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RESEARCH ARTICLE



Cost-effectiveness of dementia training for caregivers in caregiver-patient dyads: A randomized controlled study

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Abstract

Introduction: We evaluated the cost-effectiveness of the "More at Home with Dementia" intervention, a multicomponent training program for co-residing caregivers of people with dementia (PwDs).

Methods: We performed a two-armed randomized controlled trial with an intervention and a control group. Participants were community-dwelling caregivers living with a person with dementia (59 randomized to intervention and 50 to control arm). The training program lasted 5 days and took place in a holiday accommodation. Qualityadjusted life-years (QALYs) were calculated using the EuroQol-5 Dimensions 3 Levels (EQ-5D-3L) for caregivers and PwDs. Costs for informal and formal social care, as well as health care, were collected at four times over a 6-month period from baseline. Information on nursing home admission or death was collected for 2 years after baseline.

Results: QALYs for caregivers and PwDs added together were 0.12 higher in the intervention group compared with the control group (P = .11). After 1 year, there tended to be fewer nursing home admissions in the intervention group, but this difference was lost by 2 years (P = .19). The cost of the intervention was estimated at £1000 (USD 1090) per dyad. Compared with the control group, the intervention group used other health care and formal social care significantly less for a year after baseline (P = .02 and .001, respectively). The estimated decrease in total costs was €10,437 (P = .07), with an estimated 96% probability that the intervention was cost-effective vs usual care.

Discussion: The multicomponent "More at Home with Dementia" training program is effective and appears to save costs compared with usual care. Savings appear to be achieved by delaying nursing home admissions and by reducing the use of other care resources. Further research is also needed to clarify if this intervention is effective for caregivers who do not live with a PwD, such as adult children, and for the caregivers of patients with other debilitating chronic diseases. At the same time, effort is advised to implement caregiver training in standard care programs.

KEYWORDS

caregivers, cost-effectiveness, dementia, health resource, psychosocial intervention, training

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1 | BACKGROUND

It is estimated that 70% of people with dementia (PwDs) in The Netherlands live at home and receive informal care, with 35% of that care provided by spouses. 1 Caring for PwD is a challenging endeavor that can result in poor mental health and high rates of persistent burden, the latter being negatively correlated with quality of life.² Researchers have therefore explored not only the needs of caregivers but also what interventions are most effective, with results indicating that emotional and social support, improving coping strategies, and providing information about the illness and available support services can alleviate caregiver burden and reduce mental health problems. Multicomponent interventions seem particularly effective, 3-5 although reviews have needed to use narrative syntheses because of marked differences in design, intervention, cost elements, and outcome measures between studies. Nevertheless, the reviews have concluded that interventions comprising occupational therapy, home-based exercise, and helping caregivers to cope are most costeffective.⁶⁻⁸ When including the effects of spill-over costs and the health effects of caregivers on cost-effectiveness in another review, they concluded that interventions could have been cost-effective or cost saving in 85% of the analyzed studies.9 These findings underscore the importance of adopting a societal perspective that includes all relevant cost, irrespective of where they occur and how they are financed.

We have previously reported the results of a randomized controlled study on the effect of a multicomponent training program, "More at Home with Dementia" (in Dutch, Beter Thuis met Dementie), that targeted co-residing caregivers of PwDs between 2016 and 2018.¹⁰ Although quantitative analysis showed that this intervention did not affect care-related quality of life, it did have a positive effect on experienced role limitations due to physical health problems, experienced role limitations due to emotional problems, and pain as measured with the RAND SF-36 short form. 11 Qualitative analysis showed that the program met the needs of participating dyads. Secondary outcomes, including the EuroQol-5 Dimensions 3 Levels (EQ-5D-3L), revealed no significant differences by 3 months compared to care as usual. This intervention was based on an Australian protocol, "Going to Stay at Home," which was a followup study of the Prince Henry Hospital dementia caregivers' training program. 12,13 Both studies effectively delineated caregiver outcomes and costs, providing evidence that the multicomponent interventions were cost-effective because they delayed institutionalization. However, the original Australian study failed to identify any differences in health service utilization other than in institutionalization of the PwD. 14,15

In The Netherlands, total costs for dementia care in 2017 constituted 9.5% of all health care costs. ¹⁶ Given the mounting pressures on health and social budgets, it is essential that we consider the cost-effectiveness of any intervention before recommending its implementation on a wide scale. We therefore performed a secondary analysis of the cost-effectiveness of the More at Home with Dementia program.

