'More at Home with Dementia' Effects of psychosocial interventions in the community and in nursing homes
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General introduction
GENERAL INTRODUCTION

Given the current demographic change, the proportion of older people increases in society and as a consequence of people with dementia. This leads to augmented burden on caregivers in the community and in institutions.

It is important to study how caregivers and their partners with dementia can be supported in order to enhance or preserve their wellbeing. This is the core subject of this thesis. We assessed the feasibility and effects of a multicomponent intervention aimed at co-residing caregivers of PWD. So far to our knowledge, no randomized controlled studies on the effects of intensive multidisciplinary interventions like More at Home with Dementia on the wellbeing of both the caregiver and the PWD have been performed in the Netherlands.

In the first part of this general introduction the topic dementia and dementia care will be introduced. In the second part, the current knowledge about multicomponent interventions for caregivers in the community and their effect on burden and psychosocial morbidity will be discussed. Thereafter, the effects of neuropsychiatric symptoms of PWD in nursing homes, which are frequently the reason of admission, and knowledge about interventions on these symptoms will be outlined. At the end of this introduction an overview of the studies described in the upcoming chapters will be given.

PART 1 DEMENTIA

Prevalence and course

The course of dementia is usually characterized by an insidious onset followed by a gradual deterioration over several years with ever more cognitive functions declining. Somewhere during the first years of this course a diagnosis is made and mostly, during the last year(s) the PWD is admitted to a nursing home.

Dutch demographic data combined with information on the prevalence of dementia indicate that in the Netherlands 260,000 people live with dementia \(^1\). Of these, about 70,000 (27%) are institutionalized and 114,000 (44%) people diagnosed with dementia live at home. This leaves about 76,000 (29%) people with dementia without diagnosis \(^3\). The duration of these three phases: no diagnosis, with a diagnosis living at home and with a diagnosis living in a nursing
home is very variable and depending on several factors. Factors causing delay of diagnosis include that in early stages symptoms are difficult to recognize and also that patients themselves deny having memory loss. Further, not all general practitioners feel they are competent to diagnose dementia and are also reluctant to refer patients to memory outdoor clinics or they think a diagnosis is not useful due to the lack of treatment options \(^4,^5\). The median survival after diagnosis of dementia was 3.7 years but varies with sex and, in particular, with age at diagnosis. When diagnosed before 70 years life expectancy for women and men is 7.7 and 5.3 years respectively and when diagnosed after 90 years this is 2.6 and 2.4 years \(^6\). Data on the duration of nursing home admissions of PWD in the Netherlands indicate that about 15% die during the first three months after admission. After these three month death rates decline and after 18 months about 50% of PWD are still alive \(^3\).

**Costs of dementia care**

Dementia has significant social and economic implications in terms of direct health care and formal and informal social care costs. In the Netherlands, the total health care costs related to dementia amount yearly 9.1 billion, 10.3% of the total health care costs \(^4\). Due to the aging of the population and no treatment for dementia to be expected in the near future, this numbers will rise significantly in the next decades. Consequently, it is of importance that informal social care will constitute a larger share, now and in the future. Therefore, interventions aimed at caregivers so that they can perform their duties better, is of major importance and could lead to reduction of health and formal social care use and postponing nursing home admission of the PWD. However, within the Dutch health care system care for caregivers and for PWD are reimbursed via different parts of the healthcare system. As a consequence, savings on health care use of the PWD do not automatically implicate that more money can be spent on interventions aimed at caregivers.

**History of dementia care in the Netherlands**

As dementia is an illness affecting mainly older people, the development of structural care for people with dementia emerges along with the increased life expectancy. In former times, people who were old and dependent due to physical or psychological decline were taken care of by their children or other relatives.
However, for centuries in the Netherlands certain kinds of assisted living have been available for older dependent people who did not have children to take care of them. These homes were however mostly very simple and people were not taken care of very well. In the 20th century these facilities improved and in the fifties of the 20th century the government decided to build many care homes or residential homes, also to motivate elderly people to move out of their homes to relieve the shortage of homes for young families. However, this turned out too expensive and since the eighties of the 20th part of these care homes were closed or changed in nursing homes. The first nursing home in the Netherlands was built in 1929 but most nursing homes were built in the second half of the 20th century. This nursing home care distinguishes between dementia care or care for people with predominantly somatic illnesses.

With the higher prevalence of people with dementia due to higher life expectancy, preference of people to live in their own home as long as possible and the high health care costs associated with living in nursing homes, there was a growing need for specialized care for people with dementia at home. In the nineties of the 20th nursing homes started to offer day care facilities and psychiatric outdoor clinics for elderly started to develop case management for people with dementia often in collaboration with nursing homes. Due to this historical context still substantial regional differences in availability and organization of care for people with dementia in the community exist.

