

A personalized dementia care intervention for family carers from minority ethnic groups in Denmark: A pilot study

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Abstract

Background: There is a growing number of people with dementia in minority ethnic groups in Denmark. Support for the increasing number of family carers from minority ethnic groups is crucial, as caring for a relative with dementia may negatively affect the carer's health and quality of life. The aim of this study was to determine the feasibility of a personalized intervention for family carers from minority ethnic groups. The intervention was a modified version of a culturally sensitive case-management program developed in Australia which had been shown to improve carers' sense of competence in managing dementia and their mental well-being.

Methods: A small pilot trial was used to examine the feasibility and preliminary efficacy of the intervention. Feasibility indicators included data on recruitment, retention, adherence, and fidelity.

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Acceptability and suitability of the intervention was explored in post-intervention interviews with family carers, and baseline and follow-up scores for outcome measures were examined.

Results: Ten (30%) of 33 eligible family carers consented to participate in the study, but three were lost to follow-up and seven (70%) family carers completed the trial. Intervention fidelity, acceptance, and satisfaction were high. Results for outcome measures indicated that the intervention may improve family carers' sense of competence by helping them cope better with challenges relating to caring and managing dementia and improved their satisfaction with primary care services.

Conclusions: The results suggest that the intervention is feasible and worth exploring for family carers of people with dementia from minority ethnic groups in Denmark.

Keywords

dementia, Alzheimer's disease, family carers, minority groups, psychosocial intervention, services

Introduction

As in other European countries, immigration patterns and increasing life expectancy have led to an increasing number of people with dementia in minority ethnic groups in Denmark ([All Party Parliamentary Group \(APPG\) on Dementia, 2013](#); [Alzheimer's Disease International, 2015](#); [Nielsen et al., 2015](#)). Turkish-, Pakistani-, and Arabic-speaking populations represent some of the largest minority ethnic groups in Denmark. People with dementia in these populations are generally immigrants ([Nielsen et al., 2015](#)) and most of them are cared for at home by family carers, as caring for older people is more commonly viewed as a family responsibility in these minority ethnic groups ([Kenning et al., 2017](#); [Nielsen et al., 2020a, 2020b](#)).

Caring for a person with dementia at home puts a significant physical and psychological strain on carers due to challenges of providing assistance with activities of daily living, coping with behavioral and psychological symptoms of dementia (BPSD), and perceived relationship with the person with dementia ([Farina et al., 2017](#); [Pinquart & Sørensen, 2003](#); [Van Mierlo et al., 2012](#)). Although community care programs have been developed in Denmark to assist people with dementia and their carers to adjust to living with cognitive impairment and functional decline, they can be difficult to access for people from minority ethnic groups ([Nielsen et al., 2019, 2020a](#)). Primary care dementia coordinators employed in all Danish municipalities provide assistance with navigation of the health and social care system, accessing services, information and support, and advocating between health professionals, services, and users. However, this support model does not address the specific needs of people from minority ethnic communities who may find it difficult to access the available services ([Goeman et al., 2016](#); [Nielsen et al., 2020a](#)). Currently, no Danish public or private dementia care services offer language- or culture-specific services and people from minority ethnic groups remain underrepresented in mainstream community dementia care services and nursing homes ([Nielsen & Waldemar, 2016](#); [Nielsen et al., 2019](#); [Stevnsborg et al., 2016](#)).

Despite evidence of ethnic differences in family carers' needs ([Janevic and Connell, 2001](#); [Kosloski et al., 1999](#)), only very few studies have focused on developing culturally sensitive psychosocial interventions for family carers caring for a person with dementia ([Napoles et al., 2010](#)). A personalized dementia care intervention for carers from minority ethnic groups has been developed in Australia ([Xiao et al., 2016](#)). This 12-month case-management intervention comprising quarterly home visits and monthly telephone contacts delivered by care coordinators has been shown to improve carers' sense of competence in managing dementia and their mental well-being ([Xiao et al., 2016](#)).

