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Evaluating the feasibility, experiences, facilitators of and barriers to carers and volunteers delivering Namaste Care to people with dementia in their own home: a qualitative interview study in the UK and the Netherlands

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ABSTRACT

Objectives To evaluate the feasibility, facilitators of and barriers to delivering Namaste Care by volunteers and family carers to community-dwelling people with dementia, and to map family carers and volunteers' experiences with the programme.

Design Qualitative interview study with two phases: (1) preparation phase; (2) pilot phase.

Setting Private residences of community-dwelling people with dementia in the UK and the Netherlands.

Participants Family carers and volunteers of community-dwelling people with dementia (phase 1: 36 Dutch interviews, phase 2: 9 Dutch and 16 UK interviews).

Intervention Namaste Care is a multicomponent psychosocial programme, originally developed for people with dementia residing in long-term care facilities. Meaningful activities were offered by carers and volunteers. Each person with dementia was offered 10 one-hour sessions.

Results Phase 1: Namaste Care was deemed feasible for community-dwelling people with dementia and no major adaptations to the programme were considered necessary. Phase 2: perceived effects of Namaste Care on people with dementia included improved mood and increased interaction. The programme appeared enriching for both family carers and volunteers, providing joy, respite from care and new insights for coping with challenging behaviour. A flexible attitude of the Namaste provider facilitated its delivery. High caregiver burden and a strained relationship between the family carer and person with dementia were considered barriers. Experiences of family carers and volunteers with Namaste Care were very positive (mean satisfaction rating: 8.7 out of 10, SD=0.9, range 7–10).

Conclusion We recommend offering Namaste Care delivered by volunteers, preferably multiple sessions per week of 1.5–2 hours to optimise quality of life of community-dwelling people with dementia. Working with well-matched, flexible Namaste providers is pivotal. Family involvement should be encouraged, although the extent should be adapted depending on preference, caregiver burden and the relationship between the family carer and the person with dementia.

Trial registration number NL5570

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This two-phase study thoroughly prepared the transition of the Namaste Care programme, originally developed for long-term care facilities, to the home setting of community-dwelling people with dementia.
⇒ A multiperspective approach was used: experiences of family carers and volunteers with Namaste Care were analysed.
⇒ The pilot phase of the study took place in the UK and the Netherlands, supporting wider applicability of the programme.
⇒ Relatively few volunteers were interviewed for the pilot phase in the Netherlands (n=3) compared with the UK (n=10).

INTRODUCTION

Dementia is recognised as the global public health crisis of the 21st century.[1] In the UK, there were more than 885 000 people living with dementia in 2019, with approximately 60% living in the community in their own homes.[2] In the Netherlands (NL) in 2019, 71% of the 280 000 people living with dementia were living in the community.[3] A substantial part of the care for people with dementia is provided by family carers.[4] Providing care for a person with dementia is often considered burdensome[5] and associated with an increased risk of physical and psychosocial health problems.[5–7] With more

people with dementia staying at home longer, there is an urgent need to better support family carers to mitigate the negative health consequences[5] and to better meet the needs of community-dwelling people with dementia.[8]

The evidence for a beneficial impact of psychosocial and community-based interventions on quality of life and well-being for people with dementia and their carers is growing.[9–11] A programme specifically developed for nursing home residents with advanced dementia is Namaste Care.[12] Based on palliative care and person-centred care approaches, this multicomponent programme offers meaningful activities to connect to the person with dementia. Sessions take place in a calm, home-like room. The sessions focus on connecting with the person with dementia using sensory stimulation, touch, music, interactions with objects and meaningful activities to stimulate feelings of enjoyment and well-being. In the nursing home, two daily sessions of 2 hours are recommended.

There is an increasing body of research into the positive effects of Namaste Care on nursing home residents with dementia, nursing staff, and family carers,[13–16] its costs,[16–18] and the mechanisms of the programme.[19–21] Initial realist explanatory theories investigating if, how and under which circumstances Namaste Care works in the home setting suggest that the programme may also have positive effects on people with dementia and their carers living in the community.[21]

Namaste Care has not been formally evaluated in the home setting. St Joseph's Hospice in London was the first to adapt Namaste Care to a volunteer-led programme for people with dementia in their own home. The service started in Newham in April 2014 and has been expanded to include the boroughs of City of London, Hackney and Tower Hamlets. The aims of this study are (1) to evaluate the feasibility, facilitators of and barriers to delivering Namaste Care to community-dwelling people with dementia by volunteers and family carers, and (2) to map family carers and volunteers' experiences with the programme.

METHODS

Study phases and ethics

This qualitative interview study is part of the Dutch Namaste study.[22] The interview study comprised two phases: a preparation phase (December 2017 to October 2018; in NL) and a pilot phase (September 2018 to March 2019; in the UK and NL). The preparation phase evaluated the feasibility of Namaste Care for the home setting among those who had experience with the intervention in the nursing home setting in NL. The pilot phase aimed to map family carers' and volunteers' experiences with the Namaste Care in the home setting, as well as facilitators of and barriers to providing the programme at home in NL and the UK.

Patient and public involvement

In NL, family carers, volunteers and staff who participated in the Namaste study in nursing homes[22] were interviewed to prepare for the pilot phase. This is described in more detail below.

Recruitment and interviews in the preparation phase in NL

Interviews with those who had experience with Namaste Care in the nursing home setting, held in the context of a process evaluation of the Namaste study,[22] also addressed their perspectives on what would be needed to bring the intervention to the community. The interviews were conducted in the Namaste intervention group 12 months after the start of the programme.

