with age, sex, relation to patient, other caregivers and baseline scores on the MMSE, GDS, CIRS-G, RMBPC, and outcome variables as covariates. Secondary analyses were performed with the Dqol subscores at 6 and 12 weeks (only in case of positive Dqol overall score) and on all outcome measures at 12 weeks (conditional analysis: this analysis will only be performed if positive effects are found at 6 weeks). We tested two sided with a p value of 0.05 as level of significance, but as in the primary analysis seven sum scores were compared, we also reported the significance after Bonferroni correction, i.e. when $p < 0.007$. The proportion of patients and caregivers

achieving a clinically relevant improvement was computed for the Dqol outcome measure and the numbers needed to treat (NNT) with 95% confidence intervals (95% CI) were accordingly calculated. A minimal clinically relevant improvement was defined as 1 point improvement in Dqol-overall score, which was 20% of the theoretical range of the Dqol overall scale. Per-protocol analyses were also carried out. The treatment effect sizes were computed as: $d' = \Delta E / sd_r$ (ΔE = the adjusted treatment effect, sd_r = the residual standard deviation).

Results

Two hundred seventy-five consecutive, community dwelling patients diagnosed with dementia were evaluated for eligibility (see Figure 1). Of the 135 patients randomized, three patients (one in the intervention group, two in the control group) stopped the trial immediately after randomization because they were not motivated for assessments, and they did not receive the study intervention, leaving 132 patients. Six patients in the intervention group (three admitted to hospital, one to a nursing home, one to a residential home, and one started other treatments that influenced cognition and behaviour) and six patients in the control group (one died, one admitted to hospital, one to a residential home, two withdrew themselves, and one primary caregiver died) stopped the trial immediately after baseline data were recorded. Three patients in the experimental group (one admitted to a nursing home, one to hospital, one withdrawal) and three patients in the control group (one admitted to a nursing home, two did not complete assessments) dropped out just before the 6-week assessment. Consequently, at 6 weeks the per-protocol analyses included 114 patients.



ITT = Intention-to-treat.

Figure 1: Trial profile.

Table 1: Baseline characteristics of dementia patients and caregivers.

Patient and caregiver characteristics	Occupational therapy group (n = 68)	Control group (n= 67)
Mean (SD) age in years		
Patient	79.1 (6.2)	77.1 (6.3)
Informal caregiver	66.0 (15.3)	61.3 (15.4)
Sex (M/F)		
Patient	29/39	31/36
Informal caregiver	22/46	18/49
Relation caregiver to patient (N)		
Partner	41	38
Daughter	22	21
Other	5	8
Mean (SD) scores		
Mini Mental State Examination	19.0 (5.7)	19.0 (4.0)
CIRS-G	10.7 (3.5)	11.6 (4.3)
Geriatric Depression Scale	6.9 (3.0)	7.5 (3.0)
RMBPC frequency	5.6 (5.3)	5.0 (6.0)
Cornell Scale for Depression	8.3 (6.2)	8.1 (4.6)
Brief Cognitive Rating Scale	27.3 (5.1)	27.1 (4.2)
CES-D	11.7 (8.3)	11.4 (7.2)
Dqol overall (patient)	3.4 (0.7)	3.3 (1.3)
Dqol overall (carer)	3.3 (0.9)	3.4 (0.8)
GHQ-12 (patient)	10.7 (4.1)	12.3 (5.7)
GHQ-12 (carer)	12.0 (4.9)	11.3 (4.0)
Mastery Scale	12.6 (3.6)	12.0 (3.0)

SD = standard deviation; CIRS-G = Cumulative Illness Rating Scale for Geriatrics; RMBPC = Revised Memory and Behavioural Problems Checklist; CES-D = Center for Epidemiologic Studies Depression Scale; Dqol = Dementia Quality of Life Instrument, GHQ = General Health Questionnaire.

The baseline characteristics of patients and caregivers were well matched between the two groups. Dementia severity was similar, but the control group patients and their informal caregivers were somewhat younger (2.0 and 4.7 years, respectively). Comorbidity was similar as were the baseline outcomes

on general health status (GHQ-12 score) for both patients and caregivers in the intervention and control group (Table 1). All overall scores at 6 weeks differed significantly between the intervention and control group, even after Bonferroni correction (Tables 2 and 3). Patients and informal caregivers who received occupational therapy improved significantly relative to baseline as compared to controls on overall quality of life (Tables 2 and 3, Figures 2 and 3); patients on all quality of life subscales (Table 2),

Table 2: Patient outcomes (in intention- to- treat analyses) of occupational therapy versus no intervention in dementia at 6 weeks.

Patient outcomes	Occupational therapy group Observed mean (sd)	Control group Observed mean (sd)	Covariate-adjusted Treatment difference (95% CI)	p-value	Effect size
Dqol Overall	4.0 (0.6)	3.1 (0.8)	0.8 (0.6 to 1.1)	<0.0001	1.3
Dqol Aesthetics	20.4 (2.9)	16.0 (4.6)	3.7 (2.5 to 4.8)	<0.0001	1.2
Dqol Positive affect	24.8 (3.1)	18.0 (4.5)	-0.4 (-0.6 to -0.2)	<0.0001	1.1
Dqol Negative affect	17.6 (4.6)	25.3 (6.3)	-2.5 (-4.4 to -0.7)	<0.0001	0.5
Dqol Feelings of Belonging	12.8 (1.3)	10.2 (1.6)	1.1 (0.6 to 1.6)	<0.0001	1.4
Dqol Self esteem	16.9 (1.9)	12.5 (2.7)	4.0 (3.4 to 4.6)	<00001	2.5
GHQ-12	7.8 (4.2)	11.8 (5.6)	-3.5 (-5.1 to -1.8)	<0.0001	0.8
CSD	6.5 (5.3)	9.2 (6.4)	-2.8 (-4.3 to -1.3)	<0.0001	0.7

SD = standard deviation; Dqol= Dementia Quality Of Life Instrument; GHQ= General Health Questionnaire; CSD= Cornell Scale for depression in Dementia.

and caregivers on almost all quality-of-life subscales; only the differences on Dqol negative affect were not significant (Table 3). Patients and informal caregivers who received occupational therapy improved significantly relative to baseline as compared to controls on health status assessed by the GHQ-12 for patients and for caregivers (Tables 2 and 3). Patient and caregiver mood

was also significantly better in the occupational therapy group than in the control group (Tables 2 and 3). These differences were statistically significant for both patients' CSD scale and for caregivers' CES-D scale (Tables 2 and 3). Informal caregivers who received occupational therapy reported a better sense of control over life (Mastery Scale) than those who did not receive therapy (Table 3). This difference was statistically significant (Table 3).

Table 3: Caregiver outcomes (in intention- to- treat analyses) of occupational therapy versus no intervention in caregivers of dementia patients at 6 weeks.

Caregiver outcomes	Occupational therapy group Observed mean (sd)	Control group Observed mean (sd)	Covariate-adjusted Treatment difference (95% CI)	p-value	Effect size
Dqol Overall	4.0 (0.6)	3.4 (0.7)	0.7 (0.5 to 0.9)	<0.0001	1.2
Dqol Aesthetics	20.5 (3.1)	15.7 (4.1)	4.1 (3.1 to 5.0)	<0.0001	1.6
Dqol Positive affect	23.3 (2.8)	19.9 (4.2)	1.3 (0.1 to 2.5)	0.0270	0.4
Dqol Negative affect	20.2 (5.6)	26.0 (6.3)	-1.9 (-3.9 to 0.2)	0.0690	Not sign.
Dqol Feelings of Belonging	13.6 (1.0)	12.3 (1.3)	1.0 (0.5 to 1.5)	<0.0001	1.0
Dqol Self esteem	17.2 (1.5)	15.4 (1.9)	3.7 (3.0 to 4.3)	<0.0001	2.1
GHQ-12	7.0 (3.9)	11.0 (3.9)	-4.6 (-6.0 to -3.2)	<0.0001	1.3
CES-D	5.8 (4.8)	12.6 (8.5)	-7.6 (-9.7 to -5.4)	<0.0001	1.3
Mastery Scale	16.6 (3.0)	12.6 (3.0)	3.5 (2.7 to 4.4)	<0.0001	1.6

SD = standard deviation; CES-D = Center for Epidemiologic Studies Depression Scale; Dqol= Dementia Quality Of Life Instrument; GHQ= General Health Questionnaire.

All significant outcomes at 6 weeks remained significant after Bonferroni correction ($p < 0.007$). The proportion of patients achieving a clinically relevant improvement on the Dqol overall was 49% in the intervention group, and 17% in the control group; for the caregivers, Dqol overall was 54% and 14%, respectively. The NNT for the Dqol overall for patients was 3.1 (95% CI, 2.6 to 3.6) and for caregivers 3.3 (95% CI, 3.2 to 3.5). The effect size at 6 weeks for Dqol overall for patients was $d' = 1.3$, for caregivers' Dqol overall was $d' = 1.2$. For patients' GHQ-12 the effect size was $d' = 0.8$ and for caregivers' GHQ-12 $d' = 1.3$. The effect size for patients' mood was CSD $d' = 0.7$, for caregivers' mood was CES-D $d' = 1.3$ and for caregivers' Mastery Scale $d' = 1.6$ (Table 2 and 3). The per-protocol analyses showed effect sizes of $d' = 1.4$ for patients' Dqol overall, $d' = 1.2$ for caregivers' Dqol overall, $d' = 0.8$ for patients' GHQ-12, $d' = 1.3$ for caregivers' GHQ-12, $d' = 0.7$ for patients' CSD, $d' = 1.3$ for caregivers' CES-D and $d' = 1.6$ for caregivers' Mastery Scale. Blinding of the assessors was checked, and in 18% of the cases ($n = 21$) the assessors knew the treatment allocation.

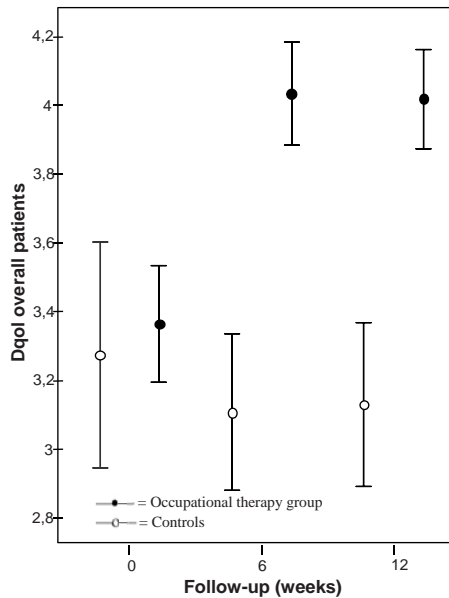


Figure 2: Means and 95% confidence intervals of Dementia Quality of Life Instrument (Dqol) overall patients at baseline, 6 weeks, and 12 weeks in occupational therapy group and control group.

Maintenance of treatment effects

At 12 weeks, 53 (78%) of 68 couples of patients and their caregivers in the intervention group and 52 (78%) of 67 couples of patients and caregivers in the control group remained in the study (Figure 1). The outcomes of patients who had received occupational therapy were still much better than those of the control group (Figures 2 and 3). Analysis of covariance of the intention-to-treat population (n=132) showed that the treatment difference in the intervention versus the control group at 12 weeks compared to baseline was significant for Dqol overall for both patients and caregivers (Tables 4 and 5, Figures 2 and 3).

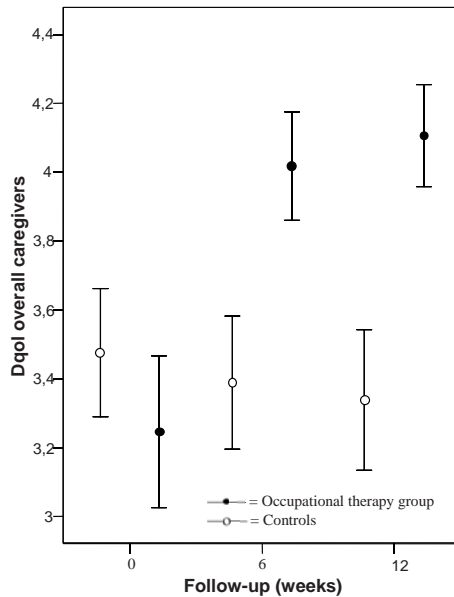


Figure 3: Means and 95% confidence intervals of Dementia Quality of Life Instrument (Dqol) overall caregivers at baseline, 6 weeks, and 12 weeks in occupational therapy group and control group.

Patients in the intervention group also had significantly better scores on all quality-of-life subscales than did patients in the control group, and the treatment differences for all quality-of-life subscales remained statistically significant at 12 weeks ($p < 0.05$) (Table 4). Caregivers who received occupational therapy reported better scores on all quality-of-life subscales, but only the differences on Dqol aesthetics and Dqol self esteem were statistically significant (Table 5). Patients' and caregivers' health status was significantly better at 12 weeks than at baseline. The differences were both statistically significant for both patients and caregivers (Tables 4 and 5). Patients' and caregivers' mood was significantly better at 12 weeks compared to baseline. These differences were statistically significant for both patients' CSD and caregivers' CES-D (Tables 4 and 5). Informal caregivers in the intervention group had a significantly better sense of control over life (Mastery Scale) than did those in the control group at 12 weeks compared to baseline (Table 5). All significant outcomes at 12 weeks remained significant after Bonferroni correction ($p < 0.007$) (Tables 4 and 5).

The proportion of patients achieving a clinically relevant improvement on the Dqol overall was 46% in the intervention group and 20% in the control group; for the caregivers Dqol overall was 55 % and 15%, respectively. NNT for Dqol overall for patients was 3.8 (95% CI, 3.7 to 4.0) and for caregivers 2.5 (95% CI, 2.4 to 2.7). The effect sizes at 12 weeks were for patients' Dqol overall $d' = 1.1$ and for caregivers' Dqol overall $d' = 1.5$. For patients' GHQ-12, $d' = 0.7$; for caregivers' GHQ-12, $d' = 1.1$; for patients' CSD $d' = 0.7$, for caregivers' CES-D $d' = 1.3$; and for caregivers' Mastery Scale $d' = 2.0$. The per-protocol analyses at 12 weeks showed effects sizes of: $d' = 1.2$ for patients' Dqol overall, $d' = 1.5$ for caregivers' Dqol overall, $d' = 0.7$ for patients' GHQ-12, $d' = 1.2$ for caregivers' GHQ-12, $d' = 0.7$ for patients' CSD, $d' = 1.3$ for caregivers' CES-D, and $d' = 2.0$ for caregivers' Mastery Scale. In 20% of the cases ($n = 21$), the assessors knew the treatment allocation. No adverse events were reported in either the intervention or control group.

Table 4: Patient outcomes (in intention- to- treat analyses) of occupational therapy versus no intervention in dementia at 3 months follow-up.

Patient outcomes	Occupational therapy group Observed mean (sd)	Control group Observed mean (sd)	Covariate adjusted Treatment difference (95% CI)	p-value	Effect size
Dqol Overall	4.0 (0.5)	3.1 (0.9)	0.8 (0.5 to 1.0)	<0.0001	1.1
Dqol Aesthetics	20.5 (2.4)	14.5 (4.6)	5.5 (4.1 to 6.9)	<0.0001	1.6
Dqol Positive affect	25.1 (2.7)	18.4 (4.2)	1.6 (0.3 to 2.8)	0.02	0.5
Dqol Negative affect	17.0 (4.1)	26.3 (7.4)	-2.7 (-1.1 to -4.9)	0.02	1.0
Dqol Feelings of Belonging	10.3 (1.7)	13.1 (1.1)	0.9 (0.3 to 1.6)	0.005	0.6
Dqol Self esteem	16.8 (2.0)	12.1 (3.4)	4.4 (5.3 to 3.5)	<00001	2.0
GHQ-12	9.1 (4.2)	14.0 (6.0)	-3.5 (-5.5 to -1.6)	0.001	0.7
CSD	6.2 (4.6)	9.2 (6.1)	-3.1 (-5.0 to -1.2)	<0.0001	0.7

Sd = standard deviation; Dqol= Dementia Quality Of Life Instrument; GHQ= General Health Questionnaire; CSD= Cornell Scale for depression in Dementia.

Table 5: Caregiver outcomes (in intention- to- treat analyses) of occupational therapy versus no intervention in caregivers of dementia patients at 3 months follow-up.

Caregiver outcomes	Occupational therapy group Observed mean (sd)	Control group Observed mean (sd)	Covariate adjusted Treatment difference (95% CI)	p-value	Effect size
Dqol Overall	4.1 (0.6)	3.4 (0.8)	0.9 (0.6 to 1.1)	<0.0001	1.5
Dqol Aesthetics	20.5 (4.4)	16.0 (3.0)	4.0 (3.4 to 4.6)	<0.0001	1.3
Dqol Positive affect	23.3 (3.2)	20.1 (4.3)	0.9 (-0.4 to 2.3)	0.163	Not sign.
Dqol Negative affect	19.8 (6.0)	26.2 (7.0)	-2.0 (-2.1 to -1.9)	0.069	Not sign.
Dqol Feelings of Belonging	17.3 (1.7)	15.3 (2.0)	0.8 (0.1 to 1.5)	0.022	0.5
Dqol Self esteem	13.7 (1.0)	12.5 (1.3)	3.8 (2.9 to 4.8)	<0.0001	1.6
GHQ-12	7.1 (3.5)	12.1 (5.0)	-4.9 (-6.6 to -3.3)	<0.0001	1.1
CES-D	5.4 (4.5)	13.1 (9.1)	-8.4 (-11 to -5.8)	<0.0001	1.3
Mastery Scale	16.7 (2.7)	12.3 (2.8)	4.1 (3.2 to 4.9)	<0.0001	2.0

Sd = standard deviation; CES-D = Center for Epidemiologic Studies Depression Scale; Dqol= Dementia Quality Of Life Instrument; GHQ= General Health Questionnaire.

Discussion

In this study, older patients with dementia and their informal caregivers who received occupational therapy had a significantly better quality of life and health status at six weeks, than those who did not. The mood of these patients and of their informal caregivers and the sense of control over life of these caregivers improved significantly as well. At follow-up, after 12 weeks, these beneficial effects remained significant, except on two caregiver quality-of-life subscales, Dqol positive affect and Dqol negative affect, which were no longer significant.

This community occupational therapy intervention is proven to be highly effective on quality of life of patients and caregivers, because the effect sizes on all outcome variables of this study were high and similar to the outcome variables (daily functioning and sense of competence) of this randomized controlled study.³

We believe that the positive effects of community occupational therapy on patients' outcomes in this study can be best explained by the strong positive association between dementia patients' daily functioning, mood, and quality of

life.^{9,32} The positive effects of community occupational therapy on caregivers' sense of control over life are supported by an earlier study, evaluating another comprehensive occupational therapy intervention for dementia patients and their caregivers, in which also positive effects on caregiver well being were also found.⁶ We believe that the effects on caregiver sense of control over life and quality of life could have been caused by the components of the intervention of training of caregivers' supervision skills and of providing individualized support to caregivers, which proved to be effective in earlier studies.^{33,34}

To our knowledge this study is the first study that found evidence for the effectiveness of community occupational therapy on mood, quality of life, and health status of patients with dementia and of their informal caregivers. Strong points of the study are that it meets the Consort Guideline Quality Criteria for randomized controlled trials and that the occupational therapy intervention was already tested in a pilot.¹ Moreover, this intervention is also available for others, as it is directly based on a meticulously described guideline developed in consensus meeting of panel of qualified and experienced occupational therapists. We had a high follow-up rate at 12 weeks (Figure 1), possibly because our study and the occupational therapy intervention evaluated was directly relevant to the daily lives of patients and their caregivers. According to the occupational therapy guideline, in all cases except the dropouts, all stages (diagnostics, goal defining, and treatment) of the occupational therapy intervention could be carried out.

