

Development, feasibility and acceptability of an intervention to improve care for agitation in people living in nursing homes with dementia nearing the end-of-life

Professor Elizabeth L Sampson^{1*}, Dr Julie Barber², Juliet Gillam³, Dr Francesca La Frenais³, Katie Lambe³, Dr Anne Laybourne³, Dr Monica Manela⁴, Dr Louise Marston⁴, Dr Kirsten Moore¹, Monica Panca⁴, Aisling Stringer³, Lucy Webster³, Professor Gill Livingston³

¹ Marie Curie Palliative Care Research Unit, Division of Psychiatry, University College London, Maple House, 149 Tottenham Court Road, London, W1T 7NF, UK

² Department of Statistical Science and Priment Clinical Trials Unit, University College, London WC1E 6BT

³ Department of Old Age Psychiatry, Division of Psychiatry, University College London, Maple House, 149 Tottenham Court Road, London, W1T 7NF, UK

⁴ Department of Primary Care and Population Health and Priment Clinical Trials Unit, University College London, Rowland Hill Street, London, NW3 2PF, UK.

***Corresponding author**

E-mail: e.sampson@ucl.ac.uk

Fax: 020 7679 9426

Telephone: 020 7679 9730

Postal Address: 6th Floor, Maple House, 149 Tottenham Court Road, London, W1T 7NF, UK

Word count: 4990

ABSTRACT

Objectives: To develop a staff training intervention for agitation in people with severe dementia, reaching end-of-life, residing in nursing homes (NHs), test feasibility, acceptability and whether a trial is warranted.

Design: Feasibility study with pre- and post-intervention data collection, qualitative interviews and focus groups.

Setting: Three NHs in south-east England with dementia units, diverse in terms of size, ownership status and location.

Participants: Residents with a dementia diagnosis or scoring ≥ 2 on the Noticeable Problems Checklist, rated as “severe” on Clinical Dementia Rating Scale, family carers and staff (healthcare assistants and nurses).

Intervention: Manualised training, delivered by non-clinical psychology graduates focussing on agitation in severe dementia, underpinned by a palliative care framework.

Measurements: Main outcomes were feasibility of recruitment, data collection, follow-up and intervention acceptability. We collected resident, family carer and staff demographics. Staff provided data on resident’s agitation, pain, quality of life and service receipt. Staff reported their sense of competence in dementia care. Family carers reported on satisfaction with end-of-life care. In qualitative interviews, we explored staff and family carers’ views on the intervention.

Results: The target three NHs participated: 28 (49%) residents, 53 (74%) staff and 11 (85%) family carers who were eligible to participate consented. 84% of staff attended ≥ 3 sessions, and we achieved 93% follow-up. We were able to complete quantitative interviews. Staff and family carers reported the intervention and delivery were acceptable and helpful.

Conclusions: The intervention was feasible and acceptable indicating a larger trial for effectiveness may be warranted.

Keywords: dementia, palliative care, nursing home, feasibility study, agitation

INTRODUCTION

Worldwide, 47 million people are living with dementia and because of increasing longevity this is expected to triple by 2050 (Prince *et al.*, 2015). Dementia is now the third commonest cause of death in higher income countries (World Health Organisation, 2017), and one third of the United Kingdom (UK) population aged over 65 will die with dementia (Xie *et al.*, 2008). Most people with dementia in the UK will die in a care home (Sleeman *et al.*, 2016) and require a palliative care approach, underpinned by careful assessment of symptoms and a holistic approach to care (World Health Organisation, 1990) (van der Steen *et al.*, 2014).

In the UK more than 420,000 people aged over 65 years live in residential care, of which approximately 220,000 reside in care homes with nursing (referred to henceforth as “nursing homes” (NHs)) (Laing and Buisson, 2017). Staff working in NHs face considerable challenges. They may have few qualifications, are poorly paid, and may be migrant workers (Skills for Care, 2019). There are recruitment challenges and high staff turnover (Orellana, 2014). Interventions developed to improve the quality of end-of-life care received by NH residents often require high levels of external facilitation (Froggatt *et al.*, 2006) and skilled (and thus costly) staff for implementation (Moore *et al.*, 2017a). These may not be feasible, cost-effective or scalable in the UK NH sector. In addition, most interventions address a range of problems, rather than focussing on specific issues such as agitation (Smets *et al.*, 2018).

