

RESEARCH ARTICLE

Feasibility of a culturally tailored dementia information program for minority ethnic communities in Denmark

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Abstract

Objectives: Proactive efforts that take language and cultural barriers into consideration may be needed to raise awareness of dementia and improve access to services in minority ethnic communities. The aim of this study was to assess the feasibility of a culturally tailored dementia information program and the immediate effects on participants' intention to seek help for memory problems, their knowledge and beliefs about dementia, and their knowledge about options for support.

Methods: A novel dementia information program, consisting of one 2-h session, was developed through a collaborative research process with primary care dementia coordinators and multicultural link workers as co-researchers. It provides basic knowledge about dementia to minority ethnic communities and can be delivered in a community setting by non-specialists.

Results: Six information program sessions were conducted with a total of 110 participants; 65 Turkish, 19 Pakistani, 20 Arabic-speaking, and 6 with another minority ethnic heritage. The program had a significant effect on participants' immediate knowledge and beliefs about dementia as measured with a quiz ($z = -2.02$, $p = 0.04$, $d = 0.90$). In a post-program focus group meeting, facilitating multicultural link workers reported satisfaction with facilitator training, adopted recruitment strategies, and content and delivery of the information sessions and provided feedback on improving the program.

Conclusions: The results provide support for the feasibility of the culturally tailored dementia information program. The program has the potential to improve knowledge and beliefs about dementia and options for formal support in minority ethnic communities and seems easily implemented in existing services, and at a low cost.

KEYWORDS

dementia, knowledge, minority groups, services

Key points

- Limited basic knowledge about dementia and normalizing and stigmatizing views of Alzheimer's disease is common in Turkish, Pakistani and Arabic speaking communities in

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Denmark, who remain under-represented in diagnostic, support, and care services for people with dementia.

- Mainstream campaigns and educational programs to increase awareness and knowledge about dementia rarely reach minority ethnic groups and it has been suggested that more proactive efforts that take language and cultural barriers into consideration are needed.
- A dementia information program tailored to the cultural and language needs of Turkish, Pakistani and Arabic communities was developed through a collaborative research process with primary care dementia coordinators and multicultural link workers as co-researchers.
- Study results support the feasibility a dementia information program for minority ethnic communities facilitated by multicultural link workers with basic theoretical training in dementia and provide some evidence for positive effects of the program on participants' immediate intention to seek help for memory problems, their knowledge and beliefs about dementia, and their knowledge about options for formal support.

1 | INTRODUCTION

It is estimated that there are currently 2000 older people from minority ethnic communities living with dementia in Denmark, and this number is predicted to quadruple by 2040 (www.videnscenterfordemens.dk). Similar to the situation in other European countries, this is a much steeper increase compared to the predictions for the general population.¹⁻³ Turkish, Pakistani and Arabic speaking populations represent some of the largest minority ethnic communities in Denmark. Older Turkish and Pakistani immigrant men generally came to Denmark as working migrants in the 1960s and 1970s due to a demand for manual labor and later settled permanently with their wife's and children through family reunification programs. Older Arabic speaking immigrants came both as working migrants in the same period and as refugees in the 1980s, mainly from countries in the Middle East and North Africa. Despite having lived in Denmark for many years, Danish language proficiency is generally limited among older Turkish, Pakistani, and Arabic speaking immigrants and many have little or no education, especially women.⁴ The majority in all communities are Muslim. Despite the increasing prevalence of dementia in these communities and the fact that free access to specialist dementia services is available for all legal Danish residents, people from minority ethnic communities remain under-represented in diagnostic, support, and care services for people with dementia.⁵⁻⁷ This may be due to limited awareness of dementia and available services in minority ethnic communities, with memory problems often being perceived as a natural part of old age.^{4,8,9} However, several barriers in accessing services have been reported in minority ethnic communities in recent Danish and international studies, including difficulties navigating complex health-care systems, language barriers, lack of culturally sensitive services, misconceptions and stigma, and different cultural values and norms for care.^{4,6,8,10}

Despite the growing evidence suggesting limited awareness of dementia in minority ethnic communities, initiatives aiming at increasing knowledge about dementia and available services in these communities have generally been sparse. Although there are local

and national campaigns and educational programs to increase awareness and knowledge about dementia in Denmark, these rarely reach minority ethnic groups and it has been suggested that more proactive efforts that take language and cultural barriers into consideration may be needed to raise awareness of dementia and improve access to services.^{4,11,12} We have previously explored information needs in middle-aged and older Turkish, Pakistani and Arabic communities in Denmark through survey- and qualitative studies.^{4,9,10} Despite some differences, having limited basic knowledge about dementia and holding normalizing and stigmatizing views of Alzheimer's disease (AD) was identified to be common across these communities.

