Knowledge About Dementia Among Family Caregivers With a Turkish or Moroccan Immigrant Background: Development and Validation of a Dementia Knowledge Scale

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Abstract

Objective: To describe the development and validation of the Dementia Knowledge Scale (DKS) among family caregivers with a Turkish or Moroccan immigrant background. **Methods:** The 11 items of the DKS, selected by professionals and people with a Turkish or Moroccan background, were translated and adapted in Turkish and Dutch. The feasibility, comprehensibility and appropriateness of the 2 language versions were examined. Subsequently, both languages were assessed among caregivers from these groups. The internal consistency of both language versions was determined by calculating Cronbach's α. The known group validity was determined by comparing mean scores between subgroups. **Results:** Both language versions of the DKS were considered feasible, comprehensible, and appropriate. A total of 117 caregivers with a Turkish background completed the Turkish version of the DKS and 110 with a Moroccan background the Dutch version. The Turkish version showed adequate internal consistency but the Dutch version did not. No differences were found in mean scores between those with a low level of education versus those with a higher level; those who frequently provided care versus those who did so less frequently; and those who lived together with a person with dementia versus those who did not. **Conclusions:** The DKS is feasible, comprehensible and reliable and can be used among groups with an immigrant background. **Practice Implications:** The DKS provides insight into various aspects of dementia knowledge, including knowledge about risk factors and symptoms, among caregivers with a Turkish or Moroccan background, and thereby supports the development of tailored education for these groups.

Keywords

dementia, dementia knowledge, family caregivers, migration background, minorities

Highlights

- A (translated) questionnaire (DKS) to assess level of knowledge of dementia, proved to be valid for use among informal caregivers with a Turkish or Moroccan migrant background.
- No differences were found in mean scores between those with a low level of education versus those with a higher level; those who frequently provided care versus those who did so less frequently; and those who lived together with a person with dementia versus those who did not.
- The DKS provides insight into various aspects of dementia knowledge, including knowledge about

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risk factors and symptoms, among caregivers with a Turkish or Moroccan background, and thereby supports the development of tailored education for these groups.

Introduction

According to the World Alzheimer Report,[1] 55 million people worldwide are living with dementia. Given the aging population, this figure is expected to double every 20 years, increasing to 78 million by 2030.[1]

Some groups are more at risk for developing dementia, including people with a non-western immigrant background.[2] This might in part be related to a relatively high prevalence of diseases such as diabetes and cardiovascular conditions among these groups, that increase the risk of dementia.[3,4]

In the Netherlands, 12.6% of the population has a non-western migrant background, of which people with a Turkish or Moroccan background are the largest 2 groups.[5] The first generation of people with a Turkish or Moroccan background that came to the Netherlands in the 1960s and 1970s are now at an age in which dementia becomes more prevalent.

A few studies show that knowledge about dementia among people with a non-western immigrant background tends to be poor, such as knowledge about symptoms and progression of the disease.[6,7] However, this type of knowledge could help recognize the disease and thereby provide access to timely care and support. Furthermore, it could help (family caregivers of) people with dementia in communicating with care professionals and with their social network about dementia and about future needs.[8]

However, in-depth insights into knowledge about dementia and associated factors among people with a non-western migrant background is currently lacking. A commonly used instrument to measure knowledge about dementia, such as the Alzheimer Disease Knowledge Scale (ADKS), that measures knowledge among healthcare professionals or among the general population is not suitable for groups with migrant backgrounds.[9,10] Furthermore, translation and cross-cultural adaptation of these scales to be used among groups with an immigrant background is also lacking.[11]

To increase knowledge about dementia among family caregivers with a Turkish or Moroccan background, the educational peer-group intervention "Knowing about Forgetting" was developed. In order to be able to test the effect this culturally sensitive intervention on knowledge about dementia, an instrument was developed to assess knowledge regarding the topics that were covered in this intervention: risk factors of dementia, disease symptoms, progression of the disease and dealing with dementia.