Agitation is one of the most common neuropsychiatric symptoms of dementia and includes restlessness, pacing, shouting and verbal or physical aggression. It occurs in over 50% of NH residents (Livingston *et al.*, 2017) and may be related to neurodegeneration or unmet needs such as pain, boredom, hunger or thirst. Agitation and distress are very common towards end-of-life, when people with severe dementia may struggle to communicate their needs, affect 75% of people with dementia, and persist even in the last month of life (Aminoff and Adunsky, 2006; Mitchell *et al.*, 2009). Essential components of palliative care such as adequate pain management and attention to psychosocial and spiritual factors are often neglected (Sampson *et al.*, 2018). Interventional research on providing palliative care for people with dementia is scant and has been criticised for lacking a strong theoretical basis (van der Steen and Goodman, 2015).

Underpinning theory for intervention development

This study is part of the Managing Agitation and Improving QUality of lifE (MARQUE) programme, which aimed to better understand causes of agitation across care settings and

develop interventions to improve care. Work was underpinned by a conceptual framework viewing agitation as usually being a manifestation of unmet needs, which we have demonstrated are strongly linked to lower quality of life (QoL) (Livingston *et al.*, 2017; Livingston *et al.*, 2014a). Needs can be unmet because the person with dementia has difficulties in knowing, or making these known. Unmet needs encompass enjoyable activities, stimulation (Rapaport *et al.*, 2018), comfort, pain relief (Husebo *et al.*, 2011) or physical contact. External factors include the degree to which staff are available, aware and skilled in providing activities, physical and emotional comfort (Livingston *et al.*, 2014b). Further theoretical development highlighted the importance of staffs' own sense of valued personhood (Kadri *et al.*, 2018; Sampson *et al.*, 2019).

To develop our intervention, we refined our theory in the context of end-of-life. We conducted non-participant observations (observing care without actively participating) in NHs and hospitals of people with severe dementia or those with moderate dementia with acute physical illness or chronic comorbidity, which may indicate they were near end-of-life. Some staff saw agitation as a signal of need, others felt it was purposeless behaviour; their reactions included fear and a sense of "not knowing what to do" (Sampson *et al.*, 2019). Staff who saw agitation as purposeless often withdrew, focussing on tasks and avoiding social interaction or identifying and managing the cause of agitation. This increased loss of personhood, reduced interaction and further worsened agitation. This theory informed a staff training intervention to improve care for agitation in people with severe dementia residing in NHs.

AIM

To test intervention feasibility and acceptability to inform whether a randomised controlled trial is indicated. Specific objectives were to:

- 1) Describe recruitment and consent rates for NHs, residents, family carers and staff to inform a larger trial
- 2) Assess feasibility of intervention delivery as whether at least 60% of staff attend at least three of the four sessions
- 3) Assess whether the intervention was acceptable
- 4) Assess the feasibility of collecting measures of QoL and use of health and social care resources
- 5) Explore potential outcome measures for a further study
- 6) Estimate the costs of delivering the intervention and associated health and social care costs

METHODS

Training development

The study team, including experts in dementia care, palliative care and NH staff drafted the manuals, based on theory described above, with topics informed by longitudinal data on unmet needs in NH residents with severe dementia and their family carers (Moore *et al.*, 2017b; Sampson *et al.*, 2018). Each topic was framed in the holistic palliative care model encompassing physical, psychological, social and spiritual domains (Clark, 1999). The four session themes were: 1) understanding severe dementia, 2) pain and discomfort in severe dementia, 3) working with others during the severe stages of dementia and 4) what works? Using new skills and strategies for the future. Our prior work and theory highlighted how neglect of staff personhood leads to burnout and emotional exhaustion. We therefore supported staff to reflect on their emotional response to caring for people with severe dementia who were agitated. Sessions included reflection on experiences, a recap of previous session(s), validation of existing knowledge and expertise, interactive group tasks, talking points and ended with a relaxation exercise (figure 1).

Figure 1

Training delivery

We designed the intervention to be sustainable and facilitated by two supervised non-clinical psychology graduates, trained to deliver the intervention. We piloted manuals with five NH staff amending them to improve clarity and delivery style. We wrote a companion facilitator manual for each session. We delivered sessions between two and four times in each NH so all eligible staff could attend.

Study type and setting

We conducted a non-randomised feasibility study in three NHs. We planned to recruit three NHs with distinct dementia units, sampled for diversity in terms of size, ownership status and location. We required them to commit to the training being compulsory for all day staff. We excluded homes due to close in the next 12 months or located more than 60 minutes' travel from the study base.