A limitation of our study design is that, as with some other types of treatment, it was not possible to carry out a double-blind study, because the patients and their caregivers knew which therapy they received, nor was it possible to blind occupational therapists to treatment. However, only in 18% to 20% of the cases the assessors knew the treatment allocation. For this reason, we believe that our results are not significantly affected by observer bias. Another limitation is that participants were primarily recruited from the outpatient clinics of the memory clinic linked to a university hospital and not from other institutions or directly from general practice. Thus our sample may not be representative of all patients with mild-to-moderate dementia in our region. We deliberately chose for this recruitment strategy, because we wanted to achieve uniformity in terms of dementia screening and diagnosis, to facilitate comparison with other national and international studies.

Conclusion

The intervention proved to be effective in increasing the mood, quality of life, and health status of dementia patients and their informal caregivers, and caregivers' sense of control over life. In the Netherlands, patients with dementia and their informal caregivers are now reimbursed for occupational therapy at home. We strongly advocate the inclusion of such interventions in dementia management programs. The impressive gains in clinically relevant outcome measures obtained with occupational therapy for both patients and their caregivers underline the importance of adequate and timely diagnosis and pro-active management in dementia.

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All investigators were involved in the study design. Maud Graff was the lead investigator, developed the study design, carried out data-acquisition, analysis, and wrote the paper. Myrra Vernooij-Dassen, Joost Dekker and Marcel Olde Rikkert were responsible for the design, were project supervisors and were involved in writing the manuscript. Marcel Olde Rikkert was also involved in data acquisition. Willibrord Hoefnagels was also project supervisor and was responsible for the study design. Marjolein Thijssen carried out data acquisition. We thank Jana Zajec and Patricia Verstraten for all occupational therapy treatments.

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Chapter 6

Community occupational therapy for older patients with dementia and their care givers: cost effectiveness study

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Abstract

Objective: To assess the cost effectiveness of community based occupational therapy compared with usual care in older patients with dementia and their care givers from a societal viewpoint.

Design: Cost effectiveness study alongside a single blind randomised controlled trial.

Setting: Memory clinic, day clinic of a geriatrics department, and participants' homes.

Patients: 135 patients aged ≥ 65 with mild to moderate dementia living in the community and their primary care givers.

Intervention: 10 sessions of occupational therapy over five weeks, including cognitive and behavioural interventions, to train patients in the use of aids to compensate for cognitive decline and care givers in coping behaviours and supervision.

Main outcome measures: Incremental cost effectiveness ratio expressed as the difference in mean total care costs per successful treatment (that is, a combined patient and care giver outcome measure of clinically relevant improvement on process, performance, and competence scales) at 3 months after randomisation. Bootstrap methods were used to determine confidence intervals for these measures.

Results: The intervention cost €1183,- (95% confidence interval €1128,- to €1239,-) per patient and primary care giver unit at three months. Visits to general practitioners and hospital doctors cost the same in both groups but total mean costs were €1748,- lower in the intervention group, with the main cost savings in informal care. There was a significant difference in proportions of successful treatments of 36% at three months. The number needed to treat for successful treatment at three months was 2.8 (2.7 to 2.9).

Conclusions: Community occupational therapy intervention for patients with dementia and their care givers is successful and cost effective, especially in terms of informal care giving.

Introduction

Dementia is one of the three major diseases with regard to healthcare consumption¹⁻⁴ and is a major cause of disability and burden of care in elderly people.⁵ Dementia is a chronic and degenerative disease that causes disorders of memory, behavioural problems, loss of initiative, loss of independent functioning in daily activities, and loss of participation in social activities. These problems decrease wellbeing of those with dementia and their care givers,⁶ put pressure on family relationships and friendships,⁷⁻¹⁰ and cause high health care costs. The world prevalence of dementia has recently been estimated at 24.3 million people. This is expected to double over the next 20 years.¹¹ In 2002, in the Netherlands alone, nearly 1% of people aged 65 had dementia. This percentage rose with increasing age to around 40% in people aged 90 and over. By 2050 it is predicted that 2.2% of 65 year olds will have dementia.¹²

In the Netherlands in 2003, 5.3% of the total healthcare budget was spent on dementia, which was 14% of the age specific total costs for people aged 75-84 and 22% for people aged 85 and older.¹³ Because of an aging population, the numbers of dementia patients and the related healthcare costs will increase substantially in the next five decades.^{2,4,12} Healthcare costs in the Netherlands are predicted to rise from 57 milliard euros in 2003 to 70 milliard euros in 2025, and 10 milliard euros of this increase will be caused by the "greying population" and related diseases such as dementia.¹⁴ In the Netherlands in 2002, 39% of people with dementia needed continuous care, 38% needed home care daily, 23% needed home care occasionally, and 60% of those living in the community needed daily or continuous care.¹⁵

In Scandinavia, informal care costs, valued at the opportunity costs of the care giver's time, made up about a third of the total annual costs in dementia and increased considerably with severity of disease.⁵ It is therefore important to implement new effective and efficient healthcare interventions that increase independence and wellbeing of the patients and decrease the burden on care giver, resulting in a more efficient use of scarce healthcare resources.¹⁶

Occupational therapy can improve daily functioning, social participation, and wellbeing in people with dementia living in the community and improve the sense of competence and wellbeing of their primary care givers.^{6,9,17-20} It might reduce healthcare costs because of improved independence in patients and improved sense of competence in care givers, which might result in lower costs of informal care, delayed admission to nursing homes, and lower costs of other healthcare and social services - for example, costs for day care, home care, or meals on wheels. Occupational therapy is not usually recommended

for patients with dementia in primary health care. Recent research has looked at the efficacy and effectiveness of community occupational therapy in patients with dementia and their primary care givers.^{6,9,17,18,20,21} In one study of an efficient preventive nine months occupational therapy programme there was a trend towards lower medical costs and more independent living.²² In a cost effectiveness study of cognitive stimulation therapy in patients with dementia, Knapp and colleagues concluded that it was cost effective because it has benefits on cognition and quality of life and has no adjuvant costs compared with usual care.²³ Melis et al reported effectiveness of a multidisciplinary home based intervention for frail older people on prevention of functional decline and improved wellbeing for reasonable costs.²⁴ Brodaty and Peters found that an intensive 10 day training programme for care givers was cost effective as it saved US \$ 5975 dollars per patient in 39 months and was associated with patients being able to live at home for longer and decreased psychological morbidity in care givers.²⁵

We determined the cost effectiveness of community occupational therapy for older people with dementia and their primary care givers compared with usual care from a societal viewpoint. We chose for a societal viewpoint because primary care givers spend many hours on care for their relatives and this intervention^{6,9,20} aimed at decreasing patients' need for assistance and improving supervision skills in care givers. Usual care means the care dementia patients and care givers usually receive (without this new community occupational therapy intervention).

Methods

Participants

From April 2001 to January 2005, we recruited people with dementia and their care givers from the memory clinic and the day clinic of a department of geriatrics. Patients were included if they were aged 65 or over, had been diagnosed with mild to moderate dementia, were living in the community, and had a primary care giver who cared for them at least once a week. The diagnosis of dementia was based on criteria from the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV).²⁶ Severity of dementia was determined with the brief cognitive rating scale (BCRS),²⁷ with a score of 9-24 indicating mild dementia and a score of 25-40 indicating moderate dementia. We excluded patients with a score > 12 on the geriatric depression scale (30 items),²⁸ severe behavioural or psychological symptoms in dementia (BPSD), and severe illnesses as judged by a geriatrician and those in whom goals of occupational therapy could not be defined or who were not on stable

treatment of a dementia drug (that is, less than three months on the same dose of a cholinesterase inhibitor or memantine). We also excluded care givers with severe illnesses. Detailed description of the participants has been published elsewhere.⁹

Randomisation and procedures

Patients were randomly assigned by blocked randomisation (block size of four) to the intervention (10 sessions of occupational therapy at home over five weeks) or control group (usual care with no occupational therapy), which was stratified by level of dementia (mild or moderate). A statistician not involved in the study carried out randomisation. Concealed envelopes were used to allocate the patients and these envelopes were opened by an independent secretary. Patients and care givers were aware of the treatment assigned. The assessors (MT or MJLG) were blinded to group allocation. Patients and care givers were asked before each assessment not to inform the assessors about the intervention. To check the success or failure of the blinding after each measurement the assessors were asked if they had been told or knew for sure to which group each patient had been allocated. The total study period per patient was three months from the moment of inclusion. The control group received occupational therapy after completion of the study (three months later). Detailed description of randomisation and procedures has been published elsewhere.⁹

Intervention

The study intervention was developed in a consensus process²⁹ and was implemented by experienced occupational therapists who had been trained (80 hours) and were experienced (at least 240 hours) in delivering treatment according to this client-centred occupational therapy guideline for patients with dementia.^{6,9-10,20} Treatment consisted of 10 one hour sessions held over five weeks and focused on both patients and their primary care givers. In the first four sessions of diagnostics and goal defining, patients and primary care givers learnt to define their problems and choose and prioritise meaningful activities they wanted to improve. To this end, the occupational therapist used three client-centred narrative interview instruments. The occupational therapist evaluated the possibilities for modifying the patient's home and environment and observed the patient's ability to perform relevant daily activities and to use compensatory and environmental strategies. Compensatory strategies are used to adapt activities of daily living to the disabilities of patients, and environmental strategies are used to adapt the patients' daily environment to

their cognitive disabilities. The therapists also observed primary care givers' abilities and supervision skills.

In the remaining six sessions, patients were taught to optimise these compensatory and environmental strategies to improve their performance of daily activities. Primary care givers were trained, by means of cognitive and behavioural interventions, to use effective supervision, problem solving, and coping strategies to sustain patients' and their own autonomy and social participation.

The total time spent for this intervention, including the time spent for treatment at home (10 hours), narrative analysis, reports, and multidisciplinary briefing was about 18 hours per patient and care giver together. More detailed description of the intervention has been published elsewhere.¹⁰

Outcome assessments of effects

We assessed patients and their primary care givers at baseline before the intervention and six weeks and three months later. Our primary outcome measure for patients was daily functioning assessed with the process scale of the Assessment of Motor and Process Skills (AMPS),³⁰ in which scores range from -3 to 4 (higher score indicate better process skills), and with the performance scale of the Interview of Deterioration of Daily Activities in Dementia (IDDD),³¹ in which scores range from 0-44 (lower scores indicate less need for assistance). The primary outcome for care givers was assessed with the Sense of Competence Questionnaire (SCQ),³² in which scores ranged from 27 to 135 (higher scores denote better sense of competence).

Over a three months period these three primary outcomes were combined in one measure for successful treatment outcome for the economic evaluation. Successful treatment outcome was defined as a clinically relevant improvement in patients and care givers for all three primary outcome measures (process scale, performance scale, and competence scale). This means that the treatment was judged successful if the process, performance and competence scale scores showed improvements of ≥ 0.5 points, $\geq 20\%$, and ≥ 5 points, respectively; the criteria for clinical significance.³⁰⁻³²

Demographic characteristics and outcome measures collected at baseline included information on the age, sex, and educational level of the patient and caregiver, and information on patients' comorbidity (assessed with the Cumulative Illness Rating Scale for Geriatrics, CIRS-G, 30 items³³) depressive mood (assessed with the Geriatric Depression Scale, GDS²⁸), cognition (assessed with the Brief Cognitive Rating Scale, BCRS²⁷), and behaviour (assessed with the Revised Memory and Behavioural Problems Checklist,

RMBPC^{34,35}). For each carer we also collected information on the relationship to the patient and depression (assessed with the Centre for Epidemiologic Depression Scale, CES-D³⁶).

Cost analysis

We evaluated costs from a societal viewpoint and included both direct costs inside and outside the healthcare service and indirect costs outside the healthcare service. This societal viewpoint includes all costs our society met as a consequence of this community occupational therapy³⁷ and thus includes not only the costs of healthcare services delivered by different health care workers but also the estimated costs for gains and losses in productivity of the care givers.³⁸ Because the study lasted only three months we did not expect a discount effect and therefore did not correct for inflation. We performed an incremental analysis in which we analyzed in detail only costs that potentially differed between the two groups.

We used several instruments to measure the consumed resources. The primary care givers kept a diary to record the patients' visits to the general practitioner, physiotherapist, social worker, or other healthcare suppliers specifically related to the dementia. Care givers also used these diaries to register their own visits to healthcare services if they had physical or emotional health complaints and their hours spent on care for their relatives (or friends or neighbours). They recorded the number of hours the patients received care at home from a nurse or a housekeeper or day care and if they received other services like meals on wheels. Finally, they noted the days of illness in the patients and the number of days patients had spent in day care or were admitted to hospital, nursing homes, or homes for the elderly. Three diaries were handed out. At six weeks and 12 weeks the researchers received the diary that was filled in by the primary care givers in the previous six weeks. At baseline, care givers filled in a diary for the past six weeks retrospectively.

The quantities measured were multiplied by unit costs (prices) to obtain the costs involved. The costs for community occupational therapy sessions were based on outpatient price for employee costs (this is, a defined price for outpatient occupational therapy per hour), and additional costs for home visits, and travelling costs (distance multiplied by price per kilometre).³⁹ The additional costs of occupational therapy (hours of administration and analysis of interview data, reports, advice and multidisciplinary briefing) were based on the employee costs per hour. We used these figures to compute standard prices for occupational therapy home visits and for additional hours spent by the occupational therapist. We based prices for visits to the general

practitioner, day care, home care or household support, and other resources, such as visits to the physiotherapist, on Dutch guidelines for economic health care.³⁸ Costs for the hospital social worker and hospital physician were calculated from the employee costs multiplied by a percentage of 39% for employer premiums as social taxes, holidays, and employee facilities. Hours invested by care givers were counted for according to Dutch guidelines, which reflect an average of costs for care givers still in paid employment and care givers not working anymore. These costs for informal care giving are computed according to the “friction cost method” in which a price for care giving in general is computed based on hours of absence because of care giving or illnesses of the care givers and which is valued at an hourly wage of a middle aged cleaning person of 8 euros an hour.³⁸

Statistical analysis

We analysed differences in outcomes by analyses of covariance of the primary outcome measures (process scale of the Assessment of Motor and Process Skills, performance scale of the Interview of Deterioration in Daily Activities in Dementia, and competence scale assessed by the Sense of Competence Questionnaire at three months) based on an intention to treat analysis of all available data and carrying forward the last observation for drop outs and those with missing data. Participant with missing data at baseline were not included in the analyses as in the randomised controlled trial.⁹ The covariates were age, sex, relationship between the patient and the care giver, other care givers and baseline scores for cognitive functioning on the Mini-Mental State Examination (MMSE, scores 10-24 for mild to moderate dementia),²⁶ depression assessed with the Geriatric Depression Scale (GDS, 30 items),²⁸ comorbidity assessed with the Cumulative Illness Rating Scale for Geriatrics (CIRS-G),³⁴ behaviour assessed with the Revised Memory and Behavioural Problems Checklist (RMBPC),^{34,35} and the outcome variable.

The study was powered to detect a clinically relevant difference in change between the groups over time of 0.5 points on the process scale,³⁰ 20% improvement on the performance scale,³¹ and a 5-point difference on the competence scale,³² with a power of 80% on the basis of one sided testing, a standard deviation of 0.8 on the process scale, and $n \geq 100$. The power calculation was based on earlier data²⁰ and on the minimal clinically relevant differences in the primary outcomes.^{30,31}

We computed the proportion of patients and care givers achieving a clinically relevant improvement for each of the primary outcome measures separately and for all three together, which was the fraction with successful

treatment outcome. We calculated the difference in treatment effect as the difference in successfully treated patients and care givers combined. Incremental treatment costs were calculated as the difference in mean total care costs. We replaced missing values in quantities of care with series mean. Based on the differences in mean total costs between the groups, and the change in outcome measure, we calculated an incremental cost effectiveness ratio (ICER), which was expressed as total costs per successful treatment. Bootstrap methods were used to explore the uncertainty in the estimates of cost effectiveness and determine confidence intervals.

We used one way sensitivity analyses to examine the robustness of the findings of the cost effectiveness analysis. In the cost analysis, we calculated prices for occupational therapy, other healthcare resources, and care giving by primary care givers during follow-up and performed a sensitivity analysis on these figures. We assessed cost effectiveness graphically with an acceptability curve to summarise the evidence in support of the intervention being cost effective compared with usual care for all potential values of the willingness to pay per patient-care giver unit per successful treatment.

Results

Effects

We evaluated 275 people with dementia who were living in the community. Of the 135 eligible patients randomised, three (one in the intervention group, two in the control group) with their care givers stopped the trial immediately after randomisation because they did not want to continue and they did not receive the study intervention. This left 132 patients with care givers for the intention to treat analysis⁹ and the cost effectiveness analysis.

The baseline characteristics of patients and care givers were well matched between the two groups (table 1). Age differences (patients and their primary care givers were 2.0 and 4.7 years younger in the control group) were corrected in the analysis of covariance.

Table 1 Demographic characteristics and outcome measures of elderly people with dementia and their care givers according to allocation at enrolment. Figures are numbers of participants unless stated otherwise

	Occupational therapy (n=68)	Usual care (n=67)
Mean (SD) age (years):		
Patient	79.1 (6.2)	77.1 (6.3)
Primary care giver	66.0 (15.3)	61.3 (15.4)
Sex (M/F):		
Patient	29/39	31/36
Primary caregiver	22/46	18/49
Relation caregiver to patient:		
Partner	41	38
Daughter	22	21
Other	5	8
Mean (SD) scores		
Domestic home care	11.6 (26.3)	16.5 (41.0)
Nurse home care	24.2 (42.2)	24.4 (47.1)
Mini-mental state examination	19.0 (5.7)	19.0 (4.0)
CIRS-G	10.7 (3.5)	11.6 (4.3)
Geriatric depression scale	6.9 (3.0)	7.5 (3.0)
RMBPC-frequency	5.6 (5.3)	5.0 (6.0)
AMPS-process	0.2 (0.8)	0.3 (0.8)
IDDD-performance	23.5 (7.9)	24.5 (8.7)
Cornell depression scale	8.3 (6.2)	8.1 (4.6)
Brief cognitive rating scale	27.3 (5.1)	27.1 (4.2)
Sense of competence	89.7 (14.9)	90.4 (13.6)
CES-D	11.7 (8.3)	11.4 (7.2)

SD = standard deviation; Mini-mental state examination: measures mental state/cognitive functioning; CIRS-G=cumulative illness rating scale for geriatrics, measures co morbidity (14 items, score 14-56); geriatric depression scale: diagnostic scale, measures depressive complaints of the patient (30 items, score 0-30); RMBPC=revised memory and behavioural problems checklist, measures memory and behavioural problems (24 items, score 0-96); AMPS=assessment of motor and process skills-process scale, measures process skills (21 items, score -3-4); IDDD=interview of deterioration in daily activities in dementia-performance scale, measures need for assistance (11 items, score 0-44); Cornell scale for depression-frequency scale, sensitive instrument to measures frequency of depressive complaints of patient over longer time (19 items, score 0-38); BCRS=brief cognitive rating scale (8 items, score 8-56); sense of competence questionnaire (SCQ), measures sense of competence (27 items, score 27-135); CES-D=Centre for Epidemiologic Studies depression scale, measures depressive complaints of care giver (20 items, score 0-60).

