The Namaste Care programme can reduce behavioural symptoms in care home residents with advanced dementia

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Objective: The objective of the study was to evaluate the effects of the Namaste Care programme on the behavioural symptoms of residents with advanced dementia in care homes and their pain management.

Methods: Six dementia care homes collaborated in an action research study—one withdrew. Inclusion criteria were a dementia diagnosis and a Bedford Alzheimer's Nursing Severity Scale score of >16. Primary research measures were the Neuropsychiatric Inventory—Nursing Homes (NPI-NH) and Doloplus-2 behavioural pain assessment scale for the elderly. Measures were recorded at baseline and at three 1–2 monthly intervals after Namaste Care started.

Results: Management disruption occurred across all care homes. The severity of behavioural symptoms, pain and occupational disruptiveness (NPI-NH) decreased in four care homes. Increased severity of behavioural symptoms in one care home was probably related to poor pain management, reflected in increased pain scores, and disrupted leadership. Comparison of NPI-NH scores showed that severity of behavioural symptoms and occupational disruptiveness were significantly lower after initiation of Namaste Care ($n = 34$, $p < 0.001$) and after the second interval ($n = 32$, $p < 0.001$ and $p = 0.003$). However, comparison of these measures in the second and third intervals revealed that both were slightly increased in the third interval ($n = 24$, $p < 0.001$ and $p = 0.001$).

Conclusions: Where there are strong leadership, adequate staffing, and good nursing and medical care, the Namaste Care programme can improve quality of life for people with advanced dementia in care homes by decreasing behavioural symptoms. Namaste is not a substitute for good clinical care Copyright © 2014 John Wiley & Sons, Ltd.

Introduction

There are currently 670 000 people with dementia in the UK (Banerjee, 2013), of whom an estimated 60 000 people die annually (Knapp *et al.*, 2007); 59 per cent of people with advanced dementia die in care homes (NEoLCIN, 2011). The later stages of dementia are associated with a heavy symptom burden (Mitchell *et al.*, 2009).

A key objective of the National Dementia Strategy is to improve end-of-life care for people with dementia

(DH 2009). However, despite guidance form the National Council for Palliative Care (2009), promoting planning ahead and good symptom management; and from the Gold Standards Framework, providing a structured, evidence based approach for general care providers (www.goldstandardsframework.org.uk; Hockley *et al.*, 2010), an Alzheimer's Society report (2012) identified that, too often, people in the later stages of dementia are not treated with dignity at the end of their lives, and their physical and emotional needs go unmet.

The Namaste Care programme seeks to address these issues through an enhanced nursing programme that integrates compassionate care with individualised meaningful activities (Simard, 2013). Namaste Care seeks to engage people with advanced dementia through sensory input, comfort and pleasure. Families are supported to acknowledge the progression of dementia in the positive context of seeking to provide quality of life. No additional staff or expensive equipment is required to implement the care programme.

Very little research is undertaken with people with advanced dementia at the end of their lives (Mitchell *et al.*, 2009) and even less in the areas of psychosocial and spiritual well-being. There is no consensus around the definition of severe dementia (Sampson, 2010), and measures to capture quality of life are necessarily complex in people with impaired cognition and communication. Studies of care interventions for people with dementia often rely upon measuring a reduction in ill-being to demonstrate improvement in well-being. Reduced severity of neuropsychiatric symptoms can stand proxy for improved comfort and well-being (Samus *et al.*, 2005).

In this study, we chose to concentrate on measuring behavioural and psychological symptoms and the success of pain management. Behavioural and psychological symptoms are recognised as particular challenges for carers of people with advanced dementia (Pace *et al.*, 2011; Pointon 2010) and often attributable to the person's need or distress (Cohen-Mansfield, 2001) including unrelieved pain (Husebo *et al.*, 2011; Corbett *et al.*, 2012). Pain is a multidimensional phenomenon (Saunders and Baines, 1989), and determining whether a behavioural pain assessment scale detects physical pain or emotional, psychosocial or spiritual distress is complex. Pain management is an essential element of good care for people with advanced dementia, and comfort is necessary for a sense of well-being.

This article presents the quantitative results from the study.

