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## **Effectiveness of case management among older adults with dementia symptoms and their informal caregivers**

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# Summary

## *Summary*

The main focus of this thesis is the effectiveness of a case management intervention by district nurses directed towards older adults with dementia symptoms and their primary informal caregivers. In this thesis persons with dementia symptoms are defined as persons with multiple cognitive impairments (i.e. memory impairment and at least one other of the following impairments: aphasia, apraxia, agnosia, disturbances in executive functioning) that lead to significant limitations in social functioning and progressive decline in general functioning. Our definition of dementia symptoms implies that it covers cognitive impairment, pre-diagnostic dementia and dementia in its early stages. In this thesis informal caregivers were spouses, children or other relatives and friends responsible for the organisation of most (informal) care or providing the most hours of care to the care recipient. They provided at least one hour of unpaid care a week. In *Chapter 1* the main concepts used in this thesis are introduced and the objectives of this thesis are presented.

Caring for patients with (early) dementia symptoms may have a major impact on informal caregivers. However, there is evidence that vulnerable informal caregivers remain unnoticed by health care professionals until they are at a point of crisis, while general practitioners (GPs) are frequently unaware of the presence of cognitive impairment and dementia in their older patients. In contrast to conventional care, pro-active care with timely detection followed by structured care focusing on both patients and informal caregivers, may be more suitable for this vulnerable group. By identifying patients with dementia symptoms and their caregivers before they are in a crisis, interventions may be offered to prevent adverse consequences of caregiving for both caregiver and patient. Moreover, both the patient and the caregiver can prepare future care and benefit from facilities that offer information and support when patient's insight is still relatively preserved.

Among community-dwelling older adults with diagnosed dementia and their primary informal caregivers, some studies showed promising effects for case management programmes and home visits on caregivers' sense of competence, well-being and burden, and on institutionalisation rate and mortality of older adults. We expected that case management would also be effective among older adults with dementia symptoms and their informal caregivers, because both older adults with early detected dementia symptoms and their primary informal caregivers may yield a profit of early identification with subsequent case management.

In co-operation with general practitioners and an organisation for home care in West-Friesland, a region in the north-western part of the Netherlands, we developed an early intervention: case management by district nurses aimed at both the care recipients with dementia symptoms and their primary informal caregivers. Preferably, the identified older adults and their informal caregivers did not receive dementia care so far. We aimed to identify the care recipients with dementia symptoms by means of a) a two-stage screening and b) cognitive testing as indicated by general practitioners.

We expected that the case management intervention would show statistically significant and clinically relevant benefits compared to usual care with regard to caregiver's sense of competence, quality of life, psychological well-being, burden, and patient's quality of life, days of temporary institutionalisation, and days until permanent institutionalisation and death.

*Chapter 2* presents the study protocol of the randomised clinical trial we performed to determine the effectiveness of a case management programme directed towards older adults with dementia symptoms and their primary informal caregivers. This study protocol includes an extensive description of the content of the case management programme, the screening for dementia symptoms and the subsequent recruitment of informal caregivers.

*Chapter 3* presents the results of a randomised clinical trial on the effectiveness of case management. The effects of the case management intervention and usual care were compared among community-dwelling older adults with dementia symptoms and their primary informal caregivers. 99 pairs of informal caregivers and older adults with early dementia symptoms were enrolled in the study: 45 pairs were allocated to the usual care group and 54 pairs to the case management group. For the last group, three district nurses who were specialised in geriatric care, acted as case-manager of dyads of informal caregivers and their care recipients during one year. The case manager had mainly a co-coordinating function consisting of assessment, giving advice and information, planning, co-ordination, organising collaboration, and monitoring of care. The case managers provided practical, informational and socio-emotional support.

In the usual care group, the participants could receive care depending on their own initiative. Usual care comprehended a diversity of health care

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and welfare services and could differ across participants. However, the participants had no or only limited access to important elements of the case management intervention because these elements were not offered regularly.

The primary outcome was caregiver's sense of competence. Secondary outcomes were caregiver's quality of life, psychological well-being, and burden, and patient's quality of life, days of temporary institutionalisation, days until permanent institutionalisation, and days until death. Measurements took place at baseline (before randomisation) and at 6 and 12 months after randomisation.

