

Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: A cluster randomised controlled trial

Nienke van Wezel^{a,*}, Iris van der Heide^b, Walter LJM Devillé^{b,d,e}, Emine Kayan Acun^a, Julie H.C.M. Meerveld^a, Peter Spreeuwenberg^b, Marco M Blom^a, Anneke L Francke^{b,c}

^a Alzheimer Nederland, Amersfoort, Netherlands

^b Nivel, Netherlands Institute of Health Services Research, P.O. Box 1568, 3500 BN, Utrecht, Netherlands

^c Department of Public and Occupational Health, Amsterdam Public Health Research Institute, VU University, Amsterdam, Netherlands

^d Julius Centre for Health Sciences and Primary Care, University Medical Centre Utrecht, Netherlands

^e Faculty of Social and Behavioural Sciences, University of Amsterdam, Amsterdam, Netherlands

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ABSTRACT

Objective: The aim of this paper is to examine the effects of an educational peer-group intervention on knowledge about dementia, perceived ability to talk about it, received support and self-perceived pressure from informal care among family caregivers with a Turkish or Moroccan immigrant background who cared for a person with dementia.

Methods: This paper is based on a cluster randomised controlled trial with three measures, including participants who knew or cared for a person with dementia. For the purpose of this study, a selection was made of participants who cared for a person with dementia. Knowledge about dementia, perceived ability to talk about dementia, support received and self-perceived pressure from informal care were assessed in the intervention and the control condition. Multi-level analyses were conducted to examine the effects.

Results: Data for 386 participants was analysed. Improvement in knowledge about dementia over time was significantly greater in the intervention condition than in the control condition. In the intervention condition, there was also a significant increase over time in the support received from home-care staff, which was not found in the control condition. No effects were found on other types of support received, the ability to talk about dementia or the self-perceived pressure from informal care.

Conclusion: Offering a culturally sensitive educational peer-group education intervention enhances knowledge about dementia and has a small but positive effect on the support received from home-care staff in these groups.

Practice Implications: Offering peer-group-based education about dementia to family caregivers with Turkish or Moroccan immigrant backgrounds is important for multicultural dementia care.

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1. Introduction

Dementia has been declared to be one of the major health challenges of the 21st century [1]. According to the WHO, there were 35.6 million people with dementia worldwide in 2010 and this number is expected to rise by 71 % by 2050 [2].

The number of people with dementia is also increasing in non-Western migrant groups [3]. They often do not receive care and support in time [4–8]. One of the major barriers to access to care

and support services is a lack of targeted information [9,10]. In addition, beliefs and perceptions with respect to dementia and professional care can play an important role in determining whether they receive timely care and support [11–14].

In the Netherlands, 22.6 % of the population is of non-Western origin; most of these first- and second-generation migrants have a Turkish or Moroccan background [15]. The first generation of Turkish and Moroccan immigrants who moved to the Netherlands in the 1960s and 1970s is now ageing and they increasingly face age-related diseases, including dementia [16].

An interview study among family caregivers with a Turkish or Moroccan immigrant background indicated that they and their families often perceive the onset and symptoms of dementia as

* Corresponding author.

E-mail address: n.vanwezel@alzheimer-nederland.nl (N. van Wezel).

inherent to ageing or as a spiritual experience rather than the characteristics of a neuro-psychiatric disorder [14]. This might inhibit people from visiting a doctor in time and thereby receiving a formal dementia diagnosis, which is important for access to professional care and support [11,17].

Furthermore, interviews with family carers with a Turkish or Moroccan background also indicated that they often refrain from talking about the mental deterioration of an older family member outside the immediate family circle because of respect for older relatives, who often do not want the wider community to know about their dementia [14]. This makes it more difficult to obtain additional informal or professional support for persons with dementia and their family caregivers.

With respect to the care for a person with dementia, migrant families with a Turkish or Moroccan background tend to prefer care that is provided by female family members, which might also inhibit the use of additional informal or professional support [13,18]. Family caregivers are therefore likely to perceive a high pressure from informal care, since support from others, including healthcare professionals, is called upon infrequently or only in a late stage of the disease [18].

A better understanding of the disease and awareness of support options might reduce the barriers preventing family carers and their relatives with dementia from arranging additional care and support, and reduce the self-perceived pressure from informal care. There are ongoing local and national campaigns and educational programmes on dementia in the Netherlands, as in other countries, that are aimed at increasing knowledge about dementia. However, very few specifically target migrant groups or are easily accessible to migrant groups, and these are often not been properly evaluated [19,10].

To address the lack of educational programmes specifically targeting people with a Turkish or Moroccan migrant background, the Dutch Alzheimer Association developed the peer-group educational intervention 'Knowing about forgetting' (Weten over vergeten). In this intervention, information on dementia and support options is provided to family carers in a culturally and linguistically sensitive manner in two two-hour interactive sessions.

The aim of the current study is to examine the effects of this educational peer-group intervention.

