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### Clinical, economic and methodological studies in elderly patients with dementia and their informal caregivers

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# Chapter 6

Comparison of clinical outcomes in community dwelling patients with dementia and their informal caregivers with and without case management. Two year results of the COMPAS study

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## ABSTRACT

### Background

Various dementia case management models have emerged in recent years but their clinical impact is unclear. We evaluated clinical outcomes for persons with dementia and their primary informal caregiver by comparing two types of case management (intensive case management model (ICMM) and linkage model (LM)) with no case management (control group).

### Methods

This was a prospective, observational, controlled, cohort study with follow-up every 6-months for 2 years. Community-dwelling participants were recruited in the Netherlands (n=521). Main outcomes were neuropsychiatric problems in persons with dementia assessed with the Neuro Psychiatric Inventory (NPI) and psychological health in informal caregivers as measured with the General Health Questionnaire (GHQ-12). Secondary outcomes included quality of life, care and support needs. Inverse-propensity-score-weighted mixed models were used to evaluate the differences in outcomes between the control group and the two case management groups.

### Results

No significant differences in changes in total NPI or GHQ-12 scores between the groups over two years were found. Secondary outcomes showed better quality of life scores for informal caregivers in the ICMM than the LM group. Total needs, met and unmet care needs increased significantly more in the control group than in the ICMM group, while the difference in total needs was better in the ICMM group than the LM group.

### Conclusion

There were no differences between groups in primary outcomes. The analysis of the secondary outcomes indicated positive effects in the intensive case management as compared to the other two groups. This warrants further research.

## INTRODUCTION

Dementia is a chronic and devastating disorder marked by memory loss, cognitive impairment and behavioral lapses resulting in pronounced consequences for the people with dementia, their families and society. Worldwide costs of dementia were estimated at US\$ 604 billion in 2010 (1). In high-income countries, informal care (45%) and formal social care (40%) make up the majority of costs (1).

A systematic review reported a global dementia prevalence of 48.1 million for 2020 and approximately 90.3 million in 2040 (2). The review noted that in high-income countries, the numbers of people with dementia will continue to grow and the provision and financing of measures to meet their long-term care needs, including support for their informal caregivers, will become an increasingly important societal and political issue (2).

Studies show that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's disease, while some live as long as 20 years (3). Although there is a variety of services available for community dwelling people with dementia and their informal caregivers, people often lack information regarding all available services that may address their care needs (4). Also, many experience insufficient alignment, management and continuity of care and support during the disease trajectory (5).

Several studies have evaluated costs and effects of case management in many countries (6-9). However, reviews and meta-analyses have yielded inconsistent results regarding case management on patient and caregivers outcomes in care satisfaction, institutionalization, hospitalization, caregiver burden, depression, and economic outcomes (6-8,10).

In the Netherlands, various models of case management are implemented. These differ with respect to how services are delivered and by whom, the training provided to its staff and the means of financing. In the COMPAS study (Case management of dementia patients and their caregivers), the two most prominent Dutch case management models, the intensive case management model and the linkage model, are compared with care in regions where there was no access to case management (control group) and with each other. The objective of this current paper was to compare clinical effects for persons with dementia and their informal caregivers over two years between the two case management models and the control group.

## METHODS

### Study design

This study was a prospective, observational, controlled, cohort study to evaluate the clinical effects and costs of two case management models and care in regions where patients have no access to case management (control group). Persons with dementia and their primary informal caregivers were followed for two years. The Medical Ethics Committee of the VU University medical center approved the study protocol.

### **Participants and setting**

Persons with dementia and their primary informal caregivers were recruited from various regions of the Netherlands. Persons with dementia were eligible for this study if they lived at home, had a diagnosis of dementia, were not terminally-ill, were not anticipated to be admitted to a long term care facility within 6 months, and had an informal caregiver. The informal caregivers were eligible if they were the primary informal caregiver responsible for looking after the patient, had sufficient language proficiency and were not severely ill. In case management regions, case managers of the participating organizations provided lists of their patients who met these criteria. In the control group, recruitment took place via outpatient geriatric or neurologic (memory) clinics, Alzheimer centers and general medical practices.

### **Care models**

Case management is defined as “a collaborative process in which a case manager assesses, plans, implements, coordinates, monitors and evaluates all options and services required to meet an individual’s health, social care, educational and employment needs, using communication and available resources to promote quality and cost effective outcomes” (11).

The case management models that were evaluated in this study as well as the content of care in regions without case management were described in detail elsewhere (12,13). We therefore summarize their most important characteristics only (Table 1).

The linkage model (LA) is a collaboration between independent care providers (e.g. home care organizations, general practitioners, social care services) who were already providing health care services in the region and who then were given the mandate to initiate case management services. After a formal diagnosis, persons with dementia are connected to a case manager who provides educational, emotional and practical support such as advice on disease-related issues and recommends supportive health and social services until time of nursing home admission or death of the patient. In general, caregivers are involved in this process whenever possible. Expert advice can be sought through multidisciplinary meetings held regularly with experts from the various collaborating organizations.

Case managers in the intensive case management model are appointed to one organization which is specialized in dementia care. They guide and support people with dementia for long periods of time mostly starting after diagnosis, and offer medical and psychosocial services from their organization (14). The case manager works in collaboration with an ‘in-home’ multidisciplinary team to tailor care needs of the person with dementia and the informal caregiver (14).