This paper aims to describe the development and validation of the "Dementia Knowledge Scale" for its use among individuals with a Turkish or Moroccan background. This paper thereby provides insights that are relevant for other researchers who aim to assess dementia knowledge or who aim to develop other disease-specific knowledge scales to be used among these groups. It thereby helps resolve the existing lack of culturally sensitive health measurement scales and our understanding of them.

The research question addressed is "What is the internal consistency and validity of the DKS as completed by family caregivers with Turkish or Moroccan backgrounds?"

Methods

Selection of the Dementia Knowledge Scale Items

For the development of the Dementia Knowledge Scale (DKS), the ADKS was used as a basis. The ADKS is a validated instrument to assess knowledge regarding Alzheimer's Disease. It contains 30 items and is suitable for use in the general population.[9] Eight professionals and 9 people with a Turkish or Moroccan background screened the 30 ADKS items in Dutch and selected the ones that they thought represented the most essential knowledge about dementia and fitted best with the content of the intervention "Knowing about Forgetting." The selected professionals were all formally trained and employed as paid professionals in dementia care. They all had a broad understanding of dementia, the course of the disease and the symptoms of dementia. Based on those individual selections, the 11 most frequently selected items, were included in the final tool (see Appendix 1).

These items were then translated from English into Dutch and (if the 8 professionals deemed it necessary), reformulated into more plain language when needed. An example of such a reformulation is: "Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease." This item was reformulated in Dutch as "*Symptomen van een ernstige depressie kunnen lijken op dementie*" (in English: "Symptoms of severe depression can look like dementia").

The Dutch statements were then translated by native speakers into Turkish and Moroccan Arabic. The statements in Turkish and Moroccan Arabic were compared by other native speakers with the Dutch statements to identify and eliminate any nuance differences in the wording.

Pilot Testing

To determine the feasibility, comprehensibility and appropriateness of the 11 statements of the DKS, a pilot test was conducted among 60 people with a Turkish or Moroccan

background: 30 filled out the Dutch version of the DKS, 15 filled out the Turkish version, and 15 filled out the Moroccan Arabic version. The respondents were recruited in community centers in a large city in the south of the Netherlands (Tilburg). This region was not part of the overall study. Respondents were between 25 and 72 years old and their level of education ranged from no education to a university degree. A researcher evaluated whether the 11 statements were comprehensible (correctly understood), feasible (easy or difficult to answer), and appropriate (seen as relevant for assessing dementia knowledge). These evaluations showed that only minor adaptations were needed. For example, changes to the sequence of the statements and starting with a relatively straightforward statement. These amendments resulted in the final versions of the DKS.

Assessing the Internal Consistency and Known Group Validity of the Dementia Knowledge Scale

Participants and setting. The final version of the DKS was part of a larger questionnaire that was used to evaluate the educational peer-group intervention "Knowing about Forgetting," intended for family caregivers with a Turkish or Moroccan background of a person with dementia. The participants were recruited in parts of the Netherlands with relatively many inhabitants with a Turkish or Moroccan background and where no educational intervention on dementia was offered before.

Participants were recruited through key figures in the communities in question (such as community workers, imams, ethnic-minority senior citizen advisers, ethnic minority care organizations, and regional branches of the Dutch Alzheimer Association). These key figures asked people in their network who had a relative with severe forgetfulness or dementia whether they would be willing to take part in the educational program. The key figures gave a verbal explanation and provided written information about the educational program and associated study.

The following inclusion criteria were applied to select participants:

- must have a relative with dementia or—if there has not yet been a formal diagnosis of dementia—with severe forgetfulness;
- must have been born in Turkey or Morocco or have at least 1 parent born in one of those countries;
- must live in the Netherlands;
- must be able to complete a written questionnaire independently or to complete the questionnaire with the aid of a trained research assistant;
- must not be suffering from severe forgetfulness or dementia themselves.