Socioeconomic status was equally divided over the groups. The occupational therapist visited those in the intervention group an average of nine times at home for one hour and spent an additional seven hours (time for administration and analysis of interview data, reports, advice and multidisciplinary briefing) per patient and care giver couple (table 2).

Table 2 Mean (SD) number of healthcare units used per patient during three months of follow-up

	Occupational therapy (n=67)	Usual care (n=65)
OT home visits	9.3 (1.8)	0
OT additional hours (telephone contacts, reports, written advice)	7.4 (1.4)	0
Physiotherapy visits	3.4 (6.5)	4.2 (8.1)
Social worker visits	0.8 (2.1)	1.0 (2.7)
General practitioner visits	0.1 (0.5)	0.2 (0.8)
Hospital specialist visits	0.2 (0.8)	0.2 (0.8)
Nursing home care (hours)	37.4 (61.1)	47.7 (79.2)
Domestic home care (hours)	23.2 (48.7)	19.0 (45.6)
Day care (days)	3.4 (9.7)	5.0 (10.7)
Meals on wheels (days)	14.9 (30.3)	15.8 (30.9)
Admission to hospital (days)	1.6 (6.8)	2.1 (8.6)
Admission to institution (days):		
Nursing home	1.6 (7.9)	2.4 (13.3)
Home for elderly	0.8 (6.8)	0.9 (6.9)
Informal care (hours)	913.5 (666.5)	1125.8 (830.2)

SD = standard deviation; OT=occupational therapy.

At three months 53 of the 68 patients in the intervention group and 52 of the 67 in the control group remained in the study and these were the same participants as in the effectiveness study.⁹

We used intention to treat analysis (n=132), with the last observation carried forward, to analyse the effects in both groups. There were significant differences between the groups on all primary outcome variables at three months. In the intention to treat analysis (n= 132), treatment was considered as successful (clinically relevant and significant improvement on all three outcome measures of patients' daily functioning and caregivers' sense of competence), in 26 patients and their care givers, of whom 25 (37%) were in the intervention group (n=67) and one (1.5%) was in the control group (n=65). The number needed to treat (NNT) for a successful treatment outcome was 2.8 (95% confidence interval 2.7 to 2.9) (table 3). No adverse events were reported in either group.

Table 3 Effect of treatment and mean (SD) costs per patient at 3 months follow-up

	Occupational therapy (n=67)	Usual care (n=65)	Difference (95% CI)
Effect			
No (%) of "successful treatments"	25 (37)	1 (1.5)	36% (23% to 47%)
No with missing data	1	2	—
NNT (95% CI)	2.8 (2.7 to 2.9)	—	—
Costs (€)*			
Total care costs	12 563 (6628)	14 311 (7833)	-1748 (-4244 to 748)
Intervention (OT):			
Visits	774 (151)	0	774 (737 to 810)
Additional	409 (78)	0	409 (391 to 429)
Total	1183 (228)	0	1183 (1128 to 1239)

SD = standard deviation; CI = Confidence Interval; NNT=number needed to treat.
*Costs per patient averaged over all patients in each group.

Costs

The occupational therapy intervention cost €1183,- per patient and caregiver couple (95% confidence interval €1128,- to €1239,-) (table 4). The usual care group received no occupational therapy. The costs for visits to a general practitioner and hospital doctor were equal in both groups. Costs for other health care, such as nursing home care (-€417,-), domestic home care (-€91,-), social worker (-€8,-), and physiotherapist (-€36,-), day care (-€197,-), and meals on wheels (-€8,-) were all lower in the intervention group (table 4), as were costs for admission to hospital (-€242,-) and nursing homes and homes for the elderly (-€172,-) (table 5). The main cost savings were from reduced informal care in the intervention group (-€1762,-) (table 5).

Table 4 Effect on costs of health care at 3 months of follow-up. Figures are mean (SD) costs (€) per patient

	Occupational therapy (n=67)	Usual care (n=65)	Difference in cost (95% CI)
Physiotherapy:			
Average cost*	152 (290)	188 (363)	-36 (-149 to 77)
No (%) who used service	27 (40)	18 (28)	—
Costs if used†	377	679	—
Social worker:			
Average cost*	26 (68)	34 (90)	-8 (-35 to 20)
No (%) who used service	11 (16.9)	13 (20)	—
Costs if used†	158	170	—
General practitioner:			
Average cost*	3 (11)	3 (17)	0 (-5 to 4)
No (%) who used service	5 (7.5)	3 (4.6)	—
Costs if used†	40	65	—
Hospital specialist:			
Average cost*	5 (16)	4 (16)	1 (-5 to 6)
No (%) who used service	6 (9)	5 (7.6)	—
Costs if used†	56	52	—
Nurse home care:			
Average cost*	1512 (2469)	1929 (3201)	-417 (-1399 to 566)
No (%) who used service	40 (59.7)	33 (50.8)	—
Costs if used†	2533	3800	—
Domestic home care:			
Average cost*	413 (990)	504 (1056)	-91 (-443 to 262)
No (%) who used service	26 (38.8)	29 (44.6)	—
Costs if used†	1064	1130	—
Day care:			
Average cost*	408 (1178)	605 (1291)	-197 (-622 to 228)
No (%) who used service	9 (13.4)	17 (26.2)	—
Costs if used†	3037	2513	—
Meals-on-wheels:			
Average cost*	134 (273)	142 (278)	-8 (-103 to 87)
No (%) who used service	14 (20.9)	16 (24.6)	—
Costs if used†	641	577	—
Admitted to hospital:			
Average cost*	739 (3215)	981 (4114)	-242 (-1512 to 1027)
No (%) who used service	6 (9.0)	7 (10.8)	—
Costs if used†	8252	9109	—

SD = standard deviation; CI = Confidence Interval.

*Costs per patient averaged over all patients in each group.

†Costs of specific service when averaged over those patients who actually used it.

Table 5 Effect of treatment on admission to institution at three month follow-up.
Figures are mean (SD) costs (€) per patient

Admission to institution	Occupational therapy (n=67)	Usual care (n=65)	Difference in cost (95% CI)
Nursing home:			
Average cost*	335 (1635)	501 (2731)	-166 (-938 to 607)
No (%) who used service	5 (7.5)	5 (7.7)	—
Costs if used†	4489	6513	—
Home for elderly:			
Average cost*	71 (582)	77 (590)	-6 (-208 to 196)
No (%) who used service	1 (1.5)	4 (6.2)	—
Costs if used†	4757	1251	—
Informal care:			
Average cost	7582	9344	-1762 (-3919 to 395)
No (%) who used service	67 (100)	65 (100)	—
Costs if used†	7582	9344	—

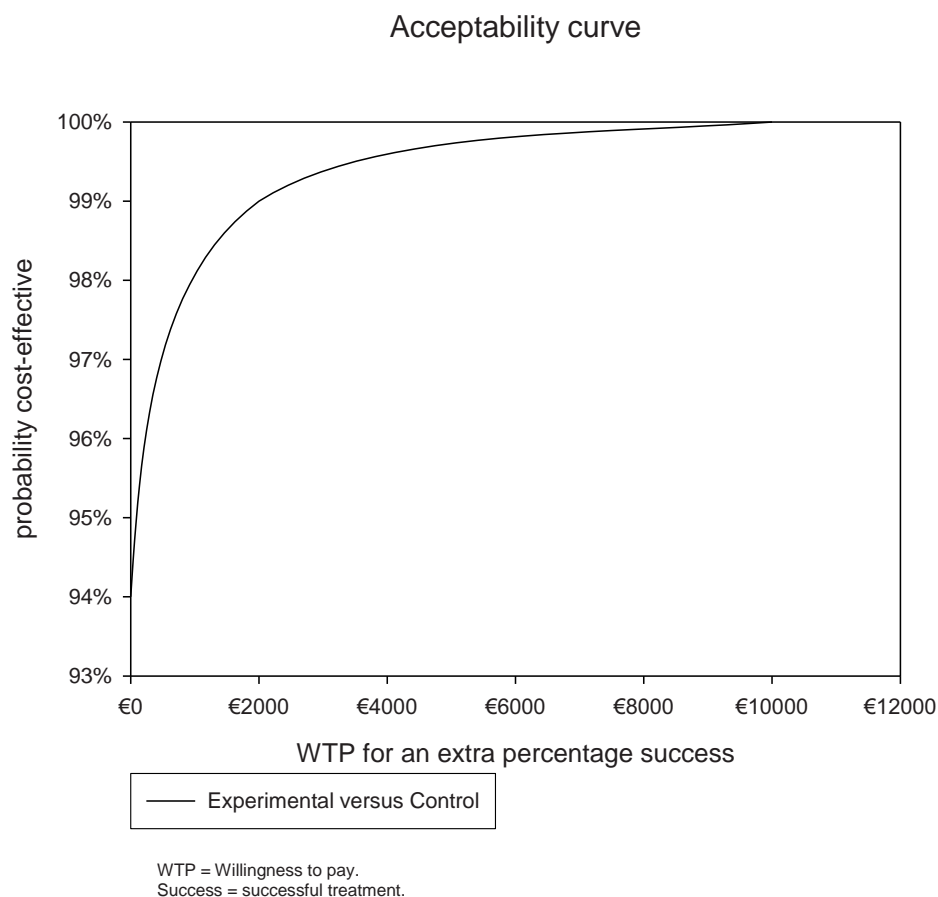
SD = standard deviation; CI = Confidence Interval.

*Costs per patient averaged over all patients in each group.

†Costs of specific service when averaged over those patients who actually used it.

The economic evaluation showed average savings of €1748,- per couple successfully treated with occupational therapy. The probability of occupational therapy being the dominant intervention was estimated to be 94% (figure 1). The acceptability curve shows, when interpreted in a Bayesian sense, that if society is willing to pay (WTP) €2000,- or more for a successful treatment then there is 99% probability that occupational therapy is efficient (figure 1).

Figure 1: Cost effectiveness acceptability curve of community occupational therapy compared with usual care



Discussion

Community occupational therapy intervention for people with dementia and their primary care givers is cost effective, at a cost of about €1200,- per patient and care giver over a three month period. The intervention was associated with a 35% higher proportion of successful treatment. The mean costs per patient and care giver of all care for the three months were €12563,- for the intervention group and €14311,- for the control group. This means that from a societal viewpoint community occupational therapy is an effective and efficient intervention strategy. It is cost effective because on average it saved €1748,- over three months (with a probability of 95%), and yielded significant and clinically relevant improvements in daily functioning in patients and sense of competence in care givers.

Relevance of results

Comparison of our results with others is difficult because of the lack of similar studies. Hay et al looked at cost effectiveness of a preventive occupational therapy for independent living older adults in a randomised controlled trial with an occupational therapy group, a social activity group, and a control with no treatment.²² The costs for the nine months preventive occupational therapy programme (US\$548 per person) and the follow-up costs at 15 months for the occupational therapy group (US\$967) were lower than for the social activity group (US\$1726) and the control group (US\$3334). The authors concluded that the programme was cost effective and showed a trend towards decreased medical expenditures. The estimated costs per quality adjusted life year (QALY) for the occupational therapy group were US\$10666 per group of about 55 patients.

Strengths and limitations

Our study was empirically robust because we used a randomised controlled design and carried out the economic analysis from a societal perspective. Another strong point is the new outcome measure “successful treatment outcome” that we used as the primary outcome in this cost effectiveness analysis. This outcome measure is innovative and combines the effect of occupational therapy on outcome in both patient and caregiver, which represents the whole content and outcome of successful occupational therapy treatment.

We did not include a generic measure for quality of life on which QALYs could be computed, which limits comparability with other interventions. QALYs are, according to most guidelines on cost effectiveness, the principal measure of effect in economic analyses. Mostly this is because there are reference values for “willingness to pay for QALYs,” which is important when costs need to be traded off against effects. In our particular case, however, in which the experimental treatment is dominant (lower costs and more effects), there is no trade off between costs and effects. Moreover, given the results (an average cost saving and a 95% probability of being the dominant strategy) the conclusion that occupational therapy is cost effective would not be altered if we included quality of life as an outcome measure.

A second limitation of our study design is that, as with some other types of treatment, we could not carry out a double blind study because the patients and their care givers and the occupational therapists could not be blinded to allocation. We tried to maintain masked conditions where possible when it came to assessment, which succeeded for 80% of the cases.⁴⁰ For this

reason, we believe that our results are not significantly affected by observer bias.

The study took place over a relatively short time, with a three months follow-up.³⁷ However, based on the remaining effects on the primary outcomes of the randomised controlled trial at three months⁹, we expect that the savings at six months would be even greater, with no more costs occurred. In future studies the effectiveness, and consequently its cost effectiveness, should be assessed to determine if effects indeed remain over time.

Our participants might not be representative of all patients with mild to moderate dementia in our health region as they were recruited primarily from the outpatient clinics of the university hospital and not from other institutions or directly from general practices. We chose this recruitment strategy because we wanted to achieve uniformity in terms of screening and diagnosis of dementia to facilitate comparison with other national and international studies. Our participants were also not representative of all older people with mild to moderate dementia living in the community because we excluded those who lived alone. The groups might be comparable on socioeconomic status because the whole range of educational levels and former and recent occupations was representative of the general population. Another issue is the costs for informal care giving, which were computed with the "friction cost method".³⁸ In our study most of the carers were retired. If other informal care givers had been used (for example, more employed sons and daughters or neighbours) another value would have been plausible. We assumed that medical costs did not increase because of the short time window.²² According to that study we have underestimated the potential medical savings associated with our intervention.

Ethical questions can be raised about the exclusion of individuals from this highly effective and efficient intervention. However, it was not previously recommended in the Netherlands because there was no sound evidence for effectiveness.

Future research

We expect that this intervention might also be cost effective for older people with dementia without an informal care giver but who have the help of a professional home care worker. Though home care workers are trained, training does not extend to occupational therapy but this would probably result in a more effective care strategy resulting in even higher savings. We will investigate this in a future study on the effectiveness of a national implementation policy of our guideline. We also expect that it would be helpful

if home care workers were educated to supervise care givers in continuing their effective way of care giving at home several months after the intervention ends. It also would be interesting to investigate whether home care workers with special training in occupational therapy would be able to deliver part of the occupational therapy under supervision of occupational therapists.

Recommendations

Well educated and well trained occupational therapists are needed to perform this complex community occupational therapy intervention (including occupational therapy diagnostics and specialised observation and interviewing skills, occupational therapy goal setting, and developing an effective treatment plan). Occupational therapists are best equipped to carry out the specific tasks, with the possible assistance of occupational therapy assistants or educated home care workers in future.

Community occupational therapy is a highly effective non-pharmacological therapy for older people with dementia and their care givers and not only improves the daily functioning of older people with dementia and their care givers' sense of competence⁹ but also improves the quality of life, mood and health status of both patients and care givers,⁶ which are recommended as major outcomes in therapeutic research in dementia.⁴¹ As this community occupational therapy intervention was also cost effective we highly recommend it in all community health services, primary care services, and outpatient services for people with dementia and their care givers. Moreover, if the National Institute for Health and Clinical Excellence (NICE)⁴² criteria for drug use were applied to this intervention, implementation would be beyond all doubt. A multi-centred study would determine the cost effectiveness in different settings and healthcare regions.

What is already known on this topic?

Community occupational therapy improves daily functioning in patients with dementia and reduces the burden on care givers.

Dementia is categorised as one of the three major diseases in healthcare costs and is a major cause of disability and burden of care in elderly people.

What this study adds

Community occupational therapy intervention is cost effective and specifically reduces costs of informal care giving.

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Chapter 7

Discussion

Maud J. L. Graff



Introduction

Dementia has far reaching consequences for patients and their primary care givers and is currently a major driver of costs in health care and social systems in developed countries.¹ Major problems are the losses in independence, initiative, and participation in social activities, decreasing the quality of life of patients and putting pressure on both family relationships and friendships. Care givers often experience feelings of helplessness, social isolation, and loss of autonomy.²⁻³ Unfortunately, drugs are not yet effective in improving the symptoms of dementia⁴. Occupational therapy is directed at improving patients' ability to perform meaningful activities of daily living and hence promote independence and participation in social activities^{5,6} and to reduce the burden on the care giver by increasing their sense of competence and ability to handle the behavioural problems they encounter.⁵⁻⁸ These outcomes are increasingly being considered equally or even more clinically relevant than measures of cognitive outcome.⁹ Earlier studies have shown community based occupational therapy given in the home can improve the functional independence of patients with dementia and decrease the burden on the care giver.⁵⁻⁷ As a systematic review questioned the methods of these earlier studies¹⁰ we decided to evaluate the effectiveness and cost-effectiveness (efficiency) of community based occupational therapy for patients with dementia and their primary care givers.

Therefore, this thesis addresses two research questions:

- 1) Is community based occupational therapy effective in older people with dementia and their caregivers?
- 2) Is community based occupational therapy efficient in older people with dementia and their caregivers?

To answer these research questions we used a systematic sequential approach for developing and evaluating a community based occupational therapy program. This systematic approach was based on the sequential stepwise scientific quest for evidence of the MRC framework for the development and evaluation of complex interventions¹¹, which was presented in the introduction of this thesis.

It is important to first define the most crucial elements in this discussion, which are the terms 'complex intervention' or 'combined intervention'. The MRC framework defines complex or combined interventions as interventions which are including several components¹¹, such as different organisations from which the intervention is delivered, heterogeneousness of the target

population (such as different types of dementia, different multi-morbidity problems and different types of caregivers), different target populations for one intervention (such as interventions directed at patients and caregivers), different approaches included in one intervention (such as cognitive and behavioural approaches) and different activities performed (as usual in tailor-made interventions). Our intervention fulfils these criteria because we treat a heterogeneous group of dementia patients, with individual loads of multi-morbidity, tailor-made, and thus with different composed occupational therapy treatment strategies. Therefore, the MRC framework for complex interventions¹¹ is applicable to our study. This framework keeps researchers from pitfalls that often arise in the evaluation of complex interventions. It is useful and important to carry out several subsequent phases during the process of development and evaluation of such interventions, because a phased approach gives room for optimizing the many parts of both intervention and evaluation.

In this discussion, we will also follow the distinct phases described in the MRC model. In doing so, we review the strengths and weaknesses of the development and evaluation of this complex occupational therapy intervention as a whole, and compare it to the latest findings on similar OT studies. Next, we describe critical factors that predict positive outcome of this community based occupational therapy intervention in different health care settings and regions, which are highly relevant for further implementation. Finally we reflect on the consequences of this study for treatment in people with other cognitive impairments (e.g. stroke or Parkinson's disease) and their caregivers and on the consequences of the results of this thesis for policy making in dementia care and future research (*chapter 7*).

Outcomes randomised controlled trial compared to outcomes other intervention trials in dementia

In this paragraph we discuss the relevance of our randomised controlled trial by comparing the outcomes of our trial to outcomes of other combined psychosocial interventions and to other cognitive behavioural interventions (*table 1 and 2*), as we could find these in recent systematic reviews and meta-analyses^{12,13}. We also discuss the relevance and outcomes of our study by comparing them with outcomes of pharmacological interventions in dementia⁴ (*table 3*).