The control group was recruited in areas without access to a case manager (15). In some cases, care may be monitored by a registered nurse working in the general practice in addition to the general practitioner. In these regions, no central coordination of dementia care is provided by a specific health care professional. Care is usually initiated by the patient, his /her informal caregiver or health care provider involved in the care for the patient dependent on local service configuration. Access to home or respite care did not differ across regions.

## Data Collection

Persons with dementia and their primary informal caregivers were interviewed at their homes by trained research interviewers using case record forms. Prior to the baseline interviews, all participants signed an informed consent form. The informal caregiver signed on behalf of the person with dementia if they were unable to understand and reproduce the study goals. Interviews and questionnaires were completed at baseline, 6, 12, 18 and 24 months. When people dropped out of the study we asked if they could complete an exit interview which contained reasons for dropping out as well as the GHQ-12, EQ-5D for the informal caregiver and relevant care resource utilization questions. We also collected the date of institutionalization or death if that was the reason for dropout.

### Outcome measurements at the person with dementia level

Information on the time of first symptoms, the dementia diagnosis and other baseline information were gathered from the informal caregiver.

The primary outcome in the person with dementia was the presence of neuropsychiatric symptoms as measured with the Neuropsychiatric Inventory (NPI) which assesses twelve neuropsychiatric domains in persons with dementia (16). The NPI was rated by a caregiver familiar with the person with dementia's behaviour (16). It assesses presence, frequency, severity and the symptom specific caregiver distress in the previous month (16). Calculation of the total score is the sum of the 12 domain scores which ranges from 0-144 points with higher scores indicating more problems (16).

Secondary outcomes in persons with dementia included institutionalization, death, quality of life measured with the Quality of Life-Alzheimer's Disease (QOL-AD) (17), care and support (met and unmet) needs that were measured with the Camberwell Assessment of Needs for the Elderly (CANE) (18), and performance of basic activities of daily life as measured with the original Katz activities of daily living (ADL) index score (KATZ-6) and the modified Katz ADL index (15 ADL+ instrumental ADL items) (19). Information regarding (date of) institutionalisation was collected via the informal caregiver if relevant.

### Outcome measurements at the informal caregiver level

The primary outcome in the primary informal caregiver was severity of psychological health as measured by the General Health Questionnaire (GHQ-12) (20). Secondary outcomes included quality of life, feelings of mastery (the Pearlin's mastery scale (21)), sense of competence (the short sense of competence scale, SSCQ (22)), loneliness (the 'Jong-Gierveld' loneliness scale (23)) and care burden, as measured with the CarerQOL (24).

## Data analyses

Baseline demographic, clinical and prognostic characteristics between the three groups were compared using chi-square tests for categorical variables, analysis of variance (ANOVA) for continuous variables and Kruskal-Wallis or Mann-Whitney U tests if the baseline variables were skewed.

As this was a non-randomized study, advanced statistical methods were needed to control for any baseline imbalances between the different treatment groups (25). First, propensity scores were calculated using generalized boosted methods for multiple treatments using the *twang* package in R (26). Balance and overlap of propensity scores distributions of the three treatment groups were assessed. The *twang* package provides propensity scores based weights for the estimation of the average treatment effects (ATE) for more than two treatment groups. All covariates where groups differed on baseline or that were associated with the baseline NPI total score were included in the calculation of propensity score and weights. The propensity score based weights were then exported to Stata to be used as sampling weights. As we had longitudinal data with repeated measurements for each pair of participants, we assumed equal weighing for all measurements within a pair.

Differences in change over time in outcomes were compared between groups using multilevel models with two-levels: measurements nested within pairs. All models included a main effect of treatment group, a linear term for time and the interaction between time and treatment group. In cases where the interaction between group and time was not significant, a simpler model was fitted including only a main effect of treatment group and a linear effect of time (assuming equal changes over time in the groups). Normality of residuals was assessed by means of QQ-plots. Estimated means were plotted as a function of time separately for the three treatment groups.

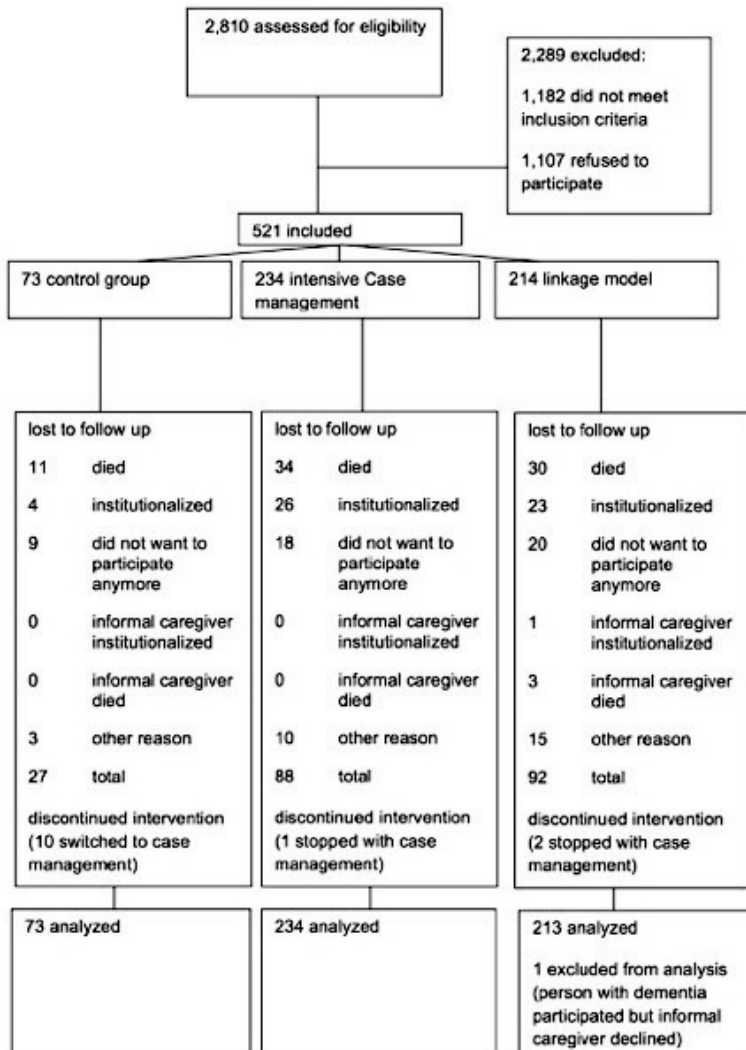
A sensitivity analysis was performed by re-rerunning the main analysis after exclusion of persons that switched treatment group during the two year study.

