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Baseline characteristics of a cohort of primary care patients with dementia receiving case management or no access to case management

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ABSTRACT

Background

Various care models for dementia exist in the Netherlands but it is unknown how they differ. This article describes and compares the baseline characteristics of persons with dementia and their informal caregivers who receive no case management or one of two types of case management.

Methods

A prospective, observational, controlled, cohort study where demographic and clinical data (n=521) were assessed using chi-squares for categorical variables, analysis of variance for continuous variables and Kruskal-Wallis or Mann-Whitney U tests for skewed non-normal variables.

Results

Mean age of persons with dementia was 80 years (range 54-97), and 55% were female. Mean age of informal caregivers was 65 (range 22-91), and 67% were female. Time in case management was 2.1 years (IQR: 1.3-3.1) in the intensive case management model and 1.7 years (IQR:0.42-2.5) in the linkage model (Mann-Whitney U=4.4, $P<0.0001$). Persons with dementia in case management were more likely to be older, female, single, with lower education and had greater multi-morbidity than those solely under general practitioner care (control group) (n=521). Median Neuropsychiatric Inventory (NPI) scores were 13 (IQR: 5 - 25) for intensive case management, 17 (IQR: 8 - 28) for linkage and 10.5 (IQR: 4.5 – 23.5) for the control group. Distribution of NPI scores was found to differ between the three models (Kruskal-Wallis $\chi^2(2, 513) = 7.146, p=0.03$). Despite overall significance of the Kruskal Wallis test, post-hoc comparisons using Mann-Whitney test and bonferroni correction for multiple testing did not show significant differences in the NPI score distributions between any pair of models. There were no differences in general health (GHQ-12) between informal caregivers with and without case management.

Conclusion

Persons with dementia in case management appeared more vulnerable than those in the control group, based on higher total NPI scores, increased age, living alone and presence of multi-morbidity.

1. INTRODUCTION

Dementia is a chronic and devastating brain disorder marked by memory loss and other cognitive impairments as well as behavioral lapses resulting in pronounced consequences for the people with dementia, their families and society. Dementia is ranked third in the top ten reasons of death in the Netherlands, next to lung cancer and coronary heart disease (1). Dementia and mental retardation are the most expensive single chronic conditions in the Dutch health care system (2). In 2013, the cost of dementia care was around four billion euros which was 5% of total Dutch health care costs. These costs are expected to increase by 2.7% per year because of the rising prevalence of dementia (3).

There are approximately 256 thousand persons with dementia in the Netherlands who live on average for eight years after they have been diagnosed and this number is expected to double by 2040. Approximately 70% of persons with dementia live at home for approximately five years and are partly cared for by their family (3-5). There are around 300 thousand informal caregivers who provide care to their loved ones with dementia for approximately 20 hours a week, and half of these informal caregivers manages to combine this with a job and/or caring for others, i.e. children (3,6-8). Around 78 percent of these caregivers are overburdened or at high risk and this is one of the major determinants for persons with dementia to go to a nursing home (8). Although there is a wide variety of services available for people with dementia and informal caregivers, people often lack information regarding the available services that address their needs and many experience insufficient alignment, management and continuity of care and support during the disease trajectory (9-11). It is essential that the various types of care and supporting disciplines involved in the disease management of people with dementia collaborate with informal caregivers to provide optimal care. This has led to the development of different case management programmes in various regions in The Netherlands.

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 cost effective outcomes”(12). It strives to provide pro-active care coordinated by a case manager who is supported by a multidisciplinary team of providers of elderly care (e.g. general practitioner, psychologist, psychiatrist, geriatrician, or neurologist). The Dutch Ministry of Healthcare stipulated 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 (13). 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 (14). At that time no special financial agreements for case management were decided by the health insurance companies.

Until now, several studies have been performed to evaluate costs and effects of case management in many different countries (15-19). However, reviews and meta-analyses

have yielded inconsistent results of case management on patient and caregivers outcomes such as institutionalization, hospitalization, caregiver burden, depression, and economic outcomes (15-19).

In the Netherlands, patients and caregivers have been shown to be highly satisfied with case management (20). However, various models of case management are implemented, that differ with respect to how services are delivered and by whom, the training provided to its staff and the means of financing. It is unknown whether there are also differences in clinical and cost-effectiveness between these case management models and compared with general practitioner care. In the COMPAS study (Case management of dementia patients and their caregivers), the two most prominent case management models in the Netherlands are compared with no access to case management and with each other to identify differences in clinical and cost outcomes for people with dementia and informal caregivers after 24 months (21). These two models are the linkage model and the Intensive case management model (see methods section for detailed explanation). The objective of this current paper was to describe and compare the baseline characteristics of the persons with dementia and their informal caregivers included in the COMPAS study stratified by the three models of care.

2. METHODS

2.1 Study design

This study was a prospective, observational, controlled, cohort study to evaluate the clinical effects and costs of case management models versus no access to case management. Persons with dementia and their primary informal caregivers receiving different forms of case management models were compared with those who had no access to case management in this study. Persons were recruited in regions with and without access to case management. Study participants were followed for two years. The Medical Ethics Committee of the VU University medical center approved the study protocol.

