Chapter 1

General introduction
The impact of dementia
Dementia is a disorder in the elderly with a growing prevalence and incidence, and is often being called the disease of the 21st century. An estimated 35.6 million people worldwide and 250,000 in the Netherlands are suffering from dementia. Because the aging of the population is proceeding rapidly, the number of dementia sufferers is estimated to nearly double every twenty years to more than 115 million in 2050 worldwide\(^1\) and more than 500,000 in the Netherlands.\(^2\) Unlike other chronic diseases such as cardiovascular disease and cancer, dementia has much more impact on disability than on mortality.\(^3\) With the progression of the disease, patients become more and more dependent on the support of others and eventually institutionalization may be necessary. Approximately one-third to half of all people with dementia live in long term care facilities. In the Netherlands, care-services are already understaffed and an important problem is how to deal with growing service demands of demented persons and their relatives in the future.\(^4\) Also the working population will decrease considerably over the coming decades. Therefore, the societal burden of dementia is likely to rise tremendously. The worldwide societal costs of dementia are estimated to be more than US$300 billion yearly, nearly US$ 11000 per demented person and 37% of these costs can be attributed to informal care.\(^5\)

Family care
Family care is a major source of help and assistance to persons with dementia. In the Netherlands, about 65% of persons with dementia are cared for in the community by family members.\(^4\) The ageing of the population, a shortage of long-term care facilities and professionals, cost-control in the health care sector and the desire of most elderly people to remain in their own environment all emphasize the importance of family care. Usually one relative takes responsibility for the care: the primary informal caregiver. In the Netherlands and other European countries, these informal primary caregivers are mostly women caring for their spouse or a parent.\(^6\) In contrast, persons with dementia in developing countries generally live in extended family households and living alone or with a spouse only is very uncommon.\(^7\) In view of the trends outlined above, it is essential that these informal primary caregivers will be enabled to provide care without becoming a patient themselves.

Consequences of family caregiving
Caregiving has been recognized as a prototypical chronic stressor. Results from a meta-analysis suggested that because of the psychosocial and biological processes involved, caregivers are at greater risk for health problems than non-caregivers.\(^8\)
Dementia caregivers report higher levels of stress, more depression and anxiety symptoms, lower levels of subjective well-being, and experience worse physical health. Moreover, one study found that, after four years of follow-up, being a caregiver experiencing mental or emotional strain was an independent risk factor for mortality. Dementia care also differs from family caregiving for other types of patients. Compared to caregivers of non-demented patients they report greater impacts in terms of employment complications, caregiver strain, mental and physical health problems, time for leisure and for other family members, and family conflict. Dementia poses specific demands on the caregiver. The care often continues for years and can become a full-time job. Dementia caregivers spend significantly more hours per week providing care than other caregivers. Moreover, due to the cognitive decline, caregivers lose their relative slowly and may experience grief over an extended period of time. Furthermore, behavioral problems frequently occur in patients. Zarit described these caregivers as “the hidden victims” of dementia and pointed out that there might be no other disorder in which caregivers are confronted that much with negative health consequences. However, it is important to notice that beside these negative outcomes, caregivers of persons with dementia may also experience a variety of positive and satisfying aspects. Caregivers reported that caregiving made them feel needed, useful, and good about themselves. Furthermore caregiving can enable them to appreciate life more, to develop a more positive attitude toward life, and strengthen their relationships with others.

Depression and anxiety in caregivers
Depressive symptoms have been one of the most widely used outcomes in caregiver research. Most studies show a substantial prevalence: 20-50% of the caregivers have clinically relevant symptoms. The prevalence of clinically diagnosed major depression ranges from 10% to 83%. Very little is known about the incidence of caregiver depression. A systematic review reported that about half of the caregivers develop depression. This estimate was based on only one sample of dementia caregivers, but indicates that the risk to develop depression might be considerable for these persons.