## RESULTS

### Participant recruitment and flow chart

Participants were recruited from April 2011 to November 2012. Figure 1 reports the number of individuals that were approached. Of the 2,810 caregiver and patient pairs assessed for eligibility, 1,628 met all inclusion criteria and were sent recruitment letters. Five hundred and twenty-one of these individuals agreed to participate (32%) and 1,107 (68%) refused to participate. We had information on the gender of the person with dementia, the gender of the caregiver and the relationship of the informal caregiver to the person with dementia for 1,172 (72%) people that were approached. The only difference we found was that informal caregivers who were the partner to the person with dementia were more willing to participate than those who had another type of relationship ( $\chi^2=11$  df= 1,  $p<0.001$ ).

The number of participants that dropped out was 207 (40%). The main reason for drop out was death (36%). Variables associated with drop out included: lower MMSE, older informal caregiver, older persons with dementia who were men and poorer Katz scores at baseline. There was no significant difference in the number of drop outs between the three groups. There was no difference in rates of institutionalization or death between groups.



**Figure 1** | Study recruitment

Table 1 presents an overview of the baseline characteristics case managers, persons with dementia and their caregivers. Persons with dementia in the case management models were more likely to be older, female, and not married, and had lower education and greater multi-morbidity than those in the control group. Two-thirds ( $n=348$ , 67%) of the informal caregivers were female. In the control group, the informal caregiver was more often a spouse as compared to the case management groups. ( $\chi^2=12.24$   $df=2$ ,  $p=0.002$ ). Seventy percent of the informal caregivers in the control group lived with the person with dementia compared with the LM (49%) or the ICMM (55%) ( $\chi^2=10.03$   $df=2$ ,  $p=0.007$ ).



**Table 1** | Baseline table of characteristics of care models, persons with dementia and caregivers

	<b>Intensive Case Management</b>	<b>Linkage model</b>	<b>Control</b>	<b>Total group</b>	<b>P- value</b>
New clients are referred by GP or health specialist to a centralized registration point	yes	yes	no		
Diagnostic work up	GP	memory clinic/ elderly care physician	GP or memory clinic		
Delivery of dementia related services in one organization	yes	no	no		
Involvement medical specialist?	yes	sometimes	sometimes		
Dementia consultant	yes	sometimes	no		
Elderly care physicians	yes	sometimes	no		
General practitioner	yes	sometimes	yes		
Geriatrician	yes	sometimes	no		
Caseload (SD)	47.2 (13.2)	32.2 (16.2)			< 0.001
Caseload based on a 1 fulltime equivalent/ 5 days (full time is 36 hours)	61.6 (16.7)	53.9 (23.3)			0.106
Person with Dementia	N=234	N=214	N=73	N=521	
Age, mean (SD) <sup>1</sup>	79.9 (7.7)	81.0 (7.5)	75.9 (8.7)	79.8 (7.9)	< 0.001
Female gender, n (%) <sup>2</sup>	122 (52.4)	134 (62.6)	32 (43.8)	288 (55.3)	0.009
Married or in a relationship , n (%) <sup>2</sup>	128 (56.4)	98 (47.8)	51 (70.8)	277 (55.0)	0.003
<b>Living situation</b>					0.065
Living alone, n (%) <sup>2</sup>	92 (40.5)	95 (46.3)	19 (26.8)	206 (41.0)	
Living with another person	130 (57.3)	105 (51.2)	49 (69.0)	284 (56.5)	
Living in an elderly home	5 (2)	5 (2.4)	3 (4.2)	13 (2.6)	
Born in the Netherlands, n (%) <sup>2</sup>	209 (92.1)	178 (86.8)	64 (88.9)	451 (89.5)	0.204
<b>Education, n (%)<sup>2</sup></b>					0.011
Elementary/lower, n (%)	93 (41.9)	99 (49.5)	21 (29.6)	213 (43.2)	
Secondary, n (%) <sup>2</sup>	111 (50.0)	81 (40.5)	37 (52.1)	229 (46.5)	