Internationally, strategies for reaching minority ethnic communities to increase knowledge and awareness about dementia include hosting health fairs or roadshows in urban areas with large minority ethnic populations, and delivering language and culture specific seminars, radio shows, television episodes, or YouTube series.¹³⁻¹⁵ However, the most successful strategies have been those building on collaboration and partnership with key community stakeholders and principles of peer support. Thus, in the present study we developed a novel dementia information program in collaboration and partnership with participating municipalities that provides basic knowledge about dementia to middle-aged and older people in minority ethnic communities and can be delivered in a community setting by non-specialists. The aim of the study was to assess the feasibility of a culturally tailored dementia information program and the immediate effects on participants' intention to seek help for memory problems, their knowledge and beliefs about dementia, and their knowledge about options for support.

1.1 | Culturally tailored dementia information program

The structure and information provided in the current program was tailored to the cultural needs of Turkish, Pakistani and Arabic communities and was developed through a collaborative research process

with primary care dementia coordinators and with multicultural link workers representing the main minority ethnic communities in Denmark as co-researchers. Primary care dementia coordinators are employed in all Danish municipalities where they organize post-diagnostic dementia care and often act as case managers for people with dementia. Multicultural link workers come from a range of ethnic backgrounds and are employed in several municipalities with large minority ethnic populations. They provide health education and promotion, information and support groups and, to a lesser extent, case management and counseling to link minority ethnic communities to Danish health- and social services. Two focus group meetings were arranged with primary care dementia coordinators and multicultural link workers to discuss target group, recruitment strategies, content and delivery of the information sessions, and outcome measures. Based on feedback from these discussions, the dementia information program was developed to target middle-aged and older adults, be brief, delivered in the languages of minority ethnic communities and include culture-specific case descriptions.

2 | MATERIALS AND METHODS

2.1 | Participants

Participants were recruited across five municipalities in the greater Copenhagen area in Denmark between March 2019 and January 2020. Adult participants of Turkish, Pakistani or Arabic-speaking heritage were purposively recruited from the community by cultural link workers through advertisements and announcements in Danish and minority languages in community centers and minority ethnic activity and social groups, and through the cultural link workers' networks. People of other ethnic backgrounds were also invited to participate in the study based on whether the multicultural link workers believed they could benefit from the dementia information program.

Participation in the study was anonymous, voluntary and without any economic incentive. Approval by an official ethics committee was not required by Danish law. The study is part of a larger research project that was approved by the Danish Data Protection Agency (jnl no.: 2012-58-0004).

2.2 | Program delivery

The dementia information program consisted of one 2-h session. During the session, the participants were provided with information about dementia, symptoms, causes, treatment options, and options for formal support. Building on principles of peer support,¹⁶ the sessions were facilitated by bilingual and bicultural multicultural link workers and had the form of a semi-structured dialog rather than a lecture. To prompt discussions around barriers and facilitators to help-seeking, all sessions began with a short vignette about an older female family member, Fatma, with memory problems strongly suggestive of early dementia, adapted from the Attitudes of People From

Ethnic Minorities to Help-Seeking for Dementia questionnaire¹⁷ (see Supporting Information S1).

The dementia information program was conducted by six facilitators (1 male, 5 females; 2 of Turkish, 3 of Pakistani, 1 of Arabic speaking heritage) and was coordinated and supervised by an experienced community nurse. Before the program sessions were conducted, the facilitators completed basic theoretical training in dementia consisting of approximately 4 h of self-study using *ABC Dementia*,¹⁸ a web-based training program for primary care staff consisting of 10 modules focusing on different aspects of dementia and dementia care. The study neuropsychologist (TRN) provided a half-day training session to follow-up on the web-based training and provided background information on dementia in relation to minority ethnic communities. Additionally, the facilitating multicultural link workers were able to consult with local primary care dementia coordinators concerning delivery of the program sessions. The study neuropsychologist provided triannual meetings with the coordinating community nurse and problem-solving support via telephone and email communication. The program sessions were conducted at different locations in the community and to the extent possible accommodated different language requirements by matching participants and facilitating multicultural link workers by language so that all could participate.