2.2 Participants and setting

Dyads of persons with dementia and their primary informal caregiver in the case management groups were recruited from regions in the Netherlands that adopted one of the case management models evaluated in this study. Case managers of the participating organisations provided lists of patients who were eligible to participate. Recruitment took place via outpatient geriatric or neurologic (memory) clinics, Alzheimer centers and general practices for persons with dementia that were in the control group. 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 long term care facilities 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. Persons with dementia and their caregivers were recruited from various regions in the North, West and Center of the Netherlands that comprise both rural and urbanized areas.

2.3 Care models

The case management models that were evaluated in this study as well as the control group are described below and their main characteristics are summarized in Table 1. Semi-structured interviews were conducted with 73 case managers from both case management models to provide greater insight on their level of education, how many hours they worked, what kinds of tasks they performed and job satisfaction. For more detail about the case management models, see MacNeil-Vroomen et al. 2012 (21) and Van Mierlo et al. (22).

2.3.1 Linkage model

The linkage model arose from independent care providers (e.g. home care organizations) who were already providing health care services in the region and who then were given the mandate to initiate case management services. Case management services were divided between care providers and a board of representatives was set up to structure the collaboration (22). Case managers can choose to give referrals for example for homecare, to their own care provider or to other care providers in the area. Case managers sometimes work part-time as a case manager and had another function like psychiatric nurse the rest of the week. Case managers offer the caregiver and patient informative, practical, and emotional support (23). In the linkage model, the case management starts directly after the patient receives the diagnosis of dementia (24). The case manager assesses the need for acute help during a telephone intake interview (24). During an interview at the patient's home a care and support plan is created that encompasses problems, needs, goals and interventions. Case managers facilitate care by referring patients and their caregivers to various providers of health, social or community care until time of nursing home admission or death of the patient.

2.3.2 Intensive Case Management Model and Joint Agency Model

The second case management model under study is a mix of two existing models: the intensive case management model and joint agency model (23). Case managers in the intensive case management model, guide and support people with dementia for long periods of time and provide care services within one organization (23). The joint agency model is based on the concept that the case manager works in collaboration with a multidisciplinary team to tailor care needs of the person with dementia (Table 1) (23). In this mixed model, the case management process starts with a referral from the general practitioner or a specialist requesting a diagnosis for possible cognitive impairment or (type of) dementia from the multidisciplinary team within the case management organization (24). The multidisciplinary team depending on the situation can consist of a psychiatrist, a psychologist, a geriatrician, a dementia specialist consultant, an activity coordinator, an elderly care physician, a physiotherapist, case managers, nurses and a nutritionist. After the initial assessment, which is predominantly based on the DSM-IV diagnostic criteria, a care plan is created by the case manager together with the informal care giver(s) and patient (24). The care plan includes problem and needs areas including social needs, intervention possibilities and yearly goals (24). The care plan is communicated with

the general practitioner. Implementation of the complete care plan is done by the case manager. Case managers in dementia care often work solely in dementia care and do have no other function. Like the linkage model, the patient and their family are mainly supported by the case manager until nursing home admission or death of the patient (24).

Table 1 | Characteristics of models of care

Characteristics of the different models	Intensive case management/joint agency model	Linkage model	Control group
New clients are referred by GP or health specialist to a centralised registration point	yes	yes	no
Diagnostic work up done in a multidisciplinary team	yes, mostly	no	no
Diagnostic work up done by a GP	sometimes	rarely	rarely
Diagnostic work up done by a memory clinic or elderly care physician	rarely	mostly yes	sometimes
Delivery of dementia related services in one organization	yes	no	no
Presence of case manager	yes	yes	no
Presence of a nurse practitioner	rarely	rarely	sometimes
Position of the multi-disciplinary team?	multidisciplinary team in one organization	expert team that case managers can consult. Not always operating in the same organization. Frequency of consultation varies.	no
Involvement medical specialist?	yes	sometimes	sometimes
Case manager	yes	yes	no
Dementia consultant	yes	sometimes	no
Elderly care physicians	yes	sometimes	no
General practitioner	yes	Sometimes	yes
Geriatrician	yes	sometimes	no

2.3.3 No access to case management (control group)

General practitioner care (the control group) is defined in this study, as “care that is primarily provided or coordinated by the general practitioner and, as a rule, does not include access to a case manager” (25). General practitioner care is care according to the guidelines for dementia patients from the Dutch College of General Practitioners (25,26). Care may be monitored by a nurse working in the general practice in addition to the general practitioner. Similar to the described models, patients have access to community services such as home care, day care or meeting centers for people with dementia and

their caregivers (21). A social psychiatric nurse from mental health services is sometimes available for people with dementia that have severe behavioral problems. Patients in the control group did not receive case management at study entry.

2.4 Measuring instruments

Patients and 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 too cognitively impaired. Persons who were unable to understand and reproduce the study goals were considered mentally incompetent.

2.4.1 Measurements at the person with dementia level

Table 2 presents an overview of the baseline characteristics of the persons with dementia and their caregivers including the scale ranges and their interpretation. Information on the dementia diagnosis and other baseline information were gathered from the informal caregiver. The caregiver was asked when they noticed first symptoms and the time of a professional diagnosis.