Ethics and consent procedures

The London - Queen Square Research Ethics Committee (17/LO/1400) approved the study. NH managers gave consent for their NH to participate. Potential resident participants had severe memory problems and did not have capacity to consent for themselves. Using the Mental Capacity Act (2005) we used a key family member or friend as a “personal consultee” and obtained written assent for the resident. For the observation of the quality of staff-resident interactions, we obtained collective consent from the NH manager. The NH manager informed staff, who were given information sheets, that they could opt out of being observed at any time and the researcher would cease observations. We approached individual NH staff via their manager and they gave individual signed informed consent to participate in the focus groups. Family carers of residents recruited to the study were invited to participate and gave signed informed consent for this.

Study population

Residents had a diagnosis of dementia or a score ≥ 2 on the Noticeable Problems Checklist which has been validated against clinical diagnosis (Levin *et al.*, 1989; Moriarty and Webb, 2000) and were rated “3-severe” on the Clinical Dementia Rating Scale (CDR) (Morris, 1993). Eligible staff were; permanently employed healthcare assistants, activity coordinators and qualified nurses who worked at least some day shifts (enabling them to attend training) on the NH’s dementia units. We aimed to recruit 60% of all eligible staff.

Intervention implementation

The study ran in three NHs over 14 weeks (pre-intervention data collection weeks 1-6, intervention period weeks 7-10, follow-up during weeks 11-14). We invited staff to attend the four sessions, which lasted two hours each, including a break. In addition, we offered catch up sessions at each NH for those who were ill or on leave. We documented the number of group intervention sessions delivered, number of staff at each session, the proportion of staff who attended at least three sessions and who attended additional catch-up sessions. We explored intervention feasibility and acceptability with staff and family carers using semi-structured qualitative interviews. We asked what they thought of manual layout, content and practical tasks. We asked staff how effectively facilitators managed group conversations, whether the programme was sustainable and deliverable by non-professional facilitators.

Data collection

Data were collected by research assistants prior to intervention (weeks 1-6) and at follow-up after intervention delivery (weeks 11-14).

Resident data

At baseline, we collected demographic data. At baseline and follow-up, we assessed residents via proxy interviews with staff using:

- Cohen Mansfield Agitation Inventory (CMAI). Scores >45 indicate clinically significant agitation (Cohen-Mansfield *et al.*, 1989).
- Pain Assessment in Advanced Dementia (PAINAD) (Warden *et al.*, 2003). To assess pain during a care task and at rest. Scores ≥ 2 indicate pain.
- Symptom Management at the End-of-Life in Dementia (SMEOLD), range 0-45, higher scores indicating greater comfort (Kiely *et al.*, 2006).
- If a resident died during the study we aimed to rate comfort around the time of death with the Comfort Assessment in Dying with Dementia (CAD-EOLD) (range 14-42, higher scores indicating better comfort when dying) (Kiely *et al.*, 2006).
- DEMQOL-Proxy (range 31-124, higher score indicates better QoL) (Smith *et al.*, 2007). We also used the Quality of Life in Late Stage Dementia (QUALID) scale (range 11–55 lower scores indicate better QoL) (Weiner *et al.*, 2000), and EuroQol EQ-5D 5 (EQ-5D-5L- Proxy) (Rabin and de, 2001) with the associated UK tariff (Devlin *et al.*, 2017; Herdman *et al.*, 2011).
- The modified Client Service Receipt Inventory (CSRI) recorded health and social care resource use from resident files and NH staff (Beecham and Knapp, 2001).

Family carer data

Prior to intervention, we collected data on age, sex, relationship to resident and number of visits per month. Prior to intervention and at follow-up, we assessed family carer satisfaction using the Satisfaction with Care at the End-of-Life in Dementia Scale (SWCEOLD) which has 10 items, score range 10-40 with higher scores indicating greater satisfaction (Kiely *et al.*, 2006)

Staff data

We collected staff demographic data at baseline; sex, ethnicity, highest level of educational

attainment, English as a first language, years working in the NH and the sector, working pattern and whether they held a UK-recognised nursing qualification. Prior to intervention and at follow-up they completed the Sense of Competence In Dementia Scale (SCID) (Schepers *et al.*, 2012) a self-report of staffs' subjective competence, with four subscales (professionalism, building relationships, care challenges, sustaining personhood, range 17-68, higher scores indicate greater competence).