Methods

An action research design was chosen to investigate the effects of the Namaste Care programme on residents, relatives and care staff in six care homes (CHs) in south London. Action research is a critical, dynamic, collaborative process whereby the researcher engages with people to implement change and reflect upon the process of that change and its effect on the culture (Hockley *et al.*, 2013). Such a design allowed the researchers to work closely with staff and reflect together on the implementation of Namaste Care and the related changes in culture and practice. This shared perspective allowed insight into the impact of other organisational changes occurring during the study.

The overall aim of our study was to investigate the effects of Namaste Care on the quality of life of residents and relatives and the work life of care staff. There were two key objectives: firstly, to establish whether the introduction of the Namaste Care programme reduces behavioural symptoms, such as agitation and lethargy; and secondly, to learn whether the programme improves pain management through influencing the quality of care by raising staff's awareness of pain and discomfort in participants. Qualitative and quantitative methods were used before, during and after the implementation. This article reports the quantitative results.

Care homes were approached in February 2012 to volunteer for the study. All provided nursing care but varied in size, in ethnic diversity of residents and staff, and in staffing ratios. Residents included people with long-term mental health problems as well as advanced dementia. Three CHs had completed the Gold Standards Framework for CHs (GSFCH; www.goldstandardsframework.org.uk) end-of-life care programme—a national programme to improve the quality of care in the last year of life. In UK CHs, medical care is provided by the community family doctor service.

Care home managers identified residents who met the inclusion criteria: a dementia diagnosis and a Bedford Alzheimer's Nursing Severity Scale (BANS-S) score of >16 at which level dementia is considered to be severe (van der Steen *et al.*, 2006).

Measures

Following admission to the study, baseline measures included the following:

- Demographic information
- Charlson index of co-morbidities (Charlson *et al.*, 1987)—an indication of physical frailty and prognosis related to co-morbidity.
- BANS-S (Volicer *et al.*, 1994)—a scale of 1–4 across seven domains (cognitive ability, activities of daily living, and pathological symptoms) with a maximum debility score of 28. A score of >16 corresponds with a mini-mental state examination of 5 (Volicer *et al.*, 1994; van der Steen *et al.*, 2006).

Primary outcome measures were the Neuropsychiatric Inventory Nursing Home version (NPI-NH)

(Cummings, 1997), and the Doloplus-2 behavioural pain assessment scale for the elderly (Lefebvre-Chapiro and the DOLOPLUS group, 2001). These measures were recorded at baseline and then at three 1–2 monthly intervals.

- The NPI-NH assesses 10 neuropsychiatric symptoms: delusions, hallucinations, agitation, aggression, dysphoria, anxiety, euphoria, apathy, disinhibition and irritability/lability. Screening questions determine the presence of behavioural changes. Once identified, further questions establish the severity and frequency of the behavioural symptom. In the nursing home version (NPI-NH), an 'occupational disruptiveness' scale assesses the impact of behavioural disturbances on professional care givers (Cummings, 2009).
- Doloplus-2 behavioural pain assessment scale (Lefebvre-Chapiro and the DOLOPLUS group, 2001): a scale developed specifically for older people who cannot communicate their pain verbally. A score of 5 or more indicates that pain is present.

All measures were undertaken by the researcher with care staff except when recording demographics and calculating the Charlson index. The implementation and evaluation period varied between 4 and 6 months in each of the homes because of real life events.

Statistical analysis

Data were analysed using SPSS version 20. Descriptive statistics were used for analysing demographic characteristics. Because NPI scores are not normally distributed, we divided residents into terciles according to the baseline scores and compared the number of residents in these terciles at consecutive intervals by chi-square tests.

Analysis of variance with least significant difference *post hoc* comparisons was used to compare pain scores in different CHs. Pearson's correlation coefficients were used to analyse relationships between measures.

An assessment was made of each resident's mental capacity to give informed consent. Where residents lacked this capacity, the decision whether they should participate was made on the basis of their best interests, taking into account the views of family members invited to represent them; or, in the absence of a family member, a professional, not directly involved in the research, was nominated to do so as laid out in legislation (Mental Capacity Act, 2007). Process consent was negotiated on a day to day basis.