The Neuropsychiatric Inventory is a measure to assess neuropsychiatric symptoms in persons with dementia (27). These 12 symptoms include delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night-time behaviour disturbances, and eating abnormalities (27). Information from the NPI is obtained from a caregiver familiar with the person with dementia's behaviour (27). It assesses presence, frequency, severity and the symptom specific caregiver distress in the previous month (27). The frequency rating is from 1 (occasionally or less than once a week) to 4 (very frequently, more than once a day or continuously) (27). The severity score is a 3 point scale categorized as mild, moderate or severe. The stress to the caregiver is rated from 0 (no distress) to 5 (very distressful). The domain score per neuropsychiatric symptom is calculated by multiplying the frequency by the severity score. Calculation of the total score is the sum of the 12 domain scores which ranges from 0-144 with higher scores indicating more problems [24]. For the purposes of comparison with previous literature (28,29) an individual domain score (frequency*severity) greater than 3 was considered to be a "clinically-relevant" per symptom and total score.

Generic Quality of life was measured by the EQ-5D (EuroQoL) including the cognitive dimension (30), and disease specific quality of life was measured using the QoL-AD (Quality of life in Alzheimer's Disease) (31). The EQ-5D was converted to a utility score using the Dutch EQ-5D tariff which is based on a time-trade off tool (32). Quality of life questionnaires were administered to the person with dementia as well as the primary caregiver filled it in as a proxy. Number of met and unmet care needs were assessed using the Camberwell assessment of needs for the elderly (CANE) (11,33) which was administered to both the person with dementia and the primary caregiver proxy.

2.4.2 Measurements at the informal caregiver level

Psychological stress of the primary informal caregiver was measured by the General Health Questionnaire (GHQ-12) (34) The GHQ-12 comprises three domains: social dysfunction, anxiety and loss of confidence (35). The scoring method is a four-point response method (35).

The sense of competence to care was measured by the Short Sense of Competence Questionnaire (SSCQ (36)), Empowerment was measured by the Pearlin Mastery scale (37) and quality of life by the CarerQoI (38) and EQ-5D (39).

2.5 Data analyses

Demographic, clinical and prognostic characteristics between 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 variables were skewed such as variables that were based on time. Post-hoc comparisons using Mann-Whitney tests and a bonferroni correction for multiple testing were used to determine significant differences in the NPI score distributions between any pair of models.

3. RESULTS

3.1 Participant recruitment and flow chart

Participants were recruited from April 2011 to November 2012. Figure 1 reports the number of individuals that were approached for eligibility, excluded and included into the study. Of the 2,810 caregiver and patient dyads assessed for eligibility, 1,628 met all inclusion criteria and were sent recruitment letters. Five hundred and twenty-one of these individuals were willing to participate (32%). Of these dyads, 360 persons with dementia were willing to be interviewed (69%). We had information on the relationship of the informal caregiver to the person with dementia for 1,172 people that were approached. Informal caregivers that were married or 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, $p<0.001$).

Informal caregivers who were approached were asked to provide a reason for not participating (shown in Figure 1). The main reason for non-participation ($n=266$) was that participating in the study was considered too burdensome for them.

3.2.1 Baseline characteristics and measurements at the person with dementia level

At baseline 288 (55.3%) of the persons with dementia were female. The mean age was 79.8 years (SD 7.9, range 54-97). Persons with dementia in case management were more likely to be older, female, and not married, and had lower education and greater multimorbidity than those in control group. Mean unmet needs were highest in the linkage model when compared to the other two groups ($\chi^2=41.3$ degrees of freedom (df) =2, $p<0.0001$). Persons with dementia were enrolled in the intensive case management groups were in case management longer than individuals in the linkage model (2.1 years (IQR: 1.3-3.1) vs. 1.7 years (IQR: 0.42-2.5) Mann-Whitney U = 4.4, $P<0.0001$).

Median NPI scores were 13 (IQR: 5 - 25) for intensive case management, 17 (IQR: 8 - 28) for linkage and 10.5 (IQR: 4.5 - 23.5) for the control group. Distribution of NPI scores was found to differ between the three models (Kruskal-Wallis $\chi^2(2, 513) = 7.146$, $p=0.03$). Despite overall significance of the Kruskal Wallis test, post-hoc comparisons using Mann-Whitney test and bonferroni correction for multiple testing did not show significant differences in the NPI score distributions between any pair of models.

Approximately 7% of the persons with dementia in the intensive case management model, 6.1% in the linkage model and 5.6% in the control group did not have neuropsychiatric symptoms at baseline as measured with the NPI (6.5% of the total group ($n=516$)). Approximately 85% (439/516) of the persons with dementia had one or more clinically relevant neuropsychiatric symptoms. The most frequent clinically relevant symptoms were: 41.1% eating problems (212/516), 31.4% apathy (162/516), and 26.7% aberrant motor behaviour (138/516) (see Table 3). Euphoria was the least frequently reported symptom in the total group at baseline.

3.2.2 Baseline characteristics and measurements at the informal caregiver level

Table 2 provides demographic, clinical and social characteristics of the informal caregivers and the persons with dementia. Two-thirds (348, 66.8%) of the informal caregivers were female. The mean age of the informal caregivers was 64.6 years (SD 12.4 range 22-91). 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 linkage model (49%) or the intensive case management model (55%) ($\chi^2=10.03$ df= 2, $p=0.007$). Scores on the general health questionnaire were similar across groups.