Anxiety in caregivers of persons with dementia has received less attention than depression, but is likely to occur as a consequence of the distress caused by the caregiving situation. The few studies that have been carried out support this hypothesis reporting that about a quarter of caregivers had clinically relevant symptom levels of anxiety. Nevertheless, no cohort studies have yet focused on the incidence of anxiety in family caregivers.
Burden of depression and anxiety
Depression and anxiety are thus highly prevalent conditions in caregivers, but also in the general population. Nearly 20% of all people will experience a major depression during their lifetime.\textsuperscript{24} Next to major depression, a considerable number of persons do not meet the criteria for a full-blown disorder, but has significant symptom levels (sub-threshold depression).\textsuperscript{25-27} About 20% of the persons with depression experiences a chronic course and 50% will face recurrent episodes.\textsuperscript{28, 29} With an estimated overall lifetime prevalence of 25% in the whole population, anxiety is even more prevalent than depression.\textsuperscript{24} The severity of disability is reported to be similar to that reported for depressive episodes\textsuperscript{30} and the course appears to be less favorable.\textsuperscript{31, 32} Comorbidity between depressive and anxiety disorders is high, with estimates ranging from 30% through 60%.\textsuperscript{24, 33-37} Due to the high prevalence of depression and anxiety and the amount of disability they both cause, these conditions have a great public health impact. Moreover, depression is expected to become the leading cause of disease burden in the Western world by 2030 and is associated with huge costs.\textsuperscript{38}

Why is caregiving stressful?
In caregiver research, ‘stress process’ and ‘appraisal models’ are frequently used to describe the connection between stressors and caregiver health outcomes like depression and anxiety. These models assume that caregivers assess caregiving events and subsequently respond with particular behaviors that are followed by health outcomes. Sörenson et al recently combined the models into one conceptual framework (Figure 1). The strongest predictors of adverse mental and physical health outcomes in the caregiver mainly include the nature and intensity of care (including patients’ behavioral problems) and perceived benefits and positive experiences.\textsuperscript{39} Although physical impairment in patients increases burden for caregivers of non-demented patients, this is rarely the case for dementia caregivers.\textsuperscript{39} Patients’ behavioral problems seem to be more important.\textsuperscript{10} Furthermore, the conceptual model incorporates mediators and moderators that might intervene between primary stressors and outcomes according to numerous studies and meta-analyses. Mediators (or secondary stressors) involve reactions of the primary stressors that may exacerbate or weaken the caregiving effect over time. In turn, moderators are assumed to change the strength of the relation between stressors and outcomes. Appraisal indicates the caregiver’s subjective evaluation of his role. Despite similar objective demands, subjective burden can differ between caregivers because of a differing evaluation of whether their coping skills will be sufficient to manage the situation. Some caregivers appear to be more vulnerable to experience adverse psychosocial and physical health effects, especially females, spouses and caregivers from lower socioeconomic groups.\textsuperscript{16, 40, 41}
Studies from the USA have also found ethnic differences, with better mental health outcomes for black and Latin American groups.42

**Caregiver interventions**
Physicians have pharmacological (prescription of medication) and non-pharmacological (psychological support, counseling) options to treat patients with mental problems. This paragraph concentrates on the effects of psychosocial (non-pharmacological) interventions for caregivers of people with dementia. In recent years, various types of psychosocial interventions have been developed to support family caregivers and several meta-analyses of their effects have been published. Based on the meta-analytic findings, it can be concluded that some approaches are beneficial for caregivers but that, overall, interventions have modest effects.43-48 Combined intervention programs for both the caregiver and person with dementia were often effective in delaying long stay care admittance, but to a lesser extent in improving caregivers’ mental health.49 The most successful interventions have several characteristics in common. First, using a psycho-educational or psychotherapeutic approach appeared to be more effective than using education alone. Furthermore, addressing multiple stressors and other risk factors was found to be successful rather than addressing a single stressor. In addition, a flexible treatment protocol tends to meet individual needs better and is likely to increase positive outcomes. Finally, programs providing a higher amount and intensity of support were more helpful.50 Most positive effects were found in the subgroup of female caregivers and caregivers caring for people with a dementia diagnosis ‘not otherwise specified’.51
Role of the general practitioner in the treatment of mental health problems

In the Netherlands, a person who has mental problems or experiences excessive (caregiver) distress can seek professional support from several sources. They may see the General Practitioner (GP) for initial help or go to a primary care psychologist. The GP is often the first point of contact for people with mental problems. Diagnostically, the GP can help patients to interpret their symptoms as related to contextual distress or a mental health disorder such as depression. Despite their contacts with their GP, a substantial number of patients with depression remain unrecognized by the GP$^{52,53}$ and consequently, untreated.$^{54}$ Adequate recognition and treatment mostly influences the course and outcome of disease beneficially.
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Although GPs have limited resources to treat persons with mental problems themselves, a minority of the persons with mental problems wants to be referred to psychiatric services. Besides, most of them prefer counseling to medication. In Dutch general practice, although not offered on a large scale, various psychological interventions can be applied (such as problem solving treatment, motivational interviewing, guided self-help, reattribution and psycho-education). Mostly, a practice nurse or a social psychiatric nurse is considered best suited to carry out the interventions.56 Also, social workers or primary care psychologists can be consulted after referral.

