

Chapter 9

General discussion

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. As discussed in the general introduction of this thesis, all studies can be considered as covering different aspects of the mental health intervention spectrum. In this chapter, we start with an overview of the main findings. Next, we will critically review these findings. Finally, we conclude with implications for practice and further research.

MAIN FINDINGS AND CONCLUSIONS

The spouses of patients with dementia have a fourfold higher risk of a diagnosis of depression than the spouses of non-demented persons, although the incidence was much lower than previously estimated (Chapter 2)

The incidence of depression as diagnosed by the general practitioner (GP) was 18.8 per 1,000 person-years for spouses of patients with dementia and 4.4 per 1,000 person-years for age and gender-matched spouses of non-demented persons. Also, a twofold higher risk for the prescription of antidepressants was found for the spouses of demented persons compared with the matched persons. In contrast to depression, spouses of people with dementia were not more likely to be diagnosed with anxiety than the comparison spouses (Incidence rates of 12.4 and 9.5 per 1,000 person-years respectively). A substantial number of the spouses of patients with dementia who developed depression or anxiety experienced their first episode after the death of their relative.

GPs are aware of mental health problems in most depressed patients, but labeling them with specific diagnostic codes is weak (Chapter 3).

GPs recognize 69% of their patients with a depression diagnosis when several indicators within the medical record are taken into account, such as diagnostic codes, antidepressant prescriptions, referrals to mental health care and free text notes related to the two main symptoms of major depression according to the DSM-IV. Recognition was 80% for the (very) severely depressed cases. Of all the separate indicators, registrations of antidepressant prescriptions resulted in the highest accuracy of recognition.

Adding the registration of the specific diagnostic codes for 'depressive disorder' and 'depressive feelings' to the definition of recognition did not result in a better accuracy. We could not investigate whether these recognition estimates also hold for caregivers of persons with dementia, because information on caregiver status was not collected in this study.

Bibliotherapy as a stand-alone intervention was not more effective in lowering depressive symptoms than usual care in very old adults with sub threshold depression (Chapter 4)

There was no clinically relevant or statistically significant difference in depressive symptoms between the intervention and usual care group, but the elderly in both groups improved by a considerable 5 points on the CES-D scale. This might be attributed to the extra attention all participants got from the interviewers or to spontaneous recovery. About 40% of the participants completed the total self-help course. The decrease in depressive symptoms was highest (but still not significant) for adherers, which might indicate that bibliotherapy only helps for patients who are motivated and acknowledge their depression.

The family meetings intervention was not more effective than usual care in the prevention of depression and anxiety (Chapter 5-7)

The incidence of depression and anxiety disorders was substantial (almost 40%) in caregivers of both the intervention and usual care group, but no significant difference between the groups was found. Also on the other outcome measures (depressive and anxiety symptoms, caregiver burden, caregiver's health related quality of life) no significant effects were found. Furthermore, the family meetings intervention did not postpone patient institutionalization more than usual care. We could not identify relevant subgroups of caregivers with a positive response to this intervention. It was unexpected that a substantial number of caregivers invited for the study were not willing to participate, mainly due to a lack of perceived need for this intervention. Among participants the adherence to the full protocol was not optimal, but most caregivers who started the intervention program were satisfied and experienced the family meetings as useful. Nevertheless, per protocol analyses revealed no other effects than the intention-to-treat analyses.

Focusing on only a few easy to assess risk indicators might contribute to a cost-effective prevention of depression in caregivers (Chapter 8).

In a cohort of caregivers of persons with dementia from the United States, three significant indicators of depression onset were identified: increased initial depressive symptoms, poor self-rated health status and white or Hispanic race/ethnicity. The incidence of depression would decrease by 72% (attributive fraction) if these risk indicators together would be targeted by a completely effective intervention. The race/ethnicity predictor was no longer a significant predictor when analyzing the sample without the caregivers of whom the patient was placed in a long-term care facility or died. Interestingly, patient-related indicators and indicators related to the specific caregiving context did not significantly contribute to the onset of depression in the caregivers.