Family carers who actively participated in at least two Namaste sessions in the past 6 months were invited to participate in an interview. Managers identified volunteers and staff who regularly participated in Namaste sessions. They were invited for an interview with one of three female psychologists (HJAS (researcher), Sarah Doncker (project coordinator), Marianne Pruis (interviewer)) at the nursing home or a location of the interviewee's choice. The interview guide for the process evaluation comprised a series of open-ended questions based on specific topic areas (for the interview guide, see ref 23). We report on a selected set of questions:

- *Would you consider the Namaste Care programme feasible for people with dementia who live at home and their relative(s)?*
- *What would be necessary to make Namaste Care suitable for the home setting?*
- *What should this service look like* (probe*: frequency of sessions, Namaste provider)?*
- For family carers: *Would you have liked to receive Namaste Care as a home service when your relative with dementia was still living at home?*

Setting and recruitment of the pilot phase

Namaste Care was provided to community-dwelling persons with mild to severe dementia in NL and the UK, and interviews were conducted to assess the experiences of those involved. Eligible participants for Namaste Care had a diagnosis of dementia, lived in the catchment area (UK: the boroughs of Newham, City of London, Hackney and Tower Hamlets; NL: province of Noord-Holland), had a family carer who could be in their home at the time of the Namaste sessions, visited at least once a week and was willing and able to fill in a questionnaire and participate in an interview in Dutch or English.

In the UK, family carers of people with dementia referred to the St Joseph's Hospice's Namaste Care service were invited to participate in the pilot phase. People with dementia were referred to the service via primary or secondary healthcare providers, family members, social services and local charities. Experienced Namaste volunteers from those who had delivered Namaste Care in people's own home were invited to participate.

In NL, participants were recruited via dementia case managers and two home care organisations. Carers

received an invitation letter, followed by a telephone call to plan an appointment if interested in participating. Dutch volunteers were recruited specifically for this pilot phase. Eligible volunteers had a background in psychology or experience in working with people with dementia and were willing to deliver Namaste Care for at least 1 day/week for 10 weeks, and to participate in the interview.

Namaste Care intervention in the pilot phase

In the UK, Namaste Care was offered by trained volunteers. The volunteers received a 2-day training, which included training on the Namaste Care service, main principles of the programme, symptoms of dementia, communication skills, meaningful activities and hand massage. The training was delivered by experts in dementia care who also had experience with providing Namaste sessions to people with dementia in their home. Each person with dementia was offered 10 weekly 1-hour Namaste sessions.[24]

In NL, the number of sessions per week was determined together with the carer, with a minimum of 10 sessions over the course of 4 weeks. The duration of the sessions was similar to the UK. The carers could choose to conduct the sessions themselves after receiving a training, do it together with a volunteer or have a volunteer providing all the sessions. The volunteers and carers received a 2-hour training, a condensed version of the UK training. The Dutch volunteers were recruited based on different selection criteria and therefore they needed less training compared with the UK volunteers. Dutch volunteers had to have a background in psychology or experience in working with people with dementia, while this was not a requirement in the UK. The Dutch trainers (HJAS, Sarah Doncker; both psychologists with experience with dementia care) were trained by the UK team. They took the 2-day volunteer course and a masterclass in setting up a volunteer-based programme in the community. In both countries, the volunteers and carers delivering Namaste Care were invited to participate in supervision sessions.

Before the start of Namaste Care, a holistic assessment was conducted with the family carer to assess suitability of the programme, put together a biography and identify meaningful activities for the person with dementia. Subsequently, this information was used to match the person with dementia with a volunteer and formed the basis of the Namaste sessions. Similar to the original programme for nursing homes, the main principles of the programme remained the comfortable environment, a loving touch approach and offering meaningful personalised activities.[12] Deviations from the original programme included the intensity of the sessions (twice daily vs at least once a week, 2 hours vs 1 hour), mode of delivery (group setting or individual vs individual) and setting (designated quiet room in nursing home vs preferred place in their own home).

Data collection in the pilot phase

The interviews were conducted within 2–4 weeks from the last Namaste session. In NL, this was done by two female psychologists (HJAS, Sarah Doncker). In the UK, the interviews were conducted by a female Namaste Care volunteer with a background as a clinical research nurse and geriatric nurse practitioner (Judi Lauerman). The interviews took place in a location chosen by the interviewee. The interview guide is presented in online supplemental file 1.

The duration of the Namaste sessions was recorded after each session. The family carer provided personal details, also about the person with dementia, by completing a questionnaire before the start of the first session. Perceived caregiving burden was measured using a self-rated visual analogue scale, with 0 anchored at '*Not at all straining*' and 10 '*Much too straining*'. Dementia severity was measured using the Bedford Alzheimer Nursing Severity Scale[25] consisting of seven items. A score ≥17 indicates severe dementia.[26]

Analyses of the preparation and pilot phase interviews

All interview data were collected using a digital recording device. The interviews were transcribed verbatim. An initial list of codes was developed inductively based on the first three transcripts by two researchers independently (HJAS, Sarah Doncker and two trained research assistants). A consensus list of codes was created. This was used to recode the first three interviews. Next, the consensus list was applied to the analysis of the next three transcripts. When new codes emerged from analysis of the second batch, they were added to a revised coding framework. Content analyses were conducted.[27] Coding was supported by ATLAS.ti. The researchers engaged in a reiterant process of discussing areas of agreement and disagreement to enhance analytical rigour and achieve consensus (HJAS and research team for the preparation phase; HJAS and MLH for the pilot study). Descriptive statistics of the samples were obtained using IBM SPSS Statistics V.25.

RESULTS OF THE PREPARATION PHASE

Figure 1 shows the flow chart of participants in the preparation phase (response rate: 79%). The final sample consisted of 36 participants (ie, family carers, volunteers and nursing home employees) from 10 nursing homes; their characteristics are presented in table 1.