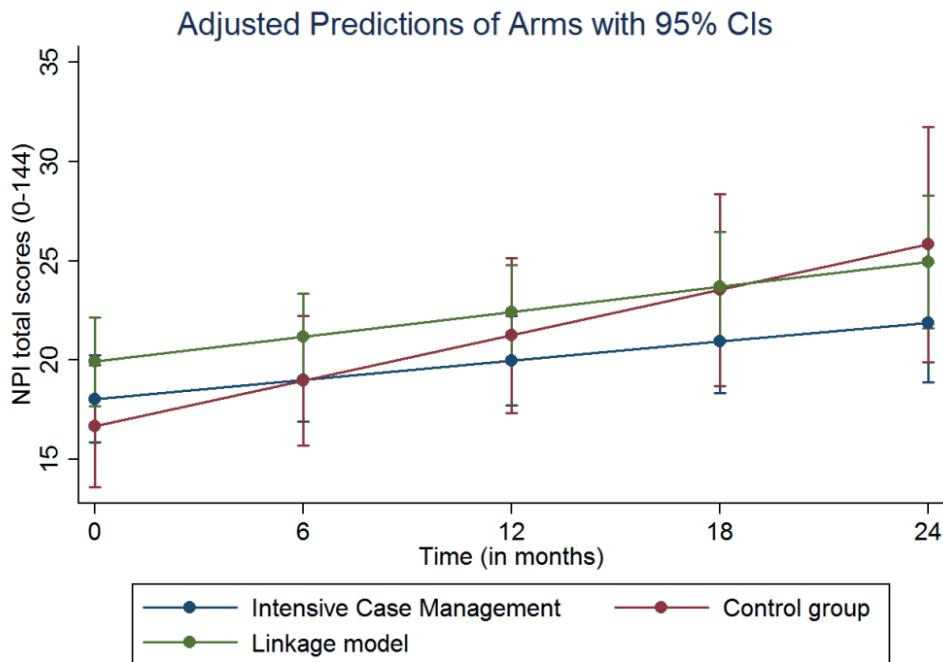
Table 1 | Continued.

	Intensive Case Management	Linkage model	Control	Total group	P- value
Higher/University, n (%) <sup>2</sup>	18 (8.1)	20 (10.0)	13 (18.3)	51 (10.3)	
MMSE, mean (0-30a) (SD) <sup>1</sup>	19.6 (5.5)	18.7 (6.4)	20.4 (4.8)	19.3 (5.8)	0.150
Time since symptoms in years, median (IQR) <sup>3</sup>	3.5 (2.0-5.0)	3.8 (2.0-5.3)	4 (2.7-5.5)	3.7 (2.0-5.2)	0.641
Time since diagnosis in years, median (IQR) <sup>3</sup>	2.4 (1.4-3.7)	2.1 (1.3-3.3)	2.0 (1.3-3.0)	2.3 (1.3-3.5)	0.267
Time in Case Management in years, median (IQR) <sup>4</sup>	2.1 (1.3-3.1)	1.7 (0.42-2.5)	NA	1.8 (1.1-2.8)	< 0.001
Multi-morbidity (more than two diseases),n (%) <sup>2</sup>	203 (88.7)	172 (83.5)	55 (76.4)	430 (84.8)	0.032
Total NPI frequency %*	84.0	86.9	80.6	84.7	0.405
Total NPI severity (0-144a) median (IQR) <sup>1</sup>	13 (5-25)	17 (8-28)	10.5 (4.5-23.5)	14 (6-26)	0.028
Utility from the EQ-5D-Proxy (0-1) a (SD)	0.74 (0.2)	0.71 (0.3)	0.74 (0.2)	0.73 (0.23)	0.299
Utility from persons with dementia (0-1) (SD)	0.82 (0.2)	0.79 (0.2)	0.83 (0.2)	0.81 (0.21)	0.415
QOL-AD proxy (13-52) (SD)	31.89 (5.1)	31.73 (5.2)	32.70 (5.0)	32.0 (5.1)	0.483
<b>Informal Caregiver</b>	<b>Intensive Case Management</b>	<b>Linkage model</b>	<b>Control</b>		<b>P-value</b>
Age (SD) <sup>1</sup>	64.5 (12.8)	64.4 (12.4)	65.8 (11.7)	64.6 (12.5)	0.687
Female gender, n (%) <sup>2</sup>	163 (70.0)	136 (63.6)	49 (67.1)	348 (66.8)	0.390
Spouse of the person with dementia, n (%) <sup>2</sup>	122 (53.3)	94 (45.6)	50 (69.4)	266 (52.5)	0.002
Living together with person with dementia, n (%) <sup>2</sup>	127 (55.5)	100 (48.8)	50 (70.4)	277 (54.9)	0.007
Multi-morbidity (one or more diseases), n (%) <sup>2</sup>	149 (65.1)	119 (57.8)	50 (69.4)	318 (62.7)	0.129
<b>Education, n (%)<sup>2</sup></b>					0.370
Elementary/lower	36 (16.0)	31 (15.3)	10 (13.9)	77 (15.4)	
Secondary	139 (61.8)	127 (62.6)	38 (52.8)	304 (60.8)	
Higher/University	50 (22.2)	45 (22.2)	24 (33.3)	119 (23.8)	

<sup>1</sup>One-way-Anova, <sup>2</sup>Chi-square test, <sup>3</sup>Kruskall-Wallis test, <sup>4</sup>Mann-Whitney test, <sup>5</sup>The underlined scores indicates the more positive outcomes. \*Frequency scores are percentage of the group than have Neuropsychiatric symptoms that are clinically relevant based on NPI total score (frequency\*severity)>3.

### Outcomes for the person with dementia

Estimated means of the total NPI scores over time are plotted over two years (Figure 2). No differences in the rate of change of NPI scores over time between the care groups were found. Differences between the means could therefore be assumed to be constant over time and were estimated to be -0.7 (95% -4.8- 3.5) for ICMM versus control, and 1.7 (95% -2.5- 5.8) for the LM versus the control group, and 2.3 (95% -0.8- 5.4) for LM versus ICMM (Figure 2). The results of the secondary outcomes are available in the supplementary section.