During follow-up, 8 pairs in the case management group and 3 pairs in the usual care group withdrew from the study. Furthermore, 3 patients died in both groups whereas 1 caregiver died in the usual care group. Finally, 81 pairs retained in the trial during the 1-year follow-up. Linear mixed model analyses showed no statistically significant and clinically relevant differences over time between the two groups on caregiver's sense of competence, quality of life, psychological well-being and burden, and on patient's quality of life. Moreover, survival analyses showed no statistically significant and clinically relevant differences between the patient groups with respect to days until death and days until permanent institutionalisation. Furthermore, logistic regression analysis showed no statistically significant and clinically relevant differences between the two patient groups on days of temporary institutionalisation. Therefore, we concluded that this study provides no reason to recommend case management in primary care above usual care for persons with dementia symptoms and their primary informal caregivers.

*Chapter 4* describes the results of a process evaluation on the delivery of the case management intervention. We found no evidence of effectiveness of case management by district nurses compared to usual care. To get insight into one of the possible causes of this absence of effectiveness, we investigated whether the case management intervention was delivered appropriately. 54 pairs of older adults with dementia symptoms and their informal caregivers allocated to the case management group and the three nurses who acted as case manager participated in this process evaluation.

Delivery of the intervention was revealed with four assessments:

1. Time between date of assignment and the first home visit (preferably

within one month); 2. Intervention fidelity (i.e. whether or not participants received the intervention as designed) of nurses according to the informal caregivers by means of marking the elements received out of a list with elements of the intervention; 3. Intervention fidelity reported by the nurses in semi-structured qualitative interviews, as well as nurses' opinion about the intervention; 4. Hours spent on case management by the nurses; 5. Caregivers' satisfaction with the quality of care received.

Our main findings on the delivery of the case management intervention comprehend:

1) Almost none of the participants received the first home visit within one month after randomisation. The mean time between randomisation and the first home visit was 3.2 months (range: 0.5-8.1 months).

2 +3) The intervention was delivered incompletely according to the participating caregivers and nurses.

4) The mean time per dyad spent on the intervention differed per nurse (range: 5.5 – 15.2 hours), but this difference did not lead to differences in outcomes of the intervention across the three nurses.

5) No differences were found in caregivers' satisfaction with the quality of care received across the three nurses. The following aspects of care could be improved: care co-ordination, spending more time on consultations, trying to understand the patient's problems, discussing problems, and organising a replacement when the regular help is absent.

This study shows that incomplete implementation of a case management intervention delivered by district nurses in a randomised clinical trial is one possible reason for not finding any surplus value of case management above usual care. The nurses often did not experience the intervention as necessary yet for the included participants. This may have contributed to the fact that the case management intervention was not delivered completely as designed. We recommend paying attention to the realisation of the planned activities during the implementation of case management interventions.

*Chapter 5* presents the results of a psychometric evaluation of the main outcome measure of the randomised clinical trial: the Sense of Competence Questionnaire (SCQ). This questionnaire was originally developed and validated for informal caregivers of patients with diagnosed dementia. It consists of three domains: 1. Satisfaction with the care recipient, 2.

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Satisfaction with one's own performance, and 3. Consequences of involvement in care for the personal life of the caregiver. In order to study the validity and usefulness of the SCQ when applied to informal caregivers of older adults with dementia symptoms, a psychometric evaluation was performed among 99 informal caregivers who participated in our randomised clinical trial.

We investigated the SCQ its construct validity, feasibility, subscales, homogeneity, and floor and ceiling effects in the new target group of informal caregivers of older adults with dementia symptoms. Firstly, to investigate construct validity, hypotheses were tested concerning the association between sense of competence and burden, mental quality of life, depressive symptoms, and mastery. Most hypotheses on construct validity were rejected. Moreover, only the subscale 'Consequences of involvement in care' was found to be partly valid. Secondly, feasibility was assessed on the basis of response rate and the proportion of missing data for each item. 93 out of 99 persons completed the SCQ. The proportion of unanswered items per item ranged from 0 - 3%. Thirdly, an exploratory principal component analysis was used to investigate whether the SCQ comprises the three subscales established in previous studies. We found that the SCQ comprised the three expected subscales. Fourthly, homogeneity was assessed for each subscale with Cronbach's  $\alpha$  and item-total correlations and they were satisfactory. Lastly, floor and ceiling effects were explored and a ceiling effect occurred on the subscale 'Satisfaction with the care recipient'.

In conclusion, the three subscales of the SCQ showed good homogeneity and feasibility, but their validity for using in our target group is insufficient: only the subscale 'Consequences of involvement' was found to be partly valid. The two other subscales might not be relevant yet for the new target population, since many of the items on these scales refer to problem behaviour and problematic interactions. Our message to clinicians and researchers is not to use these subscales among informal caregivers of older adults with dementia symptoms.