Table 1: Overall effects of combined psycho-social programmes on persons with dementia by domains of outcome¹²

Outcome category and outcome measure	Studies reporting significant effects*	Studies reporting heterogeneous effects*	Studies reporting no significant effects*
<i>Persons with dementia: mental health:</i> depression and dissatisfaction, depressive behaviour, positive affect, self esteem, feeling of belonging	<ol style="list-style-type: none"> 1. Romero and Wenz, 2002 2. Teri et al., 1997 3. Teri et al., 2003 4. Graff et al., 2007 	<ol style="list-style-type: none"> 1. Droës et al., 2004c 	<ol style="list-style-type: none"> 1. Droës et al., 2000
<i>Persons with dementia: cognitive functioning:</i> various cognitive functions	<ol style="list-style-type: none"> 1. Aupperle and Coyne, 2000 2. Moniz-Cook et al., 1998 	<ol style="list-style-type: none"> 1. Quayhagen et al., 2001 	<ol style="list-style-type: none"> 1. Berger et al., 2004 2. Riordan and Bennett, 1998 3. Graff et al., 2006 4. Graff et al., 2007
<i>Persons with dementia: behavioural problems:</i> in general, memory related problems and disruption related problems, behavioural disorder	<ol style="list-style-type: none"> 1. Romero and Wenz, 2002 2. Graff et al., 2008 	<ol style="list-style-type: none"> 1. Droës et al., 2000 2. Hinchliffe et al., 1995 3. Droës et al., 2004c 	<ol style="list-style-type: none"> 1. Gitlin et al., 2001 2. Gitlin et al., 2003 3. Ostwald et al., 1999 4. Riordan and Bennett, 1998 5. Berger et al., 2004
<i>Persons with dementia: physical functioning:</i> ADL, IADL, mobility, restricted activity	<ol style="list-style-type: none"> 1. Teri et al, 2003 2. Graff et al., 2006 	<ol style="list-style-type: none"> 1. Gitlin et al., 2001 	<ol style="list-style-type: none"> 1. Berger et al., 2004 2. Gitlin et al., 2003
<i>Persons with dementia:</i> hospital admission and long stay admission	<ol style="list-style-type: none"> 1. Brodaty and Gresham, 1989 2. Brodaty et al., 1997 3. Droës et al., 2994b 4. Teri et al., 2003 (trend) 5. Moniz-Cook et al., 1998 6. Riordan and Bennett, 1998 7. Vernooij-Dassen, 1993 8. Vernooij-Dassen et al., 1995 , 2007 9. Graff et al., 2008 (baseline to 3 	<ol style="list-style-type: none"> 1. Aupperle and Coyne, 2000 2. Chu, et al 2000. 3. Eloniemi et al., 2001. 	<ol style="list-style-type: none"> 1. Miller et al., 1999

	months follow-up)		
<i>Persons with dementia: survival</i>	1. Brodaty et al., 1997		

* Effects are defined as positive changes on the specific domains compared to changes of outcome measures in the controls. Significant effects column: includes studies that reported effects that were significant for all measures of the same outcome category.

Heterogeneous effects column: includes studies that reported effects that: a) were significant for some measures of the same outcome category but not for other; b) reached statistical significance at some but not all measurement points in longitudinal studies (except when later measurement points resulted in significant effects, whereas earlier measurements did not. In the latter case a delayed effect may have occurred); c) report positive effects for some subgroups but not for the total group that was studied.

Table 1 shows that our community based occupational therapy intervention for older people with dementia and their caregivers is one of the combined psycho-social intervention studies that found significant positive effects on several outcome measures of persons with dementia^{12,13} as defined in *table 1*. Romero and Wenz (2002), Teri (et al., 2003), and Brodaty (et al., 1997), found also positive effects on several outcome measures of patients with dementia. However, many interventions found only significant effects on a single outcome measure for persons with dementia or found heterogeneous effects. Droës (et al., 2004) found several heterogeneous effects, like significant effects on only some scales and no significant effects on other measures of the same outcome category. Also another combined occupational therapy intervention of Gitlin (et al., 2001) found heterogeneous effects on the outcome measure physical functioning (IADL-activities improved significantly and ADL activities were not significantly improved) and found no significant effects on behavioural problems. In our study we found significant positive effects on: mental health (e.g. depressive behaviour, positive affect, self esteem and feeling of belonging)³⁰, on behavioural and physical functioning²⁵ and on admission to hospital between baseline and 3 months follow-up³⁸. We did not test cognitive functioning with a responsive instrument, and thus did not find significant effects on cognitive functioning, as found by Riordan and Bennett (1998) and Berger (et al., 2004). Unfortunately, long stay admission and survival were not assessed in our study, although other studies of combined psycho-social interventions found significant effects. These outcomes would have been important outcomes for our intervention as well. In future research, effects on long stay admission to hospital or nursing home and on survival should be measured. Moreover, a combination of different successful intervention strategies is probably most successful, which should be investigated in future as well.

Table 2: Overall effects of combined programmes on caregivers of persons with dementia by domains of outcome¹²

Outcome category and outcome measure	Studies reporting significant effects*	Studies reporting heterogeneous effects*	Studies reporting no significant effects*
<i>Caregiver mental health: depressive symptoms</i>	<ol style="list-style-type: none"> 1. Romero and Wenz, 2002 2. Teri et al., 1997 3. Graff et al., 2007 	<ol style="list-style-type: none"> 1. Ostwald et al., 1999 2. Moniz-Cook et al., 1998 3. Newcomer et al., 1999 	<ol style="list-style-type: none"> 1. Chu et al., 2000 2. Berger et al., 2004
<i>Caregiver mental health: general mental health, psychological and psychosomatic complaints</i>	<ol style="list-style-type: none"> 1. Hinchliffe et al., 1995 2. Moniz-Cook et al., 1998 3. Brodaty and Gresham, 1998 4. Graff et al., 2007 		<ol style="list-style-type: none"> 1. Droës et al., 2004
<i>Caregiver mental health: well-being</i>	<ol style="list-style-type: none"> 1. Gitlin et al., 2003 2. Graff et al., 2007 		<ol style="list-style-type: none"> 1. Logiudice et al., 1999 2. Riordan and Bennett, 1998
<i>Caregiver mental health: other aspects of mental health</i>	<ol style="list-style-type: none"> 1. Anxiety (Moniz-Cook et al., 1998) 2. Psychiatric caseness (Hinchliffe et al., 1995) 3. Perceived change in affect (Gitlin et al., 2003) 4. Social interaction (Logiudice et al., 1999) 	<ol style="list-style-type: none"> 1. Alertness behaviour (Logiudice et al., 1999) 	<ol style="list-style-type: none"> 1. Mood (Romero and Wenz, 2002) 2. Behaviour upset (Gitlin et al., 2001) 3. Feelings of stress (Droës et al., 2004) 4. Dissatisfaction with life (Droës et al., 2004) 5. Emotional behaviour (Logiudice et al., 1999) 6. Sleeprest (Logiudice et al., 1999) 7. Perceived change

			somatic symptoms (Gitlin et al., 2003)
<i>Caregiver burden:</i> subjective burden	1. Ostwald et al., 1999	1. Chu et al., 2000 2. Newcomer et al., 1999	1. Aupperle and Coyne, 2000 2. Logiudice et al., 1999 3. Teri et al., 1997 4. Berger et al., 2004
<i>Caregiver burden:</i> other aspects	1. Fatigue (Romero et al., 2002) 2. Internal restlessness (Romero et al., 2002) 3. Satisfaction with marital relationship (Quayhagen et al., 2001) 4. Upset with memory problems of persons with dementia (Gitlin et al., 2003) 5. Number of unfulfilled needs, adl tasks (Yordi et al., 1997) 6. Total days adl help (Gitlin et al., 2003)	1. Experienced support of service (Droës et al., 2004) 2. Total help from third person in adl tasks (Yordi et al., 1997)	1. Positive aspects for burden (Teri et al., 1997) 2. Experienced social support (Droës et al., 2004) 3. Loneliness (Droës et al., 2004) 4. Fatigue (Romero et al., 2002) 5. Internal restlessness (Romero et al., 2002) 6. Satisfaction with material relationship (Quayhagen et al., 2001) 7. Upset with disruptive behaviour and (i)adl problems of persons with dementia (Gitlin et al., 2003) 8. Experienced problems (Riordan and Bennett, 1998) 9. Hours (i)adl help needed (Gitlin et al.,

			2003) 10. Primary caregiver task (Yordi et al., 1997) 11. Level of secondary caregiver assistance 12. Number of care giving hours (Yordi et al., 1997)
<i>Caregiver competence</i> : coping strategies, feelings of competence, mastery, skill enhancement, adl self-efficacy, knowledge on dementia, and response to disruptive behaviour	1. Oswald et al., 1999 2. Droës et al., 2004 3. Graff et al., 2006 4. Graff et al., 2007	1. Droës et al., 1999 2. Gitlin et al., 2001 3. Gitlin et al., 2003 4. Vernooij-Dassen, 1993 5. Vernooij-Dassen et al., 1995	1. Logiudice et al., 1999

* Effects are defined as positive changes on the specific domains compared to changes of outcome measures in the controls. Significant effects column: includes studies that reported effects that were significant for all measures of the same outcome category.

Heterogeneous effects column: includes studies that reported effects that: a) were significant for some measures of the same outcome category but not for other; b) reached statistical significance at some but not all measurement points in longitudinal studies (except when later measurement points resulted in significant effects, whereas earlier measurements did not. In the latter case a delayed effect may have occurred); c) report positive effects for some subgroups but not for the total group that was studied.

Table 2 shows that our occupational therapy intervention for older people with dementia and their caregivers found also significant positive effects on many outcome measures of caregivers of persons with dementia as defined in *table 2*: on mental health (e.g. depressive symptoms and general mental health)³⁰, on well-being³⁰ and on caregiver competence²⁵ and caregiver mastery³⁰. Other aspects of mental health, subjective burden or other aspects of burden were not assessed, which would be of interest for future research. A combination of successful interventions on caregivers of people with dementia might be most effective, for example occupational therapy and other specific and successful caregiver directed interventions. This should be investigated in future.

Table 3: Mean weighted effect-sizes (D') for non-pharmacological and pharmacological interventions for persons with dementia⁴.

Non-pharmacological					Pharmacological
	<i>Touch</i>	<i>Physical activity</i>	<i>Bright light</i>	<i>Overall</i>	Cholinesterase inhibitors
<i>Cognition</i>					
Within subjects	D'(8) ¹ = 0.5 (128) ²	D'(10) ¹ = 1.3 (268) ²	D'(2) ¹ = 0.30 D'(18) ¹ = 0.4 (399) ²	D'(20) ¹ = 0.9 (476) ² D'(18) ¹ = 0.4 (399) ²	D'(83) ¹ = 0.1 (13980) ² D'(71) ¹ = 0.4 (10486) ²
Between groups	D'(11) ¹ = 0.3 (224) ²	D'(6) ¹ = 0.6 (152) ²			
<i>Behaviour</i>					
Within subjects	D'(22) ¹ = 0.7 (924) ² D'(10) ¹ = 0.8 (420) ²	D'(32) ¹ = 0.3 (1172) ² D'(29) ¹ = 0.1 (1019) ² D'(2)¹ = 1.9 (135)²*	D'(39) ¹ = 0.46 D'(51) ¹ = 0.30 (1737) ²	D'(93) ¹ = 0.5 (3044) ² D'(51) ¹ = 0.3 (1737) ² D'(1)¹ = 1.2 (135)²*	D'(30) ¹ = 0.1 (8749) ² D'(33) ¹ = 0.2 (9569) ²
<i>Overall</i>					
Within subjects	D'(30) ¹ = 0.7 (1052) ²	D'(42) ¹ = 0.50 (1440) ² D'(35) ¹ = 0.17 (1191) ² D'(1)¹ = 2.5 (135)²*	D'(41) ¹ = 0.45 (1028) ² D'(13) ¹ = 0.3 (321) ²	D'(113) ¹ = 0.5 (3520) ² D'(69) ¹ = 0.3 (2136) ² D'(3)¹ = 2.2 (135)²*	D'(113) ¹ = 0.1 (22729) ² D'(104) ¹ = 0.3 (20055) ²
Between groups					

1. Number of effect-sizes

2. Number of subjects

* Graff et al., 2006²⁵

In table 3 the effect sizes of randomised controlled trials of non-pharmacological and pharmacological interventions are described. We also added effect size of our own randomised controlled trial. The effect size for physical activity of the combined occupational therapy intervention of our randomised controlled trial is based on the effect sizes of the AMPS and is 2.5²⁵, the effectsizes for physical activity combined with behaviour is the effectsizes of AMPS and SCQ and is 1.9, the effect size for behaviour on the SCQ is 1.2²⁵ and the overall effect size of all three primary outcomes as described in the measure for successful treatment outcome is 2.2³⁸, which is very high when compared to other non-pharmacological and pharmacological interventions and surpasses the effect of other non-pharmacological and pharmacological interventions.⁴ Though this overview does not pretend to have the value of a complete systematic review, it positions our intervention clearly in the current landscape of medical and psycho-social interventions. On both sides the positive results are remarkable, both quantitatively and qualitatively.

Development: *the preclinical or theoretical phase**Conclusions and discussion:*

The first study of the continuum, which was not included in this thesis but was performed before, comprised the development and testing of a theory-based and consensus based community based occupational therapy guideline aimed at reaching uniformity and giving occupational therapists a tool for practice in community based occupational therapy treatment of older people with cognitive impairments and their caregivers. The guideline should make occupational therapists' performance explicit for the treatment of community dwelling older people with cognitive impairments and their caregivers, and should be based on a theoretical occupational therapy framework and on the latest evidence found in literature. Therefore, the guideline was developed by means of extensive literature search, expert and consensus rounds and evaluation of quality and usefulness. The outcomes of the expert and consensus rounds were: community based occupational therapy should be directed at analyzing the motivation, needs, problems and capacities of older people with dementia and their caregivers as described in the framework of the Model of Human Occupation of Kielhofner¹⁴. Treatment of older people with dementia should be focused on improving autonomy and skills in daily functioning by use of compensatory strategies and adaptations in the home environment. Treatment of their caregivers should be focused on enhancing caregiver competence by training caregivers in effective problem-solving, coping and use of effective supervision skills for older people with cognitive impairments. Accordingly, the final program was developed based on literature review and expert experience on these main topics.^{15,16}

The guideline proved to be feasible, which was concluded from evaluation of the quality and practical usefulness of the guideline and the adherence to the guideline by the occupational therapists. Appropriateness of the guideline was evaluated by patients and caregivers¹⁵. The outcomes of this preclinical and theoretical phase of guideline development and testing were described in a research report and paper in the Dutch Journal of Occupational Therapy.^{16,17} For a complete description of our occupational therapy program,¹⁷ including the guideline, which fully length is beyond the limits of this thesis, we refer to a paper in the Dutch Occupational Therapy Journal¹⁸.

Strengths: The development of this theory and consensus-based guideline followed the steps of literature review, expert consultation, consensus rounds and evaluation by clients and professionals. Another strong point is that the intervention is client-centred and directed at the problems of the clients with dementia and of their primary caregivers, because occupational therapists

experienced that caregivers often had many problems and were overburdened because of a lack of competence in dealing with the consequences of dementia for their own and their relatives daily lives, and this was confirmed by literature. Occupational therapy goals should be directed at the motivation of the client with dementia and of his caregiver for meaningful daily activities, which was also confirmed by literature. Another strong point was the occupational therapy context which is the home-environment because occupational therapists experienced that the environment should be familiar and meaningful to those clients with dementia and this was the basis for effective use of skills in daily performance of both the older people with dementia and their caregivers.

Crucial elements for effectiveness: we think that the rigor with which we performed the preclinical and theoretical phase was a first and necessary step for subsequently positive effects of the trial. The innovative combined client-caregiver intervention is turned into a flexible, tailor-made, theory and consensus based intervention, with well defined program goals, based on the state of the art available in literature.^{12,13}

Weaknesses: The main topics of the guideline that were defined by consensus rounds, were not really defined as quality or process indicators, which is recommended for future implementation of the guideline. We therefore performed this step of indicator development in the experimental part of the implementation phase, which was performed recently. Another weakness is that the guideline still is only available in Dutch¹⁷, and not yet in English. So far this limited worldwide dissemination of our intervention. We will work on this in the near future.

Development: the modelling phase

Conclusions and discussion

The qualitative case study analysis was aimed to identify the context, contents and process of providing and receiving occupational therapy at home in dementia patients and their caregivers and to develop a model explaining our intervention, which together is an example of theory building and modelling in occupational therapy¹⁹ as described in *chapter 2*. Global and specific categories (daily performance, communication, patient, caregiver and occupational therapist) and themes (patient's capacity for pleasure, autonomy, appreciation in performing daily activities, caregiver's competence) were distinguished and patients' and caregivers' opinions about the occupational therapy intervention were evaluated qualitatively. Quantitative results assessed before and after the occupational therapy intervention confirmed

these qualitative findings of improved daily performance (e.g. improved initiative and motor and process skills, and decreased need for assistance), improved quality of life of the patient, and improved sense of competence, quality of life and mastery of the situation of the caregiver). The exploratory model that was developed connected occupational therapy diagnosis and occupational therapy treatment at home for older people with dementia and their caregivers.

Strengths: this case study analysis provides information on how occupational therapy can improve the daily performance, communication, sense of competence and quality of life of an older patient with dementia and his or her primary caregiver. It gives insight into the perception of the participants during the process of providing and receiving occupational therapy at home. In complex interventions^{11,20}, the underlying mechanisms are usually not clear and have a multi-component character. This qualitative research helps to understand the underlying mechanisms and to distinguish important and clinically relevant outcomes for the evaluation of effectiveness of this community based occupational therapy intervention.

Crucial aspects for effectiveness: as analyzed and presented in the exploratory model, a combination of: education, setting feasible and client-centred goals, using interesting and challenging activities, cognitive training and use of adaptations in physical environment, training compensatory skills, training caregivers' supervision skills and changing dysfunctional cognitions on patient behaviour and caregiver role seem to be successful components of our combined, flexible and tailor-made occupational therapy intervention for older people with mild to moderate cognitive impairments and their caregivers.

Weaknesses: This study was a single-patient case study. The results of this case study cannot be representative for all relevant patients, for example because they show other behavioural disturbances. This also has reduced the description of our intervention, because these other behavioural disturbances such as depression would have introduced other targets and other elements in our intervention as well. Finally, this single case study introduces selection bias by the occupational therapist, who may have selected this case study because of the positive outcome. Based on the results of this case study it could not be proven that occupational therapy really improved either the daily performance of older people with cognitive impairments or the sense of competence of their caregivers. Testing on a larger scale was needed to investigate the question of effectiveness.

Evaluation: *The exploratory trial phase*

Conclusions and discussion

In this pilot study significant changes after occupational therapy on patients' and caregivers' outcomes were found in a small and uncontrolled study (n=12 patients with mild to moderate cognitive dementia and their caregivers) with measurements before and after the occupational therapy intervention²¹. The results of this pilot study confirmed the outcomes of the qualitative research and indicated that older clients' motor and process skills and self-perception in occupational performance improved, that they needed less help and the sense of competence of their primary caregivers also improved. The measurement instruments used were feasible because they were sensitive to change in a 5-weeks-time window and proved to be of good practical usefulness in this target population.

Strengths: this study provides preliminary evidence for the effectiveness of occupational therapy in older individuals with cognitive impairments and their primary caregivers. The exploratory trial or pilot warranted the research design for a randomised controlled trial and also the application of the measurement instruments of the exploratory trial, because of their good feasibility and sensitivity to change.

Crucial aspects for effectiveness: the client-centeredness of this tailor-made program, aiming at the main problems experienced by older individuals with cognitive impairments and by their caregivers, resulting in client-centred and flexible goals set together with the patient and caregiver probably has contributed to the positive results of the exploratory trial. These aspects were also proven effective in other studies evaluating combined psychosocial, cognitive and behavioural patient-caregiver interventions.^{12,13,22-24} Also the instruments applied probably were crucial for the positive changes that were found in this pilot study. The Assessment of Motor and Process Skills (AMPS)²⁶ and the Interview for Deterioration in Daily Activities in Dementia (IDDD)²⁷ are highly fit to measure skills and need for assistance in the daily functioning of older people with cognitive impairments and the Sense of Competence Scale (SCQ)²⁸ was developed to measure caregiver' competence, and all outcome measures are very close to the heart of the intervention.