**PART 2 DEMENTIA CAREGIVING**

**Caregiving in the community**

*Caregiver burden*
Caregivers and especially partners of PWD experience high levels of burden. However, the main causes of these burden vary over the subsequent phases of the dementia of their partner. During the first phase, uncertainty about the reason for the changes they observe may play a prominent role. They also feel misunderstood by their social environment because, frequently, the behavioral changes are less observable by other people. The diagnosis brings grief but also more certainty about the reason for the changes of their partners and, in the Netherlands, also access to facilities for PWD. With the progression of the dementia dependency and
behavioral changes of the PWD increase, leading to depression, anxiety, poorer physical health, lower quality of life and aggression towards the PWD of the caregiver. Also, despite clinical guidelines recommending nonpharmacological approaches as first line in treating these symptoms, in practice psychotropic drugs are frequently prescribed to community dwelling PWD. Depending on the stage of the dementia, percentages varied from 29% to 50% of PWD used at least one psychotropic drug. Furthermore, the negative effects of the NPS on the caregivers can lead to early nursing home placement. However, unfortunately, although feelings of stress of the caregiver decrease after nursing home admission of the PWD depressive feelings and loneliness do not.

**Care as usual**

In the Netherlands interventions aimed at caregivers for PWD comprise support by the case manager dementia (CMD) and the general practitioner and if indicated, by home care. Respite care is available as day care, sometimes combined with support groups organized by these day care centers. The CMD and professionals involved in support groups provide the caregiver with information about dementia and give information on relevant literature and websites. To a small extent internet intervention are available. Some interventions such as professional caregiver coaches are generally available but not reimbursed by all health care insurances or municipalities as appropriate. Multicomponent interventions are not structurally available so far.

**Caregiver needs and support**

Research concerning needs of PWD in the community and their caregivers revealed that most needs were expressed in the domains of psychological distress, daytime activities, company and information. To meet these needs caregiver interventions should offer psychosocial support, education, help to develop caregiver support systems and respite care as a single component intervention or combine these in some way. Reviews indicate that multicomponent interventions are more effective on relieving burden and psychosocial morbidity than other categories. These effective multicomponent interventions combine counseling, support groups, education, stress and mood management (telephone) support, help to improve coping styles, social support and involvement of patients and their families.
Caregiving in institutions

Burden on nursing home staff
As neuropsychiatric symptoms (NPS) such as agitation, depression or apathy are strongly related to nursing home placement, the proportion of PWD with NPS in institutions is high\(^{19,20}\). In many cases, this disruptive behavior cannot be reduced sufficiently by care-as-usual and, therefore, psychotropic medication is usually prescribed as it is believed by the staff there is no effective alternative despite their limited effect on NPS and highly frequent and serious side effects\(^{21,22}\). Moreover, these NPS not only are bothersome for the PWD but they also can induce nursing home staff distress which in turn is related to higher psychotropic drug use\(^{23}\).

In the Netherlands about 50% of the residents of nursing homes uses at least one psychotropic drug\(^{24}\). In Europe, antipsychotic use ranges from 12% to 59% and antidepressant use from 19% to 68%\(^{21}\) with a marked difference between countries.

Care as usual in Dutch nursing homes
Nursing home care is frequently organized in units of about eight residents who share a living room. They are taken care of by nurses and nursing assistants. Frequently, nursing homes struggle to find enough sufficiently educated nurses and have to supplement this shortage with temporary workers or nurses who are less well educated. In addition, nursing home staff include elderly care physicians, psychologists, occupational therapists, physiotherapists, dieticians, speech therapists, spiritual carers and staff specialized in providing pleasant activities to residents. In most nursing homes elderly care physicians and psychologists have the possibility to consult a psychiatrist. When a resident needs extra care due to NPS extra remuneration can be demanded.

Needs and interventions in nursing homes staff
Due to the high proportion of PWD with NPS it is of major importance that psychosocial interventions are implemented in nursing homes. Many studies are performed to analyze which interventions are effective and feasible in the long term. These interventions include among others education aimed at care staff, interventions aimed at individual residents and interventions aimed at culture
change and including ongoing coaching\textsuperscript{25-29} and are typically delivered by different professionals in close collaboration with each other. However, despite the nursing homes staff consists of these professionals, implementation of effective interventions is difficult and use of psychotropic medication is relatively high.

**AIM OF THE THESIS**

As far as we know, no randomized controlled studies on the effects of intensive multidisciplinary interventions like More at Home with Dementia on the wellbeing of both the caregiver and the PWD have been performed in the Netherlands. This, despite of the importance of augmenting the knowledge and skills of caregivers living with a PWD in the context of increasing pressure on health care facilities and subsequently on health care costs due to the increased prevalence of dementia. As psychotropic drug use is a sign of inadequate handling of the neuropsychiatric symptoms that frequently come with dementia the effect of multidisciplinary interventions on psychotropic drug use should also be analyzed, in community dwelling PWD and in nursing homes.

The following research questions are addressed:

1. What is the feasibility of a multicomponent intervention ‘More at Home with Dementia’ aimed at cohabiting caregivers of PWD?

2. What is the effectiveness of ‘More at Home with Dementia’ on the care related quality of life of the caregivers and other clinically relevant outcomes?

3. What is the effect of this intervention on psychotropic drug use of community-dwelling PWD and their caregivers?

4. What is the cost-effectiveness of the ‘More at Home with Dementia’ intervention?

5. What is the currently available literature reporting on the effects of multidisciplinary psychosocial interventions aimed at neuropsychiatric symptoms of PWD in nursing homes and subsequently on psychotropic drug use?
REFERENCES


PART 1