RESEARCH IN CONTEXT

- 1. Systematic Review: In exploring which interventions for co-residing caregivers of people with dementia (PwDs) are most effective, results indicate that emotional and social support, improving coping strategies, and providing information about the illness and available support services can alleviate caregiver burden and reduce mental health problems. Multicomponent interventions seem particularly effective. In addition, reviews have concluded that interventions comprising occupational therapy, home-based exercise, and helping caregivers to cope are the most cost-effective.
- 2. Interpretation: A multicomponent intervention for coresiding caregivers of PwDs can lead to higher quality-adjusted life-years (QALYs) compared to care as usual (P = .11). It reduces costs of both social care (P = .001) and health care (P = .02) and tends to delay nursing home admission of the PwD. The estimated decrease in total costs was €10,437 (P = .07), with an estimated 96% probability that the intervention was cost-effective vs usual care.
- 3. Future Directions: Further research is also needed to clarify if this intervention is effective for caregivers who do not live with PwDs, such as adult children, and for the caregivers of patients with other debilitating chronic diseases. At the same time, effort is advised to implement caregiver training in standard care programs.

2 | METHODS

2.1 | Design and participants

In this randomized controlled trial, dyads (a caregiver and a PwD who lived together) were randomly assigned to intervention or control groups. Those in the intervention group took part in the study training program, whereas those in the control group received care as usual. Quantitative data were collected at baseline and at 3 and 6 months, with additional cost data collected at 6 and 18 weeks. After 6 months we aimed to stay connected with participants by phone or e-mail until either nursing home admission, death of the PwD, or 2 years after baseline. Participants were recruited to the intervention by professionals or by self-referral, and written informed consent was obtained from all participating caregivers and the PwD, if possible. The full trial protocol has been published elsewhere. ¹⁰

2.2 | Ethics approval

Before starting, the study was submitted for approval to the Human Research Ethics Committee of the University of Groningen, The

TABLE 1 Topics of sessions offered to the caregivers and related professionals

Professional	Session
Psychologist	Combating social isolation
	Re-rolling
	Assertion
Occupational therapist	Reminiscence and orientation
	Therapeutic use of activities
	Organization of work and safety in the home
Elderly care physician	Medical aspects of dementia
Social worker	Planning for the future
Speech therapist	Communication
Registered nurse	Nursing skills
Physiotherapist	Fitness
Dietician	Nutrition
Psychologist	Self-care
Social worker	Using community services

Netherlands, which concluded that no assessment was needed based on relevant Dutch law concerning scientific research in humans. The study was conducted in accordance with the ethical standards of the Declaration of Helsinki (1964, and subsequent revisions). The trial has been registered at the Dutch Trial Register; Trial ID, NTR5775.

2.3 | Patient involvement

To assess feasibility, workshop content and participant recruitment were assessed through discussions with caregivers during a focus group session. During the trial, a caregiver was invited to join the independent trial steering committee. Because of his duties as a caregiver, he could not participate in these meetings, but he was informed by telephone and invited to give his opinion. Published outcomes, when merged in a dissertation, will be sent to all participants.

2.4 | Intervention

In total, 16 groups, each group consisting of two to six dyads, received the intervention between May 2016 and March 2018. The intervention took place in a holiday accommodation over 5 days. Caregivers attended 14 psychoeducational sessions that were delivered in informal settings by various professionals, including a psychologist, an occupational therapist, and an elderly care physician. The sessions included psychoeducational elements, group work, modeling, and role play. An elaborate description of the sessions can be found in the protocol paper of this study. ¹⁰ In addition, a list of the topics of the sessions with the responsible professional is presented in Table 1. PwDs engaged in a separate program that comprised general pleasant activities and sessions focused on coping with the handicaps that come with dementia,

and when possible, attended certain workshops with the caregivers (dependent on their level of functioning and the workshop content). The intervention was delivered alongside usual care, as received by the control group.