2.3 | Outcome measures

To bypass linguistic and cultural barriers associated with a written questionnaire, a quiz was developed to obtain a measure of the immediate effects of the program session on participants' intention to seek help for memory problems, their knowledge and beliefs about dementia, and knowledge about options for formal support. Based on feedback from multicultural link workers in focus group meetings, the quiz was brief and simple, and used the term "Alzheimer's" rather than dementia, as the term "dementia" was deemed to be unfamiliar to most people in the minority ethnic communities. The quiz was conducted by the facilitating multicultural link workers before and after each session and was always preceded by the vignette about Fatma, an older family member with memory problems. The quiz consisted of six statements inspired by previous research^{9,19,20}: (1) "If I had memory problems like Fatma, I would seek help from my doctor"; (2) "The majority of people over the age of 80 have Alzheimer's"; (3) "Memory loss is the primary symptom of Alzheimer's"; (4) Alzheimer's is a normal part of becoming older, like gray hair and wrinkles"; (5) "Alzheimer's is a form of insanity"; and (6) "If I or someone in my family got Alzheimer's, I would know where to seek help". Participants indicated whether they agreed with each of the six statements by raising their hands. For statements (1), (3), and (6), agreeing with the statements is positive, indicating more intention to seek help for memory problems and more knowledge about AD and options for formal support. For statements (2), (4), and (5) agreeing with the statements was negative, indicating normalizing and stigmatizing beliefs about AD.

In addition, qualitative feedback was obtained from a focus group meeting with the facilitating multicultural workers after delivery of the

program to assess facilitator perceptions of the program (e.g., length of program session, usefulness of vignette to prompt discussions). Consent was attained from all participants. The focus group meeting was recorded with a digital audio recorder and transcribed verbatim.

2.4 | Data analysis

As only group level data was available, the knowledge quiz data was based on the proportion of participants who agreed with the six knowledge quiz statements in each program session. Also, an overall score for the knowledge quiz was calculated as the number of participants agreeing with the positive statements subtracted by the number of participants agreeing with the negative statements. Differences were analyzed using non-parametric statistics. Differences in knowledge quiz results pre- and post-program session were analyzed with pairwise comparisons using the Wilcoxon signed-rank test. Effects sizes were calculated by dividing the standardized test statistic z by the square root of the number of pairs. Using Cohen's classification, an effect size of 0.2 was considered a small effect, 0.5 a moderate effect, and 0.8 and above a large effect. Statistical analyses were performed using SPSS statistical software (Version 25.0 SPSS Inc.). $p < 0.05$ (two-tailed) was considered significant. Qualitative data collected from the follow-up focus group meeting with facilitating multicultural workers was thematically categorized.

3 | RESULTS

Six program sessions were completed with 5 to 28 participants in each session. A total of 110 participants took part in the dementia information program sessions of which 65 had Turkish, 19 Pakistani, 20 Arabic-speaking, or 6 another minority ethnic heritage. The majority were middle-aged and older women who had a general interest in age-related memory problems, and only a minority were experiencing memory problems or cared for someone with dementia themselves. Only one male participated in the program sessions. Program sessions were conducted at community centers ($n = 3$), minority ethnic activity and social groups ($n = 2$), and in participant's homes ($n = 1$). The characteristics of the participants are presented in Table 1.

Session	Participants (n)	Cultural heritage, n				Post-program quiz data available
		Turkish	Pakistani	Arabic	Other	
1	13	7	6	-	-	YES
2	28	20	-	4	4	YES
3	27	16	7	3	1	YES
4	5	0	5	-	-	YES
5	28	17	7	3	1	YES
6	9	7	-	-	2	NO
Total	110	65	19	20	6	

3.1 | Knowledge quiz

All participants completed the pre-program quiz and 101 completed the post-program quiz after the session. Figure 1 shows the percentage of participants agreeing with each of the knowledge quiz statements pre- and post-program sessions.

