



Comfort and symptoms at the end of life with dementia in the Namaste Care Family cluster-randomised trial

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Abstract

Background: Symptom burden at the end of life in dementia remains high. While Namaste Care may enhance comfort, its effect on symptoms during the last week of life has not been established.

Aim: To assess the frequency of symptoms experienced by nursing home residents with dementia during the last week of life, and to evaluate the delivery of Namaste Care Family during the last week of life and its effect on comfort and symptom burden.

Design: This mixed-methods study combined quantitative data from a cluster-randomised controlled trial with semi-structured interviews. Symptoms were assessed using the End-of-Life in Dementia (EOLD) Scales – Symptom Management (SM; family perspective) and Comfort Assessment in Dying (CAD; staff perspective). Multilevel analyses examined the effect of the Namaste Care Family programme on symptom burden. Interview data was analysed using a content analysis.

Setting/participants: Ten nursing homes implemented the Namaste Care Family programme, while nine provided usual care. During the study, 103 of 231 residents with moderate to advanced dementia died (47 intervention group, 56 control group). Interviews ($N=32$) were conducted with family caregivers, staff and volunteers.

Results: Serenity (80%), discomfort (72%), and pain (70%) were most frequently observed. The programme had no significant effect on symptom burden (EOLD-SM -0.14 points, 95% CI $-5.25, 4.96$, $p=0.96$; EOLD-CAD 0.35 points, 95% CI $-1.98, 2.68$, $p=0.77$). Interviews showed difficulties in implementing the programme during the last week of life.

Conclusions: Comfort and distressing symptoms were both present at the end-of-life phase with dementia. The Namaste Care Family programme did not influence this.

Clinical Trial Registration: This trial was registered with the CCMO Research with human participants (ID 5692/5570).

Keywords

dementia, palliative care, nursing homes, signs and symptoms, Namaste Care, mixed-methods study

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What is already known about this topic?

- Managing symptoms and providing comfort are essential components of optimal palliative care for persons with dementia;
- Namaste Care, a multicomponent daily care programme, has the potential to alleviate symptoms such as agitation, distress and pain in people with advanced dementia.

What this paper adds

- Distress and burdensome symptoms such as pain were observed frequently in the last week of life, but staff also observed well-being in dying in the large majority of nursing home residents dying with dementia;
- The Namaste Care Family programme has no meaningful effect on symptom burden during the last week of life for people with dementia;
- However, the use of elements of the Namaste Care Family programme during the last week of life highlighted the importance of creating a comfortable environment.

Implications for practice, theory or policy

- Implementation of the Namaste Care Family programme to provide comfort in the last week of life requires in-depth training and guidance.

Introduction

In many Western countries, dementia has become one of the leading causes of death.^{1,2} With an ageing population, the prevalence of dementia-related deaths is expected to increase even more.^{1,3,4} This makes the end-of-life care in dementia a major challenge for the coming decades. Towards the end of life, people with dementia suffer from various distressing symptoms.^{5–7} Dyspnoea and pain have been identified as the most commonly experienced symptoms in the final weeks of life.^{6,8} Managing these symptoms and providing comfort are essential components of optimal palliative care in dementia.⁹

Studies have shown that a multicomponent daily care programme, Namaste Care,¹⁰ has the potential to reduce neuropsychiatric symptoms, decreases discomfort and leads to fewer sentinel events, including pneumonia.^{11–15} Namaste Care was developed in the USA to address the psychological and social needs of people with advanced dementia who are no longer able to participate in regular activity programmes offered in long-term care facilities.¹⁰ The programme focuses on psychosocial, sensory and spiritual components to meaningfully connect with people with dementia and can be continued until the end of life.¹⁰ The environment, increased personal attention and improved nutritional intake may support physical well-being and may also decrease physical symptoms.¹² These benefits potentially persist up to the end of life. In general, staff and family caregivers' view on Namaste Care is positive, and the costs of implementing the programme are relatively low.^{15–17}

Research with Namaste Care for people with advanced dementia is promising,^{11,12} but no studies have specifically

examined its effect on symptom burden in end-of-life care. However, the holistic approach of the programme aligns with key principles of palliative care in dementia.⁹ The programme normalises the providing of daily comfort and monitoring of pain, to be continued up until the end of life. This mixed-methods study has two aims; (1) to describe the frequency of symptoms experienced by nursing home residents with dementia at the end of life, and (2) to evaluate how Namaste Care Family was delivered during the last week of life and its effect on comfort and symptom burden.