2.5 | Control group

Participants in the control group received care as usual, which consisted of routine general practitioner (GP) care. In The Netherlands, PwDs are assigned to a dementia case manager after diagnosis if they consent. Day care is also available for all PwDs, but this option tends not to be used by people with milder disease. Home care and respite care (eg, temporary nursing home admission) are also offered when appropriate.¹⁷

2.6 | Measurements

2.6.1 | Quality of life and quality-adjusted life-years

The quality of life of caregivers was assessed using the Dutch tariff ¹⁸ for the EQ-5D-3L, the Care-Related Quality of Life-7 dimensions (CarerQol-7D), ¹⁹ and the SF-6D, ²⁰, as calculated from the 36-Item RAND Short Form Survey Instrument. The quality of life of the PwD was assessed with the EQ-5D-3L and the Dementia Quality of Life Instrument (DQI). ²¹ Quality-adjusted life-years (QALYs) were calculated at 1 year as area under the utility measurements. The sum of the QALYs based on the EQ-5D-3L of the caregiver and the PwD was the primary outcome for the cost-effectiveness analysis in this report.

2.6.2 | Costs

We estimated societal costs for the first year or until date of death. Three sources were used to assess resource use by caregivers and PwDs. First, we used telephone interviews at 6 and 18 weeks to assess use of day care, home care, domestic help, and informal help, as well as the number of consultations with health professionals (temporary) nursing home admissions, hospital admissions, and attendance at outpatient clinics. Second, we provided questionnaires at baseline, 3 months, and 6 months to assess how much time the caregiver spent on care (activities of daily living and instrumental activities of daily living) and how much help the caregiver received from informal caregivers (TOPICS-MDS).²² Third, beyond the official 6-month follow-up of the study, we contacted participants by e-mail or telephone for up to 2 years after baseline to collect information about the date of nursing home admission or death of PwDs.

Interview data at 18 weeks and questionnaire data at 6 months were considered representative for the remainder of the year. Costs for the intervention were estimated from our experience during the study. Other health care use was valued using reference prices designed to standardize economic evaluations in The Netherlands.²³ The costs of

informal care were computed by multiplying the use of care in hours per year by the $\[mathebox{\ensuremath{\mathfrak{e}}}\]$ 11 minimum wage in The Netherlands in 2020. We also performed a sensitivity analysis in which only intervention costs were considered. All costs are reported in price level indices (2020 euros).

2.7 | Statistical analysis

We analyzed data on a modified intention to treat basis (excluding data for those who decided not to participate before baseline) and checked whether the data met the required assumptions.

We used multiple imputation to account for missing data, which is appropriate when data are missing at random. We imputed missing values, using 50 imputed datasets and predictors: age, sex, assignment, and the EQ-5D-3L scores of both caregivers and PwDs at baseline and at 3 and 6 months. All statistical analyses were performed using IBM SPSS, Version 24 (IBM Corp., Armonk, New York, USA).

For the primary and secondary outcomes, independent sample unequal-variance t tests were used to evaluate the response variable for differences between the intervention and control groups.

A significance level of 0.05 was used as the threshold for all *P*-values, without formally correcting for multiple comparisons. Costeffectiveness was analyzed using acceptability curves, plotting the probability that the intervention is cost-effective compared to care as usual, depending on the willingness-to-pay (WTP) for the combined QALYs of caregivers and patients. 24 This probability was calculated as the one-sided *P*-value for the difference in net benefit (NB = WTP \times QALYs – total costs). Differences in outcomes were reported as means with *P*-values and 95% confidence intervals (CIs).

Differences between the intervention and control groups concerning the time to nursing home admission were estimated, and these are presented in Kaplan-Meier survival curves censored by mortality. Differences between the two groups in PwDs admitted to a nursing home after 1 year were analyzed by chi-square tests.

3 | RESULTS

The results of our recruitment activities are described in an earlier publication on this project.²⁵ In total, 109 participating dyads were eligible for analysis: 59 in the intervention group and 50 in the control group. After the study ended at 6 months, we remained in contact with 105 of the participating dyads, although another 2 in the control group were not eligible for further analysis because they had participated in the intervention after the follow-up period. The baseline characteristics are presented in Table 2. The mean ages of caregivers in the intervention and control groups were 72.5 and 73.2 years, respectively, and the corresponding ages of the PwD were 76.3 and 77.6 years. Most caregivers were women (75%) and most PwDs had moderate to moderately severe dementia. The overall proportion of available data was 88% in the intervention group and 70% in the control group. The proportion of available telephone interviews at 6 weeks post baseline of (health)

TABLE 2 Baseline characteristics

	Intervention	Control
Caregiver, N	59	49
Age in years, mean (SD)	72.5 (8.3)	73.2 (7.1)
Women, %	76.3	74.0
Person with dementia, N	59	50
Mean age, years (SD)	76.3 (6.7)	77.6 (7.3)
Number, N	53	43
GDS, mean (SD)*	4.6 (0.79)	4.4 (0.79)