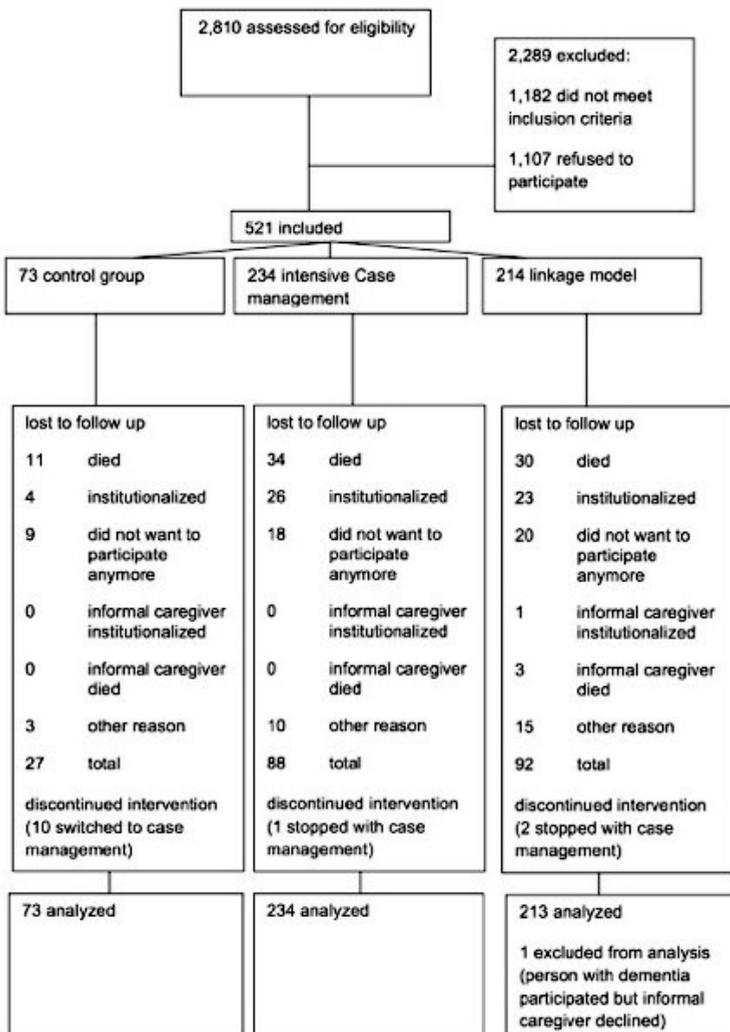


Figure 1 | The amount of individuals that were approached, excluded and included into the COMPAS study

Table 2 | Baseline table of characteristics of persons with dementia and caregivers

Person with Dementia	Intensive Case Management N=234	Linkage Model N=214	Control group N=73	Total group N=521	P- value
Age, mean (SD) ¹	79.9 (7.7)	81.0 (7.5)	75.9 (8.7)	79.8 (7.9)	< 0.001
Female gender, n (%) ²	122 (52.4)	134 (62.6)	32 (43.8)	288 (55.3)	0.009
Married or in a relationship, n(%) ²	128 (56.4)	98 (47.8)	51 (70.8)	277 (55.0)	0.003
Living situation					0.065
Living alone, n (%) ²	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 (%) ²	209 (92.1)	178 (86.8)	64 (88.9)	451 (89.5)	0.204
Education, n(%)²					0.011
Elementary/ lower, n (%)	93 (41.9)	99 (49.5)	21 (29.6)	213 (43.2)	
Secondary, n (%) ²	111 (50.0)	81 (40.5)	37 (52.1)	229 (46.5)	
Higher/University, n (%) ²	18 (8.1)	20 (10.0)	13 (18.3)	51 (10.3)	
MMSE, mean (0-30a) (SD) ¹	19.6 (5.5)	18.7 (6.4)	20.4 (4.8)	19.3 (5.8)	0.150
Modified KATZ ADL (0-15) (SD) ¹	6.8 (3.5)	7.4 (3.7)	6.4 (3.6)	7.0 (3.6)	0.070
Time since symptoms in years, median (IQR) ³ ,	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) ³	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) ⁴	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 (%) ²	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) ¹	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
Total need (met and unmet needs) CANE-proxy (0-24)(SD)	8.6 (3.6)	10.0 (3.4)	8.5 (3.9)	9.2 (3.6)	0.0001
Total met needs CANE-proxy (0-24)(SD)	7.6 (3.2)	8.2 (3.1)	7.7 (3.7)	7.9 (3.2)	0.120
Total unmet needs CANE-proxy (0-24)(SD)	1.0 (1.6)	1.8 (2.2)	0.8 (1.3)	1.3 (1.9)	0.0001
Total need (met and unmet needs) CANE person with dementia (0-24)(SD)	5.7 (3.3)	6.3 (3.4)	5.5 (3.2)	5.9 (3.4)	0.236