Methods

Study design

This mixed-methods study used data from the Dutch Namaste study.^{12,18} The Namaste study is a cluster-randomised controlled trial (RCT) in which 10 nursing homes implemented the Namaste Care Family programme, while 9 nursing homes provided usual care. Detailed information on the study design and the Namaste Care Family programme is provided elsewhere.¹⁸ A cluster consisted of a pair of nursing homes, matched on characteristics that might influence the effects of the programme. An independent statistician randomised the pairs into either the intervention or control group (1:1 ratio). Due to the nature of the intervention, blinding of providers and residents was not possible. Follow-up measurements were conducted at 1, 3, 6 and 12 months after the baseline assessment, as well as after death. After completion of the 12-month intervention period, data collection continued when participants died for up to 12 months (range 2–12 months), depending on when the

intervention began. Additionally, a process evaluation with semi-structured interviews with staff, volunteers, and family caregivers was conducted to explore opinions, attitudes, beliefs and reflections on the programme. Data were collected between December 2016 and December 2018.

This current study employed an explanatory sequential quantitative and qualitative design.¹⁹ Quantitative data collected at baseline and after death from all participants in the intervention and control homes who died during the course of the study were used to describe symptom frequencies at the end of life, and to examine the effect of the Namaste Care Family programme on symptoms as planned secondary outcomes.¹⁸ Interviews were conducted to explore potential effects in greater depth and to capture aspects that are missed with quantitative analysis in isolation. They were analysed focusing on questions regarding palliative care and the implementation of the programme during the last week of life, to help interpret the quantitative findings. The full interview guide is provided elsewhere.¹⁶

Ethical considerations

The study protocol was reviewed and approved by the Medical Ethics Review Committee of the VU University Medical Center (protocol number: 2016.399) and deemed exempt from the Medical Research Involving Human Subjects Act (WMO). The trial was registered with the CCMO Research with human participants (old ID 5692/new ID 5570). Written informed consent was provided by the family caregiver of the resident and obtained from all interviewees. No financial compensation was offered for participation.

Participants

The study was conducted in Dutch nursing homes with a psychogeriatric ward.^{12,18} Residents were eligible if they had advanced dementia and could not participate in regular activity programmes, or had moderate dementia with challenging behaviour, or were expected to benefit from the Namaste Care Family programme, or had a family caregiver who was expected to benefit from it, according to staff. Additionally, a Dutch-speaking family caregiver willing and able to complete questionnaires was required. Nursing homes sent informed consent forms to family caregivers of eligible residents.

Purposive sampling was used to recruit participants for the interviews.^{15,20} The interviewees included family caregivers who had attended at least two Namaste sessions. Staff and volunteers were eligible if they had participated in at least two Namaste sessions. No specific inclusion criteria were established for managers.

Namaste Care Family programme

The Namaste Care Family programme is largely similar to the original Namaste Care programme.¹⁰ The adaptations

include a stronger focus on involving family caregivers and volunteers in providing Namaste sessions together with nursing home staff, and a more explicit and elaborate integration of end-of-life care. Ideally, 2-h sessions were held twice daily in a serene, home-like room with soft music, pleasant scents and no external distractions. Each session began with a personalised welcome, followed by comfortable seating, pain screening and frequent offerings of appetising food and beverages. Sessions included meaningful activities, multisensory stimulation and personal care (e.g. massages, grooming, nail care) to connect with the residents, all conducted at a calm pace. The sessions ended with a personalised goodbye.^{10,18}

Namaste sessions were typically offered in a group setting. However, deviations occurred when the peaceful atmosphere was disturbed or when staff determined that one-on-one delivery was in the resident's best interest. During the last week of life, this implied that Namaste elements could be provided individually in the resident's own room. This approach allowed staff to tailor the intervention to the resident's comfort and needs at the end of life.

After the baseline assessment, staff in the intervention group received a 2-h training by one of the researchers (HS) on the programme's principles, purpose and how to apply it in the last week of life.¹⁸ Each nursing home in the intervention group was provided with a toolkit containing a manual and tools to support implementation, evaluation and sustainability of the programme, which included a separate chapter on Namaste in the last week of life.²¹

Data collection

Questionnaires were used to measure the outcomes.¹⁸ When a resident died, the nursing staff informed the research team. Shortly after death, questionnaires about the end of life were sent to nursing staff and elderly care physicians. The family caregiver also received a questionnaire about the end of life. This was 2 months later to avoid adding emotional burden and busy times immediately following bereavement.