*GDS: Reisberg Global Deterioration Scale, range 1–7, higher scores indicating more severe dementia.

care use was 87% and 80%, respectively, in the intervention and control groups. This decreased to 62% and 23% after 18 weeks. The proportion of available questionnaires at 3 months was 89% and 83% and at 6 months was 85% and 72%, respectively, in the intervention group and control group. Regarding death and nursing home admission, a main outcome of formal care cost, we managed by repeated attempts through email, phone calls, and even bereavement advertisements in the period from 6 months until 2 years post-baseline to limit missing data to 1% and 6% in the intervention and control groups.

3.1 | Quality of life

Table 3 shows the outcomes regarding quality of life. At 3 and 6 months, there was no significant difference between the intervention and control group in quality of life assessed with the EQ-5D-3L, or in the QALYs of the caregivers, PwDs, or both combined. The difference between the intervention and control group in combined QALYs, based on the EQ-5D-3L, was 0.12 (1.29 vs 1.17, P = .11, 95% CI -0.27 to 0.03). In addition, QALYs based on secondary quality-of-life outcomes, namely the CarerQol-7D and SF-6D for caregivers and the DQI for PwDs, showed no significant differences. As expected, all quality-of-life parameters tended to decline beyond 3 and 6 months after baseline. This decline was most evident in the EQ-5D-3L and DQI assessments of PwDs in the control group, although not statistically significant.

3.2 | Nursing home admission

There was a non-significant lower rate of nursing home admission among PwDs in the intervention group over a 2-year period (log rank P = .19; Figure 1). Of note, the post hoc P-value for the large 18% difference at 1 year was .06.

3.3 Costs

The costs of the intervention itself comprised staff salaries (62%), rent for the accommodation (24%), and to a lesser extent, overhead (4%)

SD, standard deviation.

TABLE 3 Outcomes related to quality of life and QALYs

	Intervention				Control	Control						
	Assessment point			Assessr	Assessment point							
	ТО	T1	T2	QALY	T0	T1	T2	QALY	MD*	P †	95% CI	
Caregiver												
EQ 5D-3L	0.78	0.71	0.71	0.72	0.74	0.63	0.69	0.68	0.04	.46	-0.12 to 0.06	
Carer Qol-7D	68.7	67.0	64.1	65.4	65.8	59.8	61.5	61.6	3.8	.29	-10.7 to 3.20	
SF-6D	0.66	0.66	0.64	0.65	0.63	0.62	0.62	0.63	0.02	.17	-0.06 to 0.11	
PwD												
EQ 5D-3L	0.63	0.58	0.56	0.57	0.60	0.50	0.45	0.48	0.09	.09	-0.19 to 0.01	
DQI	0.72	0.68	0.63	0.65	0.75	0.66	0.60	0.63	0.02	.61	-0.10 to 0.06	
Caregiver and PwD												
EQ 5D-3L				1.29				1.17	0.12	.11	-0.27 to 0.03	

Mean values are shown for each assessment point (T0 = baseline; T1 = 3 months; T2 = 6 months). *Mean Differences of the QALYs between intervention and control group. †The *P*-values and 95% CIs are for the differences in QALYs between groups. Abbreviations: MD, mean difference; EQ-5D-3L, EuroQol-5 Dimensions 3 Levels; Carer Qol-7D, Care-Related Quality of Life-7 Dimensions; DQI, Dementia Quality of Life Instrument; QALY, Quality-adjusted life-years; SF-6D, short form, six dimensions calculated from the 36-Item RAND Short Form Survey Instrument.

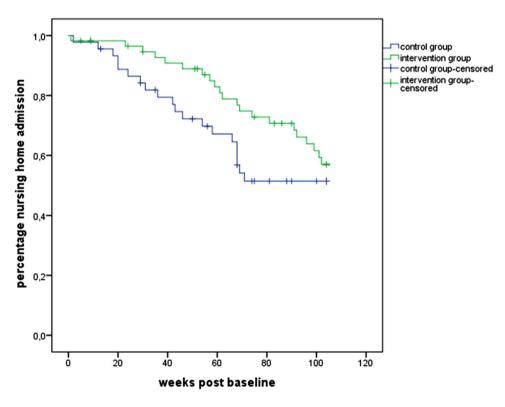


FIGURE 1 Kaplan-Meier survival curve for the differences in nursing home admission between the intervention and control groups from baseline to 2 years. Log rank P = .19

and food and drink (10%) costs. When five or six couples participated in an intervention week, the intervention cost was €1000 per dyad.