Nursing home data

We collected data from NHs on management and ownership (private or charity), CQC registration type (dementia registered, dementia specialist, mental health registered, physical disability registration), number of beds, CQC rating domains (safe, effective, caring, responsive, well led and overall), whether or not there was a specialist unit for residents with behavioural issues. We documented numbers of staff rostered during days and nights, agency staff and permanently registered staff, the number of residents and staff dementia training in the previous 6 months.

Staff-resident interactions

We collected data at baseline and follow-up on the quality of interactions between residents and staff using the Quality of Interactions Schedule (QUIS), an observational tool rating staff-resident interactions on an ordinal scale as 'positive' (2), 'neutral' (1), or 'negative' (0) (Dean *et al.*, 1993). The QUIS has good inter-rater reliability (Dean *et al.*, 1993) and reasonable test-retest reliability (McLean *et al.*, 2017).

Qualitative interviews

We held focus groups with a variety of NH staff to explore their views on the training programme, manuals, facilitators and barriers to the implementation of the training and triangulate data. We showed family carers the manuals and gave an overview of the training programme prior to their interviews. These were audiotaped and transcribed verbatim and entered onto a qualitative software programme (Nvivo) for coding, management and retrieval of data.

Sample size

No formal power calculation was carried out for this feasibility and acceptability study. Informed by our previous NH research (Livingston, 2019), we aimed to recruit three NHs which we expected to include approximately 60 paid carers, 51 residents with dementia

(Livingston *et al.*, 2019) and 15 family carers. We anticipated this sample size would provide sufficient information to address our objectives.

Analysis

Quantitative

We described participant flow using a consort-type diagram, the number of intervention sessions attended by staff and the proportion of staff attending at least three sessions. We summarised staff, family carer and resident characteristics and questionnaire scores at baseline and follow-up using means with standard deviations (SD) or medians with interquartile ranges (IQR) for continuous data (as appropriate) and frequency (%) for categorical data. We tabulated NH characteristics. We compared baseline and follow-up questionnaire scores to obtain an estimate of average change (mean difference) with 95% confidence intervals. We described missing data for each outcome. Analysis was conducted using Stata version 14 (StataCorp, 2015).

Cost estimation

We estimated health and social care costs; the intervention cost (including costs of training and delivery) was based on the number and length of sessions delivered and unit costs using published sources (Curtis and Burns, 2017). We explored the feasibility and implications of using the EQ-5D-5L proxy version, DEMQOL proxy version and QUALID to calculate QoL.

Qualitative

We coded transcripts into meaningful themes using thematic analysis (Braun and Clarke, 2006). We adopted a rigorous approach to data analysis using methods described by Spencer *et al.* (2003). Throughout the analytic process, researchers used ongoing reflection with the use of memoing and reflective diaries to engage with the data and refine emergent themes.

RESULTS

Recruitment and consent

We approached 12 NHs, six responded and three agreed to participate. Reasons for NHs not wishing to participate were having too many other challenges or believing they did not have enough residents with dementia. Recruited NHs varied from 22-215 beds. Two were

private and one was a charity. At baseline all were rated by the CQC as “good” and had provided staff with dementia training in the prior 6 months (table 1).

A total of 72 staff were working in NH dementia units and were eligible to participate, 58 of whom were approached by research assistants for informed consent. Fourteen staff were uncontactable by research assistants due to absence, leave or their shift patterns, leading to 74% of eligible staff approached consented and received the intervention.

Across the three NHs, 57 residents were eligible, 45 had contactable proxies and were approached and 28 proxies provided assent for the resident to participate (49%). Thus, over half of eligible proxies were not recruited as they either did not respond to the invitation or declined. We approached 28 family carers of residents participating in the project and 13 (46%) were recruited into the study. We were able to collect post-intervention questionnaires on 26 residents, 44 staff and 6 family carers (figure 2).

Figure 2

Participant characteristics

Staff were predominantly female with mean age of 46 years, less than half spoke English as a first language and 19% had a UK recognised nursing qualification. Residents had a mean age of 87 years and were mainly female. Family carers had a mean age of 62 years and were mainly children of the residents (table 2).

Feasibility

Staff attended a median of 4 sessions including catch up sessions where necessary (interquartile range (IQR) 3,4), 79% of staff attended three or four group intervention sessions and including catch up sessions this rose to 84% of staff (table 1).