The End-of-Life in Dementia – Symptom Management Scale (EOLD-SM)²² was completed by family caregivers at baseline and after the resident's death, each time reflecting on the preceding month. Symptoms are rated on a 6-point frequency scale (0–5) or as unknown, with total scores ranging from 0 to 45. The item calm was reverse-coded. Higher scores indicate lower symptom burden.^{22,23}

Nursing staff completed the End-of-Life in Dementia – Comfort Assessment in Dying Scale (EOLD-CAD),²² which rates 14 items referring to symptom burden and comfort in the last 7 days of life, including a subscale Well-being. Each item is scored on a 3-point intensity scale ('a lot,' 'somewhat,' 'not at all'). The items of the subscale Well-being in dying (serenity, peace, calm) were reverse-coded. Total scores range from 14 to 42, with higher scores reflecting better comfort levels.^{22,24} To dichotomise the

presence of items in the EOLD-CAD, the scores 'a lot' and 'somewhat' were combined.

The severity of dementia was determined using the Bedford Alzheimer Nursing Severity-Scale (BANS-S),²⁵ completed by nursing staff. Total scores range from 7 to 28. Scores of 17 or higher indicate severe dementia.²⁶ Measurements at baseline and after death were used.

Family caregivers provided residents' socio-demographic information at baseline through a questionnaire. So-called certified elderly care physicians, specialised in geriatric medicine in primary care,²⁷ reported the time and cause of death in an open-ended question based on clinical judgement. They also indicated whether morphine, anxiolytics, hypnotics, or sedatives were used during the last week of life, and whether continuous sedation was applied. Nursing staff recorded the total number of Namaste sessions per person.¹⁸

Process evaluation

Twelve months after the implementation of the programme, three female psychologists (HS, PhD and two research assistants) with experience in qualitative research and dementia care conducted a process evaluation consisting of interviews. The interviews did not target the last week of life specifically, but this topic was being raised and discussed. All interviews were audio-recorded and transcribed verbatim.

Quantitative analyses

Descriptive statistics were used to present characteristics of the study population. Missing items on the questionnaires were imputed with the person's item mean to generate a total score. Imputation was only performed if three or fewer EOLD-SM items, and four or fewer EOLD-CAD items were missing.²⁸

Linear mixed model analyses with a three-level structure (repeated measures clustered within subjects, subjects clustered within nursing homes) were used to analyse the effect of the Namaste Care Family programme on the scale level. The EOLD-SM model included two outcome measurements: baseline and after death. Time and the interaction between study group and time were included as independent variables. The regression coefficient for the interaction between study group and time reflected the intervention effect.²⁹ Time until death was defined as the time in days between the baseline assessment and the resident's death. Logistic mixed model analyses with the same three-level structure were used to analyse the effect on item level. All analyses were adjusted for time until death, age, gender, education and dementia severity. Analyses were conducted on an intention-to-treat basis.

Cohen's *d* effect sizes were calculated and interpreted, with < 0.2 representing a neglectable effect, 0.2–0.5 a

small effect, 0.5–0.8 a moderate effect, 0.8–1.2 large effect and > 1.2 a very large effect.^{30,31} IBM SPSS statistical software, version 29 (IBM Corp., Armonk, NY, US) was used for descriptive analyses and StataSE 18 (StataCorp LP, CollegeStation, TX, US) for linear and logistic mixed model analyses.

Qualitative analyses

YS (MD, female) screened all transcripts for relevant text units related to palliative care and any reference to the Namaste Care Family programme during the last week of life. To explore participants' experiences and identify new insights and patterns directly from the data, YS performed a conventional content analysis.³² First, interviews were repeatedly read to achieve immersion in the data. During re-reading, all text describing the use of the programme, as well as participants' opinions, emotions and experiences related to the last week of life, were highlighted. Codes were then inductively assigned to the data and added to an evolving coding framework. All relevant codes and the initial coding framework were discussed with HS, resulting in a refined coding framework that was subsequently used to recode the interviews. Codes were then grouped into categories based on how they related. This iterative process continued until no new insights emerged. Once all transcripts had been coded and analysed, the co-authors reviewed and discussed the qualitative and quantitative findings and their integration. Coding was supported by ATLAS.ti version 7.5.18 (Scientific Software Development GmbH, Berlin, 2017).

Results

Study population

Figure 1 outlines the study flow chart. During the study period, 103 of the 231 residents died; 47 in the intervention group and 56 in the control group (Table 1).