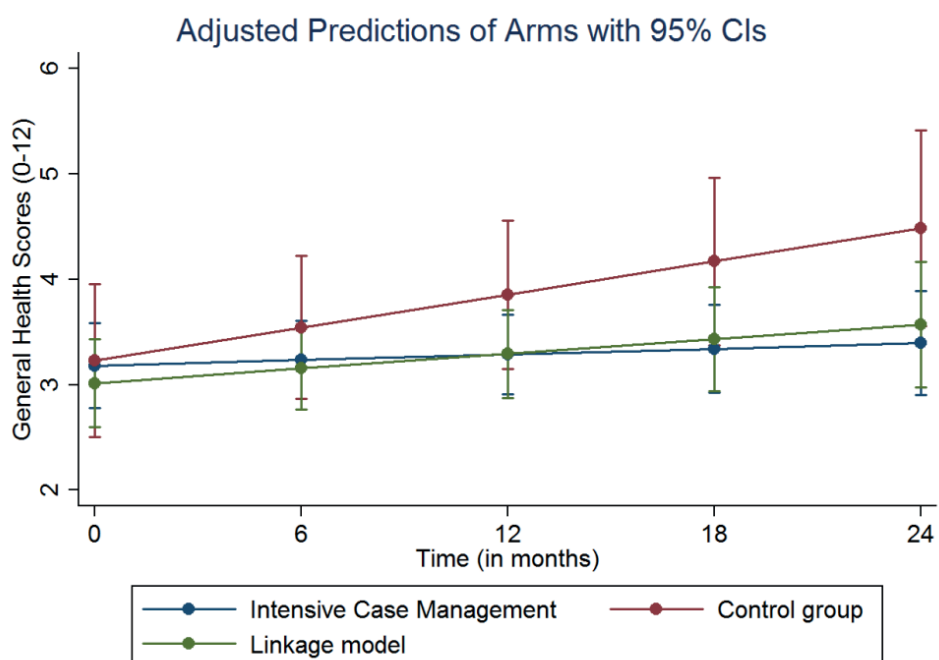
**Figure 2 |** Adjusted Neuropsychiatric symptoms over time.

Intensive Case Management mean NPI baseline value is 18.1 (95% CI: 15.9 – 20.2), and the estimated mean increase is 1.9 of a point per year (95% CI: 0.6 - 3.2). The mean baseline value of the control group is 16.7 (95% CI: 13.6 – 19.7), and estimated mean increase is 4.6 of a point per year (95% CI: 1.9 - 7.2). The Linkage model has mean baseline value is 19.9 (95% CI: 17.7 – 22.2), and the estimated mean increase is 2.5 of a point per year (95% CI: 1.0 - 4.1).

The secondary outcomes are reported in the Supplementary Table s1 and summarized here. Total, met and unmet care needs were less in the ICMM group compared to the control group. Total, met and unmet care needs were less in the LM group versus the control group. This indicates that the control group had more needs overall than the intensive case management group. All other comparisons were not statistically significant.

### Outcomes for informal caregiver

Means scores on the GHQ-12 are plotted in Figure 3. Mean GHQ-12 increased at a faster rate (indicating more psychological complaints) in persons in the control group compared to the ICMM group (time by treatment interaction 0.5 points per year, (95% CI 0.01 - 1.03, p-value =0.047), but with the Bonferoni correction this difference is no longer significant using the pre-specified alpha. There was no difference in mean scores over time between the control group compared with LM group or the LM group versus the ICMM group. The results of the secondary outcomes are available in the supplementary table S1. Mean utility scores for the informal caregiver were 0.02 points per year higher in the ICMM more than the LM (95%CI -0.01- -0.04, p-value=0.0012).



**Figure 3** | Adjusted GHQ-12 scores over time

Intensive Case Management mean GHQ-12 baseline value is 3.2 (95% CI: 2.8 – 3.6), and the estimated mean increase is 0.1 of a point per year (95% CI: -0.1 - 0.4). The mean baseline value of the control group is 3.2 (95% CI: 2.5 – 4.0), and estimated mean increase is 0.6 of a point per year (95% CI: 0.2 - 1.1). The Linkage model has mean baseline value is 3.0 (95% CI: 2.6 – 3.4), and the estimated mean increase is 0.3 of a point per year (95% CI: -0.02 - 0.6).

### Sensitivity analysis

We repeated the original analyses excluding the observations of persons with dementia that switched care groups during the study (n=13). We found no differences in the results for neuropsychiatric symptoms (NPI). Differences between the means could therefore

be assumed to be constant over time and estimated to be 0.9 (95% -3.4- 5.1) for ICMM versus control, and 3.3 (95% -1.0- 7.5) for the LM versus the control group, 2.4 (95% -0.7- 5.4) and for LM versus ICMM.

Differences between the GHQ-12 means were not significant and could therefore be assumed to be constant over time and estimated to be -0.2 (95% -1.0- 0.6) for ICMM versus control, and -0.2 (95% -1.1- 0.6) for the LM versus the control group, -0.03 (95% -0.6- 0.5) and for LM versus ICMM.

## DISCUSSION

### Key results

This study was the first to evaluate the clinical outcomes in pairs of persons with dementia and their primary informal caregiver receiving two types of case management versus pairs in a control group with no access to case management. The analyses showed no differences in NPI scores in persons with dementia between the control group, the intensive case management group (IC) and the Linkage model (LA). However, in informal caregivers, the control group performed worse on the GHQ-12 than the ICMM group although the significant effect was lost when corrected for multiple groups and when persons who switched groups during the study were excluded. There was no difference in psychological health (GHQ-12 scores) between the LM group and the control group or the LM versus the ICMM group. In all three groups, mean GHQ-12 scores were far above the suggested cut-off point for the GHQ-12 of one or two points to identify people with mental health problems (27,28) which indicates that the informal caregivers were already at increased risk of mental health problems at the start of the study.