Table 2 | Continued

Total met needs CANE person with dementia (0-24)(SD)	5.1 (3.1)	5.7 (3.2)	5.2 (3.2)	5.3 (3.1)	0.274
Total unmet needs CANE person with dementia (0-24)(SD)	0.6 (1.1)	0.6 (1.1)	0.3 (0.6)	0.6 (1.1)	0.273
Informal Caregiver	Intensive Case Management	Linkage model	Control group		P- value
Age (SD) ¹	64.5 (12.8)	64.4 (12.4)	65.8 (11.7)	64.6 (12.5)	0.687
Female gender, n (%) ²	163 (70.0)	136 (63.6)	49 (67.1)	348 (66.8)	0.390
Spouse of the person with dementia, n (%) ²	122 (53.3)	94 (45.6)	50 (69.4)	266 (52.5)	0.002
Living together with person with dementia, n (%) ²	127 (55.5)	100 (48.8)	50 (70.4)	277 (54.9)	0.007
Multi-morbidity (one or more diseases), n (%) ²	149 (65.1)	119 (57.8)	50 (69.4)	318 (62.7)	0.129
Education, n (%) ²					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)	
GHQ total score (0-12) (SD) ¹	3.1 (3.2)	3.2 (3.3)	2.9 (3.4)	3.2 (3.3)	0.849
Short sense of competence questionnaire (SSCQ) (7-35) (SD)	26.9 (5.1)	26.7 (5.0)	26.5 (5.8)	26.8 (5.2)	0.833
Pearlin Mastery Scale (5-25) (SD)	18.98 (4.1)	19.01 (4.1)	18.40 (4.7)	18.9 (4.2)	0.538
CarerQOL (SD) (15-100)	79.07 (15.3)	78.7 (16.0)	78.3 (15.9)	78.7 (16.1)	0.931
EuroQoL-5D (SD) (0-1)	0.83 (0.2)	0.85 (0.2)	0.86 (0.2)	0.84 (0.2)	0.261
Loneliness Scale (SD) (0-11)	3.74 (3.6)	3.88 (3.7)	3.50 (3.3)	3.8 (3.6)	0.739

¹ One-way-Anova, ² Chi-square test, ³ Kruskal-Wallis test ⁴ Mann-Whitney test, ^a The underlined scores indicates the more positive outcomes. * Frequency scores are percentages of the group that have Neuropsychiatric symptoms that are clinically relevant based on NPI total score (frequency*severity)>3.

Table 3 | Baseline estimates of Neuropsychiatric symptoms that are clinically relevant based on NPI domain specific score (frequency*severity) >3

	Intensive Case management	Linkage Model	Control group	Total
Delusions frequency %	13.4	23.9	12.5	17.6
Delusions severity (SD) (0-12)	1.1 (2.4)	1.9 (2.9)	1.2 (2.6)	1.4 (2.7)
Hallucinations frequency %	4.8	6.6	4.2	5.4
Hallucinations severity (SD) (0-12)	0.0 (0.2)	0.1 (0.2)	0.0 (0.2)	0.1 (0.2)
Agitation frequency %	19.5	23.9	16.7	20.9
Agitation severity (SD) (0-12)	1.4 (2.4)	1.8 (2.9)	1.3 (2.4)	1.6 (2.6)
Depression frequency %	19.5	20.7	12.5	19.0
Depression severity (SD) (0-12)	1.6 (2.4)	1.9 (2.6)	1.4 (2.2)	1.7 (2.5)
Anxiety frequency %	10.8	17.8	9.7	13.6
Anxiety severity (SD) (0-12)	1.0 (2.3)	1.6 (2.8)	1.0 (2.1)	1.3 (2.5)
Euphoria frequency %	3.5	4.2	1.4	3.5
Euphoria severity (SD) (0-12)	0.3 (1.1)	0.3 (1.1)	0.1 (0.5)	0.3 (1.1)
Apathy frequency %	31.2	31.9	30.6	31.4
Apathy severity (SD) (0-12)	2.4 (3.4)	2.4 (3.4)	1.9 (2.9)	2.3 (3.3)
Disinhibition frequency %	11.3	8.5	6.9	9.5
Disinhibition severity (SD) (0-12)	1.0 (1.8)	0.9 (2.2)	1.0 (1.9)	1.0 (2.0)
Irritability frequency %	21.7	22.1	20.8	21.7
Irritability severity (SD) (0-12)	1.7 (2.8)	1.7 (2.7)	1.6 (2.5)	1.7 (2.7)
Aberrant motor behaviour frequency %	1.6 (2.9)	2.4 (3.3)	1.5 (2.6)	1.9 (3.1)
Aberrant motor behaviour severity (0-12) (SD)	20.8	35.2	20.8	26.7
Sleep disturbances frequency %	1.1 (2.6)	1.2 (2.4)	1.2 (2.5)	1.1 (2.5)
Sleep disturbances severity (SD) (0-12)	13.4	13.6	16.7	14.0
Eating disturbances frequency %	41.1	43.7	33.3	41.1
Eating disturbances severity (SD) (0-12)	3.0 (3.7)	3.3 (3.9)	2.4 (3.6)	3.0 (3.7)