Using the Wilcoxon signed-rank test, there was a significant change in the overall knowledge quiz score ($z = -2.02$, $p = 0.04$, $d = 0.90$) and trends for significant changes in the proportion of participants agreeing with the statements "Memory loss is the primary symptom of Alzheimer's" ($z = -1.83$, $p = 0.07$, $d = 0.82$) and "Alzheimer's is a normal part of becoming older, like gray hair and wrinkles" ($z = -1.83$, $p = 0.07$, $d = 0.82$), while changes in other statements were not significant. Post-program, the number of participants agreeing with the statement: "If I had memory problems like Fatma, I would seek help from my doctor" improved after 3 of the sessions (60%) and was unchanged after 2 of the sessions (40%), "The majority of people over the age of 80 have Alzheimer's" improved after 4 of the sessions (80%) and worsened after 1 session (20%), "Memory loss is the primary symptom of Alzheimer's" improved after 4 of the sessions (80%) and was unchanged after 1 session (20%), "Alzheimer's is a normal part of becoming older, like gray hair and wrinkles" improved after 4 of the sessions (80%) and was unchanged after 1 session (20%), "Alzheimer's is a form of insanity" improved after 3 of the sessions (60%) and was unchanged after 2 of the sessions (40%), and "If I or someone in my family got Alzheimer's, I would know where to seek help" improved after 2 of the sessions (40%) and was unchanged after 3 of the sessions (60%).

3.2 | Qualitative feedback

Program evaluation was an important component to assess the feasibility of the dementia information program. Results regarding facilitator perceptions on the theoretical dementia training program, adopted recruitment strategies, the dementia information session, and benefits for participants are provided in Table 2. Overall, multicultural link workers reported satisfaction with the facilitator training program, adopted recruitment strategies, and content and delivery of the information sessions. They perceived that most

TABLE 1 Participants attending program sessions

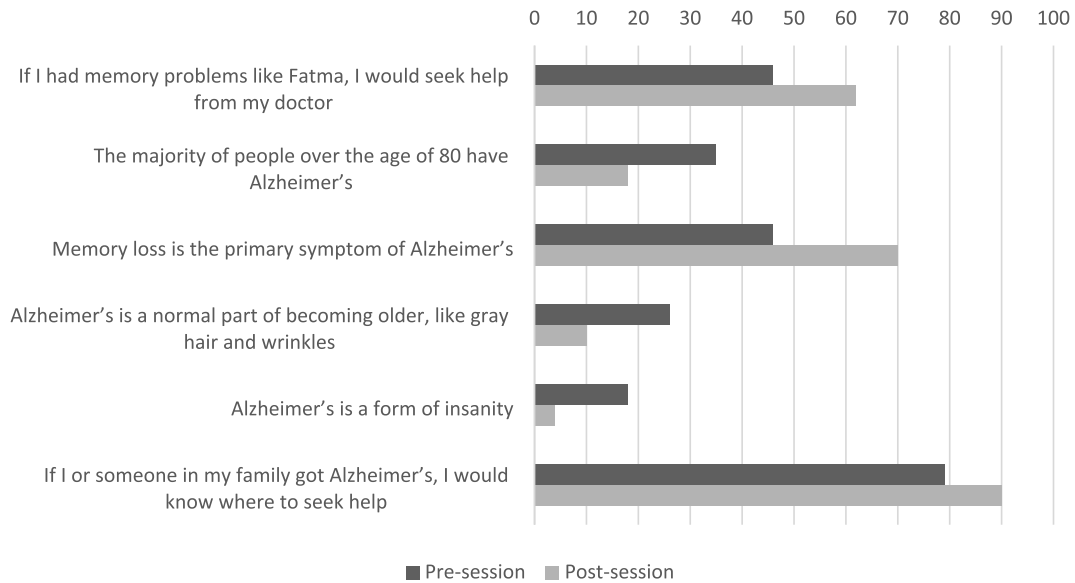


FIGURE 1 Percentage of participants agreeing with each of the quiz statements pre- and post-dementia information program (n = 101)

TABLE 2 Feedback provided by multicultural link workers on the dementia information program in focus group meeting