The specific primary research question addressed in this paper is:

- 1 Does participation in an educational peer-group intervention improve knowledge about dementia among family caregivers with a Turkish or Moroccan background?
The secondary research questions are:
- 2 Does participation in an educational peer-group intervention result in:
 - an improvement in the perceived ability to talk about dementia?
 - an increase in the use of informal or professional support?
 - a decrease in the self-perceived pressure from informal care?
- 3 Are the outcome measures associated with background characteristics?

As the intervention included education about dementia and discussions on how and where additional support could be arranged, as well as discussions about the importance of talking about dementia with other people in the family and broader community, we expected the intervention to have a positive effect on the perceived ability to talk about dementia with others, on the amount of support received (informal or professional) and

on the self-perceived pressure from informal care. This expectation was based on previous studies by Keyes et al. [20] and Smith et al. [21,22] who found that peer support had a positive emotional and social impact that was rooted in identification with others, a commonality of experience and reciprocity of support.

Some small positive changes in the outcomes of participants in the control condition were also expected since these participants also filled in questionnaires on three separate occasions at a meeting place along with other participants in the control condition in the specific region. This might result in learning effects and also in positive effects related to unstructured and spontaneous interactions with peers.

2. Methods

2.1. Design

This study is based on a cluster randomised controlled trial with repeated measures. The unit of randomisation was the region in which family caregivers lived. We applied a commonly used regional classification system (for instance used by the Dutch Alzheimer Organisation), which divides the Netherlands into 47 regions. The eligibility criteria for the regions (clusters) included (a) no educational programmes on dementia were already being offered to the target groups; (b) a relatively large numbers of people with Turkish or Moroccan backgrounds living in the region.

A total of 16 regions in the Netherlands (clusters) were included, which were then randomly assigned to either the intervention or the control condition, following simple randomisation procedures (computer-generated random numbers). The allocation sequence was concealed from the researcher (NW) who enrolled the regions. Regions were anonymised using numbers before the randomisation procedure, which was conducted by a researcher who was kept blinded with respect to the region names.

Within the regions, participants were subdivided into different groups: 15 regions included one group of participants with Turkish backgrounds and one of participants with Moroccan backgrounds and one region included three groups of participants with Turkish backgrounds and one of participants with Moroccan backgrounds. A total of 34 groups were included in the study, 16 comprising participants with Moroccan backgrounds and 18 comprising participants with Turkish backgrounds. The groups had a minimum of 4 participants and a maximum of 40. All groups within a region were assigned either to the control condition or to the intervention condition.

The study comprised a measurement directly before the first educational session (i.e. the first session in the intervention condition = T0, baseline), a measurement one to two weeks later (namely directly after the second educational session = T1) and a measurement (T2) three months after T0. Participants in a cluster (region) that was randomly assigned to the control condition completed the same questionnaires as participants in the intervention condition at T0, T1 (one to two weeks after T0) and T2 (three months after T0).

2.2. Sample size

We calculated the minimum sample size taking into account the intracluster correlation coefficient, the expected effect and the power of the study. In order to detect a difference of 35 % with a power of .80 and an α of .05, the control condition and intervention

condition should each include 129 participants. In order to account for clustering, the sample size should be enlarged by 10 %, leading to a total sample size of 284. Taking into account a 20 % loss to follow-up, a total of 340 participants should initially be included. In fact, the actual group of participants was somewhat larger as we did not want to disappoint and exclude family carers who were willing to participate in the study.

The study participants had to know someone with dementia or severe memory problems (see 2.3). However, for the purpose of the current paper, only data were analysed of the 386 participants who themselves cared for a person with dementia or in case of absence of a formal diagnosis, with severe memory problems.

2.3. Participants and recruitment

The eligibility criteria for the study participants were:

- a) knowing someone with a dementia diagnosis or severe memory problems;
- b) being born in Turkey or Morocco or having at least one parent who was born in one of these countries;
- c) not having dementia or memory problems themselves.

Potential participants were invited for participation by key figures (i.e. imams, older immigrant consultants, immigrant care organisations and regional departments of the Dutch Alzheimer Association. If potential participants were interested in participating, the key figures provided their contact details to the study coordinator (NW) after obtaining the consent of the potential participant. The study coordinator assessed whether the candidate participant fulfilled all the inclusion criteria.

This article is part of a larger study that, in addition to the outcomes described in this article also measures aspects of quality of life. It also includes questions that specifically ask about (a) the living situation of the family caregiver (with or without the person with dementia or serious forgetfulness), (b) whether they offer help to their loved one with dementia or severe forgetfulness and if so, what kind of help and (c) how often this help/care was finally provided).

2.4. Intervention

Participants in the intervention condition received two educational sessions on dementia of two hours each, together with other participants (peers) with the same cultural background (Turkish or Moroccan). In all the regions this was the first time ever that family carers came together in a group to get about a clearer understanding of dementia and to take part in a group conversation about dementia.

The two sessions were different in nature: the first was purely informational, the second was a group discussion.