Table 4 | Characteristics of case managers of the two case management models

	Intensive CM Mean or frequency	Standard deviation/n	Linkage model		Total		p
Case managers (n)	45		28		73		
Age (SD)	50.0	8.6	50.8	10.4	50.3	9.3	0.707
Gender (% Female)	41	91%	27	96%	68	93.2%	0.359
Highest education (%)							
Secondary school	10	22%	9	32%	19	26.0	0.206
College level	35	78%	17	61%	52	71.2	
University	0	0	1	4%	1	1.4	
Other	0	0%	1	4%	1	1.4	
Specific education for CM (%)	43	96%	25	89%	68	93.2	0.356
More than 5 years of dementia experience (%)	41	91%	22	82%			
Caseload (SD)	47.2	13.2	32.2	16.2	50.3	9.3	0.0001
Hours per week as a CM (SD)	28.0	5.5	22.1	8.4	25.74	7.31	0.002
Caseload based on a 1 fulltime equivalent/ 5 days (full time is 36 hours)	61.6	16.7	53.9	23.3			0.106
More than 5 years worked as CM (%)	41	91%	22	34.9%	63	87.5	0.481
Hours per week with direct contact with patient or caregiver (SD)	16.4	4.7	15.2	5.8	15.9	5.1	0.348
Work pressure							0.850
Always	2	4.4%	3	10.7%	5	6.8%	
Often	5	11.1%	4	14.3%	9	12.3%	
Sometimes	28	62.2%	16	57.1%	44	60.3%	
Neutral	2	4%	1	4%	3	4.1%	
Never	8	18%	4	14%	12	16.4%	
Job satisfaction (%)							
Indifferent	2	4.4%	3	10.7%	5	6.8%	
Satisfied	22	48.9%	10	35.7%	32	43.8	
Very satisfied	21	46.7%	15	53.6%	36	49.3	
Task performed in the last 6 month							
Participated in multidisciplinary meetings	45	100%	23	88.5%	68	95.8%	0.045
Determined co-morbidity	43	97.7%	26	92.9%	69	95.8%	0.556
Average percentage from case manager caseload that have a care plan present		87.7%		65.2%		79.5%	0.02

3.3 Characteristics of the dementia case management models

Table 4 reports characteristics of 73 case managers of both models interviewed. All case managers had college level education and 93% of all case managers received extra special training in dementia. Case managers in the intensive case management model worked on average 15 hours more (95% CI: 8.1.-21.9) per week and had a larger case load (mean difference was 5.8 95%CI: 2.2 -9.5) than the linkage model case managers. When the caseload was standardized to 1 full time equivalent there was no difference in caseload between case managers in both models.

4. DISCUSSION

4.1 Key results and comparison with literature

In the COMPAS study, persons with dementia in case management were often older, female, single and living alone along with lower education, increased multi-morbidity and higher neuropsychiatric symptoms scores than those recruited into the control group. Persons with dementia in the intensive case management model remained enrolled in case management for a longer time than in the linkage model. Informal caregivers were often in their mid-sixties, female, and were family members which is a characteristic found in other studies (28,40,41).

A comparison with existing literature revealed that the COMPAS study participants had less neuropsychiatric symptoms than participants in the MAASBED study (28). In the MAASBED study, persons with dementia in the community were recruited from psychiatric based clinics after referral from a general practitioner and were followed every six months for two years. The MAASBED NPI total scores could be slightly higher because people going to a memory clinic typically may have more neuropsychiatric symptoms than people with dementia that are recruited at the primary care level. Mood disorders were the most common neuropsychiatric problem in the MAASBED group whereas in this study the most common problem was eating disturbances. A study by Callahan et al. (40) recruited persons with dementia into a randomized control trial where people received either case management for one year or augmented usual care in a primary care setting. Neuropsychiatric symptoms [or NPI] total scores were slightly lower in the Callan study than in the COMPAS study(40).

There is a difference in NPI total score means. The reason why we cannot identify pairs that differ significantly might be a power problem. The largest differences are for the comparisons with the c but this group is much smaller than the other groups. The median NPI score was lowest in the control group followed by the intensive case management model and then the linkage model. In the intensive case management model, case managers typically work full time, meet patients very early in the disease trajectory so that rapport is created and when there are times of crisis, trust is already present in the relationship to make decisions alongside the family. This may explain why neuropsychiatric symptom total scores were slightly lower in the intensive case

management group than in the linkage model group. Another possibility is that people in the intensive case management group are enrolled earlier into case management even before the formal diagnosis. This may mean that the intensive case management group has higher cognitive functioning and less behavioral symptoms than the linkage agency despite that they have been in case management for a longer amount of time. Case managers following the care trajectory of patients for the long term (at least two years) have been shown to be more effective than case managers working for short periods of time (16). In our study we followed dyads for two years which allows us to monitor important changes in neuropsychiatric symptoms of the person with dementia and the caregiver's psychological health over time. In the intensive case management group the care providers and case managers work within the same organization. This might make the access to more or other care for persons with dementia easier (22). Van Mierlo et al. (22) found case managers in the linkage model felt the pressure to refer clients within their own care organisation, although this might not have been the most beneficial for the person with dementia at that time.

4.2 Strengths and limitations

Few studies exist that compare different case management models with general practitioner based care (42). In the study by Newcomer et al. (42), there were two types of case management compared against general practitioner-based care. They had a randomised study design and primary outcomes were caregiver burden and depression whereas our study focussed on all kinds of neuropsychiatric symptoms for persons with dementia and caregiver's psychological morbidity (42). The case management models were based on ratios of patients to case managers. In our study the case management provided starts at different times in the disease spectrum (either before or after dementia diagnosis) (42). Usual care in the Netherlands includes case management and care supervised by only the general practitioner is uncommon which is the opposite in Newcomer et al (42). We included a large sample of over five hundred pairs of people with dementia and their informal caregivers that will be followed at least two years. The interview and questionnaires included a wide variety of validated instruments enabling us to accumulate detailed clinical, psychological, economic, process and quality outcomes about people with dementia and informal caregivers. These baseline results can also be considered a cross-section of persons with dementia and they provide a current overview on NPI prevalence and severity in the group as a whole. As is common in this type of research, there may have been some selection bias due to the fact that the informal caregivers who declined to participate may have been more burdened compared to study participants. Another issue is that there may have been confounding by indication, meaning that persons in the general practitioners care group may have had access to case management and general practitioners may have selectively referred patients with dementia to case management. Based on our results the control group do appeared younger and had less co-morbidity at baseline. However, because of the observational nature and the length of time required to recruit people into this study it is difficult to know if this can be explained by confounding by indication. We attempted to address