Ethical approval was granted by the East Anglia Research Ethics Committee and the South London and Maudsley Foundation Hospital Trust NHS Research and Development Committee (12/EE/0010). A protocol was in place in the event that the study uncovered poor practice.

Intervention

'Namaste' is an Indian greeting meaning 'to honour the spirit within'.

The principles of person-centred care underpin the Namaste Care programme that seeks to meet the needs of people with advanced dementia for attachment, comfort, identity, occupation and inclusion (Kitwood and Bredin, 1992). Namaste Care is a multi-dimensional intervention seeking to engage people with advanced dementia and enrich their quality of life through sensory stimulation, shared activity and increased social interaction. Comfort is a primary aim of the care programme, which includes formal pain assessment, as well as increasing care staff's awareness and responsiveness to distress. The programme takes place 7 days a week with 2-h sessions, morning and afternoon.

The programme requires that staffing is reorganised within the CH. A care worker is allocated responsibility for up to eight residents with advanced dementia in the Namaste space, while others take responsibility for the remaining residents. Consequently, there are no additional staffing requirements.

After routine morning care and breakfast, Namaste residents are brought together in a dedicated Namaste space with a calm, welcoming ambience—soft music playing, scents and greenery. The assigned Namaste Care worker greets residents individually by name and settles them comfortably while assessing for pain.

Elements of the programme include the presence of others, pain management, sensory stimulation, food treats/hydration, meaningful activity, life story, care staff education, family meetings and care of the dying (Thompsell *et al.*, 2014). The afternoon session follows a similar pattern with varied activities.

Families are encouraged to share in care staff's efforts to connect with their family member. Family meetings help relatives acknowledge disease progression, consider the burdens/benefits of acute medical interventions, and prepare themselves for loss. Family participation in Namaste supports closer relationships with care staff.

The training for the Namaste Care workers (who did not have any special qualifications but were chosen

for their experience and commitment) consisted of a 1-day workshop.

Results

Six CHs agreed to collaborate in the study but only five took part. Changes within senior management resulted in CH A withdrawing before the Namaste Care programme was implemented (Table 1).

Forty-seven residents were identified with 37 residents being recruited to the study (Table 2). However, as a result of deaths and in one case a discharge to another CH, only 30 completed the study.

After the introduction of the Namaste Care programme, both neuropsychiatric symptom severity and occupational disruptiveness decreased in four CHs but increased in one CH (CH C) (Figure 1). The reason for an increase in NPI-NH scores in this CH was probably inadequate pain control. Not only did this CH have the highest average pain score at baseline but also the average pain score gradually increased during the study (Figure 2).

The pain scores at baseline in CH C were significantly different from scores in two other homes (CH B and D) at baseline and at time interval 2 and scores in all other homes at time intervals 3 and 4.

At the last two time intervals, all the average Doloplus 2 scores in CHs B, D, E and F were less than 5, suggesting that pain was absent or well managed in these residents (Figure 2). There was also a significant correlation between the pain score and symptom severity score at all assessments (baseline $r = 0.605$, $p < 0.001$; time interval 2 $r = 0.793$, $p < 0.001$; time interval 3 $r = 0.605$, $p = 0.001$; time 4 $r = 0.814$, $p < 0.001$).

To evaluate the statistical significance of changes after Namaste Care implementation, we compared the distribution of NPI-NH scores at the four time intervals by dividing participants into terciles based on their initial scores. This analysis showed that the frequency and severity of behavioural symptoms were significantly lower when comparing time intervals 1 and 2 with time intervals 2 and 3 (Table 3).

'Occupational disruptiveness' also reduced during these periods. However, comparison of score distributions at time intervals 3 and 4 showed a reversal of this trend with a significant worsening of both frequency and severity of behavioural symptoms and of occupational disruptiveness. This reversal was probably because of an increase in these symptoms in CH C, but there might also have been some trend for the decreasing effect of Namaste Care in CH B and CH D (Figure 1).