### Comparison with literature

Previously, several reviews and meta-analyses have been performed to evaluate costs and effects of case management in many different countries on a variety of outcomes (6-8). Callahan compared case management to a control group in the US and showed a decrease in NPI scores at 12 months in the case management group whereas in our study over two years the NPI total score went up in all 3 groups. A possible alternative explanation for Callahan's effect was the large amount of antipsychotics prescribed in the intervention group. So it might reflect not so much the psychosocial but the medical component of case management. It is possible that participants in our study had more behaviour problems as total NPI mean baseline scores were higher in our population compared to the patient population in Callahan et al (29).

A review which included both qualitative and quantitative studies looked at facilitators and barriers to successful case management implementation in the primary health care setting (10). Results indicated that high intensity case management was necessary and sufficient to produce positive clinical outcomes for patients and to optimize service use. The reviewers described high intensity case management as 1) a caseload of less than 50 patients per full-time equivalence 2) regular meetings with the informal caregiver

and the patient with at least 50% of these meetings being face to face 3) education on health conditions (4) close contact with family physicians (10,30) (5) proactive and timely follow-up (10,31) and following up with patients during hospitalizations and short-term institutionalizations (10,32). In our study, both case management groups exceed this case load recommendation and it is unclear how they rate on the other factors. The average caseloads being over the recommendation of the review could be a possible reason for there being little difference between all groups.

Reviews of case management show mixed results which may be due to the complex nature of the number of psychometric scales used to assess the effect of the interventions and the individualized customization of interventions to the needs of the informal caregiver and the person with dementia (7,33).

### **Limitations and strengths**

The Dutch Ministry of Healthcare stipulated in 2008 that “any form of case management” had to be part of usual care for persons with dementia in all regions in the Netherlands at the end of 2011. By 2011, case management was available in the majority of regions and sub regions although there were still regions where case management was not yet implemented or had limited capacity. Moreover, 14% of the participants in the control group switched into case management over time. However, a sensitivity analysis excluding these participants led to the same results. The observational design of the study may have led to baseline differences as well as selection bias. By using propensity scores, we tried to overcome this in the analyses. As we were comparing multiple groups, we took a conservative estimate by using a Bonferoni correction although this results in a loss of power.

In this study, persons with dementia and their informal caregivers were followed over a period of 2 years. This is a relatively long period of time and provides good insight into the course of NPI scores of persons with dementia and mental health of informal caregivers over time. Despite this long period of follow-up, dropout levels were relatively low. Another strength is that the case management models were implemented for many years already at the time of this study. Therefore, the results have high external validity. The wide range of secondary outcomes assessed in this study provides relevant insights into the problems of persons with dementia and their informal caregivers. Finally, the use of multilevel analyses with an adjustment for time allowed us to use all available data and to estimate effects over time.

### **Implications for research and practice**

Our results show that there were no differences in NPI scores between the two case management groups and the control group. Although GHQ-12 scores in the ICMM model were better than in the control group, this difference was not statistically significant when taking into account the necessary Bonferoni correction.

It is widely known in literature that prolonged high stress levels in caregivers is one of the highest risk factor for nursing home admission (34,35). The fact that GHQ-12 scores

were above the cut off scores during all times and interviews indicate that all caregivers experienced high psychological stress levels. Therefore, increased focus on more effective caregiver support is recommended. When we look at effective ways to deal with caregiver burden there have been no clear effective solutions. Some interventions are more effective in certain subgroups of informal caregivers, so it is important to align the support to needs and characteristics of the caregivers (36). In a review by Brodaty et al (37), it was concluded that non- pharmacological interventions taught to family caregivers could reduce the frequency and severity of behavioral and psychological symptoms of dementia as well as improve caregiver responses to these behaviors.

From previous meta-analyses and reviews we know that intervention programs that focus on 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 (38). The most successful interventions used a psycho-educational or psychotherapeutic approach, addressed multiple stressors, were better adapted to the individual needs of the caregivers and provided a higher amount and intensity of support (39,40). A review by Pinquart and Sörensen (6) found that psychoeducational interventions have the widest-ranging effects, but only if they call for active participation of the informal caregiver.

## CONCLUSION

Our study found no differences between groups in primary outcomes. However the analysis of the secondary outcomes indicated that there might be positive effects in the intensive case management as compared to the other two groups on quality of life, unmet, met and total care needs. This warrants further research.

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## SUPPLEMENTARY SECTION

### Comparison of the two year secondary outcomes

The means and their standard deviation are reported separately per group per time combination and the p-value indicating whether there was a difference between groups over time in Supplementary Table S1.

Intensive Case Management mean unmet needs baseline value is 1.1 (95% CI: 0.9 – 1.3), and the estimated mean decrease is -0.1 of a point per year (95% CI: -0.2 - 0.01). The mean baseline value of the control group is 0.7 (95% CI: 0.4 – 0.9), and estimated mean increase is 0.3 of a point per year (95% CI: 0.1 - 0.5). The Linkage model has mean baseline value is 1.5 (95% CI: 1.2 – 1.7), and the estimated mean increase is 0.04 of a point per year (95% CI: -0.2 - 0.3). Mean unmet needs were -0.04 points per year less in the IC group compared to the control group (95%CI -0.05 - -0.02, p-value=0.0001). Mean unmet needs were -0.02 points per year less in the LM group compared to the control group (95%CI -0.05 - -0.0004, p-value=0.046).