Potential outcome measures

Table 3 presents potential outcome measures for a main trial with baseline and follow-up average scores and the numbers who completed these. CMAI, QUALID, SMEOLD, DEMQOL proxy and EQ5-D were completed for at least 89% of residents at baseline and follow-up. The PAINAD at rest was completed for 78% of residents at baseline and 73% at follow-up. Completion of the PAINAD at movement was lower. SWCEOLD data was collected from 92% of family carers at baseline but only 46% at follow-up. At baseline the SCID was completed by 94% of the 53 recruited staff, and all 44 staff who were contactable

for follow-up. The SCID, SMEOLD and CMAI showed evidence of a positive change between baseline and follow-up.

Pre-intervention on the QUIS, over 10 hours and 53 minutes, we observed 174 interactions with 27 residents. There was a median of 5 (IQR 3,12) interactions per resident, of which 7% were negative, 51% neutral and 42% positive. Post-intervention, over 12 hours and 40 minutes, we observed 126 interactions with 24 residents. There was a median of five interactions per resident (IQR 3, 8), of which 8% were negative, 46% neutral and 46% positive.

Feasibility of cost estimation

All residents pre-intervention and 93% of residents post-intervention had complete data for health and social care resource use. Pre-intervention, all residents had complete data for EQ-5D-5L proxy and QUALID and 96% on DEMQOL proxy. At follow-up, 93% of the residents had complete data for EQ-5D-5L proxy and QUALID. The total cost of intervention implementation was £6,891.9. The average cost per resident was £246, assuming this is the cost required to deliver the intervention to the 28 residents on whom we collected outcome data. There was a slight increase in health and social care costs and QoL measured by DEMQOL proxy and QUALID, and a statistically significant increase in QoL measured by EQ-5D-5L proxy (see appendix 1 published as supplementary material online attached to the electronic version of this paper at <https://www.cambridge.org/core/journals/international-psychogeriatrics>).

Qualitative evaluation

We interviewed ten family carers in nine interviews (one with two family carers). All were women (nine daughters, one wife and one niece), aged 50-73 years who visited between seven and 30 times per month. We held five staff focus groups, two in two of the NHs, and one in the other. Staff members (17 females, 2 males) attended in groups varying in size from two to seven staff members. There were 13 healthcare assistants, two senior healthcare assistants, one each of assistant nursing practitioner, unit manager, clinical lead, and NH manager.

Creating a shared learning space and enhancing communication

Facilitators built rapport with staff who reported feeling listened to, understood and appreciated. The training kept staff engaged and brought those with different roles together

to share experiences.

“...they [facilitators] were interested in listening to us... asking us questions...” “...they were giving us new tools, ways of looking at pain, doing things differently... “I liked them very much...It was their way of teaching, .., it was like communication.”(focus group HCA1)

“And it was good that we had nurses and senior healthcare assistants as well [in the training]... they will be more informed...if we were in the sessions and sharing something out, like for instance palliative care, you find that the nurse or the senior healthcare assistant will have different input than we healthcare assistants coming up with. So, it did help to get everybody together. (focus group HCA2)

Investing in staff

Staff reported the training helped them feel valued, reflect on their work and increased quality of care. The training was relevant to their day-to-day practice and was easy to apply: It was preferred to “learning on the job”.

“...it’s more practical...for instance... I’m new and haven’t been in a dementia facility, and I get introduced to the sessions. I think it would be more beneficial...I’m reflecting back to the sessions. This is what I’ve learned .., so I am just going to put it into practice...Even though I’ve been here for three years, it’s still beneficial to me, and it would be beneficial for a new person as well,.” (HCA2)

“... we reflect back to your training... probably we need to do more training to exercise our minds.” (HCA5)

Manuals helped staff to follow the progression of the sessions, to make notes and provided written material for the future. The person-centred approach was valued by carers:

“...we can go back to the manuals, and when we reflect, it’s something we can go back to and read, and then, we can reflect back on what we talked about in the training.” (HCA2)

“Because they think person-centred means that this person likes trees and they don't like strawberries, you know. I think person centred means looking at somebody in a room and saying why are they agitated or why, what can I do to make their care, make them more comfortable?” (family carer 3)

Linking sessions through the introduction, recap and between-session tasks helped put it all together.