Table 1 Characteristics of care homes with nursing

Care home (CH) and size	Type of CH	GSFCH status	Medical support	Management disruption
A Medium	Corporate: one dementia unit Purpose built	Accredited	Single GP practice, allocated GP	Manager and regional manager left suddenly—company withdrew before recruitment began
B Large	Corporate (not for profit): two dementia units Purpose built	Accredited	Single GP practice, allocated GP	Manager resigned during the study
C Small	Family owned: dementia CH Victorian house conversion	Dropped out of programme	Single GP practice, visited randomly by GP partners	Two managers resigned during the study—but owner engaged with study
D Medium	Corporate: dementia CH Purpose built	Accredited	Single GP practice with allocated GP + weekly input from a psychiatrist of older people	Manager, deputy, and regional manager resigned 1 month into the study. New manager + deputy engaged with the study
E Small	NHS SCU—mental health + dementia care Purpose built	Not engaged	Psychiatrist of older people + single GP practice with allocated GP	Manager not present for initial stages but senior manager and deputy engaged
F Small	NHS SCU: mental health + dementia care Purpose built	Not engaged	Psychiatrist of older people + single GP practice with allocated GP	Manager's personal circumstances led to withdrawal. Mental health nurse specialist temporarily in charge

Small = <39 beds
Medium = 40–79 beds
Large = 80 beds and over
SCU, Specialist Care Unit; GSFCH, Gold Standards Framework programme for Care Homes

Table 2 Demographics of residents

|		All research participants		Participants with four sets of research measures	
		$n = 37$	%	$n = 30$	%
Gender	Female	22	59.4	16	53
	Male	15	40.5	14	47
Age		55–95 years (mean: 78.5 years)		55–95 years (mean: 78.6 years)	
		$n = 37$	%	$n = 30$	%
Marital state	Married	12	32.4	10	33
	Widowed	17	45.9	15	50
	Single	8	21.6	5	17
Ethnicity	White British	26	70.3	20	67
	White Irish	3	8.1	2	6.6
	White European	2	5.4	2	6.6
	Afro-Caribbean	4	10.8	4	13.2
	African	2	5.4	2	6.6
Dementia diagnosis	Alzheimer's disease	17	46	12	40
	Vascular dementia	7	19	6	20
	Mixed dementia	2	5.3	2	6.6
	Fronto-temporal dementia	1	2.7	1	3.4
	Unspecified dementia	10	27	9	30
BANS-S (17–28)	17–19	11	29.7	8	26.7
	20–22	19	51.3	16	53.3
	23–25	7	18.9	6	20
Charlson co-morbidity index (age adjusted)	1–3	5	13.5	4	13.3
	4–6	28	75.5	23	76.7
	7–11	4	11	3	10

Discussion

Neuropsychiatric symptoms improved significantly in four of the five CHs. However, in CH C, the prevalence of neuropsychiatric symptoms increased, while pain remained unrelieved. Reduction in NPI scores has been found to correlate with improved quality of life in people with dementia who are able to self-rate their quality of life (Samus *et al.*, 2005). For those unable to rate their own quality of life, a reduction in NPI scores may be taken to represent an improvement in quality of life. Cohen-Mansfield *et al.* (2012a, 2012b) found that engagement with activity is associated with positive affect and that there is a negative relationship between agitated behaviour and pleasure.

The action research methodology enabled insights into the culture and practice of the atypical CH C that offer some explanation of its status as an 'outlier' in the overall NPI-NH data. Staff had recently failed to complete the GSFCH end-of-life care programme, and the nurse manager left, leaving nursing and care workers unsupported by nursing expertise. Pain was not identified confidently, and

in consequence, medical treatment was sometimes delayed. Good pain management is an indicator of good clinical care. Whilst it is disappointing that Namaste was unsuccessful in reducing pain severity in CH C residents, Namaste Care requires the cooperation of the nursing and medical team. Not surprisingly, CH E, with the best NPI-NH results had a good relationship with their general practitioner (GP) and psychiatrist attached to the unit, well managed pain, and an environment appropriate for dementia care.