Supportive services for caregivers and attunement to their needs
At some point, caregivers may approach their GP for advice or support. In general practice, the caregiver’s (mental) health is often still neglected and the care is essentially directed at the person with dementia. However, a variety of health care and social services is available in the Netherlands to support caregivers of demented persons. The last years, case management programs have been developed and implemented in most regions.56 Furthermore, caregivers can join counseling groups, participate in buddy projects, and use support centers or other organizations that provide practical and emotional support to caregivers and patients.

Results of the Dutch National Dementia Program (NDP) show that almost all caregivers experience problems in the care for their relative with dementia. Coping with the patient’s behavioral and mood problems, the high daily burden of care and reluctance to move their relative to a nursing home were experienced as the most important problems.57 In the NDP, family caregivers also formulated several improvement areas in health care, such as systematic help in the finding and arrangement of care, improvement of the continuity in long term support, practical help and support after diagnosis and education in coping with problematic behavior.58

Although a substantial number of caregivers report a high burden and experience problems, many of them do not ask for help or the provided support does not respond to their needs.58 Not seeking or using help can be due to a perceived lack of need or lack of awareness.59 This is likely to be valid for dementia caregivers. Zarit suggests that caregivers may be at risk for depression and anxiety, but that may not be how they view themselves or why they seek help. Instead, they label their state based on the everyday problems that they face.60 Furthermore, caregivers might consider themselves to be supporters rather than persons in need of care and are often reluctant to accept help. Perhaps, sharing care with their family members and friends will be preferable for them. An empowering intervention like family meetings might connect very well to the desire to solve things on their own.
A promising research strategy: preventive interventions

Given the high prevalence, persistence, and substantial burden of depression and anxiety, providing adequate treatment for all sufferers places a heavy burden on health care resources and might not be feasible. Besides, treatment for mental disorders has been only partially satisfactory in reducing disability and particularly for caregivers the interventions that are currently available offer only limited possibilities. Alternative strategies, such as prevention, are likely to be a much-needed adjunct to care as usual. Preventive interventions have already proven to be effective in reducing the onset of depression and anxiety in non-caregiving populations. A meta-analysis showed that prevention trials were able to reduce the incidence of depression by 22%. This suggests that prevention programs might also be an effective strategy for the group of dementia caregivers.

In this thesis, preventive interventions play a central role. These types of interventions aim to reduce the risk of first onset of a mental disorder, while treatment interventions intend to stop the progression of the disease or to decrease severity. However, in practice the distinction between prevention and early interventions is sometimes not that stringent and purposes may be overlapping. A widely used model, called “The Mental Health Intervention Spectrum” (Figure 2), distinguishes between three types of prevention strategies. Universal interventions are directed at the whole population, not considering individual risk status (e.g. screening programs or media campaigns to inform the general public). Selective interventions target persons at increased risk, because they have certain characteristics or are exposed to risk factors. Finally, indicated interventions are directed at people who already have some early symptoms or signs, but do not yet meet the diagnostic criteria of the mental disorder.

Current research suggests that prevention is most likely to be effective when targeted at those with a high a priori risk of developing the disorder instead of using universal strategies (which also includes persons at low risk). This can be achieved by focusing on people exposed to established risk factors for a disorder (selective prevention), as is the case in the population of dementia caregivers or by focusing on people with increased symptoms levels (indicated prevention). Moreover, these focuses make prevention at once manageable, economically feasible and likely to generate relatively substantial health gains at population level.

To this end, in this thesis we evaluated two preventive interventions. We investigated the effectiveness of a family meetings intervention aimed at the prevention of depression and anxiety in caregivers of persons with dementia. Also, we tested a cognitive behavior therapy-based bibliotherapy intervention for older adults with increased depressive symptoms at risk of developing a mental disorder.
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The family meetings intervention
A program entailing structured family meetings for caregivers of persons with dementia and their family may help to mobilize support of existing family networks and to provide psycho-education. The assumption is that family support can work as an important resource for adapting to stress. Organizing structured family meetings might maximize the positive contributions of each member to caregiving and thereby prevent the primary caregiver from carrying the entire weight of the caregiving role.