“...from one session to next session, we reflect on the first one, then we carry along. So it’s more covered and go round like a ball throughout...We tend to understand better because it’s broken down to four sections. If... everything together, probably we would not”. (HCA3)

Relaxation techniques were regarded as valuable, enjoyable, and useful for relieving stress.

“...[relaxation exercises] are excellent...staff stress is hugely important...[their work] is immensely difficult and distressing... [staff] cope with enormous amount of stress...” (family carer 1)

“I think the relaxation side...that was the best part. Because I work in the dementia unit, sometimes can be a bit challenging, so I find that very good, using that is helpful.” (HCA6)

Family carers felt the training encouraged better communication and interaction between staff and relatives.

“...the training you are doing, is about making something that is often not implicit, but unvoiced, voiced.” (Family carer 3)

Family carers judged the training as useful and valued the focus on agitation:

“...how to handle it [agitation], or what to do, or what would help...that is crucial...” “...that’s [aggression] is really one of the most difficult things to deal with, for them [staff]...my dad gets very aggressive, and I’m sure they find that very difficult. I think also, if people can’t communicate...not knowing what to do and not knowing if things are helping...” (family carer 2)

Culture and implementation in practice

Staff understood that implementation and change takes time.

“...when you learn something new and you want to put it into practice, it takes a while...You know, people have habits.” (HCA1)

A family carer was concerned about the “culture of blame”. Staff may hesitate to raise issues, afraid of accountability. The carer felt that the training would help this.

“...if a care home creates a culture where it’s everybody’s job to think about the person and their comfort level, I think that would translate into better care.” (family carer 4)

There was some concern about training costs but the delivery by non-professional facilitators was appropriate, suitable and implementable.

“If you go for training, they [NH] have to put on more staff which is more money for them...it’s time consuming... but I don’t think they will say no to it... we are learning something...” (HCA2)

Applying skills in practice

Many staff put new skills into practice at work, sometimes immediately after the sessions.

“We really put it into production more, is like asking the daughter, did your mum love music? Do you think she preferred to listen to music in the background... We know about these things, but sometimes we don’t really put it into action, but after listening to the end-of-life training, then yes, we did.” (HCA1).

DISCUSSION

Using a palliative care approach, underpinned by theory and ethnographic work, we designed a four-session manualised training intervention to improve the care of people with severe dementia and agitation. We recruited our target of three NHs, 74% of eligible staff and 89% of family carers. We had aimed to recruit 17 residents with severe dementia from each NH (total of 51) but only recruited 28 in total (49% of eligible residents). Most (84%) staff attended at least three sessions.

We explored potential outcome measures for a full trial. In terms of feasibility, nearly all data on agitation, symptom management (SMEOLD) and quality of life (DEMQOL, QUALID and EQ-5D-5L) were collected although other scales including the PAINAD, particularly at movement were less consistently measured.

We wanted to explore the quality of interactions between NH residents and staff. We chose the QUIS as previous studies show utility in NHs (Proctor *et al.*, 1998) and with cognitively impaired NH residents (Paudel *et al.*, 2019). We were able to assess daytime resident-staff interactions for 96% of residents at baseline and 92% at follow-up. Thus, it was feasible to observe staff interactions with residents with severe dementia. Dementia Care Mapping is used more frequently to assess person-centred care but requires extensive training, which may be less practical. The median number of interactions and the type of interaction did not change between baseline and follow-up.

The SCID (staff competency) scale and the symptom management scale (SMEOLD) showed positive change between pre and post-intervention phases, indicating they may be useful outcome measures for a future study. It was feasible to estimate intervention costs using DEMQOL proxy and the EQ-5D-5L, suggesting a potential cost of £246 per resident. Health and social care costs and utility values showed slight increase post-intervention.

Analysis of qualitative data allowed triangulation with quantitative findings. The training was acceptable to staff who appreciated multi-professional learning, interactions with facilitators who listened to them, the ability to put their learning quickly into practice and the focus on their wellbeing and personhood through reflection and relaxation exercises.

There are a number of limitations to this feasibility study. The NHs in which the study was conducted may be atypical. Participating NHs were rated as “good” by the regulator and thus likely to be more willing and able to participate in research; they may not be representative. We did not formally assess how well NH managers engaged with the intervention and their support is vital for implementation (Chenoweth *et al.*, 2018) We recruited a relatively high proportion of eligible staff, but did not recruit residents or their carers to target. Relatively few residents fulfilled the criteria, despite these being quite broad and crucially, few had proxies who could participate to allow collection of family carer data. It may be challenging to recruit enough dyads for a full-scale trial. We did not collect data on the level of intervention fidelity achieved by the facilitators. Focus group participants may have been wary of criticising the intervention, however, we did ensure these occurred after the intervention finished enabling time for reflection, and they were conducted by researchers who did not deliver the intervention. Cost estimates are conservative and interpreted with caution because of small sample size and lack of control arm.