Procedure. The peer-group educational intervention was evaluated in a Cluster Randomized-Controlled Trial including 3 measurement points: T0 which was directly before the intervention (baseline), T1 which was directly after the intervention (2 weeks after T0), and T2 which was 3 months after the intervention. The unit of randomization 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. 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 randomization procedures (computer-generated random numbers). The allocation sequence was concealed from the researcher (NW) who enrolled the regions. Regions were anonymized using numbers before the randomization procedure, which was conducted by a researcher who was kept blinded with respect to the region names.

Only data from the baseline measurements, that is, the measurements before the start of the peer-group based educational intervention, were used for the psychometric analyses described in this article.

Participants who could write were asked to fill out a questionnaire themselves. Participants could choose whether they wanted to complete the questionnaire in Dutch or in Turkish/Moroccan Arabic. The questionnaires were filled out in a room at a mosque or a cultural community center under the supervision of a research assistant with a Turkish or Moroccan background. The research assistants helped participants who were low literate. For those participants, the research assistants read out the questions and scored the items according to the answers given by the participant.

Since merely 3 respondents filled out the Moroccan Arabic version of the DKS, it was not possible to perform any psychometric analyses for this version.

Prior to participation, the research coordinator gave the participants an information letter about the study together with a consent form, which were in Turkish and in Dutch. In the case of illiterate participants, a research assistant who spoke their mother tongue read out the information letter and consent form. All participants gave their informed consent in writing.

Ethics. Under Dutch law, approval from a medical ethics committee or social/societal ethical committee was not required for this study as the participants were mentally competent, they were not subject to the imposition of a certain kind of behavior and they were not subjected to burdensome interventions or measurements (https://english.ccmo. nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not).

Assessments. In addition to knowledge about dementia, the following sociodemographic variables were assessed: gender, age, level of education (no schooling or primary school, secondary school, secondary vocational education, higher pre-university education or university, or other) and country of birth. In addition to that, it was assessed whether the respondent lived together with a person with dementia and how often the respondent provided help (daily, 3-6 times a week, up to twice a week, less than once a week, less than once a month).

Statistical analyses. For this paper, a sub-selection was made of individuals who had stated that they were caring for a person with dementia at T0.

Firstly, the 11 items of both the Turkish and the Dutch version of the DKS were analyzed descriptively. Secondly, the internal consistency was determined for both versions by calculating Cronbach's alpha (with an α of at least .7 indicating adequate internal consistency). Thirdly, the known group validity scores of both versions were determined by comparing the DKS sum scores between subgroups using an independent *t*-test. It was hypothesized that:

(a) Participants who had attended upper secondary or tertiary education would score higher in the knowledge questionnaire than participants who had no education or had only attended primary school.[12]

(b) Participants who provide informal care for a relative with dementia or severe forgetfulness on a weekly basis would score higher in the knowledge questionnaire than participants who provide informal care less than once a week. This hypothesis was based on an expectation that a person who is intensively involved in informal care will see more of the condition and its symptoms and therefore know more about dementia.[12]

(c) Participants who live in the same home as the relative with dementia or severe forgetfulness would score higher in the knowledge questionnaire than participants who do not live with the relative in question. This hypothesis is also based on the expectation that a person who lives with a relative with dementia will see more of the condition and its symptoms and therefore know more about it.[12]

All statistical analyses were conducted separately for the Turkish and the Dutch version of the DKS using Stata version 15.0.

Results

Sample

For this paper, a sub-selection was made of individuals who had declared that they cared for a person with dementia at T0 (N=244). Of this subselection, 117 participants with a Turkish background completed the Turkish version of DKS and 110 participants with a Moroccan background the Dutch version. These participants were included in the analyses. A total of 16 participants with a Turkish background completed the Dutch version of the DKS and 1 participant with a Moroccan background the Moroccan Arabic version. Given these small group sizes, the Dutch version of the DKS was not validated among participants with a Turkish background and the Moroccan Arabic version not among participants with a Moroccan background.