The aim of this pilot study was to examine the feasibility of a primary care dementia coordinator-led personalized dementia care intervention for family carers from minority ethnic groups.

Methods

Participants

The study was conducted in collaboration with primary care dementia coordinator services in six urban municipalities in the greater Copenhagen area and Odense, the largest and third largest cities in Denmark. Between April 2019 and May 2020, eligible family carers were recruited by participating primary care dementia coordinators from their case records according to the following inclusion criteria: 1) identified as having Turkish-, Pakistani-, or Arabic-speaking background; 2) provided care for a community-dwelling relative diagnosed with dementia; 3) had cared for the person with dementia for ≥ 1 year and had face-to-face contact with the care recipient at least twice per week; and 4) was ≥ 18 years old. Family carers with other ethnic backgrounds were invited to participate in the pilot study based on whether the managing primary care dementia coordinator believed the carer could benefit from the intervention.

After inclusion, family carers were allocated to an intervention group and a treatment as usual group. To establish two groups of equal size while taking available human resources in participating municipalities into account, family carers from municipalities in greater Copenhagen were allocated to the intervention group and family carers from Odense municipality to the treatment as usual group.

Intervention

The intervention was based on an intervention with carers of people from minority ethnic groups with dementia in Australia (Xiao et al., 2016) that was adapted for use with minority ethnic groups in Denmark over 6 months. The intervention consisted of a “Personalized Carer Support Plan” (PCSP), a “Carer Diary,” structured follow-up, coaching, and referral to available services and education programs (Table 1). Interpreting services were available for family carers who did not speak Danish fluently and a team of multicultural link workers with basic theoretical training in dementia was available to primary care dementia coordinators for consultations regarding cultural issues. Social, cultural, and linguistic carer needs assessed by the PCSP included: activities organized by social, cultural, and religious groups or organizations the carer could be interested in; socializing with other carers; suitable social and cultural events; culturally and linguistically appropriate reading materials to develop carer’s dementia care knowledge and skills; access to interpreters when needed; and socializing with friends and family.

The pilot intervention was performed by six ethnic Danish primary care dementia coordinators (all women) aged 38–64 years, who each had 1–2 family carers assigned to them. The family carers were assigned to a primary care dementia coordinator who was currently managing the person with dementia cared for by the family carer. The qualifications of the primary care dementia coordinators included three registered nurses, two nurse assistants, and one occupational therapist who all had specialist training in dementia and 6–12 years of professional experience with community-based dementia care. The research team provided primary care dementia coordinators with a training session to learn how to use the PCSP and Carer Diary, discuss culturally sensitive issues they might encounter, and strategies used to deal with these issues. In addition, the research team provided quarterly site visits and problem-solving support via telephone and email communication.

Table 1. Six-month primary care dementia coordinator-led personalized intervention for family carers.

Intervention component	Details
Personalized carer support plan (PCSP)	Primary care dementia coordinators use a structured inventory of carer's needs when assessing family carer needs, taking actions to address these needs, and when evaluating the outcomes of their actions. Carer needs covered by the PCSP include: Information needs, educational and skills needs, environmental safety needs, social, cultural and linguistic needs, and self-care needs that reflect the current evidence in dementia carer support
Carer diary	Family carers are encouraged to use a carer diary, structured in a simple table, to record challenges they face in daily care practice concerning dressing and undressing, taking medication, eating, drinking, showering or bathing, walking, toileting
Structured follow-up	1) primary care dementia coordinators initially make a home visit to assess carer needs and establish the PCSP in collaboration with family carers; 2) make monthly phone contact to allow family carers to discuss the needs of the care recipient and family carers, and 3) make another home visit after approximately 3 months to reassess family carer needs and modify the PCSP
Coaching	At all contacts, primary care dementia coordinators provide individual coaching with family carers concerning their needs and challenges faced in daily care practice
Referral to available services and education programs	Primary care dementia coordinators refer family carers to new services and education programs based on the needs assessment

In the treatment as usual group, primary care dementia coordinator services were generally based around the person with dementia. Standard treatment consisted of biannual phone contacts to discuss emerging medical, psychological, and social issues. Carer support included referral to activities such as standard carer support group meetings and information sessions provided by the local primary care dementia coordinator or Alzheimer's Association.