In the first session, a trained educator with the same background (Turkish or Moroccan) gave information about the differences between dementia and 'normal' forgetfulness (symptoms) and explained that dementia is a brain disease. In the second session, which took place one to two weeks after the first, the trained educator facilitated a group discussion about whether or not it is important to talk openly about dementia and to talk about local options for care and support and the extent to which participants are willing to accept local options for care and support. To get the conversation started hypothetical scenarios were used to provide a safe way for participants to talk with each other about these topics during the session. The groups had a minimum of 4 and a maximum of 40 participants each. The two

sessions for each group were held in the afternoon in a meeting place, for instance in a room at a mosque or in a cultural community centre.

Participants in the control condition came together in similar meeting places to complete the questionnaires on three occasions, whereby the second occasion was one to two weeks after the first and the third three months after the first. Since participants in the control condition also met peer caregivers when coming to the meeting place to fill in the questionnaire, they had the opportunity to talk to others about their situation. Yet only participants in the intervention condition received the educational peer-group intervention during the study period; this intervention was offered to the control condition participants only after completion of the study.

2.5. Outcome measures and measurements

Knowledge about dementia was measured using a scale largely based on items in the Alzheimer Disease Knowledge Scale (ADKS) [23]. Eleven items from the ADKS that corresponded with the content of the educational peer-group intervention were translated from English into Dutch, Turkish and Moroccan Arabic and validated (Van Wezel *et al.*, submitted). The 11 items addressed characteristics of dementia, determinants of dementia and the course of the disease. All items had 'true' and 'false' as the answer options. Correct answers were scored as 1. Sum scores were calculated with a range from 0 to 11, with higher scores indicating more knowledge about dementia.

The perceived ability to talk about dementia was measured by three self-developed items asking how well participants felt able to (a) talk to the general practitioner (GP) or another healthcare provider about dementia; (b) talk to friends about dementia; (c) talk to family about dementia. Answers could be given on a five-point Likert scale ranging from feeling not at all able to talk about dementia (score 1) to feeling very able to talk about dementia (score 5).

The support received was measured with four self-developed questions asking whether respondents received (a) advice from their GP or another doctor, (b) support from their family, (c) support from friends or neighbours, or; (d) support from home-care staff in the care for a person with dementia. Answers could be given on a five-point Likert scale including the following range: 1 (No!) 2 (No) 3 (More or less) 4 (Yes) 5 (Yes!).

The perceived pressure from informal care was measured by the SPPIC- Self Perceived Pressure from Informal Care- (in Dutch: EDIZ) [24], a scale that was originally developed in Dutch and validated in Dutch and was translated for this study into Turkish and Moroccan Arabic as well [25]. The scale was based on nine items and answers could be given on a five-point Likert scale ranging from 1 (no self-perceived pressure from informal care) to 5 (high self-perceived pressure from informal care). Sum scores were calculated with a range from 9 to 45, with higher scores indicating a higher perceived pressure from informal care.

In addition the following background characteristics were assessed: age (included as a continuous variable), sex (1. male; 2. female), level of education (1. no education; 2. primary education; 3. secondary education; 4. secondary vocational education; 5. higher vocational education; 6. university), ethnicity (1. Turkish; 2. Moroccan), frequency of caregiving (1. on a daily basis; 2. three to six times per week; 3. once or twice a week; 4. less than once a week; 5. less than once a month; 6. living situation of the family caregiver (with or without the person with dementia or serious forgetfulness)).

All participants had the option of filling in the questionnaires in Dutch, Moroccan Arabic or Turkish. None of the participants chose to fill in the Moroccan Arabic version of the questionnaire, which might be related to the fact that female caregivers of Moroccan descent often cannot read or write Arabic. On all three measurement occasions, a majority of the participants with Turkish backgrounds filled in the Turkish version of the questionnaire (87 % at T0, 88 % at T1 and 96 % T2). For those who had poor literacy, a research assistant read the questionnaire out loud and wrote down the participant's answers to the questions on their behalf.

2.6. Ethical procedures

Before participation, participants were informed firstly face-to-face about the study by the key figure who recruited them, then a second time by the study coordinator over the phone and thirdly in an information letter that they received at home before the first measurement occasion. On the first measurement occasion (T0) all participants received another copy of the information letter and an informed consent form in their language of preference (Dutch, Turkish or Moroccan Arabic). The information letters and informed consent forms were read out loud by a research assistant in case some participants had poor literacy, to ensure that all participants understood the information letter and the informed consent form. The informed consent forms were provided by the research assistant during the first measurement occasion to ensure that the participants themselves provided consent and not another person (e.g. a spokesman in the family). Written consent was obtained from each participant.

No formal permission from a medical ethics committee was required for this study according to the relevant Dutch law, as the research did not concern medical research and participants were not required to follow rules of behaviour (<https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not>).