All interviewees deemed Namaste Care feasible for community-dwelling people with dementia with some minor adjustments. The majority of the family carers would have liked to receive the service when their relative was still living at home. One dyad indicated that they saw the value of the service for family carers with limited time or who feel burdened, but would not have wanted it for their relative, as they had ample time to undertake meaningful activities with their relative.

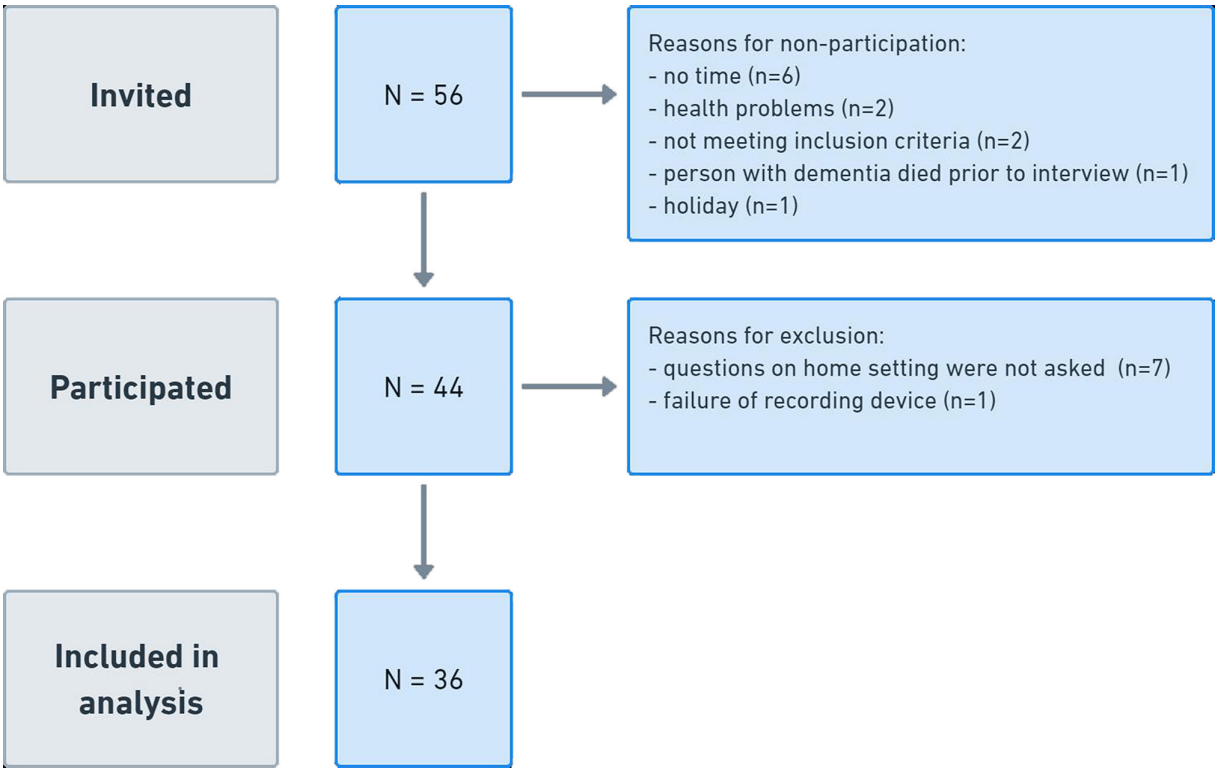

Figure 1 Flow chart of the preparation phase. The final sample consisted of 36 interviewees from 10 nursing homes. In one nursing home, the interviews were conducted after 6 instead of 12 months (three interviews), as they prematurely stopped the programme.

Some adjustments included the frequency and duration of the Namaste sessions. Although it was thought of as important to offer Namaste Care on a structural basis, daily sessions were not deemed feasible. The frequency and duration should be tailored to the needs and abilities of the person with dementia. Generally, 60–90 min sessions were recommended by the interviewees. Connecting with the person with dementia and providing meaningful individual activities remain key aspects. The Namaste activities are adapted to the preferences and needs of the person with dementia, making the programme suitable for people with mild and moderate dementia as well. Possible activities mentioned for the sessions at home were reading the newspaper together, drinking coffee, looking at photos or pictures, listening to music, having a chat, going outside and giving a hand massage. However, several staff members indicated that it may be difficult for some carers to give their relative a hand massage because they are not used to touching their relative in that way.

The size of the social support network, involvement of carers and experienced caregiver burden should be considered when deciding who should deliver the programme to the person with dementia. Home care services, volunteers and carers were all mentioned as suitable providers of Namaste Care. Interestingly, all carers suggested volunteers or home services to deliver the programme, mainly for respite, offering an opportunity to spend some time away from caregiving. Staff mentioned home care services as most suitable to deliver sessions, while managers most often suggested carers to deliver the programme. Carers delivering the sessions together with a volunteer or home service were also often mentioned by staff and by one carer. Trained Namaste providers could then teach the family carer how to conduct sessions. Offering the programme at dementia day care centres was suggested as an alternative if sessions at home were not possible.