Category	Quotes
Facilitator training	<p>It was good and very educational to receive training in dementia.</p> <p>For the level of the presentations, it's okay. But if they already know about it (dementia), and you want to go a little further, then it would be nice to be better dressed for the task.</p>
Recruitment	<p>We handed out flyers and invited people to some meetings at the community center, but no one came.</p> <p>When it is an established group or organization, it's easy to gather 15–20 people.</p> <p>Women are more active in seeking out and going to [information sessions] than men.</p> <p>Having mixed [information sessions] is difficult. It must be only for women or only for men [...] Alternatively it should be something that all could attend... something like communal dining.</p>
Content and delivery of information sessions	<p>I think [the vignette] worked quite well. Especially with the name and age... It was something they could relate to.</p> <p>The level of information has been adequate</p> <p>She was quite happy with the presentation I gave because it was on a very understandable level, and in her language.</p> <p>One could easily spend much more than two hours, but [it works] fine as an introduction to dementia.</p> <p>I think it works better with five or six people because then it's more intimate and they can be more open and convey their own opinions. When you are with larger groups in the [community] center, you can't talk about your private issues.</p>
Perceived benefit for participants	<p>They have gained more knowledge about dementia and where to seek help.</p> <p>By increasing awareness in the community in this way, they probably think, hey, this is something you need to do something about, right.</p> <p>It's been such an incredible eye-opener... people realize that just because someone forgets, it doesn't mean they are mentally ill.</p>
Limitations	<p>We are not dementia coordinators, and therefore do not know everything.</p> <p>I still think it will be difficult for them to reach out for help because it's still such a big taboo.</p> <p>If there are language barriers, even if services are available, they can't use them.</p>

participants had at least some benefit of participating in the information session and that the dementia information program could potentially help reduce stigma and increase help-seeking in the longer term. However, in order to more effectively address this additional time and sessions were considered necessary. They found recruitment through established groups or organizations and word-of-mouth to be superior to handing out flyers or putting up announcements in community centers. A lack of male participants in the program was explained by women generally being more interested and active in seeking health-related information. Also, mixing of genders in discussions about health-related issues was found to collide with established cultural norms. Suggested strategies for better reaching male participants included having separate sessions for men or arranging communal dining events incorporating dementia information sessions, as this format was considered more culturally appropriate for mixing of genders.

Overall, they had found it feasible to conduct sessions with participants of different cultural heritage in Danish. When participants had different language requirements, they had generally been able to accommodate these. Although information sessions at community centers were considered effective for reaching larger audiences, most preferred more intimate settings to facilitate discussions about private issues and addressing misconceptions and stigma.

4 | DISCUSSION

The findings from this study support the feasibility of a dementia information program for minority ethnic communities facilitated by multicultural link workers with basic theoretical training in dementia and provide some evidence for positive effects of the program on participants' immediate intention to seek help for memory problems, their knowledge and beliefs about dementia, and their knowledge about options for formal support.

The findings further provide support for the value of a collaborative and partnership research approach to development and delivery of a culturally tailored dementia information program. To ensure the program could be delivered in a community setting by non-specialists, primary care dementia coordinators and multicultural link workers were included as co-researchers in all phases of the study, including designing the information program, establishing outcome methods, recruiting participants, conducting program sessions, and collecting and interpreting data. The facilitating multicultural link workers generally reported that the facilitator dementia training program was adequate, that targeted recruitment strategies were most effective, and that use of a vignette helped introduce the concept of dementia and initiate discussion. The fact that the dementia information sessions were well attended demonstrates that people from minority ethnic communities do access services when these are designed and delivered in a culturally sensitive way, and in collaboration with representatives from minority ethnic communities.²⁰ Overall, the information program, consisting of one 2-h

session, had a significant effect on participants' knowledge and beliefs about dementia. Following the program session, there was a 24% increase in the number of participants who recognized memory loss as the primary symptom of AD, a 17% decrease in the number believing the majority of people over the age of 80 have AD, and a 16% decrease in the number of participants perceiving AD to be a normal part of becoming older. In the pre-program quiz, 18% perceived AD to be a form of insanity, with the proportion decreasing to 4% post-program. Also, following the program session, there was a 16% increase in the number of participants who felt confident that they would seek medical help for memory problems and an 11% increase in the number of participants who perceived they knew where to seek help for AD. The relatively modest improvements in perceived access to help for AD was unexpected and may be related to ambiguity of the adopted quiz statement and the high proportion agreeing with the statement in the pre-program quiz, leaving little room for improvement. Although the statement was meant to imply professional help, it may have been perceived as help in general, including help received from family and social networks. As pointed out by the facilitating multicultural workers in a post-program focus group meeting, the latter aspects may be particularly important in minority ethnic communities such as the Turkish, Pakistani and Arabic speaking as people with dementia and their family carers risk being isolated due to the high level of stigma attached to dementia and a lack of accessible culturally sensitive services.^{10,20-22} As well as raising awareness about dementia and knowledge about options for formal support, initiatives to provide a wider range of services that are tailored to the specific language and cultural needs of minority ethnic communities are needed.^{4,23,24}