Sample Characteristics

Most of the respondents were female (83% and 92% respectively), aged between 36 and 55 (56%-54%), and not born in the Netherlands (85% and 76%) in both the respondents with a Turkish background and the respondents with a Moroccan background (see Table 1).

Half of the respondents with a Turkish background had no education or had only attended primary school, among respondents with a Moroccan background this was 35%. At the same time, 19% of the participants with a Moroccan background had attended higher professional education or university, compared to 8% among participants with a Turkish background.

Most respondents in both groups did not live in the same home as the person with dementia (61% and 77%). Yet many respondents stated that they cared for a person with dementia on a daily basis: 36% among respondents with a Turkish background and 31% among respondents with a Moroccan background.

Scores on the Items of the Dementia Knowledge Scale

The overall mean score on the DKS was 7.4 (SD: 2.1; range 2-11). Table 2 shows that there is large variation between items in the percentage of respondents that answers the item correctly. This applies for both the respondents with a Turkish background who filled out the Turkish version of the DKS and the respondents with a Moroccan background who filled out the Dutch version.

In addition, Table 2 shows that both language versions of the DKS differ with respect to the percentages that answer the items correctly for example, the items that are the most and least often answered correctly based on the Turkish version are different items that the items that are the most and least often answered correctly based on the Dutch version.

Based on the Turkish version of the DKS, item D9 ("Difficulty handling money or paying bills is a common symptom of dementia") was most often answered correctly (by 88.8% of the respondents) and item D2 ("If somebody starts suffering from sudden confusion and memory problems, that is dementia") the least often (by 35.3%).

Table 1. Sample Characteristics.

	Turkish version of DKS filled out by respondents with a Turkish background (N=117)		Dutch version of DKS filled out by respondents with a Moroccan background (N=110)	
	N	%	N	%
Gender				
Female	97	83	101	92
Male	17	15	9	8
Missing	3	3	0	0
Age				
15-35	23	20	34	31
36-55	65	56	59	54
56-75	22	19	14	13
76-85	2	2	0	0
Missing	5	4	3	3
Country of birth				
Netherlands	15	13	26	24
Other country	100	85	84	76
Missing	2	2	0	0
Highest level of education				
None or primary school	59	50	39	35
Secondary school	24	21	21	19
Secondary Vocational Education	20	17	28	25
Higher professional education or University	9	8	21	19
Other additional courses	2	2	1	1
Missing	3	3	0	0
Do you live together with the person with dementia?				
Yes	45	38	24	22
No	71	61	85	77
Missing	1	1	1	1
How often do you provide help?				
Daily	42	36	34	31
3-6 times a week	15	13	23	21
Up to twice a week	26	22	25	23
Less than once a week	12	10	11	10
Less than once a month	15	13	16	15
Missing	7	6	1	1

Based on the Dutch version, item D6 ("Someone with dementia will eventually need 24-h supervision") was most often answered correctly (by 86.0% of the respondents) and item D7 ("A high cholesterol level increases the risk of getting dementia") the least often (31.4%).

A striking difference between the 2 language versions is that questions about risk factors are answered incorrectly relatively often by respondents with Moroccan backgrounds filling out the Dutch version.

Internal Consistency

Cronbach's alpha for the Turkish version of the DKS was .698, which can be considered borderline adequate. This could be increased to a maximum of .718 by dropping item D6 ("Someone with dementia will eventually need 24-h supervision"). Cronbach's alpha for the Dutch version of the DKS, which was filled out by respondents with a Moroccan background, was lower at .597. This alpha could be increased to a maximum of .613 by dropping item D1 ("Hiding memory problems is a behavioral characteristic that is often seen in the early stages of dementia").