Symptoms at the end of life

Cachexia/dehydration was the most common cause of death, affecting 37 residents (37%). Twenty-one residents (21%) died from an infection, 11 (11%) due to a cerebrovascular accident (Table 2). During the last 7 days of life, 78 residents (76%) received morphine for one or more days, and 48 residents (47%) were treated one or more days with an anxiolytic, hypnotic, or sedative. Continuous sedation was administered to 18 residents (17%) before death.

For the total study population, the mean EOLD-CAD score as assessed by nursing staff was 30.9 (Standard Deviation (*SD*) 4.6, range 14–41). Overall, serenity (80%) was the most frequently reported item. Among the distressing symptoms, discomfort (72%), pain (70%), and moaning (65%) were the most common (Table 2).

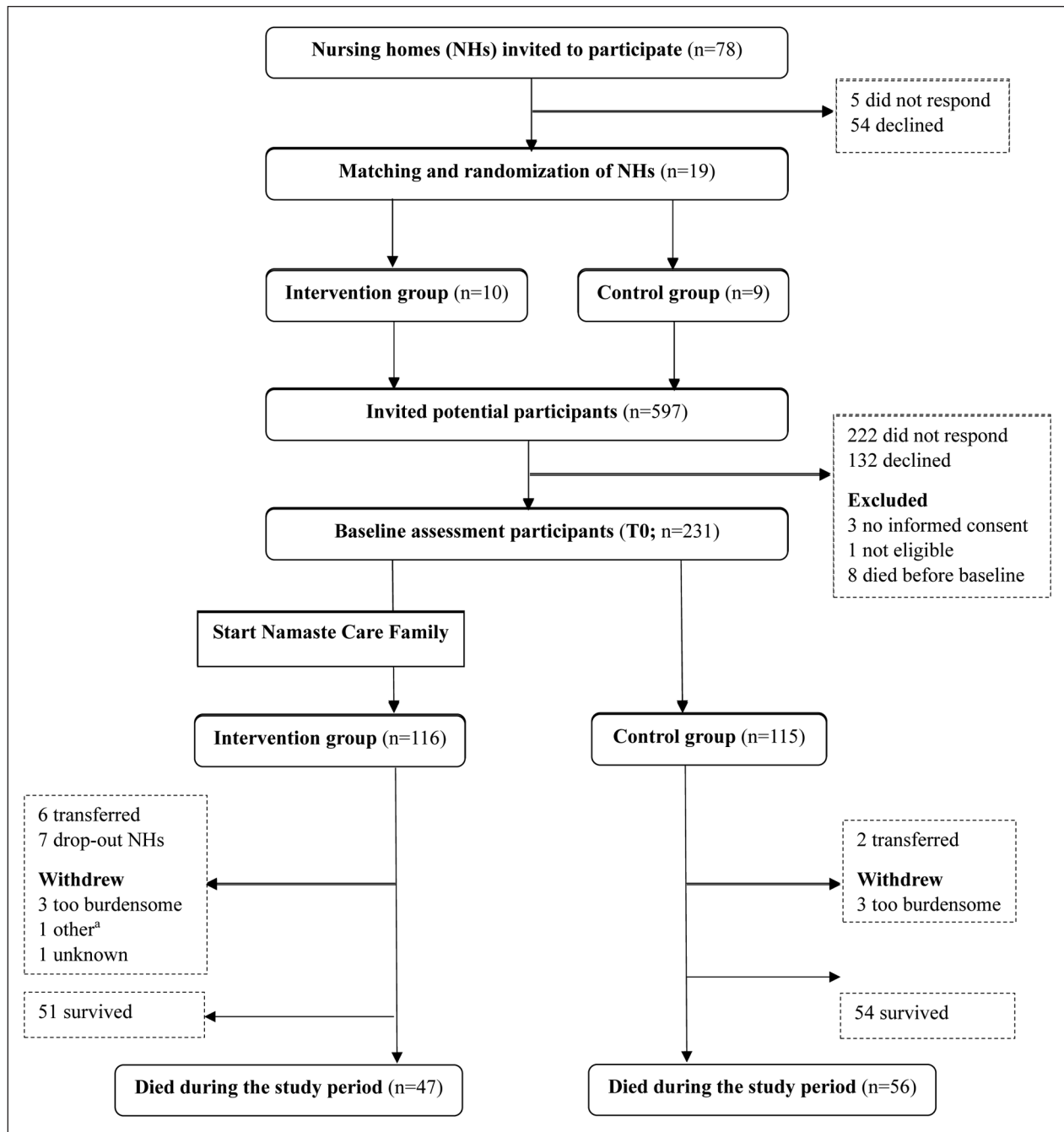


Figure 1. Flow chart nursing home and resident recruitment and participation in the Namaste study.