Despite the extensive body of literature that shows an association between social support and poor well-being, only few studies address the family as an integrated system responding to and being affected by the presence of disease and its management over time. In the treatment of other psychiatric diseases, like schizophrenia, the involvement of the family is much more conventional. In this field, family interventions consisting of combinations of psycho-education, behavioral problem solving, family support, and crisis management have been investigated extensively. The results from some studies suggested that these family interventions significantly reduce clinical, social and family difficulties and may have a positive impact on the patient and family well-being.70

Also for caregivers of persons with dementia, family support is likely to be particularly important. The mechanism through which family meetings might improve caregivers’ mental health can be explained using the theoretical model shown in figure 1. By enhancing the positive support of the family (ameliorating factor) and diminishing the negative aspects of family involvement with caregiving (secondary stressor) the intervention can improve their ability to withstand the difficulties of caregiving (appraisal) and reduce mental health problems (outcomes).

Previously, the effectiveness of family meetings was investigated by Mittelman and colleagues as part of a multicomponent intervention. Besides four family counseling sessions, this intervention consisted of individual counseling sessions, support group participation and continuous availability of ad hoc telephone counseling. It appeared to be effective in reducing depressive symptoms in caregivers.71-73 Moreover, this intervention led to a substantial delay in nursing home placement of patients compared to the control group while maintaining a comparable quality of life for the caregivers.74-76

However, the effectiveness of using only the family counseling component has not yet been tested. Also, it is not clear to what extent family meetings might have benefits in preventing mental illness in the caregiver. Our study involves also some other innovative elements.
In contrast with the studies of Mittelman et al., we also include other family caregivers than spouses caring for a demented person, measure both the effects on depression and anxiety and include also patients with non-Alzheimer Dementia’s. To our knowledge, despite the studies of Mittelman et al, there are no other studies that investigated the effects of family meetings and it remains unclear to what extent family meetings may have preventive effects. Therefore, in the study that is part of this thesis, we investigated whether structured family meetings are more effective than usual care in the prevention of depression or anxiety disorders in caregivers. We also evaluated the effects on the severity of symptoms, caregiver burden and quality of life of the caregiver.

The caregivers participating in the family meetings intervention in our study started with one individual preparation session, followed by four structured meetings that included their relatives and/or friends and finished with one additional individual evaluation session. If required, additional ad hoc counseling could be provided. Psycho-education forms an essential component of the sessions. Psycho-education shows consistent positive effects on various outcomes like caregiver burden, depression and subjective well-being. The involvement of other family members in the intervention may strengthen these positive effects. The aims of the family meetings are: 1) to educate families about the consequences of dementia and give information about resources for care support; 2) to mobilize the existing family networks of the patient and primary caregiver in order to improve emotional and instrumental support; 3) to teach problem solving techniques for coping with troublesome patient behavior that can be used after family counseling ends. Not all caregivers experience the same problems and will have the same needs. Therefore, the content of the sessions is guided by the needs of the caregiver (for example learning techniques to manage troublesome behavior, promoting communication between family members).
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Outline of this thesis

The chapters in this thesis cover different components of the mental health intervention spectrum, as demonstrated in Figure 2. To gain insight in the extent of the problem, in chapter 2 we assess the long-term incidence of depression and anxiety in the spouses of patients with dementia as recorded by general practitioners.

In chapter 3, we examine whether GPs’ medical records demonstrate a good recognition of depression in the general population. Different indicators within the medical record are included and we evaluate which combination of indications most accurately reflects a diagnosis of depression.

Chapter 4 concentrates on how people can handle mental problems themselves in an early phase. This chapter addresses the research question: to what extent does a bibliotherapy intervention influence the course of subthreshold symptoms of depression in older adults. The intervention was part of a stepped-care prevention program. The entire stepped-care program halved the incidence of major depressive and anxiety disorders in the elderly, but it is not yet clear which part of the intervention contributed most to the effectiveness.

Chapter 5, 6 and 7 focus on what the family can do in the prevention of mental disorders. These chapters report on a randomized trial evaluating the effectiveness of the family meetings intervention. In chapter 5, we present the study protocol. In chapter 6 and 7, we describe the effects of the study on different outcome measures, respectively the caregivers’ mental health and the time until institutionalization of patients.

In chapter 8, we try to identify the high-risk groups of dementia caregivers in which prevention is likely to generate substantial health gains for the least effort and hence for the lowest costs. Finally, in chapter 9 we discuss the findings and methodological aspects of the studies presented in this thesis, and we present the clinical implications and suggestions for future research.
Figure 2: The chapters of this thesis placed in context of The Mental Health Intervention Spectrum of Mrazek & Haggerty (1994)
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GENERAL INTRODUCTION


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