Intensive Case Management mean met needs baseline value is 7.7 (95% CI: 7.3 – 8.1), and the estimated mean increase is 0.2 of a point per year (95% CI: -0.02- 0.4). The mean baseline value of the control group is 7.7 (95% CI: 6.8 – 8.6), and estimated mean increase is 0.9 of a point per year (95% CI: 0.4- 1.4). The Linkage model has mean baseline value is 8.4 (95% CI: 8.1 – 8.8), and the estimated mean increase is 0.3 of a point per year (95% CI: 0.1- 0.6). Mean met needs were -0.06 points per year, less in the IC group than the control group (95%CI -.10- -0.02, p-value=0.009). Mean met needs were -0.05 points per year, less in the LM group than the control group (95%CI -.10- -0.02, p-value=0.042).

Intensive Case Management mean total needs baseline value is 8.8 (95% CI: 8.4 – 9.21), and the estimated mean increase is 0.1 of a point per year (95% CI: -0.1- 0.3). The mean baseline value of the control group is 8.4 (95% CI: 7.5 – 9.2), and estimated mean increase is 1.2 of a point per year (95% CI: 0.7- 1.8). The Linkage model has mean baseline value is 9.9 (95% CI: 9.5 – 10.4), and the estimated mean increase is 0.4 of a point per year (95% CI: 0.1- 0.7). Mean total needs were 1.2 points per year less in the IC group compared to the control group (95%CI -1.72- -0.58, p-value=0.0001). Mean total needs were -0.9 points per year less in the LM than the control group (95%CI -1.45- -0.26, p-value=0.005).

Intensive Case Management mean utility baseline scores for the informal caregiver is 0.8 (95% CI: 0.8 – 0.9), and the estimated mean increase is 0.002 of a point per year (95% CI: -0.01- 0.01). The mean baseline value of the control group is 0.9 (95% CI: 0.8 – 0.9), and estimated mean decrease is 0.02 of a point per year (95% CI: -.05- -0.001). The Linkage model has mean baseline value is 0.9 (95% CI: 0.8 – 0.9), and the estimated mean decrease is 0.02 of a point per year (95% CI: -.04- -0.008). Mean utility scores for the informal caregiver were 0.02 points per year higher in the IC group more than the control group (95%CI -0.01--0.04, p-value=0.0012).

A total of 116 persons with dementia (22.3%) were institutionalized during the study period, and institutionalisation did not differ between groups. When applying a best case or worst case scenario for persons with missing values on this outcome, no significant difference between the groups was found.

**Supplementary table S1** | Secondary outcomes unadjusted means and determination if there is a treatment effect

Variable	time	Control			ICMM			LM			Time*treatment interaction			
		n	Mean	SD	n	Mean	SD	n	Mean	SD	IC vs. CTRL	LM vs. CTRL	LM vs IC	
Person with dementia														
NPI distress scores (0-60)*														
NPI-D 0	0	72	8.5	8.5	231	9.1	8.2	213	11.0	9.3	0.087	0.108	0.967	
NPI-D 1	6	61	11.1	9.2	192	8.7	8.2	163	10.2	9.7				
NPI-D 2	12	57	11.1	8.5	171	8.3	8.2	140	10.0	8.6				
NPI-D 3	18	48	10.0	10.2	146	9.0	8.5	118	10.8	8.8				
NPI-D 4	24	43	9.8	10.4	144	8.3	8.0	112	10.8	10.3				
Informal caregiver utility (0-1)														
informal caregiver utility 0	0	71	0.9	0.2	225	0.8	0.2	202	0.9	0.2	0.054	0.987	0.012	
informal caregiver utility 1	6	60	0.8	0.2	191	0.8	0.2	167	0.8	0.2				
informal caregiver utility 2	12	59	0.8	0.2	192	0.8	0.2	147	0.8	0.2				
informal caregiver utility 3	18	56	0.8	0.2	168	0.8	0.2	134	0.8	0.2				
informal caregiver utility 4	24	49	0.8	0.2	153	0.8	0.2	125	0.8	0.2				
Short sense of competence questionnaire (SSCQ) (7-35) (SD)														
Sense of Competence 0	0	68	4.6	2.0	226	4.7	2.0	202	4.5	1.9	0.812	0.922	0.646	
Sense of Competence 1	6	61	26.0	5.9	187	26.6	5.5	155	26.6	5.0				
Sense of Competence 2	12	56	26.9	4.9	167	26.5	5.6	138	26.3	5.2				
Sense of Competence 3	18	50	27.5	4.9	149	26.8	5.0	121	26.0	5.0				
Sense of Competence 4	24	45	27.6	4.5	133	27.0	4.8	109	26.3	5.3				

Supplementary table S1 | Continued.