^aOther: disagreement between nursing home and family caregiver about care.

Table 3 presents the occurrence of symptoms and comfort in the last month of life, according to family caregivers measured with the EOLD-SM. Twenty-one family caregivers did not complete the after-death questionnaire. Among the 82 completed questionnaires, a total imputed EOLD-SM score could be calculated for 69 residents for whom three or fewer items were missing. The mean EOLD-SM score was 27.5 (*SD* 12.7, range 6–45). Sixty percent of the residents experienced daily calmness. For each item, a considerable proportion of family caregivers,

ranging from 10% to 28%, did not know whether a symptom was present or to what extent.

Quantitative findings regarding the effect of the Namaste Care Family programme on symptoms at the end of life

On average, residents in the intervention group received Namaste sessions for 7.1 months before they died (*SD* 3.8, range 1–12 months), with on average 25.5 sessions per

Table 1. Characteristics of nursing home residents who died during the study period at baseline and at the time of death.

	n	Total sample of decedents (N=103)
		Mean [SD] / n (%)
Baseline		
Age	103	86.3 [6.4]
Female	103	74 (72)
Educational level	99	
None or primary school		37 (37)
(High school preparing for) technical/trade school		52 (53)
High school preparing for BSc/MSc		3 (3)
BSc or MSc degree		7 (7)
Time in nursing home in months		36.8 [34.8]
Type of dementia	102	
Alzheimer's Disease (AD)		56 (55)
Vascular Dementia (VD)		10 (10)
Mixed type AD – VD		17 (17)
Lewy Body Disease		6 (6)
Other		13 (13)
Dementia severity	103	16.1 [4.7]
Severe dementia	103	44 (43)
Death		
Study participation in months	103	7.2 [4.8]
Dementia severity	98	19.2 [4.5]
Severe dementia	98	73 (74)

Dementia severity was measured with the Bedford Alzheimer Nursing Severity-Scale (BANS-S), possible range from 7 to 28, with ≥ 17 indicating severe dementia. SD=Standard deviation.

month (*SD* 14.6, range 2–58 sessions). In the last month before death, the average number of sessions was 20.1 (*SD* 19.3, range 0–60 sessions). In the intervention group, 35 residents (75%) received morphine during the last 7 days of life. In the control group, 43 residents (77%) received morphine.

The overall adjusted mean difference for the EOLD-SM score at the end of life between the intervention group and the control group was -0.14 points (95% confidence interval (CI) -5.25 , 4.96 , $p=0.96$), indicating no significant effect of the programme on symptom management at the end of life. For the EOLD-CAD score, the overall adjusted mean difference was 0.35 points (95% CI -1.98 , 2.68 , $p=0.77$), indicating no significant effect of the programme on comfort at the end of life. For both outcomes, the Cohen's d indicated that the effects were neglectable (-0.01 and 0.08).

Table 4 presents the results of the unadjusted and adjusted logistic mixed model analyses for the effect of the programme on symptoms and comfort during the last week of life, assessed using the dichotomised EOLD-CAD items. Residents in the intervention group experienced less gurgling than residents in the control group (odds ratio

Table 2. Cause of death, symptoms and well-being in dying during the final week of life in the total population of decedents (N=103).

Cause of death (n=100)	n	%
Cachexia/dehydration	37	37
Cancer	1	1
Cerebrovascular accident	11	11
Dementia	10	10
Heart failure	4	4
Infection	21	21
Other ^a	5	5
Unnatural death	4	4
Unknown	7	7
Symptoms and Well-being in dying during the final week of life, from the perspective of nursing staff (n=97)		
Discomfort	70	72
Pain	68	70
Restlessness ^b	59	62
Shortness of breath	51	53
Choking	30	31
Gurgling	53	55
Difficulty swallowing	60	62
Fear	58	60
Anxiety	43	44
Crying	21	22
Moaning	63	65
Serenity	78	80
Peace	69	71
Calm ^c	66	70

Cause of death was based on clinical judgement of physicians, using an open-ended question.

^aOther causes include clinical decline after syncope, femur fracture, internal bleeding, liver failure, abdominal complaints of unclear aetiology. Items were assessed by nursing staff using the End-of-Life in Dementia – Comfort Assessment in Dying (EOLD-CAD); missing ^b $n=2$, ^c $n=3$. The scores 'a lot' and 'somewhat' were combined to create a dichotomous variable indicating presence.