As presented in Table 4, we found no significant difference in total informal social care costs during the first year. However, when differentiating by household chores, personal care, and support with outdoor activities, caregivers in the intervention group spent significantly

more time than those in the control group providing support for outdoor activities. Time spent on household chores and personal care was also higher, although with a smaller and nonsignificant difference.

Participants in the intervention group used formal social care significantly less during the first year after baseline. Total formal care costs in the intervention and control groups were &22,164 and &36,172, with



TABLE 4 Mean use and cost of care during the first year after baseline, and cost differences between the intervention and control groups

	Care	use			າ €)			
	Intervention	Control	Intervention	Control	Difference	Р	95% CI interval	
Informal (social) care								
Carer household chores, hours/year	971	881	10,684	9691	993	.34	-3040 to 1055	
Carer personal care, hours/year	1311	1170	14,425	12,874	1551	.52	-6271 to 3168	
Carer support for outdoor activities, hours/year	849	552	9347	6077	3270	.05	-6529 to -11	
PwD supported by other carers, hours/year	297	303	3262	3340	-78	.90	-1244 to 1400	
Subtotal (SEM)			37,719 (2726)	31,983 (2680)	5736	.11	-12857 to 1385	
Formal social care								
Domestic help, hours/year	59	57	1411	1356	55	.87	-693 to 583	
Homecare, hours/year	83	143	4490	7711	-3221	.02	421 to 6021	
Day care, days/year	94	140	13,702	20,297	-6595	.05	11 to 13,167	
Nursing home, weeks/year	2.0	5.4	2561	6806	-4245	.1	-780 to 9271	
Subtotal (SEM)			22,164 (2610)	36,172 (3456)	-14,008	.001	5714 to 22,299	
Health care without intervention								
Dementia case manager, times/year	11.6	16.4	400	511	-111	.29	-94 to 317	
General practitioner, times/year	7.8	16.6	279	593	-314	.08	-40 to 669	
General practitioner on duty, times/year	1.6	3.0	111	213	-102	.26	-74 to 279	
Speech therapist, times/year	2.3	9.6	74	311	-237	.17	-101 to 576	
Occupational therapist, times/year	6.7	14	232	511	-279	.20	-148 to 707	
Physiotherapist, times/year	19	35	666	1264	-598	.19	-296 to 1493	
Dietician, times/year	0.7	1.5	24	53	-29	.25	-20 to 78	
Psychologist, times/year	2.4	6.7	168	467	-299	.37	-354 to 950	
Hospital outpatient clinic, times/year	6.6	12.7	646	1249	-603	.12	-150 to 1356	
Hospital day care, times/year	0.05	0.09	14	27	-13	.5	-24 to 50	
Hospital day-admission, times/year	0.85	1.6	252	479	-227	.30	-207 to 660	
Hospital admission, times/year	0.09	0.23	81	437	-356	.17	-149 to 860	
Subtotal (SEM)			2948 (590)	6115 (1257)	-3167	.02	480 to 5855	
Intervention costs			1000	0	1000			
Health care with intervention								
Subtotal			3928	6115	-2167	.10	-409 to 4744	
All costs (SEM)			63,833 (3839)	74,270 (4602)	-10,437	.07	-833 to 21,708	

Care use is presented as the mean value in that group. Care costs are provided as the mean cost in €/year. The P-values and 95% CIs are for the differences in care costs between groups.

 $Abbreviations: CI, confidence\ interval; SEM, standard\ error\ of\ the\ mean.$

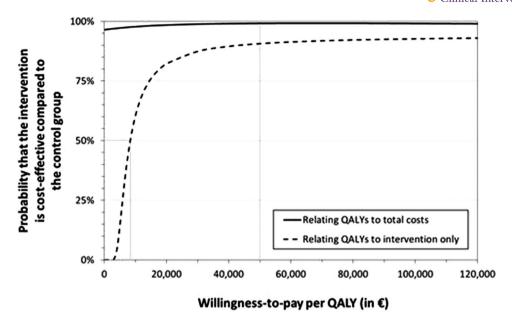


FIGURE 2 Probability that the intervention is cost-effective compared to care as usual. The data are shown dependent on the value assigned to the caregiver and patient's quality-adjusted life-years (QALYs) as well as the included costs (total costs or intervention costs only).

the €14,008 difference (95% CI €5714 to €22,299) significantly favoring the intervention group. This difference resulted mainly from the intervention group using significantly less day and home care compared with the control group. In addition, the costs of nursing home admission were non-significantly lower (95% CI, €-780 to €9271) in the intervention group.