Table 1 Characteristics of the interviewees in the preparation phase (n=36)

	% (n)/mean [SD]	Range
Age (years)	52 [13]	22–84
Gender: female	94 (34)	
Duration of interview (min)	53 [15]	28–102
Country		
Netherlands	100 (36)	
Nursing staff	47 (17)	
Experience with dementia (years)	10 [6]	2–20
Namaste programme coordinators	8 (3)	
Nursing home managers	17 (6)	
Family carer	22 (8)	
Volunteer	6 (2)	

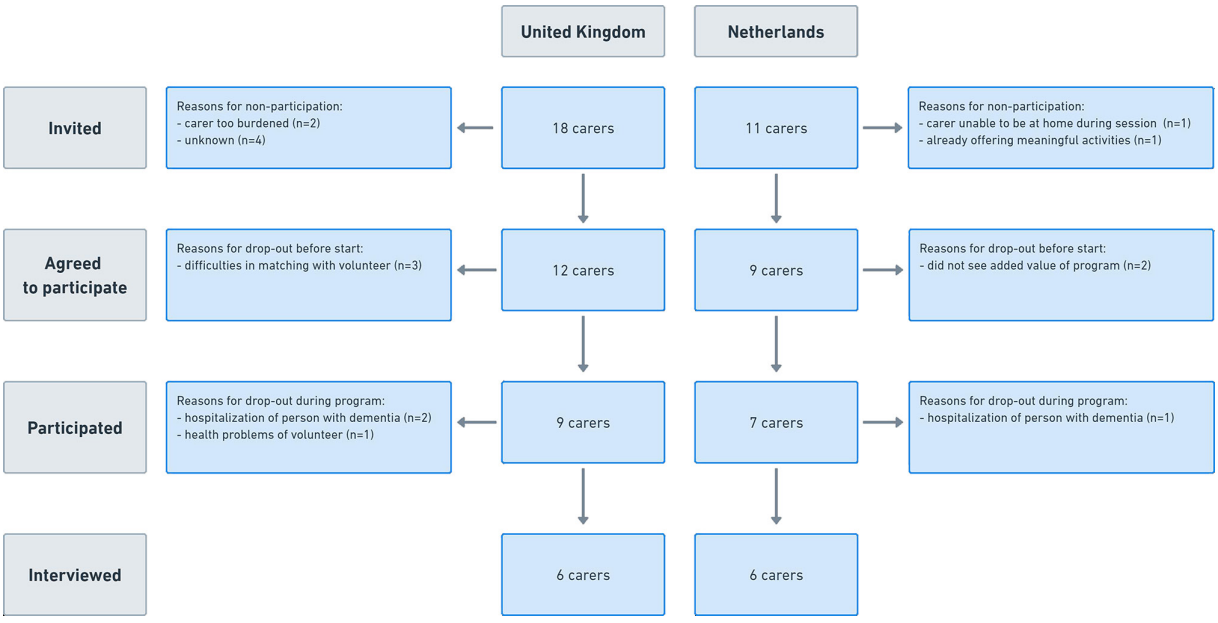

Figure 2 Flow chart of family carers in the pilot phase.

A specific need for the programme was identified for people with dementia not going to a dementia day care centre. Most interviewees also recognised the needs of carers for more support beyond what the programme does for the person with dementia. Both staff and family carers suggested it should include educating carers about dementia, focus on the acceptance of the disease and involve family carers to provide them with tools to connect with their relative in a meaningful way and to cope with challenging behaviour.

Quotes supporting these findings—and those of the pilot phase described below—are reported in online supplemental file 2.

RESULTS OF THE PILOT PHASE: EXPERIENCES IN THE HOME SETTING

Figure 2 shows the flow chart of the family carers who participated in the pilot phase (response rate UK: 67%; NL: 81%). In total, 131 sessions were provided to 16 people with dementia, with an average of 8.2 sessions (SD=2.5, range 1–10) per person and a mean duration of 67 min (SD=22, range 5–110) per session. The mean number of sessions delivered was 8.6 in NL versus 7.9 in the UK. In the UK, all sessions were provided by volunteers, and in NL the majority of the family carers also chose to have the sessions delivered by a volunteer. The only exceptions were two sisters who chose to deliver the programme together to their relative, and one family carer who delivered the sessions together with a volunteer. We conducted 25 interviews (9 in NL and 16 in the UK). Table 2 shows the characteristics of the interviewees. Table 3 shows the characteristics of the people with dementia who received the sessions. The most common type of dementia was Alzheimer's disease (44%) and dementia severity ranged from mild to severe, with 44% of the Namaste Care recipients having severe dementia.

Evaluation of Namaste Care

On average, interviewees graded Namaste Care 8.7 out of 10 (SD=0.9, range 7–10). The attention, companionship

Table 2 Characteristics of the interviewees in the pilot phase (n=26)

	% (n)/mean [SD]	Range
Age (years)*	59 [18]	19–87
Gender: female	73 (19)	
Duration of interview (min)	40 [19]	11–77
Satisfaction with Namaste Care†	9 [1]	7–10
Country		
Netherlands	38 (10)	
Family carer	23 (6)	
Volunteer	11 (3)	
Person with dementia‡	4 (1)	
UK	62 (16)	
Family carer	23 (6)	
Volunteer	39 (10)	

One interview took place with two Dutch carers of the same family simultaneously, resulting in a total of 25 interviews with 26 interviewees.
*Age had missing values for one Dutch volunteer and one UK carer.
†Satisfaction score (scale: 0–10, higher is better) was missing in one of the interviews from the pilot phase.
‡In one case, after consulting with the primary carer, the person with dementia was interviewed, as the person was able to participate in the interview and remembered some of the Namaste sessions.