The NPI-NH scores in CH B and CH D showed a slight reduction in the effectiveness of the intervention towards the end of the research period. We considered whether this reduction was related to the deteriorating health of participants, but because there was no correlation between BANS-S and/or the Charlson index with NPI-NH scores at the outset of the study, we thought that the decrease may relate to staff investing less energy in the programme after their initial interest. A study of Montessori-based activities for people with dementia in CHs also found a reduction in pleasure over time (Orsulic-Jeras *et al.*, 2000). Another suggestion is that the dying process might
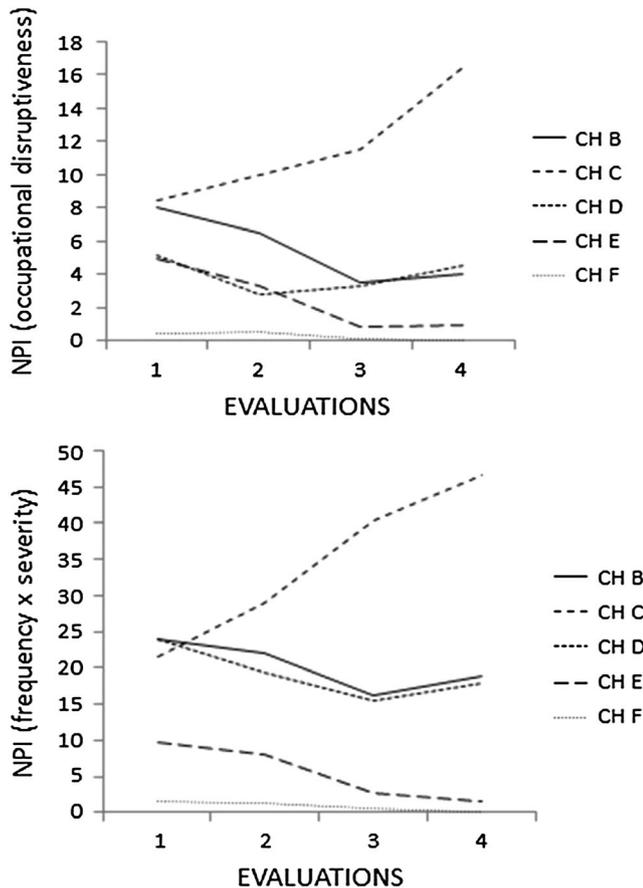
Figure 1 Effects of Namaste Care on Neuropsychiatric Inventory (NPI-NH) scores in five care homes (CHs).
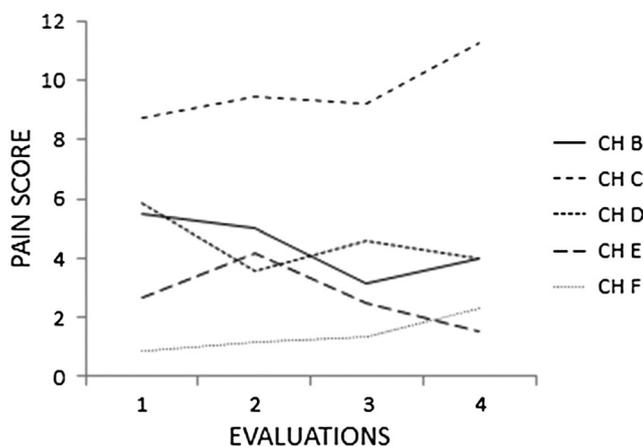
Figure 2 Pain levels determined by the Doloplus-2 scale in five care homes (CHs).

influence the quality of life independently of disease severity or burden of co-morbidities; five resident participants died during the study; a further seven died within 4 months after the study.

Some explanation for the effectiveness of Namaste Care is needed. Cohen-Mansfield *et al.* (2011) postulate a model of engagement linking the contribution of environmental factors, personal characteristics, and the attributes of stimuli, with different levels of engagement in people with dementia. Their research identified one-to-one social interaction as the most potent stimulus for engagement. They found that engagement was optimised by a long introduction for the stimulus, a moderate level of sound, and being in a group of 2–24 people. This model casts light on the effectiveness of Namaste Care: one-to-one interaction within a social group; soft music supplies background sound; residents are encouraged to engage with a variety of stimuli, including many of those found most effective in Cohen-Mansfield's extensive study (2010). Further work by Cohen-Mansfield *et al.* (2012a) suggests that for people with dementia, the ability to express pleasure is related to function rather than cognition. Like other functions, the ability to express pleasure may be lost through lack of use or strengthened through practice—as in the Namaste Care programme.