Measures

All data were collected by members of the research team at home visits to the participating family carers. Interpreting services were available for family carers who did not speak Danish fluently. Sociodemographic data and dependence level of the care recipient measured using the Clinical Dementia Rating (Morris, 1993) used as an informant instrument were collected at baseline.

Feasibility indicators included data on recruitment, retention, and intervention adherence and fidelity. Further, acceptability and suitability of the intervention was explored in post-intervention interviews with family carers, and baseline and follow-up scores for outcome measures were examined (Orsmond & Cohn, 2015).

Data on outcome measures were collected at two timepoints: at baseline and 6-month follow-up. The selection of formal questionnaires used in the study was based on two previous successful psychosocial interventions that included family carers of people from minority ethnic groups with dementia (Livingston, 2013; Xiao et al., 2016). The primary outcome was caregiver competence measured by the Sense of Competence Questionnaire (SSCQ), which includes seven items rated on

a 5-point Likert scale (Vernooij-Dassen et al., 1999). Health-related quality of life (QoL) was measured with the 12-item Short Form Health Survey version 2 (SF-12) using the two summary dimensions: physical component and mental component (Ware et al., 1995). Severity of behavioral symptoms and carer distress were measured using the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kaufer, 2000). Satisfaction with primary care support was measured using the Quality Of Care Through the Patient's Eyes (QUOTE-elderly) questionnaire-specific part (Sixma et al., 2000). As in the original Australian study, three items were added to inquire about cultural and linguistic appropriateness of services provided. The 20-item satisfaction questionnaire was rated on a 5-point Likert scale. Usage of respite care, aged care services, and dementia services was measured using 4-point scales. For all measures, except NPI-Q, higher scores are better, indicating better sense of competence, higher QoL, higher satisfaction with services received, and higher rate of service usage.

Statistical analyses

In addition to examining the feasibility of the intervention, we calculated descriptive statistics for all outcome measures and explored the preliminary efficacy of the intervention. Using analysis of covariance (ANCOVA), change from baseline scores were compared for the intervention and treatment as usual groups, correcting for differences in baseline scores. However, the study was not powered for significance. The NeuroToolkit online scoring system (www.neurotoolkit.com/sf-12/) was used to calculate SF-12 Physical Component (PCS) and Mental Component Scores (MCS). All other analyses were performed using SPSS statistical software (version 25.0; SPSS Inc, Chicago, IL, USA). $p < .05$ (two-tailed) was considered significant.

Results

Feasibility

Thirty-three eligible family carers (11 males and 22 females) were identified from the participating primary care dementia coordinators' case records, and 10 consented to participate in the study (30%). Reasons for declining participation included lack of interest ($n = 8$), lack of understanding of purpose and possible gains ($n = 6$), lack of time due to other dementia care duties ($n = 3$), and lack of trust in service providers ($n = 3$). Other reasons included respecting that the care recipient did not acknowledge the dementia diagnosis ($n = 1$) and gender incongruity between the family carer and researcher ($n = 1$). During the 6 months after baseline, three family carers from the intervention group withdrew from the study: one because the recipient of care moved to a nursing home, one because the recipient of care died, and one because the family carer did not feel the intervention had importance to her. All family carers in the treatment as usual group remained in the study at follow-up. Table 2 shows the baseline participant characteristics.

Intervention fidelity was recorded in the PCSP by primary care dementia coordinators. The primary care dementia coordinators all complied well with the planned interventions and used the PCSP to identify family carer needs and take actions to meet these needs. However, the team of multicultural link workers was only consulted on one occasion. All primary care dementia coordinators completed the two planned home visits and six telephone contacts but interventions with three family carers were delayed due to the emerging COVID-19 pandemic. Thus, the mean time between baseline and follow-up interviews was 8 months rather than the scheduled 6 months. Although primary care dementia coordinators encouraged family carers to use the Carer Diary, none

Table 2. Baseline participant characteristics.