Weaknesses: Although consecutive older patients with dementia were selected for the study, the small sample size limits the generalizability of the results. Furthermore, the positive results should be interpreted with care because of the uncontrolled design that was used in this study. Therefore, the next step was to do a randomised controlled trial.

Evaluation: *Randomised controlled trial phase*

Conclusions and discussion

The design of the randomised trial²⁵ was developed on the basis of the pilot study including the outcome measures that were tested on its feasibility, e.g. its practical usefulness and sensitivity for change. Parts of the outcome measures with the highest sensitivity for change found in the pilot study (like the AMPS process scale²⁶, the IDDD performance scale²⁷ and the whole SCQ²⁸) were used as primary outcome measures, as described in *chapter 4*. The others (the AMPS motor scale²⁶, the IDDD initiative scale²⁷, and the COPM performance scale²⁹ and COPM satisfaction scale²⁹) were used as secondary outcome measures in the design of this randomised controlled trial. Also other secondary outcome measures were added to this design³⁰, as described in *chapter 5*, like quality of life, mood, health status, and sense of control over one's life, because these were also important outcomes of the qualitative case study analysis and therefore of interest for this randomised controlled trial. A strong positive association between dementia patients' daily functioning, mood and quality of life was found in earlier studies^{35,36}. Also a positive effect on caregivers' sense of control over life was found by an earlier study of a comprehensive community based occupational therapy intervention for older people with dementia and their caregivers⁷. Therefore, these outcomes were included as secondary outcomes of our randomised controlled trial. Co-morbidity, cognitive functioning and behavioural problems were added as control measures. The research population was limited to a more homogeneous group of clients with mild to moderate dementia (in stead of cognitive impairments) and to caregivers who at least cared once a week for their family members. A second pilot study was carried out on the first ten patients with dementia and their caregivers that were included in the trial to test the whole research protocol of the randomised controlled trial on its practical usefulness. In MRC framework terms this is the experimental phase of the trial. At this stage no methodological or practical problems were met.

Accordingly, the randomised controlled trial was carried out and this study found very significant and positive effects on its primary outcome measures: older people with dementia's process skills and need for assistance in daily functioning and their caregivers' sense of competence improved after ten visits of occupational therapy at home²⁵. Also the secondary outcomes on quality of life, mood, health status and sense of control showed significant improvements, which was described in *chapter 5*.³⁰ At 3 months follow-up, these significant effects remained. The fact that both primary and secondary

outcomes are positive, that these outcomes were directed at both the clients with dementia and the caregivers and both outcomes were measured at three months, is in line with the large effect size found. Therefore, we may conclude that our community based occupational therapy intervention is evidence based both for patients and their caregivers with regard to daily functioning, quality of life, mood and health status and caregivers' sense of competence and sense of control over life, despite the patients' limited learning ability.

Strengths: In this trial we controlled for all possible confounders or influencing factors as described in the checklist for reporting on randomised controlled trials, the so called CONSORT guidelines for randomised trials³¹⁻³⁵, which allowed us to draw hard conclusions of the results that were found in the trial.

We had a relatively high response rate (50%) on recruitment, despite recruitments for other psycho-social and drug trials at our department, and the follow-up rate at 6 weeks (84%) and at 12 weeks (78%) was high, possibly because our study (the research and the intervention) was directly relevant to the daily lives of these older patients with dementia and their caregivers.

The effect sizes on all outcome variables of this study were high and much higher than those found in trials of drugs or other psychosocial interventions.⁴

Because the effects of our community based occupational therapy intervention were still present at 3 months, we conclude that implementation of this intervention is justified and recommended. We explain the effects measured at three months follow-up, with the high motivation for behavioural changes in meaningful daily activities of both patients and caregivers and the effectiveness of the caregivers' role of supervisor and problem solver who appeared to be competently able to adapt different activities and environments to the abilities of the patients.

Crucial aspects for effectiveness: In fact this is the sum of all elements mentioned in the discussion of the earlier phases of the MRC model. In the randomised controlled trial we could harvest the benefits of our former investments.

Weaknesses: The endpoint of our effectiveness and cost-effectiveness study is 3 months and therefore no long term effects could be determined. For economic reasons this choice of the 3-months endpoint was made and was plausible, because effectiveness of this intervention was not proven. Since we found evidence for the effectiveness of this intervention at 3 months follow-up, in future studies a one-year endpoint is recommended to be able to determine long-term effectiveness.

We could not carry out a double blind study because the patients and caregivers knew which therapy they received. However, researchers were

blinded for treatment allocation and only in 18-20% of the cases assessors knew the treatment allocation. For this reason we believe that our results were not significantly affected by observer bias.

We can not distinguish the beneficial effect of just getting attention from the effect of the occupational therapy intervention because our control group received usual care, which included no occupational therapy or other additional intervention, and thus received less attention. This phenomenon partly accounts for a positive effect that is seen in many psycho-social and drug interventions, which may be an important component of the placebo effect in such trials. However, the positive effects sustained in our trial after attention had stopped in our trial, which makes it unlikely that only attention caused the highly significant and positive effects. The focus of our trial was to compare community based occupational therapy to usual care because we were interested in the additional value of community based occupational therapy to the package of health care services. At the time the randomised controlled trial was performed occupational therapy was rarely delivered at the homes of older people with dementia and their caregivers, but primarily in institutes, it therefore was an additional service in community health care for this target group.

It took very long (almost 4 years) to carry out this randomised controlled trial because of the presence of competing trials. Nevertheless we kept the discipline of reviewing consecutive patients for eligibility.

Patient allocation could be biased by selection, because of geriatricians' referral of patients' with mainly disability problems in daily functioning and of some patients' preferences for the occupational therapy, because they were more motivated for non-pharmacological interventions than for drug trials.

Moreover, our study is not representative for the whole population of community dwelling older people with dementia, because community dwelling older people with dementia without caregiver, or community dwelling older people with depression, were therefore excluded from our study. Also participants were primarily recruited from the outpatient clinic linked to a university hospital and not from other institutions or directly from general practice. Thus our sample probably is not representative of all patients with dementia and their primary caregivers in our region.

Although this intervention was highly effective, the applicability can be limited in terms of manpower and time, in other countries and health care systems.

The training in effective use of this occupational therapy intervention according to the guideline (80 hours) and the intervention itself is quite comprehensive (time spent to treatment at home, narrative analyses, reports and multi-disciplinary briefing and reports is about 18 hours).

Evaluation: *The cost-effectiveness part of the randomised controlled trial*
Conclusions and discussion

The cost-effectiveness study (*chapter 6*) which was carried out alongside the randomised controlled trial was based on the outcomes of effects of the randomised controlled trial, studied the combined measure of successful treatment, and the outcomes on costs of health care consumption of the older clients with dementia and their caregivers from a societal perspective³⁸. In this study a significant difference in proportions of successful treatment was found at three months, with occupational therapy as the dominant strategy. Cost-savings of this community based occupational therapy intervention were mainly found on informal care delivered by the caregivers, and also on home care, nursing care and day care delivered by professional health care workers.

Strengths: The strengths of this cost-effectiveness study are its empirical robustness by the use of a randomised controlled design and the economic analysis done from a societal perspective alongside this trial. Another strong point is the new combined outcome measure of successful treatment used as primary outcome measure in this cost-effectiveness analysis. This outcome measure is innovative and combines the effect of occupational therapy on clinically relevant improvements in both patients' daily functioning and caregivers' sense of competence, which represents the whole content and outcome of successful occupational therapy treatment.

Crucial aspects for cost-effectiveness: the highly significant improvements in both patients' and caregivers' clinically relevant treatment outcomes were expected to be associated with decreased costs and increased cost-effectiveness. Patients' decreased need for assistance in daily performance and caregivers' increased sense of competence were associated with decreased caregiver burden and patients' and caregivers' quality of life and well-being and these are expected to be associated with decreased health care costs.^{2,3} Patients' and caregivers' showed a decrease in depressive and other health complaints and caregivers' increased sense of control over life³⁰, which probably was also important for a decrease in health care costs in the intervention group. Comparison of these results with literature was not possible because no other cost-effectiveness studies of community based

occupational therapy in older people with dementia and their caregivers were found.

Weaknesses: because the endpoint of our cost-effectiveness study was at three months follow-up, no conclusions could be drawn on possible delay of admission in nursing homes or homes for the elderly. However, based on the remaining effects on primary outcomes of this randomised controlled trial at three months follow-up, it can be expected that the savings at six months would be even more while no more costs will be made. In future studies the effectiveness and consequently its cost-effectiveness at six months should be assessed to determine if effects indeed remain over six months time

We did not include quality of life in this cost-effectiveness study because successful treatment was used (i.e. combined measure of clinically relevant improvements on both patients' daily functioning and caregiver sense of competence) as primary outcome for effect. However, given the results (on average cost-saving and a 95% probability of being the dominant strategy) the conclusion that occupational therapy is cost-effective would not be altered by including quality of life as an outcome measure.

Our sample was not representative for all older people with dementia because older people without caregiver and people with depression were excluded. Future studies should investigate if this intervention is also applicable to older people with dementia and depression or for older people without caregiver but with assistance of professional home care workers.

This study was not completely representative of all patients with mild to moderate dementia in our health region. Thus, future studies in different health care settings are needed to determine that community based occupational therapy is cost-effective across the Netherlands.

The costs for informal care giving were computed following the 'friction cost method'.³⁹ In our study the majority of the group of caregivers were retired people, who were not representative for the whole group of older people with dementia living in the community. If other informal caregivers would have been used (for example more employed sons, daughters or neighbours) or professional home care workers in cases of older people living alone with assistance of home care workers, another value would have been plausible and costs savings would have been higher.

The savings on informal care could have been over-estimated as well. In our study 913 hours (SD 666.5) informal care in the occupational therapy group, 1125 hours (SD 830) informal care in the control group and for the whole group of caregivers together at mean 1000 hours (\pm 600 to 800) informal care was delivered at three months follow-up and about two third of the informal

care givers was partner. This means that these partners spent at average 11 hours per day on informal care which is very high. Also hours spent on leisure and social activities together with the patients might have been counted in this mean total of hours informal care delivered by these care givers. This mean number of hours for informal care giving was multiplied with 8 euros per hour, resulting in at average about 2750 euro per month. Because most of the informal care givers were retired, this mean economic value was very high for their role as an informal caregiver. However, because formal care is much more expensive and these retired care givers were able to deliver the informal care needed, this economic value can be used in cost-effectiveness studies. Non-pharmacological intervention strategies are more time consuming in their application and therefore are more expensive compared to pharmacological interventions. However, cholinesterase inhibitors have side effects and are less effective in intervening in behavioural, and functional outcomes in the demented elderly.⁴ This study provides evidence for the cost-effectiveness of community based occupational therapy in older people with dementia and their caregivers. This cost-effective non-pharmacological intervention saved 1183 euro per successful treated patient-caregiver couple.

Conclusion and discussion on the framework

As described earlier, the sequence of studies carried out before the randomised controlled trial, resulted in several aspects that were critical for the final outcome of having shaped both an effective treatment and having designed an randomised controlled trial which was clearly able to show the positive effects and high efficiency.

The clinical applicability of this framework is not obvious, for example because of the lack of funding for studies of the first phases of this framework: the preclinical, modelling and exploratory trial phase. First researchers have to be aware of the concept of complexity in interventions. Whenever complexity of interventions is high, careful preliminary research phases should be seriously discussed. This will be often the case in geriatrics, because geriatric patients often suffer from multifactorial geriatric syndromes (e.g. falls, acute confusion), which ask for multifaceted interventions addressing the multiple contributing factors. Thus, research institutes should invest more in preclinical and exploratory studies, because these highly increase the chances of successful interventions and trials with high internal validity. Moreover, pilot data also increase the chances for funding of randomised controlled trials.

Conclusions and discussion on the contents of the guideline

As described in the preclinical and modelling phase and confirmed by the exploratory trial phase, many aspects of the guideline were evaluated as important for occupational therapy treatment in community dwelling older people with dementia and their caregivers. Community based occupational therapy should be directed at analyzing the motivation, needs, problems and capacities of older people with dementia and their caregivers, as described in the Model of Human Occupation.¹⁴ Treatment of older people with dementia should be focused on improving autonomy and skills in daily functioning by use of compensatory strategies and adaptations in the home environment. Treatment of their caregivers should be focused on decreasing caregiver burden and increasing patient-caregiver communication by training problem-solving, coping and use of effective supervision skills. The results of the exploratory trial phase and the randomised controlled trial phase confirmed the results of the preclinical and modelling phase. Significant positive effects were found on dementia patients' skills in daily functioning by use of compensatory strategies and adaptations in the environment and on need for assistance, after 10 hours occupational therapy at home. Caregivers' sense of competence improved significantly by use of improved problem-solving, supervision and positively changed cognitions on caregiver role, after occupational therapy at home. These improvements on patient and caregiver primary outcomes resulted in a better quality of life, mood and health status of both clients with dementia and their caregivers, and in high cost-effectiveness of this community based occupational therapy intervention. As described in the introduction of this chapter, our client-centred and tailor-made community based occupational therapy intervention was based on many components of effective combined psycho-social interventions of older people with dementia and their caregivers^{12,13,22-24}, like aiming at the main problems experienced by older individuals with cognitive impairments and by their caregivers, resulting in client-centred and flexible goals set together with the patient and caregiver. The outcomes of these reviews^{12,13,22-24} confirm the relevance of the contents of our client-centred, tailor-made community based occupational therapy intervention for older people with dementia and their caregivers, and of the results found in the different phased of the development and evaluation of this guideline.

Future implementation of the guideline

At the time the guideline was developed (1997-1998), occupational therapists and educators in occupational therapy judged the topics of the guideline as very relevant, but still preliminary and very time consuming. Only a few, not randomized controlled trial studies, were described in international literature on occupational therapy for older people with dementia, as was the same for occupational therapy for older people in general. In the Netherlands, in 1998, occupational therapy delivered at patients' homes and both directed at the patients and their caregivers was rarely performed and occupational therapy at home consisted of at maximum one or two home visits, because the managers of the occupational therapists did not allow them to deliver more time consuming visits at home.

Today, this guideline still is innovative but is appreciated as a realistic concept, because treatment at home and client-centred thinking is more common now in occupational therapy treatment. System-centred thinking is still innovative, but steadily gets implemented in occupational therapy for children and for people with cognitive impairments. Also health insurances have changed in that direction. In 1998, occupational therapy at home was only insured by few private insurances or by funded projects. Since the year 2000, occupational therapy at home is insured by all kinds of health insurance companies. However the number of occupational therapy visits that is insured differs per health insurance company between different amounts of money or 8 to 10 visits per year. Since 2005, 10 visits occupational therapy at home are insured by all health insurance companies for clients with different kinds of disabilities in daily functioning and clients with different kinds of participation problems, including dementia. This facilitated the implementation of our clientsystem-centered community based occupational therapy intervention and the total number of hours spent for this occupational therapy intervention. Another consequence of this change in health insurance was that the number of community based occupational therapy practices increased resulting in an increased need for evidence-based community based occupational therapy guidelines and post-graduate courses. This recent development also facilitates national implementation of our guideline. The evidence found for the effectiveness and cost-effectiveness of this community based occupational therapy intervention, which was published in medical journals with a high impact factor^{25,30,38} facilitates the implementation of this intervention by managers and physicians.

In other health care settings: Occupational therapy at home probably will be effective also if delivered from nursing homes, other hospitals or primary care practices. This needs further research.

For other cognitive impairments: this community based occupational therapy intervention can also be effective for other cognitive impairments, such as stroke and Parkinson's disease. Because of the tailor-made and client-centred contents, this guideline also can be used for other types of cognitive impairments. The same way of analysing the needs, problems and motivations for meaningful daily activities of the clients and of training of the caregivers in effective supervision, problem solving and coping skills could be used. Also the training of the skills of the clients in daily activities with use of compensatory strategies and adaptations of the environment can be used. However, the contents and choice of these compensatory strategies and adaptations in the environment may differ from those aimed at clients with dementia. This was confirmed by similar positive and significant effects found in a randomised controlled trial of another community based occupational therapy intervention in stroke patients and their caregivers.⁴⁰ A recently developed occupational therapy guideline for clients with Parkinson's Disease⁴¹ is based on the concepts and evidence of our guideline. However, the effectiveness and cost-effectiveness of our intervention for people with Parkinson's disease and their caregivers and for stroke patients and their caregivers, should be investigated in future research.

Threats:

The economics consequences of implementing this intervention in practice could be a problem in different countries. The training in effective use of this occupational therapy intervention according to the guideline was 80 hours and OT intervention is quite comprehensive (time spent to treatment at home, narrative analyses, reports and multi-disciplinary briefing and reports was about 18 hours). In the Netherlands this intervention is insured by 10 hours occupational therapy on patients' disabilities and another 10 hours on caregivers' disabilities. In other health care systems and in other countries this could be a problem.

The guideline is only available on the post-graduate course for occupational therapists and is in Dutch. Implementation of this guideline in other countries is therefore not directly possible. However, the qualitative case study article is frequently used to analyse the main concepts and other aspects of our community based occupational therapy intervention. Yet, different countries have applied for funding for replicate studies next year. Moreover, since we found firm evidence for this guideline we decided to translate the whole

occupational therapy program in English and publish it in a book with CD-r for skills training. Next year, this book and CD-r will be available.

Recommendations: This community based occupational therapy intervention for dementia patients and their caregivers should be advocated in dementia management programs, because of its impressive gains in clinically relevant patient' and caregiver' outcome measures.

We recommend policy makers to include this community based occupational therapy in dementia care because of its high effectiveness and cost-effectiveness on both patients' and caregivers' clinically relevant treatment outcomes. Internationally, insurances should include this intervention in their health insurances, or should invest in studies to show cost-effectiveness in their health system. This intervention should also be insured for caregivers who have no health complaints, to prevent them from being overburdened, which also is expected to be a cost-effective intervention.

Future research

At the moment, a pilot research is being carried out funded by the Codde & van Beresteijn Award⁴², to investigate the barriers and possibilities of implementation of this guideline in community based occupational therapy practice. Often heard barriers are the lack of referrals to occupational therapy, because community based occupational therapy is very unknown and the rejection to allow occupational therapists to spend 10 or more visits occupational therapy at home for one couple of an older client with dementia and caregiver. The pilot- implementation study is focused at getting as much as possible information about these changes and barriers for implementation. The pilot implementation-study is directed at three groups of health care professionals: the managers, the physicians and the occupational therapists. Also process and quality indicators of the guideline were defined in this study by analysing the process and contents of the occupational therapy intervention from the different publications of our studies performed and by use of expert and consensus rounds. Accordingly, if funded an implementation study will be carried out which will be focused on the implementation of this guideline in different health care settings using different strategies directed to change the knowledge, attitudes and behaviour of the occupational therapists, physicians and managers⁴³. Evaluation of this implementation should be focused on the increase of knowledge, change in attitudes and behavioural changes of those three different groups of health care professionals and on patient and caregiver outcomes. This implementation study should also be evaluated at

one-year follow-up to determine if behaviour changes contain and delay of institutionalization is reached.