REFLECTION ON THE FINDINGS

Above, we have described the main findings of this thesis. To summarize, dementia caregiving seems to constitute a higher risk of developing depression, but not anxiety. Particularly caregivers who already present some depressive symptoms and with 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 did not confirm our hypotheses. Below, we will first reflect on the findings of the cohort studies described in this thesis (Chapter 2, 3 and 8), mainly focusing on their representativeness. Subsequently, the two intervention studies (Chapter 4-7) will be considered.

Cohort studies

The studies described in Chapters 2, 3 and 8, all with a considerable sample size, allowed us to investigate consecutively the incidence of depression and anxiety in spouses of demented persons, the risk indicators of incident caregiver depression and the recognition of depression in general practice. With regard to the two studies using primary care records studying a) the incidence of depression and anxiety (Chapter 2) and b) the recognition of depression (Chapter 3), potential bias due to the selection of participating GPs might have influenced our estimates. In the related chapters, we already discussed that under- as well as overestimation could have been the case. Reconsidering, a) the incidences of depression and anxiety will perhaps have been underestimated and b) the recognition rates might have been overestimated.

GPs in both studies might have been better aware of and recorded a depression diagnosis than the average GP in the Netherlands due to their possibly improved training in diagnostic coding. Nevertheless, in chapter 3 we found that the use of specific diagnostic codes was still weak. This might partly explain why the incidence of depression we found in Chapter 2 was much lower than the 48% reported in a review on depressive disorders in caregivers of dementia patients conducted by Cuijpers and colleagues.¹ Our lower estimate can also be explained by the fact that we used routinely recorded data while the incidence reported by Cuijpers et al. was based on data from an intervention study. In the family meetings intervention study we conducted, a more comparable high incidence was observed. This might imply that caregivers who are willing to participate in such intervention studies are more likely to develop depression than other caregivers. It is important to recognize this when interpreting the results of such trials. In Chapter 2 spouses of dementia patients were compared with matched subjects selected from the same general practices as the spouses, so the conclusion that the spouses were far more likely to be diagnosed with depression by their GP is still valid and indicates the vulnerability of persons caring for a relative with dementia.

In the study that investigated significant risk indicators of depression onset and explored risk profiles of caregivers, subjects were originally recruited for an intervention trial in the United States (Chapter 8). Therefore, this sample might not be representative of the total population of caregivers of dementia patients. Besides, the risk factors and profiles we identified might not be simply applicable in the Dutch setting. For example, the ethnic/racial groups present in the US sample differ from the ethnicities/races found in Dutch society. Furthermore, we were able to use only a selection of relevant risk factors. Inclusion of other important variables such as information on history of depression, personality of the caregiver and caregivers' coping style will be desirable in future research.

Intervention studies

As described in Chapter 6 and 7, an intervention including family counseling that was carried out in the US, showed significant- but not very large- effects on depressive symptomatology in caregivers²⁻⁴ and was able to delay nursing home placement of patient considerably compared with a control group.⁵⁻⁷ Also for bibliotherapy (Chapter 4), previous research has shown that such an intervention can be effective for treating depression.⁸⁻¹⁴ This begs the question: why did the intervention studies we conducted not establish any statistical significant or clinically relevant effects? Several explanations are possible:

Intensity & dosage were too low

Interventions that provide more treatment generally have better outcomes.¹⁵ Within caregiver research, even single-component interventions tend to have stronger effects than less intensive multi-component interventions if they last longer or involve more frequent interactions.^{16,17} Also for self-help interventions, the intensity of the guidance has shown to be important. Previous research proved that self-help without guidance is not effective.^{14,18} Counselors in the family meetings study reported that it was sometimes hard to plan the family sessions, particularly when caregivers and/or family members had a job or did not live in the same region. Furthermore, a considerable number of participants did not complete the maximum number of sessions although most of them were satisfied about it. The bibliotherapy study showed similar findings. Taking this into consideration, a more intensive intervention seems to be even less feasible.