	Treatment as usual (n=3)	Intervention (n=4)
Family carers		
Age (years)	39.0 ± 10.6 [29–50]	44.5 ± 11.1 [28–52]
Gender (Male/Female), n	1/2	2/2
Education ^a	6.3 ± 0.6 [6–7]	4.5 ± 1.7 [3–6]
Ethnicity, n		
Arabic	1	–
Pakistani	2	2
Turkish	–	1
Other	–	1
Born abroad, n	2	1
Language spoken at home other than Danish, n	3	2
Living with care recipient, n	2	2
Adult child of care recipient, n	3	4
Duration of carer role (years)	2.7 ± 1.5 [1–4]	1.9 ± 1.2 [1–3.5]
Hours spent on caregiving per week	30.0 ± 34.7 [8–70]	24.4 ± 21.9 [8–56]
Perceived financial burden, n	0	2
Received support from other family members, n	3	4
Number of chronic conditions	0.4 ± 0.6 [0–1]	0.8 ± 1.5 [0–3]
Recipients of care		
Age (years)	75.0 ± 1.4 [74–79]	72.5 ± 9.6 [59–81]
Gender (Male/Female), n	1/2	0/4
Education ^a	4.0 ± 3.5 [0–6]	3.0 ± 1.7 [2–4]
Diagnosis		
Alzheimer's disease	3	2
Mixed Alzheimer's disease/vascular dementia	–	1
Frontotemporal dementia		
Duration of dementia (years)	3.0 ± 2.0 [1–5]	3.6 ± 2.9 [2–8]
Clinical dementia rating score	2.0 ± 1.0 [1–3]	1.8 ± 1.0 [1–3]
Number of chronic conditions	1.3 ± 0.6 [1–2]	1.0 ± 0.8 [0–2]

n = number

Unless otherwise stated, data are presented as mean ± standard deviation [range].

^aEducation: 0 = No education; 1 = Primary education; 2 = Lower secondary education; 3 = Higher secondary education; 4 = Post-secondary, non-tertiary, education; 5 = Short post-secondary education; 6 = Bachelor's degree or equivalent; 7 = Master's degree or equivalent

of them returned their Carer Diaries for analysis. Interpreting services were not required as all participating family carers were fluent in Danish.

Qualitative feedback

Acceptability and suitability of the intervention was explored in semi-structured interviews with family carers. They all reported great satisfaction with the intervention and highlighted the benefits of the structured and proactive approach to identify their needs: “*It has been a great help that it was her who contacted us and asked all the questions. This also made it easier to discuss even smaller everyday issues,*” individual coaching on challenges faced in daily care practice: “*She has been our*

lifeline,” and referral to available services: “*The coordination of care services has been a great help to us. Things have been running more smoothly.*” Reasons for not adhering with the Carer Diary mainly concerned practical issues and a lack of perceived benefit.

Changes in outcome measures at follow-up

Figure 1 compares the baseline and follow-up outcome scores for family carers in the intervention and treatment as usual groups. Using ANCOVA correcting for differences in baseline scores, significant group differences were observed in change from baseline scores for NPI-Q Carer Distress (mean difference: -5.14 [95% confidence interval: -8.44 to -1.83], $F(1,4) = 18.62$, $p = .01$) and QUOTE-elderly (mean difference: $.50$ [95% confidence interval: $-.01$ to 1.00], $F(1,4) = 7.45$, $p = .05$), while there was a trend for a significant difference for the SSCQ (mean difference: 6.32 [95% confidence interval: -1.34 to 13.98], $F(1,4) = 5.25$, $p = .08$), all in favor of the intervention. Differences for the NPI-Q (mean difference: -6.04 [95% confidence interval: -15.15 to 3.07], $F(1,4) = 3.39$, $p = 0.14$, $\eta^2 = 0.46$), SF-12 PCS (mean difference: 1.93 [95% confidence interval: -15.99 to 19.85], $F(1,4) = 0.09$, $p = 0.78$, $\eta^2 = 0.02$), and SF-12 MCS (mean difference: 13.76 [95% confidence interval: -7.97 to 35.49], $F(1,4) = 3.09$, $p = 0.15$, $\eta^2 = 0.44$) were not significant but all in the expected direction.