*Chapter 6* presents the results of a psychometric evaluation of the self-report Informant Questionnaire on Cognitive Decline (IQCODE-SR). The IQCODE-SR was the first stage of the two-stage screening for dementia symptoms. The original proxy version of the IQCODE has been successful in identifying demented persons in a general population. However, we administered the IQCODE in a different way: we used self-reports (with

or without help from a proxy) instead of proxy reports only. Therefore, we investigated feasibility, homogeneity and construct validity of the IQCODE-SR. 4823 community-dwelling older adults received an IQCODE-SR. Feasibility was assessed on the basis of response rate, the proportion of missing data for each item, and the number of persons who received help in completing the questionnaire. Feasibility was acceptable, with a response rate of 58.9%. Missing answers per item ranged from 2.5-7.3%, and 915 out of 2841 participants received help in completing the questionnaire. Homogeneity was checked with Cronbach's  $\alpha$  and was good, with Cronbach's  $\alpha=0.94$ . To investigate construct validity, hypotheses on performance of the IQCODE-SR were tested. The majority of hypotheses on construct validity were confirmed.

We concluded that the IQCODE-SR meets the basic requirements of a good measurement instrument: the psychometric properties of the IQCODE-SR demonstrated acceptable feasibility and good homogeneity, and most of the hypotheses on construct validity were confirmed. Further research is necessary to determine the IQCODE-SR's accuracy to identify older adults who are at risk of dementia. In addition, the extent to which cognitively impaired persons can validly complete the IQCODE with and without assistance needs further evaluation.

*In chapter 7* the results of a cross-sectional comparison between two methods to identify older adults with dementia symptoms is presented:

- 1) The usual identification of dementia by general practitioners (GPs);
- 2) A two-stage screening method that we used to identify older adults with dementia symptoms. The methods were carried out on the same population: 3449 community-dwelling older patients of 44 GPs in West-Friesland, the Netherlands. We examined whether the screening that identified patients with dementia symptoms who needed further examination yielded patients who were not detected by their GP. Moreover, we assessed which factors were associated with GPs' awareness of patients identified by the screening.

What did the usual identification of dementia by GPs imply? Based on their actual knowledge and filed patient information, GPs identified prevalent and suspected cases of dementia on a list of their patients who were 75 years of age and older and lived at home. They also indicated patients of whom insufficient information was available to provide a judgment.

What did the two-stage screening imply? In stage one, patients

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received a postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE). This questionnaire has been successfully in distinguishing demented persons from a general population sample. We used self-reports (with or without help from a proxy) instead of proxy reports only. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE) and the seven minute screen (7MS). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7MS, were regarded as having dementia symptoms.

Of the 3449 persons approached for the screening, 2101 returned a questionnaire (60.9%). Therefore, we were able to compare the two methods among 2101 community-dwelling older general practice patients aged 75 years and older. The two-stage screening yielded 117 patients with cognitive impairment who needed further examination; in most cases ( $n=82$ , 70.1%) their GP was unaware of the symptoms. Among patients identified by the screening, GPs' awareness was associated with co-morbidity of chronic diseases (odds ratio (OR) = 3.19; 95% confidence interval (CI) = 1.25 to 8.15), depressive symptoms (OR = 0.41; 95% CI = 0.17 to 0.99), and cognitive functioning (per point on the MMSE, OR = 0.88; 95% CI = 0.79 to 0.98).

We concluded that a two-stage screening and increased alertness for cognitive impairment and dementia among patients with depressive symptoms may improve the detection rate of dementia in general practice. To decide whether screening for dementia is useful in general practice, a more detailed study of the diagnostic accuracy of the screening, and a critical evaluation of the advantages and disadvantages for GPs and patients is needed. The screening has limitations and we do not recommend implementing it before the majority of Wilson and Jungner's criteria on screening are met.

*Chapter 8* summarises the main findings and conclusions of this thesis. Important topics related to the trial are discussed in more depth, as well as the methodology used. Finally, recommendations for further research and daily health care are given.

*The main finding of this thesis is:*

Case management by district nurses showed neither statistically significant nor clinically relevant benefits compared to usual care with regard to caregiver's sense of competence, quality of life, psychological well-being, burden, and patient's quality of life, days of temporary institutionalisation, and days until permanent institutionalisation and death.