Analyzed separately by care type, care costs, and facility use, we identified no significant differences during the first year. When combined, however, the intervention group had significant less health care use than the control group, with a difference of $\[\epsilon \]$ 3167 (95% CI $\[\epsilon \]$ 480 to $\[\epsilon \]$ 5855).

3.4 Cost-effectiveness

From a societal perspective, the intervention was estimated to reduce total costs and improve the QALYs of both caregivers and the PwD. In The Netherlands, the value assigned to a QALY ranges from 20,000 to 800,000 euros per QALY, depending on the severity of the disease. Regardless of the value assigned to QALYs, the intervention was at least 96% likely to be cost-effective compared with care as usual, as shown by the solid line in Figure 2. The results of the sensitivity analysis are shown by the interrupted line, which provides a less optimistic analysis by ignoring the savings on non-intervention costs. Nevertheless, QALYs still improved by an average of 0.12, albeit with the intervention costs increasing by €1000. In this analysis, the associated cost-effectiveness ratio was €8000 per QALY (€1000/0.12). This is still considered very acceptable in The Netherlands, 26 and there is a 91% probability that the intervention is cost-effective compared to care as usual.

4 | DISCUSSION

4.1 | Principal findings

Multicomponent training aimed at caregivers living with PwD is cost-effective, with our data showing that the costs of the intervention (£1000) are outweighed by the savings in formal social and health care provision. Indeed, the mean costs of formal social care were £14,008 (38.7%) lower in the intervention group compared with the control group, mainly because of savings in the costs for nursing home admission (62.4% lower), home care (41.8% lower), and day care (32.5% lower). Furthermore, mean non-intervention health care costs were lower in the intervention group, with a significant difference of £3167. Contrasting with this, participants in the intervention group reported spending more time on activities related to caregiving. Valuing this time at minimum wages, informal care costs were £5736 higher in the intervention group, mainly because of the time spent on supporting PwD in outdoor activities.

4.2 | Strengths and weaknesses of the study

This study benefited from using a randomized controlled design, and having access to information from an earlier effect analysis and process evaluation. The latter data showed high internal validity for the study. Moreover, data on costs were collected from a broad perspective and the effect of the intervention was assessed with multiple internationally adopted quality-of-life scales and their corresponding utility scores, making the outcomes comparable with those of other studies.

There were also several limitations. First, we could not blind either the caregiver-patient dyads or the research assistant to group assignment. Second, participants of the study were relatively better educated and younger than their peers in the general population (both PwDs and their caregivers). This precludes generalization of the results to an extent. Third, requiring participants to have greater awareness of caregiving activities may have led to a higher reporting rate for informal care. Finally, due to the attrition rates, especially after 6 months of follow-up, we had to impute data. We consider multiple imputations with a relatively large number of imputations the most appropriate approach to deal with these missing data.

4.3 Comparison with existing literature and meaning of the findings

This study was based on the Australian intervention, Going to Stay at Home, a follow-up study of the Prince Henry Hospital dementia caregivers' training program. The cost-effectiveness analyses of both studies produced broadly comparable results. ^{13–15} In both studies, cost savings resulted mainly from fewer nursing home admissions among the PwD who had participated in the intervention with their partners. In our study, cost saving also resulted from a lower rate of institutionalization among PwDs and from a lower use of other care resources. Together, these results underpin our conclusion that multicomponent caregiver training has a favorable effect on health care. It appears that the knowledge and skills that participants acquire during the intervention help to prevent, or help them to cope with, problems that lead to nursing home admissions among PwDs.

Reviews of economic evidence for home support interventions in dementia have consistently shown that occupational therapy, home-based exercise, and psychological interventions are cost-effective options. ^{6,8} Because our multicomponent intervention included all these components, this may account for the overall reduction in costs. In another caregiver dementia support and counseling program, the New York University Caregiver Intervention, it was shown that 5% to 6% more PwDs remained in the community each year when such a program was widely implemented. ²⁷ In the present study, we believe the almost significant increase in informal care in the intervention group to be noteworthy. This resulted mainly from the increased support provided by these caregivers for outdoor activities hours compared with the control group. This reflects an important change in attitude among caregivers, with them recognizing that outdoor activities were both possible and beneficial despite their partners' dementia.