One family carer in the intervention group participated in carer education at baseline but no longer did so at follow-up. One recipient of care in the treatment as usual group received home care with unchanged frequency between baseline and follow-up. No other services were used during the study period.

Discussion

The results from this small pilot study provide some preliminary support for the feasibility of a 6-month personalized dementia care intervention for family carers from minority ethnic groups. 10 of the 33 identified eligible family carers (30%) consented to participate in the intervention. Retention rates between baseline and follow-up was 70% and there were no adverse events during the intervention. Despite encouragement from primary care dementia coordinators, none of the caregivers adhered with the Carer Diary which they mainly related to practical issues concerning its implementation in everyday care routines and a lack of perceived benefit. However, reticence to complete the diaries may also have been related to a lack of comfort writing in Danish. Intervention fidelity was high, with all primary care dementia coordinators completing all scheduled home visits and telephone contacts. However, it was noteworthy that multicultural link workers were only consulted on one occasion. Feedback from primary care dementia coordinators revealed that this was mainly due to time constraints, access issues, and perceived importance of emerging cultural issues.

Recruitment and retention of participants from minority ethnic groups in dementia research has been recognized as a challenge (Gilmore-Bykovskiy et al., 2019) and, not surprisingly, the participation rate was lower than those typically reported in psychosocial dementia carer interventions (Qiu et al., 2019). Participation hesitancy was mainly due to lack of interest and time. However, reasons also included lack of understanding of the purpose and possible gains, lack of trust and gender incongruency, which may be all related to cultural issues. However, the retention rate among those consenting to participate was comparable to those reported in most psychosocial dementia carer interventions (Qiu et al., 2019), including interventions tailored to carers from minority ethnic groups (Belle et al., 2006; Kally et al., 2014; van der Heide et al., 2020; Xiao et al., 2016). Although the study incorporated known facilitators of research participation, including building of trust and rapport, availability of interpreter services, and visit locations and timing that were convenient for