Table 3 Characteristics of the people with dementia who received Namaste sessions (n=16)

	% (n)/mean [SD]	Range
Age (years)	82 [10]	63–98
Country		
Netherlands	44 (7)	
UK	56 (9)	
Gender: female	81 (13)	
Type of dementia		
Alzheimer's disease	44 (7)	
Vascular dementia	12 (2)	
Other/mixed	25 (4)	
Unknown	19 (3)	
Bedford Alzheimer Nursing Severity Scale	15 [5]	8–25
Severe dementia (score ≥17)	44 (7)	
Perceived caregiving burden visual analogue scale	7 [2]	2–10

Bedford Alzheimer Nursing Severity Scale (BANS-S), range: 7–28, higher scores indicate more severe dementia.
Perceived caregiving burden visual analogue scale (VAS), range: 0–10, higher scores indicate a higher burden.

and interaction facilitated by the programme were most frequently reported as valuable aspects. Having someone who is dedicated to the person with dementia to fulfil their social needs, and who shows sincere interest, was deemed valuable. Stimulating senses, for example, through music or touch, and reminiscence were also often appreciated.

> The thing is, you don't have to talk all the time. Just by holding hands and by massaging your hand […] it sends a good vibration to your mind, to your heart. And you know, you get that little feeling of belonging, that little feeling of wanted. […] It will give them the new lease for life. (UK family carer)

Other perceived advantages of the programme were its low costs and its ability to raise awareness in carers and show them new ways of interacting with their relative. The volunteers indicated the programme matched their way of life and working, and their desire to contribute. Aside from the time investment required of the family carer and the limited number of sessions, no disadvantages of Namaste Care were reported.

Perceived effects on people with dementia

Of the 22 interviewees who reported on mood of the person with dementia, 19 reported a positive impact of the programme regardless of dementia stage. General feelings of pleasure and happiness were described most frequently, often confirmed by smiles of the recipients. Having conversations and listening to music together were repeatedly mentioned as activities leading to pleasure. A relaxing and calming effect was also mentioned frequently and was mostly attributed to the hand massage. However, certain elements, such as music, could also be perceived as energising. Overall, a reduction in aggression and increased tolerance of physical contact were noted.

> She could get rather irritable, passionately, her dementia levels were high. She would get quite annoyed about things. During a Namaste session, she would calm down. Speak with less—aggression. (UK volunteer)

Multiple family carers who doubted whether the programme would suit the person with dementia were positively surprised by the impact. Three family carers of persons with varying stages of dementia indicated they did not observe any change in mood, although the sessions were enjoyable for the people with dementia. One family carer of a person with dementia who was not in the severe stage indicated that they did not seem to enjoy the sessions, even though certain elements did lead to an improved and more relaxed mood.

In addition to its effects on mood, Namaste Care appeared to stimulate verbal and non-verbal interactions. Examples of non-verbal interactions reported by family carers and volunteers were holding hands and waving goodbye to the volunteer at the end of the session. Volunteers witnessed increases in affectionate and physical contact and trust over the course of the programme. They also mentioned factors that stimulated interaction, for example, reading aloud to the person with dementia, sensory stimulation, looking at pictures and discussing common interests. Particularly when the sessions were provided by volunteers, being able to talk to someone outside the family appeared to stimulate the verbal interaction of people with dementia. One family carer of a person with less severe dementia and one volunteer reported that looking at pictures led to challenging behaviour, possibly because the pictures evoked bad memories, or reminded the people with dementia of their difficulty with recalling certain memories.

Other benefits reported by family carers and volunteers were improved recall through exposure to music or pictures, reduced pain after a massage, increased engagement and independence and improved liquid intake. Although the perceived effects were not always retained after the sessions, some family carers noted that the person with dementia appeared to be more communicative and in a better mood during the hours or days following the sessions. Furthermore, some family carers and volunteers reported that people with dementia seemed to look forward to the next session.

Perceived effects on family carers

Family carers generally experienced the Namaste sessions as enjoyable and relaxing, regardless of their caregiver burden. They experienced a shared responsibility, care respite and a sense of gratitude when sessions were provided by volunteers. In some cases, Namaste Care was

an eye-opening experience for the family carer, as the volunteer provided them with new ideas for activities or new topics of conversation to engage their relative. The programme also led to increased awareness among family carers about the potential benefits of calm presence and physical contact. As a result, they engaged more often in physical contact. On occasion, Namaste Care provided the family carer insight into causes of challenging behaviour and new ways of coping with these behaviours.

Incidentally, Namaste Care led to unfamiliar or unexpected situations causing stress and unease for the family carer when the impact of the programme on their relative was not in line with their expectations. One family member with moderate caregiving burden, who had a strained family relationship and high expectations, was disappointed in the programme's impact. This was the same carer who indicated that the person with dementia did not seem to enjoy the sessions.

> For me, it turned into a big disappointment, actually. Perhaps in part because I had high expectations, as I see so many things that are no longer possible with my mother, and this—this can have an effect. This is also really going to generate a kind of gentle—attentive contact. And that just hasn't happened—at least in the sessions I attended. (Dutch family carer)

Perceived effects on volunteers

Namaste Care offered volunteers an opportunity to continue learning and expand their network. The knowledge and experience gained from providing Namaste was found to be enriching and useful outside the sessions as well. Some volunteers reported they especially enjoyed the creative aspect of preparing the sessions. Providing Namaste Care generally made volunteers feel rewarded and satisfied. Seeing the person with dementia smile and experiencing gratitude from the carers contributed to these feelings. Volunteers frequently reported a relaxing impact of the sessions, particularly after giving a massage.

> I felt I got the same benefit from meditating or practising loving kindness through meditation. (UK volunteer)

Volunteers often reported that they developed a close relationship with the person with dementia and the family carers. Seeing the struggles of the person with dementia could also make volunteers feel sad or worried at times.

Perceived facilitators, barriers and recommendations

Facilitators of and barriers to delivering Namaste Care to community-dwelling people with dementia, as perceived by family carers and volunteers, could be grouped in four categories: (1) characteristics of the person with dementia, (2) characteristics of the Namaste provider, (3) family, and (4) practicalities (table 4).