An important outcome of our effect analysis was that participants in the intervention group experienced significantly fewer role limitations due to emotional and physical problems than those in the control group.²⁵ Thus, although caregivers who participated in the intervention spent more time on caregiving tasks, they felt less limited. This could be explained by the improved acceptance, self-confidence, and coping abilities reported in the qualitative effect analysis.

The abovementioned positive effects of the intervention are not in line with the non-significant outcomes related to quality of life. In

the current study we saw a non-significant difference in decline in the EQ-5D-3L and DQI assessments of PwDs in favor of the intervention group, which could reflect an effect of the intervention on the skills of the caregiver in coping with the decline in cognitive functions of the PwD. We described in an earlier report on this intervention that the main themes of the positive qualitative outcomes showed only limited or no agreement with the questions in the instruments used to assess quality of life.²⁵ We assume that the intervention did have positive effects just not so much on issues assessed with quality-of-life questionnaires.

These positive effects justify an investment such as this intervention, and these positive effects may also account for the positive effects on use of formal social care and health care. In fact, based on the qualitative results, the municipality of Rotterdam decided to reimburse the intervention for its inhabitants, and some participants living outside Rotterdam have paid for the costs out of pocket.

In conclusion, our intervention had beneficial effects on the caregiver, while also saving costs, and we showed that the probability of the intervention being cost-effective compared with care as usual was at least 96%. Moreover, this probability remained as high as 91%, even when we ignored the net-savings on non-intervention costs.

4.4 Unanswered questions and future research

A multicomponent intervention targeting the caregivers of PwDs can benefit caregivers, PwDs, and the wider society. As such, there is a convincing argument for it to be included as an element of routine care for PwDs. In most countries, however, care is typically financed differently for caregivers and patients, which may prevent adequate reimbursement. To be of maximal benefit, this study must, therefore, serve as a stimulus for policymakers to implement changes to practice and reimbursement standards. Further research is also needed to clarify if this intervention is effective for caregivers who do not live with PwDs, such as adult children, and for the caregivers of patients with other debilitating chronic diseases, such as multiple sclerosis or Parkinson's disease.

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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REFERENCES

- Deltaplan Dementie: Cijfers over dementie. Accessed February 06, 2021. http://www.deltaplandementie.nl
- Scholzel-Dorenbos CJ, Draskovic I, Vernooij-Dassen MJ, Olde Rikkert MG. Quality of life and burden of spouses of Alzheimer disease patients. Alzheimer Dis Assoc Disord. 2009;23(2):171-177.
- Dickinson C, Dow J, Gibson G, Hayes L, Robalino S, Robinson L. Psychosocial intervention for carers of people with dementia: what components are most effective and when? A systematic review of systematic reviews. *Int Psychogeriatr*. 2017;29(1):31-43. https://doi.org/ 10.1017/s1041610216001447.
- Jutten LH, Mark RE, Wicherts JM, Sitskoorn MM. The Effectiveness of Psychosocial and Behavioral Interventions for Informal Dementia Caregivers: meta-Analyses and Meta-Regressions. J Alzheimers Dis. 2018;66(1):149-172. https://doi.org/10.3233/jad-180508.
- Williams F, Moghaddam N, Ramsden S, De Boos D. Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of randomised controlled trials. *Aging Mental Health*. 2018: 1-14. https://doi.org/10.1080/13607863.2018.1515886.
- Clarkson P, Davies L, Jasper R, Loynes N, Challis D. A Systematic Review of the Economic Evidence for Home Support Interventions in Dementia. *Value Health*. 2017;20(8):1198-1209. https://doi.org/10. 1016/j.jval.2017.04.004.
- Jones C, Edwards RT, Hounsome B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. *International psychogeriatrics*. 2012;24(1):6-18. https://doi.org/10.1017/ s1041610211001207.
- Nickel F, Barth J, Kolominsky-Rabas PL. Health economic evaluations of non-pharmacological interventions for persons with dementia and their informal caregivers: a systematic review. *BMC Geriatr.* 2018;18(1):69. https://doi.org/10.1186/s12877-018-0751-1.
- Lin PJ, D'Cruz B, Leech AA, et al. Family and Caregiver Spillover Effects in Cost-Utility Analyses of Alzheimer's Disease Interventions. *Pharma-coEconomics*. 2019;37(4):597-608. https://doi.org/10.1007/s40273-019-00788-3.
- Birkenhager-Gillesse EG, Kollen BJ, Zuidema SU, Achterberg WP. The "more at home with dementia" program: a randomized controlled study protocol to determine how caregiver training affects the wellbeing of patients and caregivers. *BMC Geriatr*. 2018;18(1):252. https: //doi.org/10.1186/s12877-018-0948-3.
- Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. Research Support, Non-U.S. Gov't. J Clin Epidemiol. 1998;51(11):1055-1068.
- Brodaty H, Gresham M. Effect of a training programme to reduce stress in carers of patients with dementia. Clinical Trial Controlled Clinical Trial. Research Support, Non-U.S. Gov't. BMJ (Clinical research ed. 1989;299(6712):1375-1379.
- Gresham M, Heffernan M, Brodaty H. The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *Int Psychogeriatr.* 2018;30(11):1697-1706. https://doi.org/10.1017/s1041610218000686.