Variable	time	Control			ICMM			LM			Time*treatment interaction		
		n	Mean	SD	n	Mean	SD	n	Mean	SD	IC vs. CTRL	LM vs. CTRL	LM vs IC
Pearlin Mastery Scale (5-25) (SD)													
Pearlin Sense of Mastery 0	0	70	18.4	4.7	224	19.0	4.1	202	19.0	4.1	0.949	0.381	0.160
Pearlin Sense of Mastery 1	6	60	17.9	4.6	184	18.6	4.4	154	19.2	4.0			
Pearlin Sense of Mastery 2	12	56	17.9	4.4	168	18.7	4.3	139	18.5	4.3			
Pearlin Sense of Mastery 3	18	48	17.5	4.8	149	18.5	4.3	122	18.0	4.2			
Pearlin Sense of Mastery 4	24	44	17.5	5.0	137	18.5	4.2	109	18.1	4.6			
Loneliness Scale (SD) (0-11)													
Loneliness 0	0	70	3.5	3.3	232	3.7	3.6	208	3.9	3.7	0.322	0.174	0.556
Loneliness 1	6												
Loneliness 2	12	55	4.8	3.6	167	3.7	3.4	136	3.4	3.3			
Loneliness 3	18												
Loneliness 4	24	45	4.2	3.3	136	3.7	3.6	108	3.8	3.5	0.320	0.588	0.506
Modified KATZ ADL (0-6)													
Katz 6 0	0	72	2.3	1.6	228	2.3	1.5	204	2.6	1.9			
Katz 6 1	6	39	1.8	2.0	146	1.6	1.7	106	1.9	1.7			
Katz 6 2	12	57	2.1	2.2	165	1.9	1.8	139	2.2	1.9			
Katz 6 3	18	49	2.6	2.2	151	2.1	1.9	121	2.2	1.9			
Katz 6 4	24	45	2.6	2.2	135	2.1	1.9	108	2.6	1.9			
Modified KATZ IADL+ADL (0-15)													
											0.246	0.319	0.808

Supplementary table S1 | Continued.

Variable	time	Control			ICMM			LM			Time*treatment interaction		
		n	Mean	SD	n	Mean	SD	n	Mean	SD	IC vs. CTRL	LM vs. CTRL	LM vs IC
Katz 15 0	0	69	6.4	3.6	227	6.9	3.5	202	7.5	3.7			
Katz 15 1	6	55	8.3	4.4	158	8.1	3.6	137	8.9	3.4			
Katz 15 2	12	37	7.9	4.0	142	7.5	3.5	101	8.3	3.2			
Katz 15 3	18	47	8.6	4.3	146	8.4	3.6	118	9.1	3.5			
Katz 15 4	24	43	9.1	4.1	132	8.7	3.3	104	9.5	3.5			
CareerQOL (SD) (15-100)											0.812	0.833	0.991
Careqol0	0	66	78.3	15.9	219	79.1	15.3	203	78.7	16.0			
Careqol1	6	59	76.3	15.0	181	79.9	14.8	152	80.8	15.4			
Careqol2	12	56	77.9	16.1	161	79.0	16.8	132	79.8	17.0			
Careqol3	18	46	77.6	15.6	148	78.6	14.2	118	78.5	16.7			
Careqol4	24	45	78.6	14.8	130	80.0	14.1	108	78.6	18.1			
Person with dementia													
QOL-AD proxy (13-52) (SD)											0.247	0.937.	0.094
proxy Qol-AD 0	0	56	32.7	5.0	161	31.9	5.1	139	31.7	5.2			
proxy Qol-AD 1	6	61	30.9	5.6	192	31.2	5.2	163	31.0	5.4			
proxy Qol-AD 2	12	56	31.2	5.0	166	31.4	4.8	141	29.4	4.9			
proxy Qol-AD 3	18	49	31.3	5.0	140	30.9	4.9	119	29.7	4.8			
proxy Qol-AD 4	24	43	31.1	5.5	129	31.2	4.9	107	29.2	4.8			
Total unmet needs CANE-proxy (0-24)											0.0001	0.046	0.216

Supplementary table S1 | Continued.

Variable	time	Control			ICMM			LM			Time*treatment interaction		
		n	Mean	SD	n	Mean	SD	n	Mean	SD	IC vs. CTRL	LM vs. CTRL	LM vs IC
CANE Unmet needs 0	0	70	0.8	1.3	230	1.0	1.6	209	1.8	2.2			
CANE Unmet needs 1	6	59	0.6	1.1	191	1.2	2.0	164	1.1	1.6			
CANE Unmet needs 2	12	56	0.9	1.2	169	0.9	1.5	141	1.1	1.4			
CANE Unmet needs 3	18	49	1.0	1.3	147	0.9	1.2	124	1.7	1.8			
CANE Unmet needs 4	24	44	1.4	1.4	136	0.8	1.2	109	1.7	2.0			
Total met needs CANE-proxy (0-24)											0.009	0.042	0.484
CANE met needs 0	0	70	7.7	3.7	230	7.6	3.2	209	8.2	3.1			
CANE met needs 1	6	59	8.2	3.4	191	7.6	3.2	164	8.6	2.9			
CANE met needs 2	12	56	8.6	3.2	169	8.1	3.4	141	8.8	3.1			
CANE met needs 3	18	49	8.8	3.0	147	7.5	3.1	124	8.6	2.9			
CANE met needs 4	24	44	9.3	2.7	136	7.4	2.9	109	8.7	2.8			
Total need (met and unmet needs) CANE person with dementia (0-24)											0.0001	0.005	0.129
CANE total needs 0	0	70	8.5	3.9	230	8.6	3.6	209	10.0	3.4			
CANE total needs 1	6	59	8.8	3.4	191	8.8	3.4	164	9.7	3.1			
CANE total needs 2	12	56	9.5	3.2	169	9.0	3.7	141	9.9	3.0			
CANE total needs 3	18	49	9.8	3.1	147	8.3	3.4	124	10.2	3.0			
CANE total needs 4	24	44	10.7	3.1	136	8.2	3.1	109	10.5	3.0			

\* Underlined scores indicate being better off.