2.7. Statistical analyses

Descriptive statistics, a two-sample *t*-test, Chi-squared tests and a Kruskal-Wallis test were used to provide insight into participants' background characteristics and into differences in background characteristics between the intervention and the control condition. Subsequently, nine repeated-measures (RM) multi-level analyses were conducted, taking into account the effects of clustering at the region level [35]. At the participant level an unstructured covariance structure between the three measurement occasions was modelled to control for the correlation between measurements within participants. This was done separately for the control and intervention conditions. The model was used to estimate the corrected mean scores for the conditions for: the dementia knowledge scale; the three items about the perceived ability to talk about dementia; the four items about received support; and the items on the self-perceived pressure from informal care. These mean scores were calculated for the intervention condition and the control condition at T0, T1 and T2 and adjusted for age, sex, level of education, migration background and frequency of caregiving. The analyses estimating the effect of the intervention on the perceived ability to talk about dementia, on the support received and on the self-perceived pressure from informal care were also adjusted for dementia knowledge. All the co-variables were included in the multi-level analyses at the same time. RM multilevel regression analysis takes into account differences in baseline scores. Chi-squared tests were performed to test for significant trends in both the intervention and the control condition and to test whether trends in the intervention condition differed from trends in the control condition. In repeated measure RM multilevel analyses, participants are included when having at least one completed outcome measure (at T0, T1 and/or T2) as well as no missing data on any of the co-variables [36]. The analyses were conducted in MLwiN.

Table 1
Participants' background characteristics.

	Intervention condition (n = 202)	Control condition (n = 184)	p-value
Age, mean (SD)	45.5 (13.7)	41.4 (13.9)	0.004*
Sex, %			0.02**
Male	9.5	17.4	
Female	90.0	81.5	
Missing	0.5	1.1	
Migrant background, %			0.22
Turkish	60.0	53.8	
Moroccan	40.0	46.2	
Country of birth, %			0.000**
The Netherlands	10.0	29.3	
Other	88.5	69.6	
Missing	1.5	1.1	
Level of education, %			0.0001***
No education	23.5	8.2	
Primary education	28.0	22.2	
Secondary education	14.5	15.8	
Secondary vocational education	18.0	31.0	
Higher vocational education	12.5	14.7	
University	1.5	6.5	
Other or missing	2.0	1.6	

* Based on two-sample *t*-test.

** Based on Chi-squared test.

*** Based on Kruskal-Wallis equality-of-populations rank test.

Table 2

Mean scores in dementia knowledge scale at T0, T1 and T2 for the intervention and control conditions (N = 340).

	Intervention condition	Control condition
T0, mean (95 % CI)*	7.6 (7.1–8.1)	6.7 (6.2–7.2)
T1, mean (95 % CI)*	9.0 (8.6–9.5)	6.9 (6.5–7.4)
T2, mean (95 % CI)*	8.9 (8.4–9.4)	7.4 (6.9–7.8)
Does T1 differ significantly from T0? Chi-squared (df); p-value	47.15 (1); p < 0.001	1.54 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared (df); p-value	37.48 (1); p < 0.001	10.27 (1); p < 0.01
Trend over time, Chi-squared (df); p-value	51.03 (2); p < 0.001	10.50 (2); p < 0.01
Do the trends differ significantly? Chi-squared (df); p-value	22.21 (2); p < 0.001	

* Corrected for region, sex, age, level of education, ethnicity and frequency of caregiving.

Table 3

Mean scores for support received at T0, T1 and T2 for the intervention condition and the control condition (N = 340; 338; 340; 340).

	Intervention condition	Control condition
	<i>Received advice from a doctor</i>	
T0, mean (95 % CI)*	2.7 (2.3–3.1)	2.7 (2.3–3.1)
T1, mean (95 % CI)*	2.8 (2.4–3.2)	2.8 (2.4–3.1)
T2, mean (95 % CI)*	2.6 (2.3–3.0)	2.8 (2.5–3.2)
Does T1 differ significantly from T0? Chi-squared; p-value	0.36 (1); p > 0.1	0.14 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	0.22 (1); p > 0.1	0.38 (1); p > 0.1
Trend over time, Chi-squared; p-value	1.11 (2); p > 0.1	0.38 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	1.11 (2); p > 0.1	
	<i>Received support from family</i>	
T0, mean (95 % CI)*	3.3 (2.9–3.6)	3.4 (3.0–3.7)
T1, mean (95 % CI)*	3.3 (3.0–3.6)	3.4 (3.1–3.6)
T2, mean (95 % CI)*	3.5 (3.2–3.8)	3.5 (3.2–3.7)
Does T1 differ significantly from T0? Chi-squared; p-value	0.06 (1); p > 0.1	0.00 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	3.79 (1); p > 0.05	0.48 (1); p > 0.1
Trend over time, Chi-squared; p-value	4.26 (2); p > 0.1	1.59 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.87 (2); p > 0.1	
	<i>Received support from friends or neighbours</i>	
T0, mean (95 % CI)*	2.2 (1.7–2.6)	2.4 (1.9–2.8)
T1, mean (95 % CI)*	2.1 (1.6–2.6)	2.2 (1.8–2.6)
T2, mean (95 % CI)*	2.4 (1.9–2.9)	2.4 (1.9–2.8)
Does T1 differ significantly from T0? Chi-squared; p-value	0.27 (1); p > 0.1	2.11 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	3.53 (1); p > 0.05	0.00 (1); p > 0.1
Trend over time, Chi-squared; p-value	7.16 (2); p < 0.05	3.04 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	2.33 (2); p > 0.1	
	<i>Received support from home care or nurses</i>	
T0, mean (95 % CI)*	2.0 (1.6–2.5)	2.5 (2.1–2.9)
T1, mean (95 % CI)*	2.2 (1.7–2.6)	2.4 (2.0–2.8)
T2, mean (95 % CI)*	2.4 (1.9–2.9)	2.4 (2.0–2.8)
Does T1 differ significantly from T0? Chi-squared; p-value	1.14 (1); p > 0.1	0.78 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	7.87 (1); p < 0.05	1.21 (1); p > 0.1
Trend over time, Chi-squared; p-value	7.91 (2); p < 0.05	1.41 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	8.44 (2); p < 0.05	

* Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge.

3. Results

3.1. Participants and background characteristics

Initially, a total of 288 participants were assigned to the intervention condition and 262 to the control condition, see Appendix, Fig. A1. For this paper, a sub-selection was made of individuals who had declared that they cared for a person with dementia (n = 202 in the intervention condition and n = 184 in the

control condition), see Appendix, Fig. A1. Of this sub-selection 319 participants completed the questionnaire at T0, 313 at T1 and 290 at T2.

Equivalence between participants in the intervention condition versus those in the control condition was examined based on age, sex, ethnicity and level of education. There were more women, slightly more respondents of Turkish origin (although this difference was not statistically significant) and more respondents with no or only primary education in the intervention condition

Table 4

Mean scores for ability to talk about dementia at T0, T1 and T2 for the intervention condition and the control condition (N = 339; 340; 339).

	Intervention condition	Control condition
	<i>Talking to a GP</i>	
T0, mean (95 % CI)*	3.8 (3.5–4.1)	3.8 (3.6–4.1)
T1, mean (95 % CI)*	3.9 (3.6–4.2)	4.0 (3.7–4.2)
T2, mean (95 % CI)*	3.8 (3.5–4.2)	3.9 (3.6–4.2)
Does T1 differ significantly from T0? Chi-squared; p-value	0.75 (1); p > 0.1	3.65 (1); p > 0.05
Does T2 differ significantly from T0? Chi-squared; p-value	0.11 (1); p > 0.1	0.28 (1); p > 0.1
Trend over time, Chi-squared; p-value	0.81 (2); p > 0.1	3.81 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.36 (2); p > 0.1	
	<i>Talking to family</i>	
T0, mean (95 % CI)*	3.9 (3.6–4.2)	3.8 (3.5–4.1)
T1, mean (95 % CI)*	4.0 (3.7–4.3)	3.9 (3.6–4.2)
T2, mean (95 % CI)*	3.9 (3.6–4.3)	3.9 (3.6–4.2)
Does T1 differ significantly from T0? Chi-squared; p-value	3.67 (1); p > 0.05	0.19 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	0.70 (1); p > 0.1	1.58 (1); p > 0.1
Trend over time, Chi-squared; p-value	3.77 (2); p > 0.1	1.59 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	1.52 (2); p > 0.1	
	<i>Talking to friends</i>	
T0, mean (95 % CI)*	3.7 (3.4–4.0)	3.5 (3.2–3.8)
T1, mean (95 % CI)*	3.6 (3.3–4.0)	3.4 (3.1–3.7)
T2, mean (95 % CI)*	3.6 (3.3–4.0)	3.4 (3.1–3.7)
Does T1 differ significantly from T0? Chi-squared; p-value	1.41 (1); p > 0.1	0.71 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	1.60 (1); p > 0.1	0.21 (1); p > 0.1
Trend over time, Chi-squared; p-value	2.04 (2); p > 0.1	0.72 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.18 (2); p > 0.1	

* Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge.

Table 5

Mean scores for perceived pressure from informal care at T0, T1 and T2 for the intervention condition and the control condition (N = 333).

	Intervention condition	Control condition
T0, mean (95 % CI)*	26.0 (23.8 to 28.2)	24.6 (22.5 to 26.6)
T1, mean (95 % CI)*	25.6 (23.4 to 27.9)	24.1 (22.0 to 26.2)
T2, mean (95 % CI)*	25.2 (23.0 to 27.4)	24.8 (22.7 to 27.0)
Does T1 differ significantly from T0? Chi-squared; p-value	0.27 (1); p > 0.1	0.77 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	1.17 (1); p > 0.1	0.15 (1); p > 0.1
Trend over time, Chi-squared; p-value	1.07 (2); p > 0.1	1.23 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	1.68 (2); p > 0.1	

* Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge.

Table 6

Associations between background characteristics and outcome measures.