0.31 , 95% CI 0.12 , 0.82). The effect on the other items was not significant and varied widely.

Qualitative findings regarding the effect of the Namaste Care Family programme on symptoms at the end of life

Palliative care and the Namaste Care Family programme during the last week of life were discussed in 32 of 40 interviews. In two of these 32 interviews, participants were interviewed in pairs at their request, resulting in a total of 34 interviewees (Table 5).

Overall, staff who implemented the Namaste Care Family programme during the last week of life reported positive experiences. They reported that Namaste Care contributed to a more comfortable environment for both

Table 3. The occurrence of symptoms and comfort in the last month of life in the total population of decedents, from the perspective of family caregivers (N= 103).

Item	Item mean [SD]	Daily	Several days a week	Once a week	2 or 3 days a month	Once a month	Never	Unknown
Pain	1.6 [1.8]	22 (27%)	17 (21%)	4 (5%)	6 (7%)	3 (4%)	9 (11%)	21 (26%)
Shortness of breath	3.3 [2.0]	8 (10%)	14 (17%)	1 (1%)	4 (5%)	4 (5%)	36 (44%)	15 (18%)
Skin breakdown	4.0 [1.8]	10 (12%)	2 (2%)	2 (2%)	1 (1%)	7 (9%)	52 (63%)	8 (10%)
Calm	4.3 [1.6]	49 (60%)	7 (9%)	0 (0%)	1 (1%)	1 (1%)	7 (9%)	17 (21%)
Depression	3.4 [2.1]	11 (13%)	6 (7%)	3 (4%)	1 (1%)	2 (2%)	36 (44%)	23 (28%)
Fear	2.8 [2.3]	18 (22%)	11 (13%)	1 (1%)	1 (1%)	3 (4%)	31 (38%)	17 (21%)
Anxiety	2.5 [2.2]	19 (23%)	15 (18%)	3 (4%)	3 (4%)	3 (4%)	25 (30%)	14 (17%)
Agitation	3.0 [2.1]	11 (13%)	13 (16%)	5 (6%)	3 (4%)	3 (4%)	31 (38%)	16 (20%)
Resistance to care	2.5 [2.1]	17 (21%)	13 (16%)	7 (9%)	6 (7%)	3 (4%)	24 (29%)	12 (15%)
EOLD-SM score	27.5 [12.7]							

Items were assessed by family caregivers using the End-of-Life in Dementia – Symptom Management (EOLD-SM); missing n=21. Each item is scored from 0 (daily) to 5 (never) or as unknown. Item calm is reverse coded before calculating the total score.

Table 4. Results of the logistic mixed model analyses examining the effect of the Namaste Care Family programme on symptoms and comfort during the final week of life (N= 103).

Item	n	Unadjusted odds ratio (95% CI)	Adjusted odds ratio (95% CI)
Discomfort	97	1.17 (0.39 to 3.51)	1.67 (0.42 to 6.55)
Pain	97	2.14 (0.87 to 5.27)	2.73 (0.98 to 7.58)
Restlessness	95	0.72 (0.29 to 1.75)	0.84 (0.20 to 3.44)
Shortness of breath	97	0.49 (0.18 to 1.34)	0.30 (0.09 to 1.03)
Choking	97	1.40 (0.44 to 4.50)	1.21 (0.30 to 4.90)
Gurgling	97	0.42 (0.19 to 0.95)	0.31 (0.12 to 0.82)^a
Difficulty swallowing	97	0.65 (0.29 to 1.48)	0.45 (0.18 to 1.14)
Fear	97	0.65 (0.20 to 2.13)	0.45 (0.08 to 2.52)
Anxiety	97	1.11 (0.49 to 2.53)	1.06 (0.31 to 3.57)
Crying	97	1.29 (0.49 to 3.39)	1.21 (0.43 to 3.38)
Moaning	97	1.78 (0.76 to 4.16)	1.43 (0.45 to 4.52)
Serenity	97	0.34 (0.12 to 0.98)	0.28 (0.08 to 1.02)
Peace	97	1.30 (0.53 to 3.14)	1.56 (0.59 to 4.15)
Calm	94	1.09 (0.45 to 2.63)	1.02 (0.38 to 2.74)

The intervention effect is in reference to the control group. Unadjusted models are controlled for clustering at the nursing home level. Adjusted models are controlled for clustering, time until death, age, gender, educational level and severity of dementia. Items were assessed by nursing staff using the End-of-Life in Dementia – Comfort Assessment in Dying (EOLD-CAD). The scores 'a lot' and 'somewhat' were combined to create a dichotomous variable indicating presence.