Matching Namaste providers on language, culture and religion with the person with dementia was deemed important by both volunteers and carers, as it is easier for the provider to engage people with dementia in conversation and activities when they are able to converse in their native tongue and share the same cultural and religious background. A linguistic mismatch may hamper personalisation of the programme, as described by a UK volunteer who experienced disappointment as a result. Also, Namaste providers should ideally have a flexible attitude and experience in working with people with dementia. The limited number and duration of sessions provided was often described as a drawback. Both family carers and volunteers indicated that more and longer sessions were desirable, preferably multiple sessions per week of

Table 4 Perceived facilitators of and barriers to delivering Namaste Care to community-dwelling people with dementia

Facilitators	Barriers
Characteristics of the person with dementia	
Compliant and adaptive behaviour	Uncommunicative and reserved attitude
Reciprocal relationship with Namaste provider*	Unaccustomed to touch
	Diminished physical function, for example, hearing impairment
Characteristics of the Namaste provider	
Reciprocal relationship with person with dementia*	Native language different from the person with dementia
Similar personality and interests as the person with dementia	Culture different from the person with dementia
Emphatic and patient	Religion different from the person with dementia
Flexible and adaptive	
Creative	
Experienced in working with people with dementia	
Family	
Involvement of an experienced and supportive family carer during the sessions	High caregiver burden
	Strained relationship between carer and person with dementia
	Presence of the carer can cause the person with dementia to be less engaged
Practicalities	
Structure and regularity of the programme	Limited funding
Quiet and hygienic setting	Limited number of volunteers
Prepared Namaste room	Limited number and duration of sessions

*Illustrated by quote 13 in online supplemental file 2.

1.5–2 hours. Most importantly, the duration and timing of the sessions should match the attention span and energy level of the person with dementia.

Multiple volunteers indicated that involvement of the family carer during the sessions is an important facilitator for delivering Namaste Care. This could be either by codelivering the sessions or by joining in activities. Their involvement could help to further personalise the contents of the sessions making them more meaningful and enjoyable for the person with dementia. When given the choice, only two families decided to (co)deliver the sessions, whereas the others opted for delivery by volunteers. Factors considered to impede family involvement based on the interviews were high caregiver burden and a strained relationship between the family carer and person with dementia. Whether a family carer or a volunteer is most suited to provide Namaste Care therefore depends on preference and the family's situation.

In addition, family carers mentioned that providing additional background about dementia and the aim of Namaste Care during the training would be beneficial. Moreover, volunteers recommended including information in the training about how to structure a session, especially when providing the programme to people with more advanced dementia. Both carers and volunteers emphasised the value of feedback over the course of the sessions. Sharing experiences among volunteers was found to be very helpful and inspiring and a yearly refresher course was suggested.

DISCUSSION

This study aimed to evaluate the feasibility, facilitators of and barriers to delivering Namaste Care by volunteers and family carers to people with dementia living in their own home. Namaste Care was deemed feasible for Dutch community-dwelling people with mild to severe dementia, in line with a recent study from Canada.[28] In general, experiences of family carers and volunteers with Namaste Care were very positive, although some potential drawbacks were identified. Experiences from NL and the UK regarding satisfaction and perceived effects were remarkably similar. Perceived effects of Namaste Care on people with dementia included improved mood and increased interaction. In addition, Namaste Care was found to be enriching for both carers and volunteers, providing joy, care respite and new insights for coping with challenging behaviour. Incidentally, Namaste Care led to unfamiliar or unexpected situations, making the family carer or volunteer feel uneasy or worried.

Only 44% of our Namaste Care recipients were in the regular Namaste target group, that is, people with severe dementia, indicating Namaste Care works regardless of the level of dementia. This may be due to the person-centred approach.[28] Although Namaste Care requires minimal resources, it does require time, and motivated and trained people to deliver the sessions. Facilitators of and barriers to delivering Namaste Care related to the characteristics of the person with dementia and the Namaste provider, family and practicalities. Recommendations regarding the training have already been incorporated in established practice in the UK.

Both the results from the preparation phase and the pilot phase highlight the importance of person-centred programmes such as Namaste Care for people with dementia. A person-centred approach to dementia care is also recommended by the National Institute for Health and Care Excellence guidance on dementia, which advises to choose activities based on an understanding of the person's unique life experiences, circumstances, preferences and needs.[29] Moreover, a personalised approach is one of the working mechanisms of Namaste Care in the home setting described in the qualitative realist evaluation by Dalkin *et al*.[21] It is suggested that such an approach evokes emotional responses in the person with dementia, leading to positive outcomes such as increased relaxation and engagement, as observed in our pilot phase. A randomised controlled trial, including 100 people with dementia and their family carers, also showed that scheduling personalised activities across a 12-week period reduced disruptive and depressive behaviour and improved quality of life in people with dementia.[30]

In line with expectations from the preparation phase, Namaste Care indeed seemed to help some family carers cope with challenging behaviour of their relative. Consistent with the preferences expressed by family carers in the preparation phase, the majority of family carers chose to have the programme delivered by a volunteer. Family carers in the pilot phase reported that Namaste Care provided them with much appreciated respite when delivered by volunteers. In other words, they were given respite, offering an opportunity to do something for themselves. This is an important finding, as high caregiver burden is common among carers for people with dementia.[31] Moreover, this break from caregiving allows for participating in social and leisure activities away from the caregiving context, which can cultivate purpose,[32] forming a psychological resource that contributes to positive caregiving outcomes.[33] Care respite has been identified as one of the main working mechanisms of Namaste Care in the home setting.[21]