Background characteristics	Outcome measures								
	Dementia knowledge	Self-Perceived pressure from informal care	Talking with a GP	Talking with family	Talking with friends	Advice from doctor /b18	Support from family /b19	Support from friends/ neighbours /b20	Support from home-care staff /b21
	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)
Age	0.006 (0.01)	0.07 (0.03)*	−0.01 (0.003)*	−0.001 (0.003)	−0.003 (0.004)	−0.001 (0.005)	−0.003 (0.005)	0.005 (0.005)	0.012 (0.005)*
Sex (reference group: male)	0.42 (0.28)	1.43 (1.11)	0.05 (0.10)	0.02 (0.11)	0.28 (0.13)*	−0.16 (0.17)	−0.43 (0.18)*	0.24 (0.15)	0.14 (0.18)
Level of education	0.18 (0.07)	0.002 (0.30)	0.10 (0.03)*	0.06 (0.03)*	0.10 (0.03)*	0.13 (0.05)*	0.11 (0.05)*	0.10 (0.04)*	0.16 (0.05)*
Frequency of caregiving	0.002 (0.05)	−1.50 (0.20)*	−0.06 (0.02)*	−0.06 (0.02)*	−0.11 (0.02)*	−0.20 (0.03)	−0.06 (0.03)	0.02 (0.03)	−0.06 (0.03)*
Migrant background (reference group: Turkish)	−0.49 (0.21)*	−3.10 (0.84)*	−0.44 (0.07)*	−0.38 (0.08)*	−0.25 (0.09)*	0.03 (0.13)	0.18 (0.13)	−0.16 (0.12)	0.09 (0.14)
Dementia knowledge	–	0.31 (0.13)*	0.02 (0.01)*	0.01 (0.02)	0.03 (0.02)	0.07 (0.02)*	−0.01 (0.02)	0.00 (0.02)	0.04 (0.02)*

* Significant association (p < .05).

compared to those in the control condition, see Table 1. Furthermore, participants in the intervention condition were generally slightly older than participants in the control condition (mean age 45.5 versus 42.5; $p = 0.04$).

3.2. Effects on knowledge about dementia

In both the intervention condition and the control condition there was a significant trend of increased knowledge about dementia over time, see Table 2. This increase was significantly stronger in the intervention condition than in the control condition (Chi-squared (2) = 22.21; $p < 0.001$). The increase in knowledge shows a different pattern over time for the two conditions: whereas the participants in the intervention condition show the largest knowledge gain between T0 and T1, the participants in the control condition showed the largest gain between T1 and T2. A higher level of education and a Turkish migration background were associated with higher scores in the dementia knowledge test ($p < .05$), see Table 5.

3.3. Effects on talking about dementia, support received and self-perceived pressure from informal care

In the intervention condition there was a small but significant increase over time in the support received from home-care staff (Chi-squared (2) = 7.91; $p < 0.05$), which was not found in the control condition (Chi-squared (2) = 8.44; $p < 0.05$) (see Table 3). No significant differences were found at T1 and T2 compared to T0 in either the intervention condition or the control condition for advice received from a doctor, support received from family and support received from friends or neighbours. Furthermore, no significant differences were found over time in the perceived ability to talk about dementia (see Table 4) and the self-perceived pressure from informal care (see Table 5) in either the intervention condition or the control condition.

3.4. Associations between background characteristics and outcome measures

Table 6 shows that a higher level of education, a higher frequency of caregiving and having a Turkish background were significantly ($p < 0.05$) associated with a higher perceived ability to talk about dementia with a GP, with family member and with friends. In addition, being younger was associated with a higher perceived ability to talk about dementia with a GP ($p < 0.05$) and being a woman with a higher perceived ability to talk about dementia with friends ($p < 0.05$).

With respect to the support received, a higher level of education, a higher frequency of caregiving and more knowledge about dementia were associated with receiving more advice from a doctor ($p < 0.05$). Furthermore, being a male caregiver, having a higher level of education and a higher frequency of caregiving were associated with receiving more support from family ($p < 0.05$). A higher level of education was also associated with receiving more support from friends or neighbours and with receiving more support from home-care staff ($p < 0.05$). In addition, being older, having a higher level of education, a higher frequency of caregiving and more knowledge about dementia were associated with receiving more support from home-care staff ($p < 0.05$).

A higher self-perceived pressure from informal care was associated significantly with being older, a higher frequency of caregiving, a Turkish background and more knowledge about dementia ($p < 0.05$), see Table 6.

4. Discussion and conclusion

4.1. Discussion

This study aimed to examine the effects of the educational peer-group intervention 'Knowing about forgetting' for caregivers with a Turkish or Moroccan background.

The intervention, consisting of two interactive group sessions, improved knowledge about dementia among the family caregivers. Knowledge about dementia also improved in the control condition, which might be explained by the unguided and unstructured social interactions between the control participants who came together in a meeting place to complete the questionnaires. Besides, there might have been some learning effects from repeatedly completing the same knowledge questions. However, as the increase in knowledge about dementia was significantly greater in the intervention condition than in the control condition, the educational element of the intervention seems to have had an additional positive effect on knowledge about dementia on top of the social interactions and the learning effect.