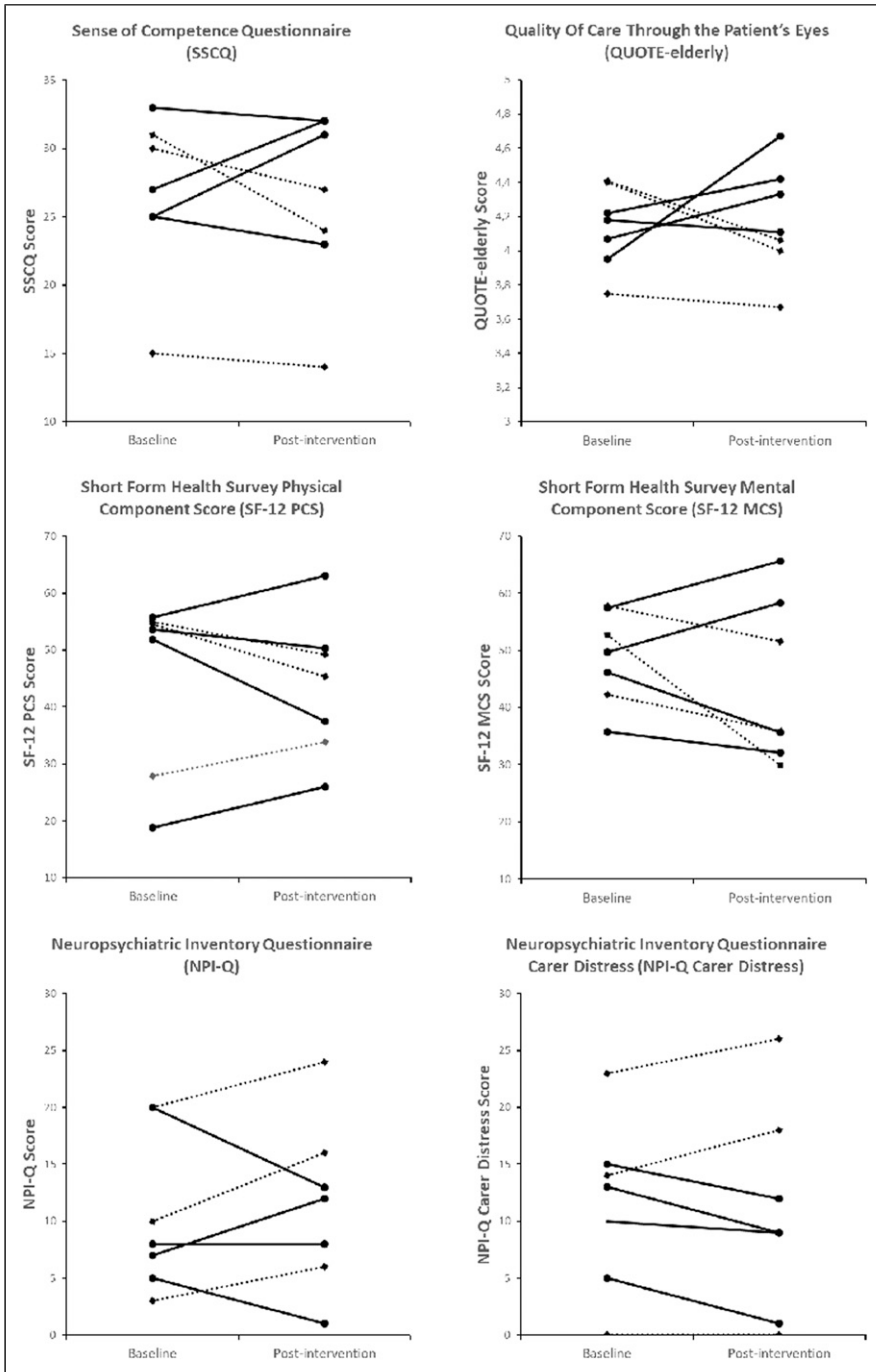


Figure 1. Individual data for baseline and follow-up outcome measures for family carers in the intervention and treatment as usual groups. Solid lines: family carers in the intervention group. Dotted lines: family carers in the treatment as usual group.

participants (Gilmore-Bykovskiy et al., 2019), the low participation rate suggests that recruitment strategies should be adjusted before commencing on a larger trial. For instance, providing research staff who speak relevant minority languages rather than relying on interpreters may make the families, especially the older care recipient, more comfortable with the intervention and more likely to participate.

Regarding program acceptance and satisfaction, all family carers reported great satisfaction with the intervention in post-intervention interviews and highlighted the benefits of the structured and proactive approach, individual coaching, and case management. This seems to indicate that individualized support and in-home coaching was culturally acceptable despite cultural and linguistic discordance between family carers and primary care dementia coordinators. Cultural awareness and sensitivity in participating primary care dementia coordinators may have been facilitated by the ongoing supervision provided by the research team as well as the structured assessment of social, cultural and linguistic carer needs in the PCSF. As in the original Australian study (Xiao et al., 2016), it was challenging to have family carers adhere with the Carer Diary, while intervention fidelity from primary care dementia coordinators was high. Furthermore, although not powered for efficacy, a reduction of carer distress from BPSD and increased satisfaction with primary care support was shown by family carers in the intervention group, when comparing NPI-Q Carer Distress and QUOTE-elderly change from baseline scores with those of family carers in the treatment as usual group. Sense of competence in managing dementia and mental well-being also increased slightly, as shown by differences in change from baseline scores for the SSCQ and SF-12 MCS, while the intervention had no influence on usage of respite care, aged care services, and dementia services. These preliminary findings are generally consistent with the 6-month follow-up data from the original RTC by Xiao et al. (2016), which is encouraging.

