

Summary

Dementia is a prevalent disorder in –primarily- the elderly. Because the aging of the population is proceeding rapidly, the number of dementia sufferers will increase substantially over the coming decades. Most persons with dementia are cared for in the community by family members. Dementia often has far-reaching consequences the patient, but also his relatives. Caregivers of persons with dementia often experience a high burden and the prevalence of mental illnesses like depression and anxiety is substantial within this population. This thesis focuses on depression and anxiety in caregivers of persons with dementia. We estimated the incidence, evaluated a preventive intervention, and identified high-risk groups for the onset of depression. In addition, we carried out two studies among non-caregiver populations: 1) a study evaluating the effectiveness of a self-help intervention that was part of a preventive stepped care program for very old adults (aged 75 years and older), and 2) a study among primary care patients that investigated how accurately several indications of depression in GPs' medical records reflect the diagnosis of depression. Below, we summarize the results from the studies in this thesis.

Chapter 2: Incidence of depression and anxiety

Good quality prospective studies on the incidence of depression and anxiety in dementia caregivers are rare. In Chapter 2, we used data from medical GP records of 218 spouses of patients with dementia and 353 age and gender matched spouses of non-demented persons to analyze long term incidence of depression and anxiety. The spouses of demented persons had a fourfold higher risk of a diagnosis of depression than the matched persons. We could not establish this for anxiety.

Chapter 3: Recognition of depression by GPs

Previous estimates of depression recognition in primary care are low and inconsistent, perhaps due to registration artifacts and limited extraction efforts. To estimate GPs recognition of depression accurately, we used data from the medical records of 816 primary care patients that could indicate depression, such as diagnostic codes, antidepressant prescriptions, referrals to mental health care and free text notes. GPs recognized 69% of their patients with a depression diagnosis and 80% of the (very) severely depressed cases. The registration of the diagnostic codes added least to GPs' recognition. We therefore conclude that GPs are aware of mental health problems in most depressed patients, but labeling them with specific diagnostic codes is weak.

Chapter 4: Bibliotherapy for very old adults

In a randomized controlled trial, we investigated the effectiveness of bibliotherapy (guided self-help) for depressive symptomatology in very old adults (aged 75 and older). Although the elderly in both groups improved in the severity of the depressive symptoms, we did not find any clinically relevant and statistically significant differences between the intervention group and the control group. The decrease in depressive symptoms was highest (but still not significant) for adherers. These results might indicate that bibliotherapy as a stand-alone intervention can only be effective for patients who are motivated and acknowledge their depression.

Chapter 5: Design of a family meetings intervention

A randomized trial was designed to investigate the effectiveness of a family meetings intervention aimed at the prevention of depression and anxiety in family caregivers of persons with dementia. In chapter 5, we present the background and design of this study. We hypothesized that family support could work as an important resource for adapting to stress and thereby prevent the primary caregiver from developing a mental disorder and placement of the patient in a nursing home. The intervention consisted of four family meetings with the caregiver and his own family or friends, added with a preparation and evaluation session with the caregiver individually. The family meetings were organized once every 2 to 3 months for a year and led by a trained counselor. The main outcome measures after 12 months were the incidence of a DSM-IV major depressive or anxiety disorder and change in depressive and anxiety symptoms. Secondary outcomes included caregiver burden, health related quality of life. In addition, information on institutionalization of the patient was collected.

Chapter 6 and 7: Effectiveness of family meetings

Although the incidence of depression and anxiety disorders was substantial in the sample of caregivers (almost 40% within 12 months), the intervention did not prevent the onset of depression or anxiety disorders, nor reduced symptom levels and caregiver burden. Furthermore, the intervention did not postpone patient institutionalization more than usual care. About half of the intervention caregivers completed the intervention according to the protocol. Comparing these adherers with the usual care group revealed no other effects. We could not identify relevant subgroups of caregivers with a positive response to the intervention. We discussed possible explanations for the lack of effects, such as a low intervention dosage or intensity, an inappropriate timing of the intervention, a low uptake and a limited contrast with usual care.

Chapter 8: Identifying target groups for depression prevention

It is not yet clear which caregivers are at increased risk of developing depression. We used longitudinal data of 725 caregivers from the United States to identify high-risk groups in which prevention programs might generate substantial health gains for the least effort. Three significant indicators of depression onset were identified: 1) increased initial depressive symptoms levels, 2) poor self-rated health status and 3) race/ethnicity of the caregiver. The incidence of depression would decrease by 72.3% (attributive fraction) if these risk indicators together are targeted by a completely effective intervention. Focusing on these easy to assess characteristics might contribute to a cost-effective prevention of depression in caregivers. The race/ethnicity predictor was no longer a significant predictor when analyzing the sample without the caregivers of whom the patient was placed or died.

Chapter 9: General discussion and conclusions

In this chapter, we present and review the main findings of Chapter 2 to 8, and we highlight several implications for practice and further research. This thesis showed that dementia caregiving seems to constitute a higher risk of developing depression, but not anxiety. Particularly caregivers who already present some depressive symptoms and have a poor self-rated health seemed to be at higher risk for depression onset. Fortunately, GPs are able to recognize depression in most depressed patients. The two psychological interventions we conducted both demonstrated a lack of effect and it is therefore currently not advocated to implement these interventions on a large scale in Dutch routine health care. This thesis again confirms that prevention of mental disorders is very complicated, both with regard to reaching target groups as well as in finding strategies to support them effectively.