Our findings regarding the improvement of knowledge about dementia as a result of an educational peer-group intervention fills a gap in scientific research. So far there has been limited evidence on the effects of educational group interventions on family carers' knowledge about dementia, as indicated by the systematic review by Moore and colleagues [26]. The two studies described in this review that included knowledge about dementia as an outcome measure showed either no effect on knowledge [27] or a short-term effect after three months [28]. As far as we know, no study so far has evaluated the effects of educational interventions specifically targeting family caregivers with a migration background.

This paper also shows that the educational peer-group intervention did not affect family carers' perceived ability to talk about dementia. This might in part be explained by high baseline scores, indicating that most participants already found it fairly easy to talk about dementia. A possible explanation for these high baseline scores is that participation in this study in itself required a willingness to talk about dementia with others. Besides, a different type of intervention specifically focusing on communication, such as communication training, might be more effective in improving the ability to talk about dementia than our intervention, which was directed primarily at improving knowledge about dementia and options for care and support [29].

Our findings also indicate that offering the educational peer-group intervention might result in family caregivers receiving more formal support (i.e. support from home-care staff) but not informal support (i.e. from other relatives, friends or neighbours). This finding indicates that the intervention raises awareness on options for formal support and on how to organise formal support.

It could be that the intervention condition included more participants caring for a person with more advanced dementia than the control condition. Participants who cared for a person with advanced dementia seem more likely to receive formal support during the study period. In part we controlled for this, since the analyses were adjusted for frequency of caregiving, which can be regarded as an indication of dementia severity.

The finding could also imply that those who know more about the nature of dementia and available care and support options might be more likely to call on professional support, as suggested in the literature [10]. The fact that the educational intervention had a small but significant effect on the support received from home-care staff supports this latter assumption.

One healthcare system implication, following this finding, is that efforts should be put into reaching out to and informing family caregivers of people with dementia with Moroccan or Turkish

immigrant backgrounds, to ensure they are familiar with available care and support options, in case they are needed. In addition, it seems important at the healthcare system level to develop and keep refining culturally and linguistically competent dementia home care, which is currently not generally offered in the Netherlands.

No significant intervention effects were found on the self-perceived pressure from informal care experienced by family carers. This suggests that the self-perceived pressure from informal care depends on factors other than the support received from home-care staff. The self-perceived pressure from informal care might for instance be more dependent on the stage of the disease, on personal circumstances, on a person's resilience, and possibly on cultural beliefs regarding family care [30–33].

Another finding is that the participating family caregivers with a Moroccan background generally knew less about dementia and had a lower perceived ability to talk about dementia with the GP, family and friends than the participants with a Turkish background. On the other hand, the participating family caregivers with Turkish backgrounds perceived a higher pressure from informal care than caregivers with Moroccan backgrounds. These findings are not easy to explain, and further research is needed comparing variations in outcomes and experiences of family caregivers from different migrant groups.

4.2. Strengths and limitations

A major strength is that this study evaluated an intervention that was developed specifically for family caregivers with a Turkish or Moroccan background. This means that the information was shared, presented and discussed in a culturally and linguistically sensitive manner, which is shown to be essential for effective education for family caregivers with a migration background [34].

Another strength is that the educational programme was provided exclusively by trainers with a Turkish or Moroccan background, who spoke the participants' language and understood their culture. This might have been attractive for participants and might explain why we were able to recruit large groups of family caregivers with Turkish or Moroccan backgrounds.

However, a limitation of this study is that no long-term effects were measured, e.g. with regard to knowledge about dementia. It would be relevant to know if family caregivers experience any benefits in the long term from their increased knowledge about dementia, for instance in terms of coping with dementia.

4.3. Conclusion

Offering peer-group-based education enhances knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background. In addition, this intervention seems to lead to more support from home-care staff. No evidence was found for the effectiveness of the peer-group educational intervention on the perceived ability to talk about dementia, the self-perceived pressure from informal care or additional support from family, friends or neighbours and advice from doctors.

4.4. Practice implications

We found that older family carers had a lower perceived ability to talk about the dementia of their relative with a GP than younger family carers. A recommendation for GPs is therefore

that they should be aware that older people with Turkish or Moroccan backgrounds might not inform them about problems such as memory loss and that dementia might therefore be diagnosed at a relatively late stage in these groups.

As we found no effect of the educational intervention on the self-perceived pressure from informal care, it is recommended on the one hand that more information should be included in the intervention about coping with the pressure from informal care. On the other hand, this finding suggests that education alone might not be sufficient to decrease the perceived pressure of informal care. It is therefore recommended that more research should be conducted into the determinants of the perceived pressure from informal care in family caregivers with Turkish or Moroccan backgrounds and into additional ways or interventions for supporting these family caregivers.