This feasibility study informs future work in this area. We did not aim to detect differences pre or post-intervention, but found signals of improvement in staff competency (SCID scale) and resident symptom management (SMEOLD). More work is required to understand whether these are true changes, underlying mechanisms of change and the “active ingredient” of the intervention. Whilst improving factual knowledge is important, it may be that engagement of the facilitators and attention given to staff wellbeing and personhood were actually the mediators of change. Future research should assess staff wellbeing, exploring emotional distress, anxiety and job satisfaction. We do not have data on longer-term implications of the study including lasting culture change within the NHs.

There has been an increase in recent research on interventions to improve end-of-life care for NH residents, particularly those with dementia. Many of these interventions are complex,

for example the UK “Gold Standards Framework” (Gold Standards Framework, 2008) or the Palliative Care for Older People (PACE) Steps to Success Program, a multicomponent intervention aiming to integrate basic non-specialist palliative care in NHs (Van den Block *et al.*, 2019). Whilst palliative care takes a broad and holistic approach, it is challenging for complex interventions to achieve their desired outcomes such as improved resident comfort or staff knowledge (Van den Block *et al.*, 2019).

NH residents with severe dementia have complex needs requiring specialised support from external health and social care services (Sampson 2018). Many multicomponent interventions involve expensive external facilitation from senior staff, training and multidisciplinary input. It may be more feasible in the current climate to implement focused interventions on agitation, advance care planning (Livingston *et al.*, 2013) or pain management (Petyaeva *et al.*, 2018). However, we still lack evidence for the effectiveness of these approaches (Murphy *et al.*, 2016).

Conclusion

This is the first feasibility study of an intervention designed to improve agitation in NH residents with severe dementia underpinned by a palliative care approach. The training was acceptable, positively received by staff and family carers, and inexpensive. Further studies will be required to understand implementation and how the intervention promotes change in practice.

Conflict of interest declaration: none

Description of authors’ roles: GL & ELS obtained funding, designed the study and protocol. LM, JB, MP designed and conducted the quantitative data analyses. AL, AS, FLaf, KL, JG, LW, MM, KM were involved in intervention design, delivery, data acquisition and analysis. AL was study manager. All authors were involved in data interpretation and drafting the paper.

Acknowledgements: Funded by the UK Economic and Social Research Council and National Institute of Health Research (NIHR/ESRC ES/L001780/1). ELS is supported by Marie Curie core grant (grant number MCCC-FCO-16-U). GL and ELS are supported by National Institute for Health Research (NIHR) University College London Hospital Biomedical Research Centre. GL received funding from the NIHR Collaborations for Leadership in Applied Health Research and Care North Thames at Barts Health National Health Service (NHS) Trust. GL is an NIHR senior investigator. Views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the UK Department of Health. We thank all participating NHs, residents, families, and staff.