^ap = 0.018.

Table 5. Description of the interviews (N=32) and interviewees (N=34).

Interviews/Interviewees	n	Median (IQR) / n (%)
Age	33	52 (41–59)
Female	34	33 (97)
Respondent type	34	
Family member		3 (9)
Staff		30 (88)
Volunteer		1 (3)

(continued)

Table 5. (continued)

Interviews/Interviewees	n	Median (IQR) / n (%)
Profession of staff	30	
Manager		9 (30)
Nurse		11 (37)
Activity coordinator		7 (23)
Namaste coordinator		3 (10)
Duration of the interview in minutes	32	50 (40–58)

IQR = interquartile range.

the person who was dying and those around them. Elements of Namaste that were used included aromatherapy, music, lighting and massage. Staff mentioned several positive effects on comfort and symptom burden:

We used music and simply tried to make the environment a bit more pleasant. We then observed that the person appeared more comfortable in bed. That worked well, actually. (nurse 14)

We currently have a resident who is very afraid of dying. We now use music at specific times, and we provide physical contact through hand massages. He responds well to that. (Namaste coordinator 11)

Participants noted that the programme aligned well with the organisation's palliative care goals, the concept of quality of dying and personalised care, which they found helpful in this context. Many staff indicated that using the programme led to a greater sense of togetherness. Moreover, it increased their awareness of creating a calm and comfortable environment:

I do have the idea that we are now more consciously focused on it, and someone might not be aware of it anymore, but it smells nice and there is some quiet music in the background. That just gives a sense of peace. (nurse 02-G)

On the other hand, there were differences in the use of the programme during the last week of life. Some participants indicated that there were no changes in providing end-of-life care during the study period. One of the reasons for this was that elements of Namaste were already incorporated into their standard end-of-life care:

No, it's not so much that we do things differently. I know that, for example, aromatherapy is used for people who are terminally ill. We also have special lamps, and we now also have a sensory projection system that can be used for that purpose. But we were already doing that. (activity coordinator 02-S)

Others did not use it at all during the last week of life and experienced barriers to its implementation. They mentioned barriers including a personal preference of staff or family caregivers:

Is the family very involved, and what does the family find comforting? Then we usually use aroma, for example, or music, or both, or neither. It really depends on the family what they want. Often when someone is very close to death, if the family is already sitting by and keeping vigil, we leave it up to them to decide what they want. (nurse 02-G)

Another barrier was that some staff did not see any connection between the programme and palliative care, considering them as two separate forms of care. One family caregiver was unsure which elements to provide when a relative was dying. Other staff mentioned that no deaths

had occurred during the study period, or that deaths happened so suddenly that the programme could not be implemented. Providing more information about offering Namaste during the last week of life was recommended.

Discussion

Key findings

This mixed-methods study assessed symptoms at the end of life in nursing home residents with dementia and the delivery of the Namaste Care Family programme during the last week of life and its effect on symptom burden and comfort. Among the items of the dementia-specific EOLD-CAD scale, serenity was the most frequently observed item during the last week of life, according to nursing staff. At the same time, more than two-thirds of the residents experienced discomfort and pain. No effects of the programme were found on symptom burden in the last month and week of life. Gurgling occurred less frequently in the intervention group during the last week of life. Not all nursing homes implemented the Namaste Care Family programme during the last week of life and several barriers to implementation were identified. Participants who did use elements of Namaste at the end of life reported a strong sense of togetherness and an increased awareness of creating a comfortable environment.

What this study adds

Although the data of this study were collected more than 5 years ago, the findings remain relevant as this is the first study that provides insights into the potential role of Namaste Care during the last week of life. Moreover, recent evidence suggests that comfort and symptom burden in Dutch nursing homes have remained relatively stable over time.³³

Both burdensome symptoms as well as items related to comfort were frequently assessed by nursing staff and family caregivers, which is in line with previous research.^{5,7} Nursing staff and family caregivers each completed the EOLD-CAD or the EOLD-SM once, reflecting on either the last week or the last month of life, respectively. While using a single after-death assessment to reflect on the entire end-of-life phase is the most feasible approach, it limits the ability to determine the duration and frequency of symptoms. It is possible that both comfort and distress alternated during these time frames, stressing the complexity of the dying phase. For future research, it would be valuable to collect data at multiple time points during the last week of life to better understand the occurrence and course of symptoms.