Limited contrast with usual care

Participants in the usual care group were free to seek out support on their own. The provided standard care in The Netherlands is already quite intensive. Many supportive services are available to caregivers. A considerable number of participants in our study received support from a casemanager. This high level of standard care may have resulted in a limited contrast between the intervention and usual care condition. Perhaps, the benefits of the family meetings were not large enough to distinguish from benefits possibly gained from the usual care.

Poor uptake

In both the family meetings and the bibliotherapy study, the intervention uptake was quite low. While we ensured that persons entering the study would be willing to use the intervention, the number of persons that actually participated in the full intervention dosage was relatively low and some participants received no intervention at all. This implies that actually participating in an intervention may not be the same as willingness to do so initially. It would be challenging to investigate this finding more into detail and to use this knowledge within the development of future interventions. Although poor adherence might be an explanation for the lack of effect, the per protocol analyses did not indicate that a better adherence would have altered the effects. For bibliotherapy, the full-adherers did reach a greater decrease in depressive symptoms, but this was still not significant compared to the usual care group.

Wrong target sample

Preventive interventions are most likely to be effective when targeted at those with a high a priori risk of developing the disorder.^{19, 20} Based on the existing literature, we assumed that persons caring for a relative with dementia form a high risk group and that also caregivers without symptoms are probably at increased risk to develop depression and anxiety. The results presented in Chapter 2 indeed confirm their higher vulnerability compared to persons not caring for a demented relative. Therefore, we chose to include all caregivers free from a mental disorder at intake, regardless of their level of symptoms. Additional use of a recruitment criterion including a minimum threshold of symptoms (an indicative prevention approach) would perhaps have been a better approach. Previously, a large trial in the United States only enrolled caregivers who had at least moderate levels of strain in their role.²¹ Outcomes were indeed more positive compared to a prior study from the same research group.

A strategy that takes into account multiple risk indicators might be even more promising. In Chapter 8, we explored the potential of such a strategy in a sample of caregivers in the United States. It would be worthwhile to replicate such an analysis on the Dutch caregiver population. Also, matching type and dose of interventions to individual risks may improve effectiveness. However, for the caregivers in our sample with clinically relevant depressive or anxiety symptoms at baseline, additional analyses did not indicate that these persons would benefit more from the intervention.

In contrast to the family meetings study, the bibliotherapy intervention study we conducted did make use of an indicative preventive approach (all participants suffered from sub threshold symptoms at intake). Although the entire stepped care program this intervention was part of, showed to be very beneficial, we could not establish significant effects of the self-help program alone. Possibly, the very old target group might not have had the necessary skills for such a self-help approach and might need more guidance.

The follow up period was too short

It might be possible that the follow up period in the family meetings study was too short to show significant effects. Some families did only complete the intervention shortly before the last measurement and some were still participating in the intervention program. This might have been a reason why we were not able to establish significant findings after 12 months. Also in case of the bibliotherapy study, the follow up period (three months) might have been too short, but is unlikely to be a major reason for the lack of significant results.

The outcome measures were not appropriate

An alternative explanation for the lack of effects of the interventions could be that the intervention might be helpful in some ways, but not for the outcomes that have been measured. We expected that by organizing family meetings, (more) support from family and friends would be created and caregiver burden (and consequently the risk to develop mental disorders) would decrease. We could not establish effects on mental health outcomes, caregiver burden and family support. However, it may be possible that the intervention was not useful as a treatment for these outcomes, but that it addresses other types of problems (such as helping caregivers feel less trapped in their role or dealing with feelings of guilt).

With regard to both the family meetings intervention and the bibliotherapy intervention, we believe it is unlikely that their ineffectiveness was due to methodological limitations of these studies. Both studies had a relatively large sample size, the random allocation sequence was performed adequately and blinded and independent interviewers assessed the outcome measures. Moreover, in contrast to a low adherence, in both trials, few participants refused to be re-interviewed and thus loss to follow up was relatively low. Only a few characteristics in the family meetings study (poorer physical health of the caregiver) and in the bibliotherapy study (older age, not living independently, and randomization to the intervention) were associated with loss to follow-up, namely a poorer physical health of the caregiver. Thus, possible selection bias is likely to be limited.