The results from this small-scale pilot study emphasize the potential usefulness of a personalized dementia care intervention for family carers from minority ethnic groups in Denmark that is low cost and accessible. Importantly, the intervention can be delivered in the community setting using existing human resources and is tailored to the basic needs of family carers from minority ethnic groups providing care at home. Family carers from minority ethnic groups in Denmark often provide care at home with limited or no involvement of available community care services (Nielsen et al., 2019; Nielsen et al., 2020a, 2020b). For them to provide the best care possible, appropriate and effective support is needed. The personalized dementia care intervention for family carers from minority ethnic groups can be expected to contribute to this support.

Limitations

The intervention was delivered by ethnic Danish primary care dementia coordinators employed in mainstream services. In contrast, the intervention in the original Australian RCT study (Xiao et al., 2016) was mainly delivered by case managers employed in ethno-specific services who had cultural and linguistic concordance with family carers. Thus, results from the two studies cannot be directly compared. In addition, there were two important differences between the studies. First, all participants in the original study were carers of people with dementia who were users of community aged care, whereas this was only the case for one participant in the present study. Second, the original study included participants from any minority ethnic group, whereas participants in the present study were restricted to family carers from Turkish-, Pakistani-, and Arabic-speaking minority groups. These differences in study populations may have influenced the results. In particular, the different inclusion criteria could help explain the paucity of eligible family carers, despite that we had more than 1 year to recruit participants. The study was not powered for efficacy and there were only few participants in the

trial, with all being adult children of the person with dementia. Thus, results for outcome measures are only indicative. As it is often found (Janevic and Connell, 2001; Kosloski et al., 1999), in Denmark family carers of people with dementia in minority ethnic groups are most commonly adult children of the recipient of care (Nielsen et al., 2020b). This could explain the lack of spousal carers in the study.

Conclusions

The results from this pilot study suggest that the primary care dementia coordinator-led personalized intervention is a feasible intervention worth exploring for family carers of relatives with dementia from minority ethnic groups in Denmark. However, recruitment strategies and inclusion criteria should be adjusted before commencing on a larger trial. Although the preliminary data indicate that the intervention may have potential to help increase carers' sense of competence in managing dementia, reduce carer distress from BPSD, and increase satisfaction with community care services, this needs to be demonstrated in larger controlled studies.

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Ethical approval/Patient consent

Participation was anonymous, voluntary and without any economic incentive. Informed consent was obtained at baseline. Approval by an official ethics committee was not required by Danish law but the study was approved by the Danish Data Protection Agency (jnl no.: 2012-58-0004) as part of a larger research project.

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References

- All Party Parliamentary Group (APPG) on Dementia (2013). *Dementia does not discriminate. The experience of black, Asian and minority ethnic communities*. London: Alzheimer's Society.
- Alzheimer's Disease International (ADI) (2015). *World alzheimer report 2015: The global impact of dementia. An analysis of prevalence, incidence, cost and trends*. London, Alzheimer's Disease International.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K. M., Lee, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., Zhang, S., & Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Investigators (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of internal medicine*, 145, 727–738.

- Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, *13*, 572–581.
- Gilmore-Bykovskiy, A. L., Jin, Y., Gleason, C., Flowers-Benton, S., Block, L. M., Shah, M. N., & Zuelsdorff, M. (2019). Recruitment and retention of underrepresented populations in Alzheimer's disease research: A systematic review. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, *5*, 751–770.
- Goeman, D., Renehan, E., & Koch, S. (2016). What is the effectiveness of the support worker role for people with dementia and their carers? A systematic review. *BMC Health Services Research*, *16*, 285.
- Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: Recent findings. *Gerontologist*, *41*, 334–347.
- Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., Higgins, M., Connolly, L., & Hepburn, K. (2014). The savvy caregiver program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. *Journal of Gerontological Social Work*, *57*, 681–693.
- Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. *J Neuro-psychiatry Clin. Neurosci*, *12*, 233–239.
- Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: A meta-synthesis of qualitative studies. *BMC Psychiatry*, *17*, 316.
- Kosloski, K., Montgomery, R. J., & Karner, T. X. (1999). Differences in the perceived need for assistive services by culturally diverse caregivers of persons with dementia. *Journal of Applied Gerontology*, *18*, 239–255.
- Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., & Cooper, C. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: Pragmatic randomised controlled trial. *BMJ*, *347*, f6276.
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology*, *43*, 2412–2414.
- Napoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet?. *American Journal of Alzheimer's Disease & Other Dementias*[®], *25*, 389–406.
- Nielsen, T. R., Antelius, E., Spilker, R. S., Torkpoor, R., Toresson, H., Lindholm, C., Plejert, C., & Nordic Research Network on Dementia and Ethnicity. (2015). Dementia care for people from ethnic minorities: A nordic perspective. *Int. J. Geriatr. Psychiatry*, *30*, 217–218.
- Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2019). Barriers to post-diagnostic care and support in minority ethnic communities: A survey of danish primary care dementia coordinators. *Dementia*, *19*(8), 2702–2713. DOI: [10.1177/1471301219853945](https://doi.org/10.1177/1471301219853945).
- Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2020a). Barriers in access to dementia care in minority ethnic groups in Denmark: A qualitative study. *Aging Ment Health*, *14*, 1–9.
- Nielsen, T. R., & Waldemar, G. (2016). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. *Int. J. Geriatr. Psychiatry*, *31*, 222–230.
- Nielsen, T. R., Waldemar, G., & Nielsen, D. S. (2020b). Rotational care practices in minority ethnic families managing dementia: A qualitative study. *Dementia*, *20*(3), 884–898. <https://dx.doi.org/10.1177/1471301220914751>
- Orsmond, G. L., & Cohn, E. S. (2015). The distinctive features of a feasibility study: Objectives and guiding questions. *OTJR: Occupation, Participation and Health*, *35*, 169–177.
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*, 250.
- Qiu, D., Hu, M., Yu, Y., Tang, B., & Xiao, S. (2019). Acceptability of psychosocial interventions for dementia caregivers: A systematic review. *BMC Psychiatry*, *19*, 23.
- Sixma, H. J., van Campen, C., Kerstens, J. J., & Peters, L. (2000). Quality of care from the perspective of elderly people: The QUOTE-elderly instrument. *Age Ageing*, *29*, 173–178.

- Stevnsborg, L., Jensen-Dahm, C., Nielsen, T. R., Gasse, C., & Waldemar, G. (2016). Inequalities in access to treatment and care for patients with dementia and immigrant background: A danish nationwide study. *J Alzheimers. Dis*, 54, 505–514.
- van der Heide, I., van Wezel, N., Blom, M., Spreeuwenberg, P., Devillé, W. L., & Francke, A. L. (2020). Effects of an educational intervention on health-related quality of life among family caregivers of people with dementia with a Turkish or Moroccan immigrant background: Insights from a cluster randomised controlled trial. *Patient Education and Counseling*, 104(5), 1168–1175.
- Van Mierlo, L. D., Meiland, F. J., Van der Roest, H. G., & Dröes, R. M. (2012). Personalised caregiver support: Effectiveness of psychosocial interventions in subgroups of caregivers of people with dementia. *International Journal of Geriatric Psychiatry*, 27, 1–14.
- Vernooij-Dassen, M. J., Felling, A. J., Brummelkamp, E., Dauzenberg, M. G., van den Bos, G. A., & Grol, R. (1999). Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: A Short Sense of Competence Questionnaire (SSCQ) suitable for clinical practice. *J Am Geriatr Soc*, 47, 256–257.
- Ware, J. E., Keller, S. D., & Kosinski, M. (1995). *SF-12: How to score the SF-12 physical and mental health summary scales*. London: Health Institute, New England Medical Center.
- Xiao, L. D., De Bellis, A., Kyriazopoulos, H., Draper, B., & Ullah, S. (2016). The effect of a personalized dementia care intervention for caregivers from Australian minority groups. *Am J Alzheimers Dis Other Demen*, 31, 57–67.

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