Known Group Validity

For both the Turkish and the Dutch versions of the DKS, no significant differences were found in mean DKS scores, based on *t*-tests between those who had received no

Table 2. Number of Missing Answers Per Item, % Answering Correctly and Cronbach's Alpha If Item Dropped.

	Turkish version of the DKS (N = 117)			Dutch version of the DKS (N = 110)		
	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[a]	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[b]
D1. Hiding memory problems is a behavioral characteristic that is often seen in the early stages of dementia	0	84.6	.696	0	85.5	.613
D2. If somebody starts suffering from sudden confusion and memory problems, that is dementia	1	35.3	.675	3	54.2	.603
D3. A poor diet (insufficiently varied diet, few vitamins, a lot of fats and carbohydrates) increases the risk of dementia	1	72.4	.675	2	38.9	.549
D4. Dementia can occur in someone aged 35	1	50.0	.676	2	49.1	.585
D5. Someone with dementia runs an increasing risk of falling as the disease gets worse	0	87.2	.657	3	80.4	.575
D6. Someone with dementia will eventually need 24-h supervision	0	82.9	.718	3	86.0	.609
D7. A high cholesterol level increases the risk of getting dementia	3	63.2	.651	5	31.4	.535
D8. Symptoms of severe depression can look like symptoms of dementia	2	85.2	.673	1	70.6	.551
D9. Difficulty handling money or paying bills is a common symptom of dementia	1	88.8	.683	1	64.2	.588
D10. One possible symptom of dementia is being convinced other people are stealing your things	1	83.6	.700	3	82.2	.566
D11. High blood pressure increases the risk of getting dementia	1	64.7	.636	5	36.2	.520

[a]Cronbach's alpha based on 11 items for the Turkish version of the DKS = .698.
[b]Cronbach's alpha based on 11 items for the Dutch version of the DKS = .597.

education or primary education and those who had received mid-level or higher education (see Table 3). Furthermore, no significant differences were found in mean DKS scores between those who cared for a person with dementia at least once a week and those who cared for a person less than once a week. Finally, no significant differences were found in mean DKS scores between those who lived with a person with dementia and those who did not live together.

Discussion

This paper describes the development, internal consistency, and known group validity of the Dementia Knowledge Scale in Dutch and the Turkish among family caregivers with a Moroccan or Turkish backgrounds.

The internal consistency of the Turkish version of the DKS filled out by respondents with a Turkish background

Table 3. Known-Group Validity.

			Turkish version of the DKS		Dutch version of the DKS	
Hypotheses	Subgroups	N	Mean (SE) DKS score	N	Mean (SE) DKS score	
1*	None or primary school	55	7.9 (0.3)	35	6.9 (0.3)	
	Middle or higher education	50	8.0 (0.3)	60	6.8 (0.3)	
2**	Caring for a person with dementia minimal once a week	78	8.1 (0.2)	72	6.9 (0.3)	
	Caring for a person less than once a week	26	7.5 (0.4)	23	6.5 (0.4)	
3***	Living together	42	8.2 (0.3)	21	6.7 (0.5)	
	Not living together	67	7.9 (0.2)	75	6.8 (0.2)	

*The level of education influences knowledge of dementia.
**The intensity of caring for the person with severe memory loss or dementia influences knowledge of dementia.
***Living together with the person with severe memory loss or dementia influences knowledge of dementia.

was adequate. On the other hand, the internal consistency of the Dutch version of the DKS, filled out by respondents with a Moroccan background, was poor. This implies that there is more variation among the respondents who filled out the Dutch version in the extent to which items are answered correctly or not answered, compared to respondents who filled out the Turkish version.

A lot of variation was found in the scoring on the individual DKS items, indicating especially that respondents with a Moroccan background filling out the Dutch version of the DKS have relatively good knowledge of aspects related to symptoms of dementia but know less about the risk factors for dementia. This is in line with the study by Jorge et al[13] who found that the risk factors for dementia are often unknown.