- 14. Brodaty H, Peters KE. Cost effectiveness of a training program for dementia carers. *Int Psychogeriatr Spring*. 1991;3(1):11-22.
- Dyer SM, Standfield LB, Fairhall N, et al. Supporting communitydwelling older people with cognitive impairment to stay at home: a modelled cost analysis. Austr J Ageing. 2020. https://doi.org/10.1111/ aiag.12818.
- 16. Nederland A, Factsheet https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie
- Janssen O, Vos SJB, Handels R, et al. Duration of Care Trajectories in Persons With Dementia Differs According to Demographic and Clinical Characteristics. J Am Med Direct Assoc. 2020;21(8):1102-1107. https://doi.org/10.1016/j.jamda.2020.01.008.
- 18. Lamers LM, McDonnell J, Stalmeier PF, Krabbe PF, Busschbach JJ. The Dutch tariff: results and arguments for an effective design for national EQ-5D valuation studies. *Health Econ.* 2006;15(10):1121-1132. https://doi.org/10.1002/hec.1124.
- Hoefman RJ, van Exel J, Rose JM, van de Wetering EJ, Brouwer WB. A discrete choice experiment to obtain a tariff for valuing informal care situations measured with the CarerQol instrument. *Med Decis Making*. 2014;34(1):84-96. https://doi.org/10.1177/0272989x13492013.
- Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. J Health Econ. 2002;21(2):271-292.
- Scholzel-Dorenbos CJ, Arons AM, Wammes JJ, Rikkert MG, Krabbe PF. Validation study of the prototype of a disease-specific index measure for health-related quality of life in dementia. *Health Quality Life Outcomes*. 2012;10:118. https://doi.org/10.1186/1477-7525-10-118.
- Lutomski JE, Baars MA, Schalk BW, et al. The development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): a large-scale data sharing initiative. *PloS One*. 2013;8(12):e81673. https://doi.org/10.1371/journal.pone.0081673.
- Nederland Z, richtlijn-voor-het-uitvoeren-van-economischeevaluaties-in-de-gezondheidszorg. https://www. zorginstituutnederland.nl/publicaties/publicatie/2016/02/29/ richtlijn-voor-het-uitvoeren-van-economische-evaluaties-in-degezondheidszorg. Accessed October 19, 2020.
- Fenwick E, Marshall DA, Levy AR, Nichol G. Using and interpreting cost-effectiveness acceptability curves: an example using data from a trial of management strategies for atrial fibrillation. *BMC Health Serv* Res. 2006;6:52. https://doi.org/10.1186/1472-6963-6-52.
- Birkenhäger-Gillesse EG, Achterberg WP, Janus SIM, Kollen BJ, Zuidema SU. Effects of caregiver dementia training in caregiverpatient dyads: a randomized controlled study. *Int J Geriatr Psychiatry*. 2020. https://doi.org/10.1002/gps.5378.
- Nederland Z, Kosteneffectiviteit+in+de+praktijk. https://www.zorginstituutnederland.nl/publicaties/rapport/2015/06/26/kosteneffectiviteit-in-de-praktijk. Accessed October 20, 2020.
- Foldes SS, Moriarty JP, Farseth PH, Mittelman MS, Long KH. Medicaid Savings From The New York University Caregiver Intervention for Families with Dementia. *Gerontologist*. 2018;58(2):e97-e106. https://doi.org/10.1093/geront/gnx077.

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