With regard to the family meetings intervention study, concern may arise about the potential generalizability of the results towards the total population of caregivers. It was more difficult to recruit participants than we had expected. Although criteria for inclusion were broad and we tried to limit barriers for participation in several ways, a substantial number of caregivers invited for the study were still not willing to participate. This was mainly due to a lack of perceived need for this intervention (because persons already used other services, could (still) manage on their own or did not expect to benefit from this intervention). Because of the high number of refusals, it is not totally clear how well the results of our evaluation would generalize to the total population of caregivers. On the other hand, only a few caregivers refused to participate in the study because of reasons not related to participation in the intervention (such as having difficulties with the randomized design). This indicates that the included sample is representative for the persons willing to accept a family meetings intervention.

FUTURE DIRECTIONS

Based on the results from the studies in this thesis, we want to highlight several implications for practice and further research.

Implications for practice

Pay attention to the high-risk group of persons who care for relatives with dementia

GPs are aware of mental health problems in most of their patients who are depressed. Therefore, training of recognition in general is less of a priority. However, the high-risk group of persons who care for a relative (and in particular a spouse) with dementia are in need of extra attention with regard to their mental health. GPs could provide information about available support resources and bring caregivers into contact with relevant professionals. The use of only a simple checklist of the relevant risk indicators we identified in Chapter 8 can be applied to recognize in which caregivers preventive efforts should be undertaken.

Low-intensity psychological interventions should not be applied solely

Based on the results from the bibliotherapy and the family meetings interventions in this thesis, we can conclude that at least a minimal dosage or guidance is needed to be able to demonstrate significant effects. Since this were the first studies that investigated effects of these interventions in the current form, more studies on such interventions are needed to determine whether they might be more beneficial if some factors are taken into account that may have caused the lack of effects in our studies.

No evidence for the implementation of family meetings in routine health care

We have demonstrated that the family meetings intervention did not result in the preventive effects we expected beforehand. Hence, it is currently not advocated to implement the intervention in Dutch routine health care in this form.

Suggestions for further research

Conduct prospective studies investigating the incidence of mental disorders in caregivers

To date, good quality prospective studies that examine the incidence of mental disorders in caregivers of persons with dementia are still limited. Our data in Chapter 2 reflect recorded incidences of depression and anxiety. Population-based estimates of the incidence of depression and anxiety in caregivers are needed. When extracting data from medical records for future research, researchers should also use other recorded data than just the specific diagnostic codes to provide accurate estimates.

Determine which caregivers are at increased risk for developing mental disorders

In addition to expanding the number of incidence studies, it is important to investigate the factors that influence the development and the long-term prognosis of anxiety and depression in caregivers. It would be interesting to apply the methodology we used in Chapter 8 also on other samples of caregivers to determine whether the risk profiles we identified are replicated.

Link risk profiles of caregivers to specific interventions

In Chapter 8, we showed that it is possible to select a very small set of risk indicators to identify the most vulnerable caregivers for depression onset. In particular, it seems to be promising to target preventive interventions on caregivers who already have some symptoms. It is worth investigating whether targeting caregivers with specific risk profiles will actually improve intervention outcomes. Linking specific risk factors to intervention components that most successfully address these factors can make a next step. Therefore, we first need to determine which subgroups might benefit most from specific interventions.

Gain insight in the preferences of caregivers and the barriers to use support

Although a substantial number of caregivers report a high burden and develop mental illnesses, a part of them do not ask for help or are not willing to accept support. In the family meetings study, a minority of participants completed the full program, although the observed incidence of depression and anxiety in the study was considerable. More insight is needed in the preferences of caregivers for specific interventions and the barriers they have to participate. Perhaps the available support does not respond to their needs. Qualitative research methods and analyses on the process of interventions can be used to gather this information.

TO END WITH

Looking back to the Mental Health Intervention Spectrum referred to in the General Introduction, we wanted to contribute to the current knowledge on several aspects of this spectrum. We gained insight in the magnitude of mental disorders in caregivers, the risk profiles of caregivers for developing such a disorder and the extent to which depression is recognized and to which specific interventions can be beneficial for mental problems. 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.

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