We also need future studies on effectiveness and cost-effectiveness of our guideline for community dwelling older people with other types of cognitive impairments, for patients with dementia and co-morbidity, and for patients without informal caregivers. Replication studies of our randomised controlled trial in other countries or regions are needed to reach a higher level of evidence for this intervention, and assess the effects of the potential biases in our study. At the moment Germany⁴⁴ and England⁴⁵ are applying for funding of these replicate studies in cooperation with us. Also Australia and Canada have plans to perform a replicate study. Some higher evidence is already being prepared because recently our study was included in a systematic review to the effectiveness of community based occupational therapy in community dwelling older people with dementia,⁴⁹ and also three Critical Appraised Proposals were carried out that judged our randomised controlled trial of good methodological quality⁴⁶⁻⁴⁸.

Studies directed at the critical aspects for effectiveness as described in this chapter or to underlying mechanism's that also would be important and may have predicted or influenced the effectiveness are important and needed for further understanding of the effectiveness found in our studies. Examples of such kind of studies are studies that are directed at the explanation of compensation mechanisms in older people with dementia, by investigating mechanisms inside their brains. For example, some parts of the brains will possibly reflect higher activity than other parts, after dementia patients have performed daily activities with use of compensation mechanisms, and their brains perhaps show higher activity than before they were trained in daily activities. Also studies investigating the changes that occur by improved interaction between people with dementia and their caregivers are interesting. Do changes in compensational strategies and interaction retain for a longer time or will they decrease over time? Does something change in the brains of those people (MRI) and are these changes only functional or also structural? Does occupational therapy lead to a delay in cognitive decline in dementia patients? Future studies investigating the mechanisms that explain the positive outcomes of our studies are needed and both important for theory building in dementia care and occupational therapy. The important positive outcomes of our studies warrant such further in depth research.

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Chapter 8

Summary

Maud J. L. Graff

Summary

The focus of this thesis is to evaluate the effectiveness and cost-effectiveness of a community based occupational therapy intervention for older people with dementia and their caregivers.

Chapter one is the introduction and describes the backgrounds of the problem definition, the prevalence of dementia and current effective treatments in people with dementia and their caregivers. Accordingly, the history and definition of occupational therapy in general and of occupational therapy at home for community dwelling older people with dementia and their caregivers was described. Both the client-centered and the family-centered focus of community based occupational therapy in older people with dementia and their caregivers is described. Accordingly, the aim of this research project is described. Finally, a framework for complex interventions that underlies this thesis is presented.

Dementia is one of the three major diseases with regard to health care consumption and is a major cause of disability and care burden in the elderly. Dementia is a chronic and degenerative disease that causes disorders of memory, behavioural problems, loss of initiative, loss of independent functioning in daily activities and loss of participation in social activities. These problems decrease the quality of life of patients and put pressure on both family relationships and friendships. Caregivers often experience feelings of helplessness, social isolation, and loss of autonomy. The world prevalence of dementia recently has been estimated at 24.3 million people. This is expected to double over the next 20 years. In 2002, in the Netherlands alone, nearly 1% of 65 year olds suffered from dementia. This percentage rose with increasing age to around 40 % in people aged 90 and over. Drugs are not yet very effective in reducing the symptoms of dementia. Although non-pharmacological strategies are generally more time-consuming than pharmacological therapy, these non-pharmacological interventions seem to reduce symptoms. As dementia is affecting multiple cognitive and non-cognitive domains treatments often consist of multiple components targeted to different outcomes. Often, complex or multi-component interventions for older people and for caregivers, tailored to the individual priorities, are more effective than single component interventions. Community based occupational therapy is such a multi-component intervention that is tailored to individual needs and might be effective for older people with dementia and their caregivers. Previous studies have shown community based occupational

therapy, given in the home, to improve the functional independence and autonomy of patients with dementia and to decrease their caregiver burden. However, a systematic review has shown these earlier studies to be methodologically unsound and therefore insufficient evidence is found for the effectiveness of community based occupational therapy in older people with dementia and their caregivers. A methodological sound randomised controlled trial to the effectiveness and cost-effectiveness of community based occupational therapy for older people with dementia and their caregivers is needed.

The profession of occupational therapy (OT) was founded at the beginning of the previous century in the United States of America. Within the Dutch health care system occupational therapy is a young profession, which was introduced after the Second World War. The first patients treated by Dutch occupational therapists were former soldiers admitted in nursing homes and rehabilitation centres who had to be trained for their come back in society and in former work places. The definition of occupational therapy by the World Federation of Occupational Therapy (WFOT) is: occupational therapy is a profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation. In the past, occupational therapy in dementia was offered in institutions. However, two thirds of the patients with dementia are cared for at home by relatives. From the moment occupational therapy could be offered at home; occupational therapy in dementia was primarily directed at the client with dementia and at his primary caregiver. The primary focus of community based occupational therapy in dementia is to improve clients with dementia's autonomy and abilities (or to enable clients) to perform meaningful activities of daily living in their own environment and hence promote their independence and social participation and to reduce caregiver burden, by increasing caregivers' competence and ability to handle the behavioural problems they encounter. Both the clients with dementia and their caregivers are actively involved in the therapeutic process. The relevance of community based occupational therapy in dementia is supported by findings that problems in initiative and performing daily functioning often are the reason for a decrease in quality of life in dementia patients and that information, emotional support and training of skills improved the quality of life of patients and their caregivers. It is expected and

hypothesized that patients' and caregivers' daily performance and quality of life can be improved and that caregiver burden can be decreased by community based occupational therapy.

The aim of our research project is to investigate the effectiveness and cost-effectiveness (or efficiency) of a community based occupational therapy intervention on the daily functioning and quality of life of older people with dementia and on the sense of competence and quality of life of their caregivers, which is delivered in accordance to a guideline. This guideline, which is published as an occupational therapy program with a manual and workbook, is not included in a paper in this thesis because of its length, but formed the essential base of this community based occupational therapy intervention for older people with dementia and their caregivers.

The outline of this thesis' route to evidence based occupational therapy in dementia is presented in this chapter and is based on the UK's Medical Research Council's framework for complex interventions (MRC framework) and illustrated by the "continuum of increasing evidence" is presented. All studies described in this thesis are illustrations of phases of this MRC-framework or of the continuum of increasing evidence (e.g. the preclinical and theoretical phase, the theory building and modelling phase, the exploratory trial phase, the randomised controlled trial phase, the implementation phase). The part of *the preclinical or theoretical phase* of the framework in which we developed and tested our theory- and consensus based occupational therapy guideline, was performed before start of this research project and is therefore not included in this thesis, but is described earlier in two papers in the Dutch Journal of Occupational Therapy and in a report for the Board of Higher Education and Dutch Ministry of Education. This preclinical phase was performed by the occupational therapy department and geriatric department of the University Medical Centre Nijmegen in cooperation with the School for Occupational Therapy in Amsterdam. The guideline itself is an extended occupational therapy program available at our post-graduate courses for occupational therapists, that have been run several times per year in the Netherlands since 1999.

Chapter two focuses on *the theory building and modelling phase* of the framework and describes a qualitative study in occupational therapy. This qualitative case study analysis is aimed at identifying the context, contents and process of providing and receiving occupational therapy at home for older

people with dementia and their caregivers, and at developing a model explaining how occupational therapy influences dementia care at home. The intervention used is our client-system-based “occupational therapy guideline for older people with cognitive impairments and their caregivers”. In the analysis we made use of triangulation of the results to compare the qualitative content analysis and the quantitative description of changes on outcomes. The qualitative content analysis was performed by two independent researchers. They analysed two different occupational therapy records. These records were chosen by two experienced occupational therapists, as an example of good clinical guideline application. The study shows what categories and themes play a central role in this occupational therapy treatment. The global and specific categories derived from content analysis were: “daily performance”, “communication”, “the older individual with dementia”, “his caregiver”, and “the occupational therapist”. Important themes derived from content analysis were “patient’s capacity for pleasure”, “autonomy” and “appreciation in performing daily activities” and “caregiver’s competence”. The patient changes reported after occupational therapy were: more initiative, autonomy and pleasure in performing daily activities and increase of quality of life. The caregiver changes reported after occupational therapy were: improved communication and supervision skills, more positive cognition on patient behaviour and caregiver role, improved competence. The quantitative results confirmed these qualitative findings and show an improved daily performance (e.g. improved initiative and motor and process skills, and decreased need for assistance) an improved quality of life of the patient, and an improved sense of competence, quality of life and mastery of the situation of the caregiver after OT intervention. The categories and themes that were determined, were accordingly placed in an explorative client-system-centred model to understand the process and content of occupational therapy at home for older people with dementia and their caregivers. According to this explorative model, the components of a successful program are: a combination of: education, setting feasible goals, using interesting and challenging activities, using adaptations in physical environment, training compensatory skills, training caregivers’ supervision skills and changing dysfunctional cognitions on patient behaviour and caregiver role. The model is related to older people with mild to moderate dementia and their caregivers. We conclude that this case study analysis delivers information on how occupational therapy can improve the daily performance, communication, sense of competence and quality of life of an older individual with dementia and his caregiver.

Chapter three is an example of *the exploratory trial phase*, and describes the preliminary evaluation of pilot changes on clients' and caregivers' outcomes in a small (n=12 clients with cognitive impairments and caregivers) and uncontrolled study with measurements before and after 5 weeks occupational therapy intervention and evaluation of the feasibility of the measurement instruments with regard to sensitivity for change. The older clients with cognitive impairments and their primary caregivers received occupational therapy in hospital and at home after discharge in accordance with our occupational therapy guideline.

The main outcome measures were based on the results of the qualitative study and were: older clients' motor and process skills, initiative, need for assistance, self-perception in occupational performance, and satisfaction with this performance in daily activities and primary caregivers' sense of competence. This exploratory trial indicates that in older clients with cognitive impairments motor and process skills and self-perception in occupational performance improve, that they need less help, and are more satisfied with their occupational performance. This study also indicates an improvement of sense of competence of their primary caregivers. These encouraging changes were found following the occupational therapy intervention and confirmed the results found in our qualitative case study analysis. The measurement instruments used were feasible because they were sensitive to change in a 5-weeks-time window and proved to be of good practical usefulness in this target population.

We discuss that the positive effects of this study may be explained by the client-centeredness of the program, aiming at the main problems experienced by older individuals with cognitive impairments and their caregivers. Also the adaptations in the physical environment which were used to compensate for cognitive impairments, may have been contributed to the positive effects that were found on the older individuals with cognitive impairments. The flexibility and individuals goals of the method of the guideline used may also have contributed to these positive effects on the caregivers' sense of competence. We conclude that this study provides preliminary evidence for the effectiveness of occupational therapy in older individuals with cognitive impairments and their primary caregivers, which should be tested in a randomized controlled trial.

Chapter four is an example of *the randomised controlled trial phase*, in which the primary outcomes of a randomised controlled trial are described. This study is aimed at determining the effectiveness of community based occupational therapy on the daily functioning of older patients with dementia and the sense of competence of their caregivers. The design used is a single blind randomised controlled trial in which the assessors were blinded for treatment allocation. Hundred thirty five patients (aged 65 years and older) with mild to moderate dementia and living in the community and their caregivers were recruited from the memory clinic and day clinic of a geriatrics department. Ten sessions occupational therapy over five weeks were delivered at participants' homes. This community based occupational therapy intervention was based on our guideline, which includes cognitive and behavioural interventions to train patients in the use of aids to compensate for cognitive decline and care givers in coping behaviours and supervision. The main outcome measures used were: patients' daily functioning, assessed with the assessment of motor and process skills (AMPS) and the performance scale of the interview of deterioration in daily activities in dementia (IDDD), and care giver burden assessed with the sense of competence questionnaire (SCQ). Participants were evaluated at baseline, at six weeks, and at three months after baseline. We found significant positive results relative to baseline both on patients' and caregivers' outcomes in the intervention group compared with the control group. The differences that were found are 1.5 (95% confidence interval 1.3 to 1.7) for the AMPS process scale; -11.7 (-13.6 to -9.7) for the IDDD performance scale; and (11.0; 9.2 to 12.8) for the SCQ-competence scale. This improvement was still significant at three months. The number needed to treat to reach a clinically relevant improvement in process skills score was 1.3 (1.2 to 1.4) at six weeks. Effect sizes were 2.5 for AMPS process scale, 2.3 for IDDD performance scale, and 1.2 for SCQ competence scale, respectively, at six weeks and 2.7, 2.4, and 0.8, respectively, at 12 weeks.

We conclude that this community based occupational therapy intervention improved the daily functioning of older patients with dementia and reduces their care giver burden, despite the patients' limited learning ability. We also conclude that the effect sizes found in our trial are much higher than those found in trials of drugs or other psychosocial interventions. Because the effects of our community based occupational therapy intervention were still present at 3 months, we conclude that implementation of this intervention is justified.

In *Chapter five* the secondary outcomes of *the randomised controlled trial phase* are described. This study is aimed at the investigation of the effects of community based occupational therapy on dementia patients' and caregivers' quality of life, mood and health status and caregivers' sense of control over life. The study described is the same single blind randomised controlled trial design as described *in chapter four*.

The outcomes that were measured in this study at baseline, 6 and 12 weeks, were: patients' and caregivers' quality of life assessed with the Dementia Quality of Life Instrument (DQoL), patients' mood assessed with the Cornell Scale for Depression (CSD), caregivers' mood assessed with the Centre for Epidemiologic Studies Depression Scale (CES-D), patients' and caregivers' health status assessed with the General Health Questionnaire (GHQ-12) and caregivers' sense of control over life assessed with the Mastery Scale. The results that were found in this study were significant improvements on quality of life of 0.8 (95% Confidence Interval [CI], 0.6 to 1.1, effect size 1.3) on patients' DQoL overall, and of 0.7 (95% CI, 0.5 to 0.9, effect size 1.2) on caregivers' DQoL overall, in the intervention group compared to the control group. Scores on other outcome measures also improved significantly. Differences in mood were -2.8 (95% CI, -4.3 to 1.3, effect size 0.7) on patients' CSD, and -7.6 (95% CI, -9.7 to -5.4, effect size 1.3) on caregivers' CES-D. Differences in health status were -3.5 (95% CI, -5.1 to -1.8, effect size 0.8) on patients' GHQ and -4.6 (95% CI, -6.0 to -3.2, effect size 1.3) on caregivers' GHQ-12. Also caregivers' sense of control over life, improved 3.5 (95% CI, 2.7 to 4.4) on caregivers' mastery scale. These improvements were still significant at 12 weeks.

We conclude that this community based occupational therapy intervention improved the quality of life, mood and health status of older people with dementia and their care givers and improves care givers' sense of control over life. This community based occupational therapy intervention is proven to be highly effective on quality of life of patients and care givers, because the effect sizes on all outcome variables of this study were high and similar to the primary outcome variables (daily functioning and sense of competence) of this randomized controlled trial and these effects were still present at 3 month follow-up.

This community based occupational therapy intervention for dementia patients and their caregivers should be advocated in dementia management programs, because it is based on all important outcomes of systematic reviews on effective intervention programmes for community dwelling older people and their caregivers. We also conclude that the impressive gains in clinically

relevant outcome measures obtained with this community based occupational therapy intervention for both patients and their caregivers underline the importance of adequate and timely diagnosis and pro-active management in dementia.

In *chapter six* the cost-effectiveness of this community based occupational therapy intervention is described, as a result of a study carried out alongside the randomised controlled trial. This study is also part of the *randomised controlled trial phase*.

The objective of this study is to assess the cost-effectiveness of community based occupational therapy in comparison to usual care in older patients with dementia and their care givers from a societal viewpoint.

The main outcome measure used in this study was the incremental cost effectiveness ratio (ICER) and is expressed as the difference in mean total care costs per successful treatment (i.e. combined patient and caregiver outcome measure of clinically relevant improvements on patients' AMPS process and IDDD performance scale and on care givers SCQ competence scale) at 3 months from randomisation. Bootstrap methods were used to determine confidence intervals for these measures. The results found were the incremental costs for the community based occupational therapy intervention of €1183,- (95% Confidence Interval, 1128 to 1239) per patient and primary caregiver couple for community based occupational therapy compared to usual care at 3 months. There was a significant difference in proportions of successful treatments of 36% at 3 months. The number needed to treat for successful treatment at 3 months was 2.8 [2.7-2.9]. The economic evaluation showed that community based occupational therapy was a dominant strategy, because it saved €1748,- per successful treatment, of which main cost savings were from informal care giving, and because it was overall more successful.

In this study a new combined patient-caregiver outcome of successful treatment was developed, which was used for the economic evaluation of an innovative community based occupational therapy intervention of ten sessions community based occupational therapy over five weeks. We conclude that this intervention was convincingly proven to be cost-effective from a societal viewpoint and especially saved costs for informal care giving. Therefore, we strongly advocate further implementation of this cost-effective intervention, especially because currently there probably are no other equally effective interventions in dementia care.

In *Chapter 7* we compare our results found in the randomised controlled trial to the most recent results found in systematic reviews of psychosocial or non-pharmacological intervention and in pharmacological interventions in dementia. The main results and conclusions of the first four phases of the MRC framework (e.g. the preclinical, modelling, exploratory and randomised controlled trial phase) are presented and discussed. We discuss the implementation of this community based occupational therapy intervention for older people with dementia and their caregivers, by describing the possible chances and threats of this future implementation and end this thesis with recommendations for clinical practice and for future studies.

Terminology

In this thesis different kinds of terminology are used because the chapters were published in different journals (medical, social or occupational therapy journals). Therefore, different terms were used for people with dementia. We used terms such as patients with dementia, clients with dementia and individuals with dementia. With all these terms the same group of older people with dementia is meant. With the terms informal caregivers, primary caregivers and caregivers, also the same people (partners, family members, neighbours or friends) are meant that deliver informal care to older people with dementia. The terms community based occupational therapy, community occupational therapy, occupational therapy at home or occupational therapy in primary health care, include all the same occupational therapy that is delivered at the homes of older people with dementia, as described in our studies. Cost-effectiveness and efficiency are concepts that are used for the same understanding.

Chapter 9

Samenvatting

Maud J. L. Graff

Samenvatting

Dit proefschrift behandelt de evaluatie van de effectiviteit en doelmatigheid van een ergotherapie interventie aan huis voor ouderen met dementie en hun mantelzorgers.

Hoofdstuk 1 is het inleidende hoofdstuk waarin de achtergrond van de probleemstelling wordt belicht. Hiertoe wordt de prevalentie van dementie beschreven en worden effectieve behandelingen voor mensen met dementie en hun mantelzorgers besproken. Vervolgens wordt in dit hoofdstuk speciale aandacht besteed aan het ontstaan van ergotherapie en de mogelijkheden die deze vorm van hulpverlening in het algemeen biedt en specifiek bij thuiswonende ouderen met dementie en hun mantelzorgers. De gerichtheid op samenwerking met zowel de cliënt als de familie wordt hierbij toegelicht. Vervolgens wordt het doel van dit onderzoeksproject beschreven. Ten slotte wordt de opbouw van de studies uit dit proefschrift toegelicht aan de hand van een raamwerk voor de evaluatie van complexe interventies.