Notably, volunteers in the pilot phase reported they developed a strong emotional connection with the person with dementia as a result of providing Namaste Care. The formation of meaningful relationships through one-on-one interactions is an important working mechanism of Namaste Care identified in multiple studies, leading to increased recognition, friendship and possibly increased quality of life for both.[20 21] This is consistent with companionship being considered one of the most valuable aspects of the Namaste programme in our study and a Canadian study.[28] Various studies have confirmed associations between social interaction and well-being of people with dementia.[34 35]

To our knowledge, this is the first study evaluating the feasibility of and experiences with Namaste Care

for people with dementia in the home setting. A study on Namaste Care for community-dwelling people with dementia in Canada is underway.[36] A major strength of this study is the fact that both family carers and volunteers from two countries were interviewed, supporting wider applicability of the programme. Moreover, the elaborate preparation phase preceding the pilot study allowed for thorough preparation of the transition of the programme from nursing homes to community-dwelling people with mild to severe dementia in NL. The pilot phase included sufficient interviews to reach data saturation. Results from the preparation phase and the pilot phase were consistent, indicating the robustness of our findings.

Limitations include the relatively low number of volunteers who were interviewed for the pilot phase in NL (n=3) compared with the UK (n=10), and the low number of men compared with women among our interviewees. Moreover, the small sample may imply saturation is not being reached in understanding the diversity in the experiences of family carers and volunteers by gender of the person with dementia, dementia severity, characteristics of the Namaste provider or the level of caregiver burden. Future research is needed to assess the impact of these factors on the feasibility of Namaste Care in the home setting. Unfortunately, only few family carers chose to (co)deliver the sessions, making it difficult to assess the feasibility of getting family carers to deliver sessions. We did not ask family carers to motivate their decision regarding (co)delivery of the sessions. More research is needed to investigate the feasibility of family carers delivering Namaste Care to people with dementia at their home.

In order to facilitate people with dementia to live at home as long as possible with the best possible quality of life, we need to ensure the physical, emotional and social care needs of those with dementia and their family carers are met.[21] Offering Namaste Care to community-dwelling people with dementia using volunteers, preferably multiple sessions per week, may be a way to facilitate this. However, further research is necessary to provide a formal evaluation of and recommendations for sustainability of volunteer recruitment. Whether delivering multiple sessions per week would be feasible in the UK also requires further exploration, as the present pilot study in the UK comprised one session per week. To maximise the impact on care respite and thereby possibly prevent or delay admission to a long-term care facility, it could be beneficial to start Namaste Care when people are still in a mild to moderate dementia stage, when the family carer is not yet overburdened, facilitating connections between those involved.

The programme also has the potential to improve the transition from home to a nursing home that also offers the programme. The structure of Namaste Care may trigger feelings of familiarity, reassurance, engagement and connection,[20] and may facilitate continued family involvement, which may ease the transition. Therefore, an interdisciplinary approach to dementia care with healthcare professionals from both the nursing home and home care, as well as family carers, is recommended to allow the continuation of meaningful activities after nursing home admission.[37 38] Working with well-matched Namaste providers who have a flexible attitude is pivotal, and family involvement should be encouraged, although the extent of family involvement should be adapted to the dyad depending on caregiver burden and the relationship between the carer and the person with dementia. Future research should examine whether implementation of Namaste Care in the home setting enables people with dementia to remain living at home longer.

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Competing interests HJAS became the associate director of Namaste Care International (non-financial association) after the data collection was completed and the data were analysed.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants. The study protocol was reviewed by the Medical Ethics Review Committee of VU University Medical Center and judged exempt from the Medical Research Involving Human Subjects Act (protocol number: 2016.399). The Namaste study is registered in the Netherlands Trial Register: NL5570. The purpose of data collection in the UK was regarded as a service evaluation and thus exempt from evaluation by the hospice research ethics committee. Participants provided written informed consent. The Namaste Care service was free of charge. Participants gave informed consent to participate in the study before taking part.