Residents in the intervention group experienced less gurgling during the last week of life compared to those in the control group. The significant effect with small effect size may be an inaccurate or incidental finding due to

multiple testing, or related to the established association between the Namaste Care Family programme and a lower prevalence of pneumonia.^{12,34}

In the final days of life, most residents received morphine, presumably to relieve symptoms. The observed frequency of opioid use was comparable to that in other Dutch nursing homes but higher than in some European countries.^{6,35,36} The opioid use aligns with the reported pain and discomfort, suggesting adequate attention to symptom management. However, we did not collect data on dosage, timing and clinical indication. Medication use was a secondary outcome rather than an integral component of the non-pharmacological Namaste intervention; therefore, it is impossible to draw conclusions about its effectiveness in relieving symptoms.

The mean EOLD-CAD and EOLD-SM scores in our study are comparable to those in previous international research,^{7,28,37–40} suggesting similar levels of symptom burden among residents with dementia at the end of life in other nursing homes, based on proxy ratings. However, many family caregivers were unsure about the presence or severity of symptoms when completing the EOLD-SM. This may reflect differences in presence or feeling competent to assess symptoms compared to nursing staff.

The absence of a significant effect of the Namaste Care Family programme on symptom burden at the end of life should be interpreted with caution, as it may reflect challenges in implementation during the last week of life rather than a null effect of the programme specifically at the end of life. The interviews showed that both family caregivers and staff felt highly engaged with dying residents in a careful and respectful manner, regardless of the intervention. Some incorporated elements of Namaste during the last week of life and reported positive effects on their work experience and the care environment, consistent with earlier studies.^{15,41} However, many felt they may not have optimally implemented the programme in the last week of life, and awareness of its connection to palliative care was limited, resulting in inconsistent delivery of the programme. Quantitative data on the average number of Namaste sessions support this perception, showing a lower number of sessions provided in the last month before death. Although the manual and training addressed Namaste in the last week of life and its connection to palliative care, this guidance may not have been sufficient and should be emphasised more during the training. Additionally, there was no active follow-up on the implementation in the last week of life afterwards. As training and continuous involvement are recognised as key aspects for Namaste implementation,⁴² they should be emphasised more strongly in future studies and clinical practice.

Strengths and limitations

A strength of this study is the mixed-methods design. The combination of a cluster-RCT with data collected until

after death and semi-structured interviews with caregivers provides valuable insights into dying with dementia. Because participants with diverse roles and from different nursing homes were interviewed, a variety of perspectives was represented. Limitations include the possibility of recall bias, as one-third of the EOLD-SM scores after death were missing due to unreturned questionnaires and many family caregivers rating multiple items as unknown. Another limitation is the inability to determine the extent to which participants received Namaste Care during the last week of life. Consequently, potential variation in exposure to the intervention may have influenced the observed effects. Future studies should consider using daily session logs to document intervention exposure during this period.

Conclusion

Most nursing home residents with dementia appeared to experience comfort at the end of life, although distressing symptoms were also present. Implementing the full Namaste Care Family programme during the last week of life was challenging, which may have contributed to the absence of an effect on symptom burden. The primary contribution of the programme in this phase may lie in enhancing a comfortable environment rather than directly affecting physical symptoms. The Namaste Care Family training should place greater emphasis on its application during the last week of life.

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Ethical considerations

The study protocol was reviewed and approved by the Medical Ethics Review Committee of the VU University Medical Center (protocol number: 2016.399) and deemed exempt from the Medical Research Involving Human Subjects Act (WMO). The trial was registered with the CCMO Research with human participants (old ID 5692/new ID 5570).

Consent to participate

Written informed consent was provided by the family caregiver of the resident and obtained from all interviewees.

Author contributions

JvdS obtained funding for the research. HS was responsible for data collection. All authors have contributed to the design of this study. YS performed the descriptive analyses. JT conducted the

analyses for the secondary outcome. The first draft of this manuscript was produced by YS. All authors have reviewed, edited, and approved the final version. The corresponding author attest that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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Declaration of conflicting interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: HS became the associate director of Namaste Care International (unpaid position) after the data collection of this study was completed. WA is the chair of the SIG EUGMS on geriatric rehabilitation. The other authors have nothing to disclose.

Data availability statement

The data that support the findings of this study are available from the principal investigator (JvdS), upon reasonable request and following appropriate agreements.

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