Dementie hoort bij de top drie van ziektebeelden met de hoogste kosten voor de gezondheidszorg en vormt een belangrijke oorzaak van beperkingen en overbelasting bij ouderen. Dementie is een chronische en degeneratieve ziekte die stoornissen in het geheugen, gedragsproblemen, verlies van initiatief, verlies van onafhankelijk functioneren in dagelijkse activiteiten en verlies van deelname aan sociale activiteiten tot gevolg heeft. Deze problemen zorgen voor vermindering van kwaliteit van leven en zetten zowel familierelaties als vriendschappen onder druk. Bovendien ervaren mantelzorgers vaak gevoelens van hulpeloosheid, sociale isolatie en verlies van autonomie. De wereldprevalentie van dementie is recentelijk geschat op 24.3 miljoen mensen. Er wordt verwacht dat dit aantal zal verdubbelen in de komende 20 jaar. In Nederland leed in 2002 ongeveer 1% van de mensen van 65 jaar en ouder aan dementie. Dit percentage nam toe met het toenemen van de leeftijd tot ongeveer 40 % onder ouderen van 90 jaar en ouder. Helaas blijken de symptomen van dementie nog niet effectief te verbeteren met de beschikbare medicatie. In een systematische review werd vastgesteld dat niet-medicamenteuze interventies, hoewel tijdsintensiever dan medicamenteuze interventies, wel de symptomen van dementie doen verminderen. Interventies bij dementie bestaan veelal uit diverse componenten die gericht zijn op verschillende uitkomsten. Dit heeft te maken met het feit dat dementie zorgt voor aantasting van diverse cognitieve en niet-cognitieve domeinen. Complexe ofwel multi-component interventies voor ouderen en hun mantelzorgers die

zijn toegespitst op de individuele behoeften, blijken effectiever te zijn dan enkelvoudige interventies. Ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers is een voorbeeld van een dergelijke complexe ofwel multi-component interventie die zich richt op de individuele behoeften van deze ouderen met dementie en van hun mantelzorgers en die wordt verondersteld effectief te zijn. Eerdere studies vonden dat ergotherapie aan huis de autonomie en onafhankelijkheid van mensen met dementie kan vergroten en de draaglast van hun mantelzorgers kan verminderen. Echter, een systematische review heeft laten zien dat deze eerdere studies van onvoldoende methodologische kwaliteit waren en hierdoor werd onvoldoende bewijs gevonden voor de effectiviteit van ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers. Er is daarom behoefte aan een methodologisch goed opgezet gerandomiseerd en gecontroleerd klinisch experimenteel onderzoek om de effectiviteit en kosteneffectiviteit van ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers vast te kunnen stellen.

Het beroep ergotherapie werd opgericht aan het begin van de vorige eeuw in de Verenigde Staten van Amerika. In de Nederlandse gezondheidszorg is ergotherapie nog een jong beroep, dat voor het eerst werd geïntroduceerd na de tweede wereldoorlog. De eerste patiënten die werden behandeld door Nederlandse ergotherapeuten waren gewezen soldaten die waren opgenomen in verpleeghuizen en revalidatiecentra en die moesten worden getraind om terug te gaan in de maatschappij en naar hun vroegere werk. De definitie van ergotherapie van de Wereldfederatie voor Ergotherapie (WFOT) is: ergotherapie is een beroep dat zich richt op het bevorderen van gezondheid en welzijn door het uitvoeren van betekenisvolle activiteiten. Het primaire doel van ergotherapie is om mensen in staat te stellen deel te nemen aan betekenisvolle dagelijkse activiteiten. Ergotherapeuten bereiken dit door mensen in staat te stellen om dingen te doen die hun mogelijkheden om deel te nemen aan dagelijkse activiteiten te vergroten of deze deelname te ondersteunen door het aanpassen van de omgeving. Ergotherapie werd in het verleden aangeboden vanuit instellingen. Echter, twee derde van de patiënten met dementie wordt thuis verzorgd door familieleden. Vanaf het moment dat ergotherapie aan huis in onze gezondheidszorg mogelijk werd, richtte ergotherapie zich primair op zowel de persoon met dementie als op zijn of haar mantelzorger. De primaire focus van ergotherapie aan huis bij dementie is om de autonomie en mogelijkheden van mensen met dementie te verbeteren en hen in staat te stellen betekenisvolle dagelijkse activiteiten uit te

voeren in hun eigen omgeving. Met als doel hun onafhankelijkheid en sociale participatie te bevorderen en de draaglast van hun mantelzorgers te verminderen, door het vergroten van de competentie en mogelijkheden van deze mantelzorgers in het omgaan met gedragsproblemen die met de dementie samenhangen. Zowel de cliënten met dementie als hun mantelzorgers worden actief betrokken in het therapeutische proces. De relevantie van ergotherapie aan huis wordt ondersteund door de bevindingen dat problemen in iniatiefname en in het uitvoeren van dagelijkse activiteiten, vaak redenen zijn voor een vermindering van de kwaliteit van leven bij mensen met dementie en dat informatie, emotionele ondersteuning en training van vaardigheden, hun kwaliteit van leven doet toenemen. Het wordt verwacht en verondersteld dat het dagelijks functioneren en de kwaliteit van leven van mensen met dementie en hun mantelzorgers zou kunnen verbeteren en de draaglast van hun mantelzorgers zou kunnen verminderen, door ergotherapie aan huis.

Het doel van ons onderzoeksproject is om te onderzoeken wat de effectiviteit en kosteneffectiviteit is van ergotherapie aan huis op het dagelijks functioneren en de kwaliteit van leven van ouderen met dementie en op de draaglast en kwaliteit van leven van hun mantelzorgers, waarbij ergotherapie wordt uitgevoerd volgens een richtlijn. Deze richtlijn, die is gepubliceerd als een uitgebreid ergotherapie programma, met een werkboek en handleiding, is vanwege de omvang niet opgenomen in dit proefschrift, maar vormde de basis voor deze ergotherapie behandeling aan huis bij ouderen met dementie en hun mantelzorgers.

De rode draad van dit proefschrift is de route naar een op bewijs gebaseerde ergotherapiebehandeling aan huis bij ouderen met dementie en hun mantelzorgers. Deze route is gebaseerd op het "UK's Medical Research Council's raamwerk voor complexe interventies (MRC raamwerk)" en wordt geïllustreerd door het "continuüm van toenemend bewijs". Alle onderzoeken die worden beschreven in dit proefschrift, zijn illustraties van fases uit dit MRC-raamwerk van het continuüm van toenemend bewijs (zoals de preklinische en theoretische fase, de theorieopbouwende en modelvormende fase, de exploratieve onderzoeksfase, de gerandomiseerde onderzoeksfase en de implementatiefase).

De *preklinische ofwel theoretische fase* uit dit raamwerk, waarin we een op theorie en consensus gebaseerde ergotherapie richtlijn ontwikkelden en testten, werd uitgevoerd voorafgaand aan dit onderzoeksproject en is daarom

niet opgenomen in dit proefschrift. De inhoud en het proces van het ontwikkelen en testen van de richtlijn werd eerder beschreven in twee artikelen in het Nederlandse Tijdschrift voor Ergotherapie en in een rapport voor de HBO-Raad en toenmalige Ministerie voor Onderwijs. Deze preklinische ofwel theoretische fase werd uitgevoerd door de afdelingen ergotherapie en geriatrie van het UMC St. Radboud in samenwerking met de opleiding ergotherapie van de Hogeschool van Amsterdam. De richtlijn zelf is als behandelprogramma verkrijgbaar binnen de post-HBO cursussen, die vanaf 1999 jaarlijks meerdere malen gegeven worden.

Hoofdstuk 2 gaat over de *theorie opbouwende- en modelvormende fase* en beschrijft een kwalitatief onderzoek in de ergotherapie. Deze kwalitatieve casusanalyse was gericht op het identificeren van de context, inhoud en het proces van het geven en ontvangen van ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers. Doel van dit kwalitatieve casuonderzoek was tevens om een model te ontwikkelen dat kan verklaren hoe ergotherapie aan huis de zorg voor een oudere met dementie kan beïnvloeden. De interventie die in dit onderzoek werd toegepast is onze cliëntgerichte ergotherapiebehandeling volgens de richtlijn “ergotherapie aan huis voor ouderen met niet-ernstige cognitieve stoornissen en hun mantelzorgers”. In de analyse werd gebruik gemaakt van triangulatie, door de resultaten van de kwalitatieve inhoudsanalyse en de kwantitatieve beschrijving van verandering in uitkomstmaten met elkaar te vergelijken. De kwalitatieve inhoudsanalyse werd door twee onafhankelijke onderzoekers verricht. Ze analyseerden twee verschillende ergotherapie statussen en onderscheidde welke categorieën en thema’s een centrale rol speelden binnen deze ergotherapiebehandeling. De statussen waren gekozen door twee ervaren ergotherapeuten, als voorbeelden van goede klinische richtlijn toepassing. De categorieën en thema’s die waren vastgesteld, werden vervolgens in een explorerend cliëntensysteem- gericht model geplaatst, om het proces en de inhoud van ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers, te begrijpen. De globale en specifieke categorieën die werden verkregen uit deze inhoudsanalyse waren: “dagelijks handelen” en “communicatie”, “de oudere met dementie”, “zijn mantelzorger” en “de ergotherapeut”. Belangrijke thema’s die werden verkregen uit de inhoudsanalyse waren: “de mogelijkheid tot plezier van de oudere met dementie”, “autonomie” en “waardering voor het uitvoeren van dagelijkse activiteiten” en “de competentie van de mantelzorger”. De veranderingen die de oudere met dementie rapporteerde na ergotherapie aan huis waren: meer initiatief, autonomie en plezier in het

uitvoeren van dagelijkse activiteiten en een betere kwaliteit van leven. Veranderingen die de mantelzorgers rapporteerde waren: verbeterde communicatie- en supervisievaardigheden, positievere cognities ten opzichte van het gedrag van de patiënt en van de rol van de mantelzorgers en een toegenomen competentie. De kwantitatieve resultaten bevestigden de kwalitatieve bevindingen en lieten een toename in: dagelijks functioneren (initiatief, motorische en procesvaardigheden en afname van behoefte aan hulp) en kwaliteit van leven van de oudere met dementie zien. Het gevoel van competentie, gevoel van controle over het leven en de kwaliteit van leven bij de mantelzorgers nam eveneens toe, na ergotherapie aan huis.

Volgens het explorerend cliëntsysteem-gericht model zijn de componenten van een succesvol programma: een combinatie van educatie, het stellen van haalbare doelen, het gebruik van interessante en uitdagende activiteiten, het gebruik van aanpassingen in de fysieke omgeving, training van compensatoire- en supervisievaardigheden en het veranderen van disfunctionele cognities over het gedrag van de patiënt en over de rol van de mantelzorgers. Het model heeft betrekking op ouderen met lichte en matige cognitieve stoornissen en hun mantelzorgers. We concluderen dat deze casusanalyse informatie oplevert over hoe ergotherapie het dagelijks handelen, de communicatie, het gevoel van competentie en de kwaliteit van leven kan verbeteren van een oudere met dementie en zijn mantelzorgers.

Hoofdstuk 3 is een voorbeeld van *de explorerende onderzoeksfase* en beschrijft een eerste evaluatie van veranderingen op cliënt- en mantelzorgers uitkomstmaten in een ongecontroleerd explorerend onderzoek met een kleine steekproefomvang ($n = 12$ cliënten met cognitieve stoornissen en hun mantelzorgers) na 5 weken ergotherapie aan huis en evalueert daarnaast de geschiktheid van de meetinstrumenten op gevoeligheid voor verandering. Oudere cliënten met cognitieve stoornissen en hun mantelzorgers ontvingen in het ziekenhuis en na ontslag aan huis, ergotherapie volgens onze richtlijn.

De belangrijkste uitkomstmaten waren gebaseerd op de resultaten van de casusanalyse uit de theorieopbouwende en modelvormende fase en waren bij oudere cliënten met dementie: motorische en procesvaardigheden, initiatief, behoefte aan hulp en beoordeling van het eigen handelen in dagelijkse activiteiten en de tevredenheid hiermee en bij hun mantelzorgers: het gevoel van competentie. Dit explorerende onderzoek laat zien dat de motorische en procesvaardigheden en het waargenomen dagelijks functioneren van oudere cliënten met cognitieve stoornissen verbeterden, dat deze ouderen met dementie minder behoefte hadden aan hulp en meer tevreden waren met hun

handelen. De studie laat eveneens zien dat het dagelijks handelen van hun mantelzorgers verbeterde. Deze indrukwekkende en significante veranderingen werden na afloop van ergotherapie aan huis gevonden en bevestigden de resultaten die in onze kwalitatieve casusanalyse gevonden werden. De meetinstrumenten waren geschikt omdat ze gevoelig waren voor verandering na 5 weken en ze een goede praktische bruikbaarheid voor onze onderzoekspopulatie hadden.

We denken dat de positieve en significante veranderingen die in deze studie gevonden werden, verklaard kunnen worden uit de cliëntgerichtheid van het ergotherapie behandelprogramma, dat zich richt op de belangrijkste problemen die de cliënten met cognitieve stoornissen en hun mantelzorgers ervaren. Ook de aanpassingen in de fysieke omgeving, die werden gebruikt ter compensatie van hun cognitieve stoornissen, hebben wellicht bijgedragen tot de positieve effecten die werden gevonden bij deze ouderen met cognitieve stoornissen. Daarnaast kunnen de flexibiliteit en individuele doelen van de methode die wordt gebruikt in de richtlijn, ook hebben bijgedragen tot de positieve effecten op het gevoel van competentie van de mantelzorger. We concluderen in dit hoofdstuk dat dit onderzoek voorziet in een eerste, maar nog beperkt bewijs voor de effectiviteit van ergotherapie aan huis bij ouderen met cognitieve stoornissen en hun mantelzorgers. Daadwerkelijk bewijs hiervoor zou in een gerandomiseerd en gecontroleerd onderzoek onderzocht moeten worden.

Hoofdstuk 4 is een voorbeeld van de gerandomiseerde gecontroleerde onderzoeksfase, waarin de primaire uitkomsten van een gerandomiseerd en gecontroleerd onderzoek worden beschreven. Dit onderzoek richt zich op het vaststellen van de effectiviteit van ergotherapie aan huis op het dagelijks functioneren van ouderen met dementie en het gevoel van competentie van hun mantelzorgers. In het enkelblinde onderzoeksdesign van dit onderzoek, waren de patiënten en mantelzorgers op de hoogte van de behandeltoewijzing. De onderzoekers waren hiervoor geblindeerd. Er werden voor dit onderzoek 135 thuiswonende ouderen (leeftijd 65 jaar en ouder) met lichte en matige dementie en hun mantelzorgers geworven van de geheugenpoli en dagkliniek van een geriatische afdeling. De behandeling bestond uit tien behandelingen ergotherapie aan huis gedurende 5 weken. Deze ergotherapie behandeling aan huis was gebaseerd op onze richtlijn die bestaat uit cognitieve trainingsprincipes en interventies gericht op gedragsverandering. Ouderen met dementie leerden hulpmiddelen en aanpassingen in de omgeving te gebruiken ter compensatie van hun

verminderde cognitieve vermogens en mantelzorgers leerden effectieve coping, probleemoplossing en supervisievaardigheden toe te passen. De primaire uitkomstmaten die gebruikt werden waren: het dagelijks functioneren van de patiënten, gemeten met de processchaal van de Assessment of Motor and Process Skills (AMPS) en de uitvoeringsschaal van het Interview naar Achteruitgang in Uitvoering van Dagelijkse Activiteiten bij Dementie (IDDD). De draaglast van de mantelzorgers is gemeten met het Meetinstrument Gevoel van Competentie (Sense of Competence Questionnaire, SCQ). Uitkomstmaten werden bij de start, na zes weken en na drie maanden gemeten. De verschillen tussen baseline en zes weken waren voor alle drie de uitkomstmaten significant verbeterd bij de patiënten en mantelzorgers in de ergotherapiegroep vergeleken met de controlegroep. Deze verschillen bedroegen 1.5 (95% betrouwbaarheidsinterval 1.3 tot 1.7) voor de AMPS processchaal; -11.7 (-13.6 tot -9.7) voor de IDDD uitvoeringsschaal; en 11.0 (9.2 tot 12.8) voor de SCQ competentie schaal. Deze verbeteringen waren klinisch relevant en na 3 maanden nog steeds significant. De Number Needed to Treat om een klinische relevante verbetering te verkrijgen in procesvaardigheden was 1.3 (1.2 tot 1.4) na 6 weken. Effectgroottes waren respectievelijk 2.5 voor AMPS proces, 2.3 voor IDDD uitvoering en 1.2 voor SCQ competentie na 6 weken en 2.7, 2.4 en 0.8 na 3 maanden.

Conclusie: ergotherapie verbetert het dagelijks functioneren van patiënten met dementie, ondanks hun beperkte leermogelijkheden, en vermindert de draaglast van hun mantelzorgers. We concluderen tevens dat de effectgroottes die in dit onderzoek gevonden werden veel hoger waren dan die uit medicijntrials of uit andere psychosociale interventies bij dementie. Deze significante verbeteringen waren na 3 maanden nog steeds aanwezig, hetgeen implementatie van deze nieuwe interventie rechtvaardigt.

In *hoofdstuk 5* worden de secundaire uitkomsten van de *gerandomiseerde gecontroleerde onderzoeksfase* beschreven. Dit onderzoek stelt zich ten doel om de effecten van ergotherapie aan huis op de kwaliteit van leven, stemming en gezondheidstoestand van ouderen met dementie en hun mantelzorgers te onderzoeken. Daarnaast wordt het effect van deze ergotherapie-interventie op het gevoel van controle over het leven bij mantelzorgers onderzocht. Het onderzoek is gebaseerd op hetzelfde gerandomiseerde gecontroleerde onderzoeksdesign als beschreven in *hoofdstuk 4*.

De uitkomsten die in dit onderzoek op baseline, na 6 weken en 3 maanden werden gemeten, waren bij patiënten en mantelzorgers: de kwaliteit van leven, gemeten met de Dementia Quality of Life Instrument (DQoL); de stemming, bij

patiënten, gemeten met de Cornell Schaal voor Depressie (CSD) en bij mantelzorgers met de Centre for Epidemiologic Studies Depression Scale (CES-D); de gezondheidsstatus, bij beiden gemeten met de Algemene Gezondheidsvragenlijst (AGV-12) en het gevoel van controle over het leven gemeten bij de mantelzorgers met de Mastery Schaal. De resultaten uit dit onderzoek laten significante verbeteringen zien op kwaliteit van leven: 0.8 (95% betrouwbaarheidsinterval [BI], 0.6 tot 1.1, effect grootte 1.3) op de globale DQoL score bij de patiënten en 0.7 (95% BI, 0.5 tot 0.9, effect grootte 1.2) op de globale DQoL bij de mantelzorgers, uit de interventiegroep vergeleken met de controle groep. De scores op de andere uitkomstmaten laten eveneens significante verbeteringen zien: de verschillen in stemming waren: -2.8 (95% BI, -4.3 tot 1.3, effect grootte 0.7) op de CSD bij de patiënten en -7.6 (95% BI, -9.7 tot -5.4, effect grootte 1.3) op de CES-D bij de mantelzorgers. De verschillen in gezondheidsstatus waren: -3.5 (95% BI, -5.1 tot -1.8, effect grootte 0.8) op de AGV-12 bij de patiënten en -4.6 (95% BI, -6.0 tot -3.2, effect grootte 1.3) op de AGV-12 bij de mantelzorgers. Ook het gevoel van controle over het leven verbeterde met gemiddeld 3.5 punten (95% BI, 2.7 tot 4.4) op de Mastery Schaal van de mantelzorgers. Deze significante verbeteringen waren na 3 maanden nog steeds aanwezig.

We concluderen dat als gevolg van deze ergotherapie behandeling aan huis, de kwaliteit van leven, stemming, gezondheidsstatus en het gevoel van controle bij ouderen met dementie en hun mantelzorgers verbeterde. Deze ergotherapie-interventie aan huis blijkt zeer effectief te zijn omdat de effect groottes op alle uitkomstvariabelen van dit onderzoek hoog en vergelijkbaar waren met de effect groottes die op de primaire uitkomstvariabelen (dagelijks functioneren en gevoel van competentie) gevonden werden en na 3 maanden nog steeds hoog waren.