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REFERENCES

1 World Health Organization (WHO). The epidemiology and impact of dementia: current state and future trends Geneva, Switzerland: World Health organization, 2015. Available: https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf?ua=1 [Accessed 16 March 2022].
2 Wittenberg R, Hu B, Barraza-Araiza L, *et al*. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*. London: London School of Economics, 2019.
3 Alzheimer Nederland. Factsheet cijfers en feiten over dementie, 2021. Available: https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie [Accessed 16 March 2022].
4 Wimo A, Guerchet M, Ali Gemma-Claire. The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & Dementia* 2017;13:1–7.
5 Abreu W, Tolson D, Jackson GA, *et al*. A cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia. *Dementia* 2020;19:301–18.
6 Joling KJ, van Hout HPJ, Schellevis FG, *et al*. Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *The American Journal of Geriatric Psychiatry* 2010;18:146–53.
7 Richardson TJ, Lee SJ, Berg-Weger M, *et al*. Caregiver Health: Health of Caregivers of Alzheimer's and Other Dementia Patients. *Curr Psychiatry Rep* 2013;15:367.
8 Black BS, Johnston D, Leoutsakos J, *et al*. Unmet needs in community-living persons with dementia are common, often non-medical and related to patient and caregiver characteristics. *International Psychogeriatrics* 2019;31:1643–54.
9 van der Steen JT, Smaling HJA, van der Wouden JC, *et al*. Music-based therapeutic interventions for people with dementia. *Cochrane Database of Systematic Reviews* 2018;2018.
10 Dugmore O, Orrell M, Spector A. Qualitative studies of psychosocial interventions for dementia: a systematic review. *Aging Ment Health* 2015;19:955–67.
11 McDermott O, Charlesworth G, Hogervorst E, *et al*. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health* 2019;23:393–403.
12 Simard J. *The end-of-life Namaste care program for people with dementia*. 2nd edition. Baltimore, Maryland: Health Professions Press, Inc, 2013: 274.
13 Amrollah Majdabadi Kohne Z, Nikpeyma N, Bayat F, *et al*. The effects of a Namaste care program on quality of life: A pilot study in Iranian women with late-stage Alzheimer's disease. *Geriatr Nurs* 2021;42:78–82.
14 Smaling H, Smaling H, Joling K, *et al*. Perceived impact of the Namaste care family program on people with advanced dementia, nursing staff, and family caregivers: a qualitative study. *J Am Med Dir Assoc* 2019;20:B31.
15 Stacpoole M, Hockley J, Thompsell A, *et al*. The Namaste care programme can reduce behavioural symptoms in care home residents with advanced dementia. *Int J Geriatr Psychiatry* 2015;30:702–9.
16 Stacpoole M, Thompsell A. OA25 The namaste care programme can enrich quality of life for people with advanced dementia and those who care for them without additional resources. *BMJ Support Palliat Care* 2015;5:A8.2–A8.
17 El Alili M, Smaling HJA, Joling KJ, *et al*. Cost-Effectiveness of the Namaste care family program for nursing home residents with advanced dementia in comparison with usual care: a cluster-randomized controlled trial. *BMC Health Serv Res* 2020;20:1–11.
18 Bray J, Brooker D, Latham I, *et al*. Costing resource use of the Namaste care intervention UK: a novel framework for costing dementia care interventions in care homes. *International Psychogeriatrics* 2019:1–10.
19 Bray J, Brooker DJ, Garabedian C. What is the evidence for the activities of Namaste care? a rapid assessment review. *Dementia* 2021;20:247-272.
20 Bunn F, Lynch J, Goodman C, *et al*. Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste care and other multisensory interventions. *BMC Geriatr* 2018;18:303.
21 Dalkin SM, Lhussier M, Kendall N, *et al*. Namaste care in the home setting: developing initial realist explanatory theories and uncovering unintended outcomes. *BMJ Open* 2020;10:e033046.
22 Smaling HJA, Joling KJ, van de Ven PM, *et al*. Effects of the Namaste care family programme on quality of life of nursing home residents with advanced dementia and on family caregiving experiences: study protocol of a cluster-randomised controlled trial. *BMJ Open* 2018;8:e025411.
23 Tasseron-Dries PEM, Smaling HJA, Doncker SMMM, *et al*. Family involvement in the Namaste care family program for dementia: a qualitative study on experiences of family, nursing home staff, and volunteers. *Int J Nurs Stud* 2021;121:103968.
24 St Joseph's Hospice. Namaste Care service London (UK): St Joseph's Hospice, 2020. Available: https://www.stjh.org.uk/our-care/community-and-day-services/dementia-care-namaste/ [Accessed 21 November 2021].
25 Volicer L, Hurley AC, Lathi DC, *et al*. Measurement of Severity in Advanced Alzheimer's Disease. *J Gerontol* 1994;49:M223–6.
26 van der Steen JT, Volicer L, Gerritsen DL, *et al*. Defining severe dementia with the minimum data set. *Int J Geriatr Psychiatry* 2006;21:1099–106.
27 Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *African Journal of Emergency Medicine* 2017;7:93–9.
28 Yous M-L, Ploeg J, Kaasalainen S, *et al*. Adapting the Namaste care program for use with caregivers of community-dwelling older adults with moderate to advanced dementia: a qualitative descriptive study. *Can. J. Aging* 2022;10:1–13.
29 NICE. *Dementia: quality standard*, 2019.
30 Lai FH-Y, Yan EW-H, Tsui W-S, *et al*. A randomized control trial of activity scheduling for caring for older adults with dementia and its impact on their spouse care-givers. *Arch Gerontol Geriatr* 2020;90:104167.
31 Huang C-Y, Sousa VD, Perng S-J, *et al*. Stressors, social support, depressive symptoms and general health status of Taiwanese caregivers of persons with stroke or Alzheimer's disease. *J Clin Nurs* 2009;18:502–11.
32 Han A, Radel J. Spousal caregiver perspectives on a person-centered social program for partners with dementia. *Am J Alzheimers Dis Other Demen* 2016;31:465–73.
33 Polenick CA, Sherman CW, Birditt KS, *et al*. Purpose in life among family care partners managing dementia: links to caregiving gains. *Gerontologist* 2019;59:e424–32.
34 Haaksma ML, Rizzuto D, Leoutsakos J-MS, *et al*. Predicting cognitive and functional trajectories in people with late-onset dementia: 2 population-based studies. *J Am Med Dir Assoc* 2019;20:1444–50.
35 Lee KH, Boltz M, Lee H, *et al*. Does social interaction matter psychological well-being in persons with dementia? *Am J Alzheimers Dis Other Demen* 2017;32:207–12.
36 Yous Marie-Lee, Ploeg J, Kaasalainen S, *et al*. Namaste care delivered by caregivers of community-dwelling older adults with moderate to advanced dementia: a mixed methods study protocol. *J Adv Nurs* 2021;77:1027–36.
37 Groenendaal M, Loor A, Trouw M, *et al*, eds. *Perspectives of healthcare professionals on meaningful activities for persons with dementia in transition from home to a nursing home: An explorative study. Healthcare*. Multidisciplinary Digital Publishing Institute, 2019.
38 Groenendaal M, Smaling HJA, Achterberg WP, *et al*. Maintaining meaningful activities for persons with dementia during transitions of care: a systematic review. *Geriatr Nurs* 2022;44:176–83.