Further explanation for the effectiveness of Namaste Care comes from a systematic review (Kong *et al.*, 2009) of non-pharmacological interventions for agitation which found that sensory interventions have moderate efficacy for agitation in people with advanced dementia. Many psychosocial and sensory interventions are effective in reducing agitation for people with dementia, but the evidence is for short-term effect during the intervention with little or no longer term effect (Cohen-Mansfield *et al.*, 2010). Namaste Care overcomes this short-lived effectiveness by scheduling the programme: 7 days a week, 2-h morning and afternoon. Residents with dementia express happiness over seven times more often during structured recreational time than during unstructured time (Schreiner *et al.*, 2005). The Namaste Care programme imposes structure on the 'empty time' when residents with advanced dementia are not engaged in personal care or mealtimes and empowers care staff to connect with residents, engaging them in meaningful activity.

This study has limitations. Proxy measures were unavoidable within the population that we studied. The NPI-NH was chosen because it was the NHS Specialist Care Units' routine measure of the effectiveness of treatments; none of the other CHs had any measure of neuropsychiatric symptoms or quality of life. Wood *et al.* (2000) advised that

Table 3 Comparison of Neuropsychiatric Inventory scores before and during Namaste Care implementation

Time Interval		Frequency × severity %(n)				Occupational disruptiveness %(n)			
		Terciles				Terciles			
		1	2	3	Chi-square	1	2	3	Chi-square
1 vs 2, n = 34	1	33.3 (11)	33.3 (11)	33.3 (11)	29.0, $p < 0.001$	30.3 (10)	33.3 (11)	36.4 (12)	24.1, $p < 0.001$
	2	39.4 (13)	27.3 (9)	33.3 (11)		36.4 (12)	42.4 (14)	21.2 (7)	
2 vs 3, n = 32	2	40.6 (13)	28.1 (9)	31.3 (10)	24.9, $p < 0.001$	34.4 (11)	43.8 (14)	21.9 (7)	16.1, $p = 0.003$
	3	53.1 (17)	28.1 (9)	18.8 (6)		50.0 (16)	34.4 (11)	15.6 (5)	
3 vs 4, n = 24	3	62.5 (15)	16.7 (4)	20.8 (5)	22.9, $p < 0.001$	54.2 (13)	29.2 (7)	16.7 (4)	19.9, $p = 0.001$
	4	54.2 (13)	20.8 (5)	25.0 (6)		41.7 (10)	41.7 (10)	16.7 (4)	

the NPI-NH should be used with caution by any untrained rater in CHs to track outcomes of a behavioural intervention. Another limitation was related to defining quality of life negatively through a reduction in neuropsychiatric symptoms.

In this study, we used a cut-off point of >16 on the BANS-S as a measure of severe dementia (Van der Steen *et al.*, 2006) and as an inclusion criterion for the study. However, in the CHs that had open access to the Namaste room, many of those who benefited most conspicuously had moderate dementia and had been excluded from the study. A different study with wider inclusion criteria would provide a more comprehensive assessment of the effectiveness of Namaste Care. Finally, CH staff reported that residents gained weight with Namaste, that infection rates fell, and that there were fewer falls and 'incidents'. Future research should collect evidence to verify such claims.

Conclusion

Where there is strong leadership and good nursing and medical care, the Namaste Care programme significantly decreased behavioural symptoms of residents with advanced dementia. The focus on comfort in Namaste Care supported good pain management in four out of five CHs; however, Namaste cannot be a substitute for good clinical care. The Namaste Care programme required no extra resources and has the potential to transform care for residents with advanced dementia in CHs.

Conflict of interest

Joyce Simard developed the Namaste Care programme and is the author of *The End-of-Life Namaste Care Programme for People with Dementia*.

Key points

- The Namaste care programme can enhance quality of life for people with advanced dementia by decreasing behavioural symptoms and improving pain management.
- Strong leadership and adequate staffing must already be in place for the Namaste Care programme to succeed.
- The Namaste Care programme provides a framework for developing a compassionate culture of care that does not require additional staff or expensive equipment.

Acknowledgements

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