The gender distribution, with only one male participating in the program sessions, can be explained by a general tendency for women being more worried about dementia,²⁵ more prepared to discuss sensitive issues concerning dementia care with peers,²⁶ and more likely to have the main responsibility for family dementia care,²⁷ also among families with minority ethnic backgrounds. Similar patterns have been demonstrated in other information programs for people from minority ethnic groups.^{14,20} At the same time, mixing of genders in intimate discussions about health-related issues may collide with established cultural norms, why it may be necessary to arrange separate program sessions for men. Alternatively, incorporating dementia information sessions in communal dining events could be a culturally appropriate format for mixing genders, an approach adopted other information campaigns targeting minority ethnic communities.¹³ Advantages of the present dementia information program include its ease of organization and planning, its inclusiveness of people from communities that often have mixed cultural and language backgrounds, and its ease of implementation in existing services at a low cost. However, the program may be improved by having sessions with smaller groups of peers, sharing the same cultural and language background, and offering follow-up sessions. In line with the reports from an educational intervention among family carers of people with dementia with Turkish or Moroccan immigrant

backgrounds,¹⁴ multicultural link workers anticipated this could help build trust to better initiate discussions about private issues and address misconceptions and stigma.

In this study, we were only able to assess the immediate effects of the dementia information program. It remains unknown whether the improved knowledge and beliefs about dementia among middle-aged and older people will lead to actual changes in help-seeking behavior if they develop symptoms. This will be important to explore in future research. However, recent studies adopting similar approaches to increase knowledge about dementia and options for formal support among family carers with Turkish and Moroccan backgrounds in the Netherlands¹⁴ and South Asian backgrounds in the United Kingdom²⁰ found some evidence that the positive effects of the interventions remained after three and six months, respectively. Liaison or partnership with representatives of minority ethnic communities, active outreach, and peer support is central to all three interventions, highlighting the value of such approaches in reaching out and informing about dementia in minority ethnic communities.

4.1 | Limitations

The study has some limitations that should be addressed. One limitation was the use of a quiz to measure the effects of the program. Multicultural link workers were responsible for facilitating the meetings and conducting the quiz, which proved to be challenging in some sessions, resulting in incomplete data from one program session. Further, it cannot be ruled out that participant responses to some extent were influenced by social desirability. A self-completed questionnaire would have been preferable. However, this would be culturally inappropriate for these specific minority ethnic communities due to linguistic and literacy barriers in older generations. The quiz format was chosen as this had been found to be acceptable in previous work in South Asian communities in the United Kingdom.^{13,20} Another limitation was the lack of a control group. It is difficult to estimate the typical variation in the outcome measure in people who did not participate in the program. However, the pre-program quiz data seems to reflect the knowledge and beliefs in the broader Turkish and Pakistani communities in Denmark,⁹ which supports that the program had an effect on participants' knowledge and beliefs about dementia. Further, the program was largely attended by female participants. Consequently, it may not be possible to generalize the results or the suitability of the program for reaching male members in the minority ethnic communities. Finally, as the study design did not allow us to collect paired data from each participant, we were only able to compare proportion data from each program session resulting in low statistical power, increasing the risk of type II errors ("false negative" findings). Although more sessions were planned, recruitment had to be terminated after completing six program sessions due to the emerging COVID-19 pandemic and associated societal restrictions.

5 | CONCLUSIONS

The findings from this study provide support for the feasibility of a culturally tailored dementia information program, with some evidence suggesting that the program had positive effects on participants' immediate intention to seek help for memory problems, their knowledge and beliefs about dementia, and their knowledge about options for formal support. The program has the potential to improve knowledge and beliefs about dementia and options for formal support in minority ethnic communities and seems easy to implement in existing services in Denmark and other countries with similar dementia support systems, and at a low cost.

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CONFLICT OF INTEREST

None.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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