Strikingly, our 3 hypotheses with respect to the known group validity were not confirmed. Respondents with a higher level of education did not score higher on the DKS than respondents with a lower educational level. Furthermore, respondents who took care for a person with dementia more often did not get higher scores than those who took care for a person with dementia infrequently. Thirdly, those who lived with a person with dementia did not get higher scores than those who did not live with a person with dementia.

We do however see variation between respondents in mean scores on the DKS. This indicates that there may be other background characteristics than those we included that are associated with right or wrong answers on the DKS. To validate the DKS further, people who have nothing to do with dementia in their family could also be included, to compare their scores against the family caregivers of people with dementia. This will provide another opportunity to assess known group validity. As this is one of the first studies that addresses dementia knowledge among persons with a Turkish or Moroccan migration background, additional (qualitative) research is needed to examine if this could indeed be the case and to obtain a better understanding of factors that do relate to dementia knowledge among these groups. More research, explaining differences in dementia-related knowledge between subgroups of people with non-western migrant backgrounds is therefore recommended.

Because we expected that written language skills would be limited in some participants, the decision was made to have a maximum of 11 items in the questionnaire. It would be interesting to explore whether extending the questionnaire, using different wording of the items or a combination of the 2 could increase the internal consistency and the known-group validity.

The number of missing answers was low, which indicates that the participants understood the questions and had the motivation to fill them in. The fact that participants could choose between different language versions and the fact that participants who could not read and write could be helped by a trained research assistant who spoke their language might also have contributed to the low rate of missing answers.

Participants with a Turkish background stated that they had greater reading and writing competence in Turkish than in Dutch. Consequently, these participants more often opted to fill out the Turkish version of the DKS instead of the Dutch version. This was different for the participants with a Moroccan background, who were more likely to choose the Dutch version than the Arabic version. Most of these participants had stated that they had greater competence in Dutch (reading and writing) than in Moroccan Arabic. This underlines the importance of verifying with the target population what preferred languages are in which an instrument such as the DKS is offered, especially since some mother tongues or dialects are rarely written down.

A recommendation for future research is to assess the psychometric properties of the DKS among family caregivers without migrant backgrounds. It would specifically be interesting to verify whether different patterns of answers can be found among family caregivers without migration backgrounds compared to those with Turkish or Moroccan backgrounds.

Conclusion

This study shows that the internal consistency of measurement scales can differ according to the population to which it is applied. This underlines the importance of cross-cultural adaptation of measurement scales that are used among groups with immigrant backgrounds. The Dutch and the Turkish versions of the Dementia Knowledge Scale can be used to obtain a picture of the level of knowledge among family caregivers with a Turkish or Moroccan background about the risk factors, symptoms, and characteristics of dementia. These understandings could assist in the development of tailored information and education for these groups.

Appendix 1

Alzheimer Knowledge Scale

You will find 11 statements about dementia below. After reading each statement, you can circle the answer that you think is correct.

D1. Hiding memory problems is a behavioural characteristic that is often seen in the early stages of dementia.
Agree/disagree

D2. If somebody starts suffering from sudden confusion and memory problems, that's dementia.
Agree/disagree

D3. A poor diet (insufficiently varied diet, few vitamins, a lot of fats and carbohydrates) increases the risk of dementia.
Agree/disagree

D4. Dementia can occur in someone aged 35.
Agree/disagree

D5. Someone with dementia runs an increasing risk of falling as the disease gets worse.
Agree/disagree

D6. Someone with dementia will eventually need 24-h supervision.
Agree/disagree

D7. A high cholesterol level increases the risk of getting dementia.
Agree/disagree

D8. Symptoms of severe depression can look like symptoms of dementia.
Agree/disagree

D9. Difficulty handling money or paying bills is a common symptom of dementia.
Agree/disagree

D10. One possible symptom of dementia is being convinced other people are stealing your things.
Agree/disagree

D11. High blood pressure increases the risk of getting dementia.
Agree/disagree

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