Furthermore, as the effects of the educational intervention on the support received were limited, another recommendation is to intensify the intervention slightly, for instance by offering a third session that focuses primarily on how to arrange additional informal and formal support.

Submission declaration

This article has not been published previously, is not under consideration for publication elsewhere, has been approved by the responsible authorities where the work was carried out and (if accepted) will not be published elsewhere in the same form, in English or in another language, including electronically, without the written consent of the copyright holder.

Informed consent and patient details statement

We confirm that all patient/personal identifiers have been removed or disguised so the patients/people described are not identifiable and cannot be identified through the details of the narrative.

CRediT authorship contribution statement

Nienke van Wezel: Conceptualization; Data curation; Formal analysis; Investigation, original draft; Writing- original draft; Writing- review & editing; Project administration. **Iris van der Heide:** Conceptualization; Formal analysis; Methodology; Writing- original draft; Writing- review & editing. **Walter LJM Devillé:** Supervision; Writing- original draft; Writing- review & editing. **Emine Kayan Acun:** Data curation; Supervision; Writing- original draft. **Julie H.C.M. Meerveld:** Supervision; Writing- original draft. **Peter Spreeuwenberg:** Conceptualization; Formal Analysis, Methodology; Writing- original draft; Writing- review & editing. **Marco M Blom:** Funding acquisition; Resources; Supervision. **Anneke L Francke:** Conceptualization; Supervision; Writing- original draft; Writing- review & editing.

Declaration of Competing Interest

The authors declare that they have no competing interests.

Appendix A

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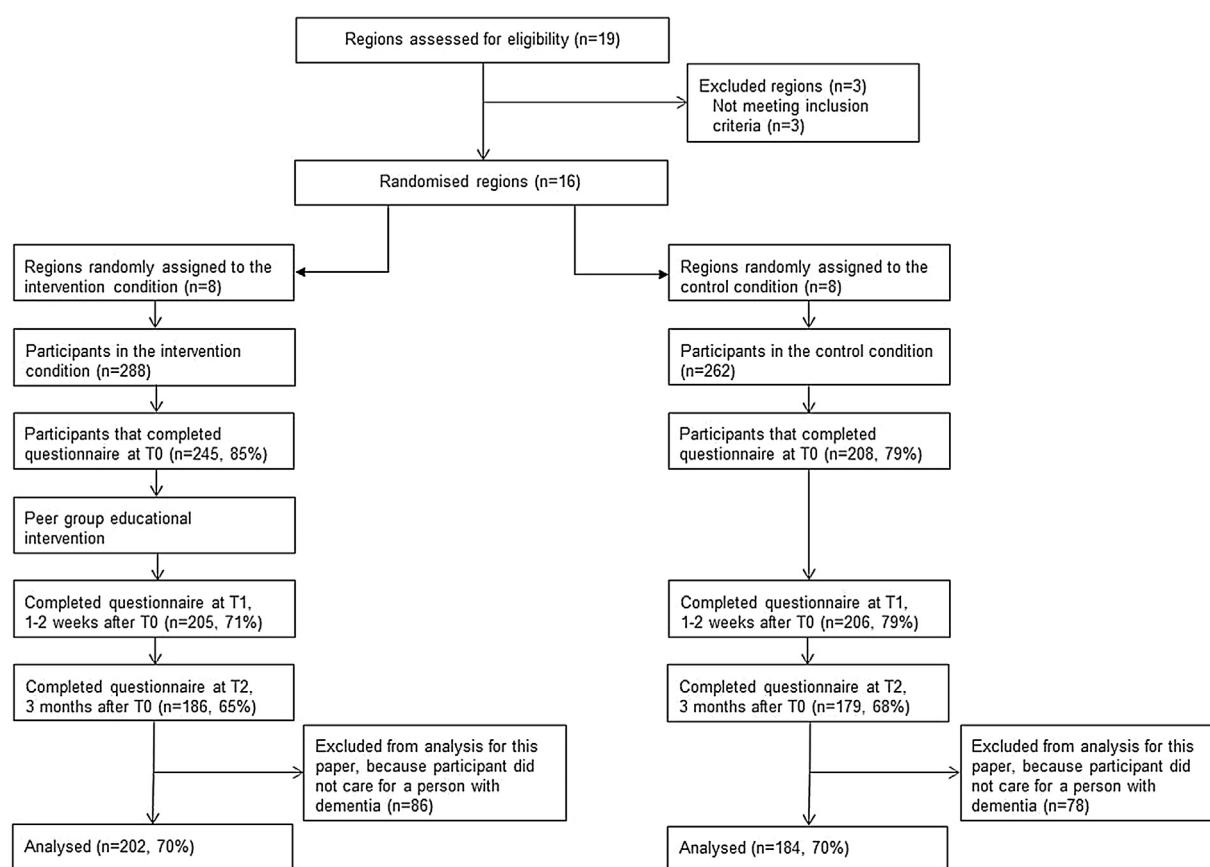


Fig. A1. Flow diagram for participants.

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