this potential bias by randomly calling participating general practitioners to ask if they ever sent persons with dementia to case management outside of their region or how did they handle patients with dementia that exhibited complex neuropsychiatric symptoms. In these control regions it could potentially be easier to send someone to a nursing home quicker than in case management regions. We found that the answers varied enough that for future analysis, we will use techniques like a propensity score which can help to adjust for selection bias (43). Because time varying measurements of confounders were measured repeatedly throughout this study we have more correction options. The relative small size of our control group is a limitation since the majority of regions provide people with dementia case management.

4.3 Implications and conclusion

The data we have collected provide valuable insight about whether there are differences in people receiving different forms of case management or general practitioner care. People who receive case management appear more vulnerable than that in general practitioner-based care as they have increased co-morbidity and neuropsychiatric symptoms. The suggested cut-off point for GHQ-12 has been shown to vary per country but in general a cut-off of 1 or 2 is suggested to identify people with mental health disorders where all groups exceed this cut-off (44,45). A previous meta-analysis (15) showed that tailoring multicomponent interventions could reduce the risk of institutionalization. It is important that case management provides a holistic approach to caring for persons with dementia and their informal caregivers, by also addressing comorbid conditions and by avoiding fragmented care. This should be done in close consultation with the general practitioner as the general practitioner is the logical coordinator of patient care based on Dutch national guidelines.

REFERENCES

1. Poos MJJC (RIVM), Gommer AM (RIVM). Wat zijn de belangrijkste doodsoorzaken? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, <<http://www.nationaalkompas.nl>> Nationaal Kompas Volksgezondheid\Gezondheidstoestand\Ziekten en aandoeningen, 30 augustus 2013.
2. Meijer S, Willemse B, Noordt m van der. Dementie: Hoeveel zorg gebruiken patienten en wat zijn de kosten? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, <<http://www.nationaalkompas.nl>> Nationaal Kompas Volksgezondheid\Gezondheidstoestand\Ziekten en aandoeningen\psychische-stoornissen/dementie\welke-zorg-gebruiken-patienten-en-kosten\#kosten, 2014.
3. Ministry of Health Welfare and Sport, Zorgverzekeraars Nederland, Alzheimer Nederland, ActiZ. Guideline for Integrated Dementia Care [excerpt]: An aid for the development of integrated dementia care 2009.

4. Ott A, Breteler MMB, Birkenhäger-Gillesse EB, Harskamp F van, Koning I de, A. H. De prevalentie bij ouderen van de ziekte van Alzheimer, vasculaire dementie en dementie bij de ziekte van Parkinson; het ERGO-onderzoek. *Ned Tijdschr Geneeskd*. 1996 140:200-205.
5. Perenboom RJ, Boshuizen HC, Breteler MM, Ott A, Van de Water HP. Dementia-free life expectancy (DemFLE) in The Netherlands. *Soc Sci Med*. Dec 1996;43(12):1703-1707.
6. José Peeters, Alice de Boer, Julie Meerveld, Klerk. Md. Problemen van mantelzorgers bij dementie stapelen zich op. *Tijdschrift voor Verpleegkundigen* 2011.
7. Peeters J, Werkman W, Francke AL. *Dementiemonitor Mantelzorg: Problemen, zorgbehoeften, zorggebruik en oordelen van mantelzorgers*. Utrecht: NIVEL;2012.
8. Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurs J*. 2013;7:6-13.
9. Health Council of the Netherlands. Dementia. In: Health Council of the Netherlands, ed. *The Hague: Health Council of the Netherlands*; 2002:21-31.
10. Peeters JM, Van Beek AP, Meerveld JH, Spreeuwenberg PM, Francke AL. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nurs*. 2010;9:9.
11. van der Roest HG, Meiland FJ, van Hout HP, Jonker C, Droes RM. Validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly in community-dwelling people with dementia. *Int Psychogeriatr*. Dec 2008;20(6):1273-1290.
12. Case Management Society of America. What is a Case manager? 2015;<http://www.cmsa.org/Home/CMSA/WhatisaCaseManager/tabid/224/Default.aspx>. Accessed February 24, 2015.
13. Hunter SB, Griffin BA, Booth MS, Ramchand R, McCaffrey DF. Assessing the generalizability of the CSAT-sponsored GAIN dataset: are the CSAT sites representative of adolescent treatment programs in the U.S.? *J Subst Abuse Treat*. Feb 2014;46(2):238-243.
14. Almirall D, Griffin BA, McCaffrey DF, Ramchand R, Yuen RA, Murphy SA. Time-varying effect moderation using the structural nested mean model: estimation using inverse-weighted regression with residuals. *Stat Med*. Sep 10 2014;33(20):3466-3487.
15. Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr*. Dec 2006;18(4):577-595.
16. Pimouguet C, Lavaud T, Dartigues JF, Helmer C. Dementia case management effectiveness on health care costs and resource utilization: a systematic review of randomized controlled trials. *J Nutr Health Aging*. Oct 2010;14(8):669-676.

17. Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of caregiving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*. Jun 2010;66(2):191-200.
18. Low LF, Yap MH, Brodaty H. A systematic review of different models of home and community care services for older persons. *BMC Health Serv Res*. May 9 2011;11(1):93.
19. John M. Eisenberg Center for Clinical Decisions and Communications Science. Effectiveness of Outpatient Case Management for Adults With Medical Illness and Complex Care Needs. Comparative Effectiveness Review Summary Guides for Clinicians. Rockville (MD): Agency for Healthcare Research and Quality (US); 2013 Aug 30.
20. Minkman MM, Ligthart SA, Huijsman R. Integrated dementia care in The Netherlands: a multiple case study of case management programmes. *Health Soc Care Community*. Sep 2009;17(5):485-494.
21. Zwaanswijk M, Van der Ende J, Verhaak PF, Bensing JM, Verhulst FC. Factors associated with adolescent mental health service need and utilization. *J Am Acad Child Adolesc Psychiatry*. Jun 2003;42(6):692-700.
22. Ganguli HC. Behavioural research in sexuality. New Delhi: Vikas Pub. House; 1988.
23. Banks P. Case management. In: Berman NPC, ed. Integrating services for older people – a resource book for managers. : EHMA; 2004:101-112.
24. Ligthart SA. Aanpak en effecten van casemanagement bij dementie. Een exploratieve studie in het kader van het Landelijk Dementieprogramma [internship]. Nijmegen: Kwaliteitsinstituut voor de Gezondheidszorg CBO, Radboud Universiteit 2006.
25. Jansen AP, van Hout HP, van Marwijk HW, et al. (Cost)-effectiveness of case-management by district nurses among primary informal caregivers of older adults with dementia symptoms and the older adults who receive informal care: design of a randomized controlled trial [ISCRTN83135728]. *BMC Public Health*. 2005;5:133.
26. Luning-Koster M, Perry M, Moll van Charante EP, Vernooij-Dassen M, Wiersma T, Burgers JS. [Summary of Dutch College of General Practitioners' (NHG) practice guideline 'Dementia']. *Ned Tijdschr Geneeskd*. 2012;156(49):A5323.
27. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*. Dec 1994;44(12):2308-2314.
28. Kisely SR, Goldberg DP. The effect of physical ill health on the course of psychiatric disorder in general practice. *Br J Psychiatry*. Jun 1997;170:536-540.
29. Robertson-Smith J, McCaffrey FT, Sayers R, Williams S, Taylor BJ. A comparison of mid-forehead and axillary temperatures in newborn intensive care. *J Perinatol*. Aug 14 2014.

30. Hoeymans N, van Lindert H, Westert GP. The health status of the Dutch population as assessed by the EQ-6D. *Qual Life Res.* Apr 2005;14(3):655-663.
31. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med.* May-Jun 2002;64(3):510-519.
32. Houttekier D, Cohen J, Van den Block L, Bossuyt N, Deliëns L. Involvement of palliative care services strongly predicts place of death in Belgium. *J Palliat Med.* Dec 2010;13(12):1461-1468.
33. Reynolds T, Thornicroft G, Abas M, et al. Camberwell Assessment of Need for the Elderly (CANE). Development, validity and reliability. *Br J Psychiatry.* May 2000;176:444-452.
34. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. *Psychol Med.* Feb 1979;9(1):139-145.
35. Hankins M. The reliability of the twelve-item general health questionnaire (GHQ-12) under realistic assumptions. *BMC Public Health.* 2008;8:355.
36. Vernooij-Dassen MJ, Felling AJ, Brummelkamp E, Dauzenberg MG, van den Bos GA, Grol R. Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: a Short Sense of Competence Questionnaire (SSCQ) suitable for clinical practice. *J Am Geriatr Soc.* Feb 1999;47(2):256-257.
37. Pearlín LI, Schooler C. The structure of coping. *J Health Soc Behav.* Mar 1978;19(1):2-21.
38. Brouwer WB, van Exel NJ, van Gorp B, Redekop WK. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Qual Life Res.* Aug 2006;15(6):1005-1021.
39. EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy.* Dec 1990;16(3):199-208.
40. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *Jama.* May 10 2006;295(18):2148-2157.
41. Dias A, Dewey ME, D'Souza J, et al. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PLoS One.* 2008;3(6):e2333.
42. Ganguli M. *A pilgrimage to the Nagas.* New Delhi: Oxford & IBH; 1984.
43. McCaffrey DF, Griffin BA, Almirall D, Slaughter ME, Ramchand R, Burgette LF. A tutorial on propensity score estimation for multiple treatments using generalized boosted models. *Stat Med.* Aug 30 2013;32(19):3388-3414.
44. Goldberg DP, Gater R, Sartorius N, et al. The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychol Med.* Jan 1997;27(1):191-197.
45. Goldberg DP, Oldehinkel T, Ormel J. Why GHQ threshold varies from one place to another. *Psychol Med.* Jul 1998;28(4):915-921.