We adviseren om deze ergotherapie behandeling bij ouderen met dementie en hun mantelzorgers in de huidige en in toekomstige dementieprogramma's op te nemen omdat deze interventie is gebaseerd op vrijwel alle belangrijke uitkomsten uit systematische meta-analyses over effectieve interventie programma's bij thuiswonende ouderen met dementie en hun mantelzorgers. We concluderen tevens dat met deze enorme winst op klinisch relevante uitkomstmaten, bereikt met ergotherapie aan huis gericht op ouderen met dementie en hun mantelzorgers, het belang van een adequate en tijdige diagnose en proactief management bij dementie wordt onderstreept.

In *hoofdstuk 6* wordt de kosteneffectiviteit ofwel doelmatigheid van deze ergotherapie behandeling aan huis bij ouderen met dementie en hun mantelzorgers beschreven, als resultaat van een onderzoek dat werd uitgevoerd parallel aan het gerandomiseerde gecontroleerde onderzoek. Dit onderzoek vormt eveneens een onderdeel van de *gerandomiseerde gecontroleerde onderzoeksfase*.

Het doel van dit onderzoek was om de kosteneffectiviteit van ergotherapie aan huis bij ouderen met dementie en hun mantelzorgers in vergelijking met gebruikelijke zorg vast te stellen, vanuit een maatschappelijk perspectief.

De belangrijkste uitkomstmaat die werd gebruikt in deze studie was de incrementele kosteneffectiviteitsratio (ICER) en werd uitgedrukt in het verschil in gemiddelde totale zorgkosten per succesvolle behandeling (dit is een samengestelde patiënt en mantelzorger uitkomstmaat van klinisch relevante verbeteringen bij de patiënten op de AMPS processchaal en de IDDD uitvoeringsschaal en bij de mantelzorgers op de SCQ competentieschaal) na 3 maanden na randomisatie. Bootstrap methoden werden gebruikt om betrouwbaarheidsintervallen voor deze uitkomstmaten vast te stellen. De incrementele kosten voor ergotherapie aan huis bleken €1183,- per patiënt met mantelzorger te bedragen (95% Betrouwbaarheidsinterval, 1128 tot 1239), vergeleken met gebruikelijke zorg na 3 maanden. Er was een significant verschil in proporties succesvolle behandeling van 36% na 3 maanden ten voordele van de ergotherapiegroep. De Number Needed to Treat voor succesvolle behandeling na 3 maanden was 2.8 [2.7 tot 2.9]. De economische evaluatie liet zien dat ergotherapie aan huis de dominante strategie bleek te zijn, omdat het €1748,- per succesvolle behandeling bespaarde, waarbij de grootste besparingen afkomstig waren van de uren zorg geleverd door mantelzorgers en daarnaast omdat deze interventie in zijn geheel succesvoller bleek te zijn dan gebruikelijke zorg.

In dit onderzoek werd een nieuwe samengestelde patiënt en mantelzorger uitkomstmaat voor succesvolle behandeling opgesteld, die werd gebruikt voor de economische evaluatie van een innovatieve ergotherapie behandeling aan huis voor ouderen met dementie en hun mantelzorgers van 10 behandelingen binnen 5 weken. We concluderen dat deze interventie vanuit een maatschappelijk perspectief beschouwd, duidelijk kosteneffectief bleek te zijn en in het bijzonder kosten bespaarde voor mantelzorg. Daarom adviseren we ten zeerste om deze nieuwe en kosteneffectieve ergotherapie behandeling aan huis te implementeren, vooral vanwege het feit dat er momenteel waarschijnlijk geen andere vergelijkbaar effectieve interventies in de zorg bij dementie beschikbaar zijn.

In *hoofdstuk 7* vergelijken we de resultaten die we vonden in het gerandomiseerde gecontroleerde onderzoek, met de meest recente resultaten uit systematische meta-analyses over psychosociale en niet-medicamenteuze interventies. Eveneens vergelijken we de resultaten uit ons gerandomiseerde gecontroleerde onderzoek met de resultaten die in meta-analyses over medicamenteuze interventies bij dementie werden gevonden. De belangrijkste resultaten en conclusies van de eerste vier fasen van het MRC model (*de preklinische fase, de theorie opbouwende, modelvormende fase, de explorerende onderzoeksfase en de gerandomiseerde, gecontroleerde onderzoeksfase*) worden vervolgens gepresenteerd en bediscussieerd. We stellen de toekomstige *implementatiefase* van deze ergotherapie behandeling aan huis voor ouderen met dementie en hun mantelzorgers eveneens ter discussie, door het bespreken van mogelijke kansen en bedreigingen van deze toekomstige implementatie. We besluiten de discussie met aanbevelingen voor de toekomst voor de klinische praktijk.

Dankwoord

Maud J. L. Graff

Dankwoord

Promotiecommissie

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EDO (Ergotherapie Dementie Onderzoek) projectteam

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Lieve mama, papa en Ine

Mama, jou wil ik bedanken dat jij ons, Ine en mij, gestimuleerd hebt om ons te ontplooiën in muziek, creativiteit, sport en studie. Jullie beiden, papa en mama, hebben met jullie genen en opvoeding, de liefde voor de natuur, muziek, vriendschappen, kunst, reizen en doorzettingsvermogen aan ons doorgegeven, waarvoor ik jullie erg dankbaar ben. Hierdoor was het mogelijk dat wij beiden zowel de middelbare school als de universiteit doorliepen en onze hobby: de muziek, konden voortzetten met een piano in ons studentenleven. Muziek klonk altijd in ons huis en ik weet niet beter of ik maakte huiswerk met op de achtergrond Mozart, Chopin, Bach, of Rachmaninov pianomuziek van jou, Ine, of operamuziek van jou, mama, op de achtergrond. *Papa*, jij hebt helaas niet lang de vruchten mogen plukken van dit alles, je werd ernstig ziek en overleed toen Ine 7 en ik 4 jaar oud was. Maar toch was jouw geest altijd in ons leven aanwezig, door de verhalen die mama, opa en oma ons over jou vertelden. Jij studeerde Engels en Frans en wat zou ik vaak, als je nog geleefd had, hebben opgezocht in het kader van mijn internationale activiteiten en artikelen van de afgelopen jaren. Ik denk dat je op een dag als vandaag heel trots zou zijn geweest en in gedachten ben ook jij nu bij mij en draag ik dit boek ook op aan jou. *Ine*, mijn lieve zus, wat mis ik jou ook nu weer. Wat zou ik jou graag, net als bij mijn propedeuse ergotherapie en

de (theater)koorconcerten in Amsterdam en Maastricht, ook nu in de zaal willen zien zitten. Wat hebben we van veel dingen samen genoten in ons leven, zoals het gewoon zusjes zijn, samen musiceren, sporten, wandelen en reizen in onze jeugd en studententijd. We zagen elkaar als dikke zussen en dikke vriendinnen, van plan om elkaar nooit meer los te laten. Helaas werd ook jij ziek en ging jij veel te vroeg heen. In onze studententijd in 1990, toen je de scriptie voor je studie muziekwetenschappen had afgerond en de eindsctie voor de studie Italiaans nog aan het schrijven was, nam je op je 25^e afscheid. Ook jou mis ik vandaag heel erg. Jij was mijn voorbeeld in zowel de muziek, de wetenschap en het reizen. Dit boek draag ik daarom in het bijzonder ook op aan jou, Ine. *Mama* jij hebt ondanks dat je zo jong alleen kwam te staan, altijd veel met ons ondernomen en ik zal nooit de wandelvakanties door de bergen van Oostenrijk en Zwitserland vergeten, waar jij in ons kleine fiatje naartoe reed. Je bent nog steeds heel ondernemend en reist voor de muziek, kunst, familie en vrienden nog steeds door Nederland, Duitsland, België en Engeland, nu per trein omdat je na je ziekte geen auto meer hebt mogen rijden. Ik ben ontzettend blij dat de twee ernstige ziekten die jou in 2003 en 2004 velden, het niet van jou hebben gewonnen en dat jij dapper en krachtig weer door bent gegaan met je leven zoals je dat altijd gedaan hebt. Vandaag hoop ik dat je kunt genieten van de dag en het resultaat dat je dochter mede dankzij jouw opvoeding, inspanningen als opasoma en mentale ondersteuning, heeft kunnen bereiken.

Lieve Jules

Zonder jou was dit proefschrift zeker niet mogelijk geweest. De steun die je me gaf door met veel plezier met de kinderen op pad te gaan, als ik in de weekenden weer 's ochtends of de hele dag moest werken. Het waren altijd leuke dagen voor de kinderen en hierdoor misten ze mama veel minder. En de vele avondjes die ik achter de computer doorbracht en jij me hierin steunde, hoewel je het veel gezelliger vond als dat ding een keer uit werd gezet. Ik ben blij dat dit product, het proefschrift, er nu is en ik 's avonds en in het weekend weer meer samen met jou kan ondernemen. Echter, ondanks deze drukke periode hebben wij heel veel leuke dingen samen met de kinderen ondernomen, zoals lekker wandelen en fietsen in de weekenden, vrienden opzoeken, zeilen, mooie vakanties en reizen, zoals onze reis van 5 weken per camper door Australië. We hebben ervan genoten, ook met zijn tweeën, zoals tijdens ons wekelijkse avondje uit en ons weekje Amerika vorig jaar. Van 2003 tot en met 2005 kenden we heel zware jaren. We zaten midden in een verbouwing en ik was zwanger van ons derde kind en druk met het

onderzoeksproject, toen we de eerste keer geconfronteerd werden met een ernstige ziekte van mama. In de week dat ik beviel van onze derde, nam jij een nieuwe praktijk over, kwam mama een paar weken later uit de revalidatie, maar werd na 3 maanden opnieuw geveld door een tweede ernstige ziekte: ze had darmkanker. Daarnaast waren de kinderen veel ziek met operaties daarbij en hadden we veel slapeloze nachten. We reisden voor mama veel naar Roermond en Hoensbroek om de nodige ondersteuning te bieden, daarnaast was er jouw werk en mijn promotieonderzoek dat gewoon doorging. Mama, die onze vaste steun en toeverlaat was en wekelijks op donderdag oppaste, viel weg maar we vingen alles samen op. Helaas werd ik toen ook nog een half jaar behoorlijk ziek van een schildklierontsteking en kreeg je die zorg er nog bij. Jules, je bent een erg zorgzame en liefhebbende partner die er altijd erg voor mij is. Ik dank je voor al je steun tijdens deze enerverende promotiejaren en daarbij de vele life events. Het waren zware tijden, maar ook mooie tijden met de geboorte van onze drie kinderen en alles waarvan we genoten hebben. Dank je wel voor dit alles.

Lieve Maartje, Sven en Lars

Jullie zijn onze grote rijkdommen en wat heb ik van jullie genoten de afgelopen jaren en natuurlijk nog steeds. Jullie waren het die het leven pas echt in balans brachten met jullie vrolijkheid, kinderlijke humor, jullie enthousiasme, jullie blik op de wereld en eerlijkheid. Samen hebben we veel ondernomen en heel veel plezier gehad en we doen nog ieder weekend en op woensdag- en vrijdag middag spelletjes, we knutselen samen, maken muziek, gaan naar wedstrijden en de natuur in. Ook als jullie mama werkte was er die dag altijd weer tijd om samen iets te doen en riepen jullie blij dat jullie dat zo leuk vonden. Maar even vrolijk gingen jullie met jullie papa op pad en wensten mama veel succes met werken, wat mij enorm steunde en ook deed uitkijken naar het moment dat jullie weer thuis kwamen en we samen weer iets konden gaan ondernemen. Ik hoop dat jullie vandaag ook genieten van het feest. Dank jullie wel dat jullie mijn kinderen mogen zijn.



Wat ben ik zonder anderen?

Leven is 'leven met anderen'!

*'Leven met anderen' is leven met hen,
Met wie ik alles wil delen, die ik wil aanvaarden,
Die ik geen pijn wil doen, die ik wil liefhebben.*

*Zonder de anderen is leven, lief hebben en gelukkig zijn een utopie!
We zijn met ontelbare banden met elkaar verbonden.
Ik kom pas tot ontplooiing, dankzij de anderen.
Ik heb de anderen nodig...niet alleen omdat zij zoveel voor mij doen,
Maar ook omdat ik zoveel voor die anderen kan betekenen.*

*Ik heb ogen en oren, om de ander te ontdekken,
Voeten om naar hen toe te gaan,
Handen om te geven en te helpen
En een hart om lief te hebben.*

En dan nu: eind goed al goed!
Ik dank jullie allen voor dit alles!
Maud



Maud (2008) bij de in ontvangst name van de Alzheimer Stimuleringsprijs.

Curriculum vitae

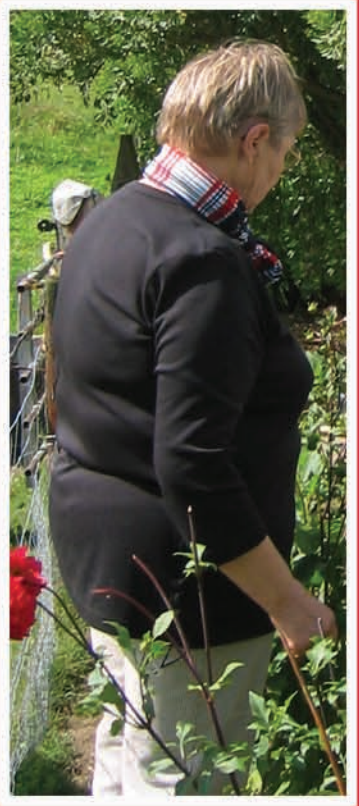
Maud J.L. Graff

Curriculum Vitae

Maud Graff is geboren in Roermond als jongste in een gezin met twee dochters. In 1986 behaalde zij haar diploma VWO-B aan het Bisschoppelijk College Schöndeln. Na haar propedeuse Industriële Vormgeving in Eindhoven behaald te hebben, besloot zij haar creativiteit en ontwerpergeest binnen haar hobby's nader vorm te geven en koos zij voor een studie op sociaal wetenschappelijk en gezondheidskundig gebied. Zij begon in 1987 met haar studie Gezondheidswetenschappen aan de Rijksuniversiteit van Limburg in één van Nederlands oudste en mooiste steden: Maastricht. Ze combineerde de eerste twee jaar van haar studie met een voorzitterschap bij de PR commissie en een algemene bestuursfunctie bij Agora, de faculteitsvereniging van Gezondheidswetenschappen. Hier leefde zij een heerlijk studentenleven (zij was o.a. actief als musicus binnen het Universiteitskoor en bij de roeivereniging van Maastricht). Na twee jaar Gezondheidswetenschappen besloot zij in 1989 de opleiding Ergotherapie in de mooie en bruisende stad Amsterdam te gaan volgen naast haar studie Gezondheidswetenschappen, waarmee zij voltijds treinstudent werd met een verblijfplaats in Amsterdam en Maastricht. Reden voor deze keuze was, dat zij de voeling met de praktijk, de patiënt, als ook met de organisatie en beleid van binnenuit, binnen haar studie Gezondheidswetenschappen, miste. Ze wilde niet in de rol van adviseur, beleidsmaker of onderzoeker treden, zonder praktische en inhoudelijke kennis en ervaring op deze gebieden. Beide studies bleken elkaar vervolgens geweldig te bevruchten en daarmee werd haar motivatie voor beide beroepen meer dan verdubbeld. In 1992 behaalde zij versneld haar diploma ergotherapie aan de Hogeschool van Amsterdam en behaalde in 1993 naast een deeltijd baan als ergotherapeut in het Revalidatie Centrum Hoensboeck, haar diploma Gezondheidswetenschappen aan de Rijksuniversiteit Limburg. Na haar afstuderen reisde zij twee maanden door Indonesië, Maleisië en Thailand, waarna het werken in het buitenland haar lokte. Zij werkte vervolgens in een tijdelijke functie als Consultant Health Promotion bij de Wereld Gezondheidsorganisatie (WHO) in Kopenhagen. Dezelfde reden als die destijds haar keuze tot de studie Ergotherapie bepaalde, maakte dat zij de WHO in Kopenhagen verruilde voor een baan als ergotherapeut in Psychiatrisch Centrum Welterhof te Heerlen, alwaar zij in 1994 werd weggevoerd door het voormalige hoofd Ergotherapie van het UMC St. Radboud om in Nijmegen te komen werken in de functie van ergotherapeut en onderzoeksassistent. Zij vertrok in de zomer van 1994 naar deze oudste stad van Nederland en werkte binnen het UMC St. Radboud als ergotherapeut op de afdelingen geriatrie en neurologie en als onderzoeksassistent binnen het

paramedische promotieonderzoek van dr. Margreet Oerlemans. Daarnaast genoot zij van het bruisende leven in de binnenstad van Nijmegen, bekleedde een functie van algemeen bestuurslid bij Ergotherapie Nederland, werd actief als schipper en lid van de activiteitencommissie van de zeilvereniging van het UMC St. Radboud en musiceerde bij het Gelders Muziek Collectief. Op de afdeling Ergotherapie en het Alzheimercentrum Nijmegen werkte zij vervolgens in functies van ergotherapeut, wetenschappelijk onderzoeker en projectleider op projecten die samen dit proefschrift en de weg er naartoe vormden. De projecten die zij in het UMC St. Radboud uitvoerde waren: onderzoek naar de praktische toepassing van een theoretisch model (MOHO) binnen de ergotherapie bij geriatrische patiënten, de ontwikkeling en het testen van een ergotherapie bij dementie richtlijn, een kwalitatief onderzoek, een pilot-onderzoek, een effectstudie, een kosteneffectiviteitsstudie, een pilot-implementatie studie en een Duitse replicatiestudie. Alle genoemde studies hadden betrekking op deze ergotherapie bij dementie behandeling en richtlijn. Financiering voor de studies wist zij te verkrijgen bij het vernieuwingsfonds van het cluster NSC van het UMC St. Radboud, de HBO raad, het fonds VCVGZ, Alzheimer Nederland, Ergotherapie Nederland, de Codde en van Berensteijn Gerontologieprijs en het Duitse Ministerie, met cofinanciering van de afdelingen Ergotherapie, Geriatrie en cluster NSC van het UMC St. Radboud en de Hogeschool van Arnhem en Nijmegen. Met haar promotieonderzoek won zij drie wetenschappelijke prijzen: in 2006 de wetenschappelijke posterprijs in de geriatrie, 2007 de Codde en van Berensteijn Gerontologieprijs en in 2008 de Alzheimer Stimuleringsprijs. Zij verzorgde regelmatig lezingen op congressen en symposia in binnen en buitenland. Momenteel is Maud als seniorwetenschappelijk onderzoeker werkzaam bij de afdelingen: Ergotherapie, Alzheimer Centrum Nijmegen en Kwaliteit van Zorg van het UMC St. Radboud en begeleidt nationale en internationale projecten die een vervolg vormen op de studies uit haar proefschrift, als ook andere onderzoeksprojecten naar psychosociale interventies bij ouderen met geheugenstoornissen, visus en gehoorstoornissen.

Maud is getrouwd met Jules Reintjes, fysio- en manueel therapeut en praktijkhouder. Zij hebben samen 3 kinderen, die tijdens de eerste jaren van de opeenvolgende studies van haar promotieonderzoek werden geboren: Maartje (2000), Sven (2001) en Lars (2003). Hun gezamenlijke passies zijn wandelen en fietsen in de natuur, zeilen en reizen. Maud speelt piano, jogg en is graag creatief bezig met de kinderen.



Effectiveness and efficiency of community occupational therapy for older people with dementia and their caregivers.

Maud Graff