REFERENCES

- Aminoff, B. Z. and Adunsky, A.** (2006). Their last 6 months: suffering and survival of end-stage dementia patients. *Age Ageing*, 35, 597-601.
- Beecham, J. and Knapp, M.** (2001). Costing psychiatric interventions. In G. Thornicroft (Ed.) *Measuring Mental Health Needs* (pp. 200-224) London: Gaskell.
- Braun, V. and Clarke, V.** (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 24.
- Chenoweth, L., Jessop, T., Harrison, F., Cations, M., Cook, J. and Brodaty, H.** (2018). Critical Contextual Elements in Facilitating and Achieving Success with a Person-Centred Care Intervention to Support Antipsychotic Deprescribing for Older People in Long-Term Care. *Biomed Res Int*, 2018, 7148515.
- Clark, D.** (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Soc Sci Med*, 49, 727-736.
- Cohen-Mansfield, J., Marx, M. S. and Rosenthal, A. S.** (1989). A description of agitation in a nursing home. *J.Gerontol.*, 44, M77-M84.
- Curtis, L. and Burns, A.** (2017). Unit Costs of Health and Social Care 2017. Personal Social Services Research Unit, University of Kent, Canterbury. .
- Dean, R., Proudfoot, R. and Lindesay, R.** (1993). The quality of interactions schedule (QUIS): development, reliability and use in the evaluation of two domus units. *International Journal of Geriatric Psychiatry*, 8, 7.
- Devlin, N. J., Shah, K. K., Feng, Y., Mulhern, B. and van Hout, B.** (2017). Valuing health-related quality of life: An EQ-5D-5L value set for England. *Health Econ.*
- Froggatt, K. A., et al.** (2006). End-of-life care in long-term care settings for older people: a literature review. *Int J Older People Nurs*, 1, 45-50.
- Gold Standards Framework** (2008). The Gold Standards Framework. NHS End of Life Care Programme.
- Herdman, M., et al.** (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res*, 20, 1727-1736.
- Husebo, B. S., Ballard, C., Sandvik, R., Nilsen, O. B. and Aarsland, D.** (2011). Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ*, 343, d4065.
- Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S. and Higgs, P.** (2018). Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PloS one*, 13, e0200031.
- Kiely, D. K., Volicer, L., Teno, J., Jones, R. N., Prigerson, H. G. and Mitchell, S. L.** (2006). The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis.Assoc.Disord.*, 20, 176-181.
- Laing and Buisson** (2017). Care of Older People UK Market Report.
- Levin, E., Sinclair, I. and Gorbach, P.** (1989). *Families, services, and confusion in old age*. Aldershot: Avebury: National Institute for Social Work.
- Livingston, G., et al.** (2017). Prevalence of and associations with agitation in residents with dementia living in care homes: MARQUE cross-sectional study. *BJPsych Open*, 3, 171-178.
- Livingston, G., et al.** (2019). Clinical and cost-effectiveness of the Managing Agitation and Raising Quality of Life (MARQUE) intervention for agitation in people with dementia in care homes: a single-blind, cluster-randomised controlled trial. *Lancet Psychiatry*, 6, 293-304.
- Livingston, G., et al.** (2014a). Non-pharmacological interventions for agitation in dementia: systematic review of randomised controlled trials. *Br J Psychiatry*, 205, 436-442.
- Livingston, G., et al.** (2014b). A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. *Health Technol Assess*, 18, 1-226, v-vi.
- Livingston, G., et al.** (2013). Improving the end-of-life for people with dementia living in a care home: an intervention study. *Int Psychogeriatr*, 25, 1849-1858.

- McLean, C., Griffiths, P., Mesa-Eguiagaray, I., Pickering, R. M. and Bridges, J.** (2017). Reliability, feasibility, and validity of the quality of interactions schedule (QULS) in acute hospital care: an observational study. *BMC Health Serv Res*, 17, 380.
- Mitchell, S. L., et al.** (2009). The clinical course of advanced dementia. *N.Engl.J.Med.*, 361, 1529-1538.
- Moore, K. J., et al.** (2017a). Implementing the compassion intervention, a model for integrated care for people with advanced dementia towards the end of life in nursing homes: a naturalistic feasibility study. *BMJ Open*, 7, e015515.
- Moore, K. J., et al.** (2017b). Experiences of end of life amongst family carers of people with advanced dementia: longitudinal cohort study with mixed methods. *BMC Geriatr*, 17, 135.
- Moriarty, J. and Webb, S.** (2000). *Part of their lives: community care for older people with dementia*. Bristol. Bristol: Policy Press.
- Morris, J. C.** (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412-2414.
- Murphy, E., et al.** (2016). Palliative care interventions in advanced dementia. *Cochrane Database Syst Rev*, 12, CD011513.
- Orellana, K.** (2014). *Care Home Managers: A scoping review of evidence*. London: Kings College.
- Paudel, A., Resnick, B. and Galik, E.** (2019). The Quality of Interactions Between Staff and Residents With Cognitive Impairment in Nursing Homes. *Am J Alzheimers Dis Other Demen*, 1533317519863259.
- Petyaeva, A., et al.** (2018). Feasibility of a staff training and support programme to improve pain assessment and management in people with dementia living in care homes. *Int J Geriatr Psychiatry*, 33, 221-231.
- Prince, M., Wimo, A. G. M., Ali, G. C., Wu, Y. T. and Prina, M.** (2015). *World Alzheimer Report 2015 – The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*. London.
- Proctor, R., et al.** (1998). An observational study to evaluate the impact of a specialist outreach team on the quality of care in nursing and residential homes. *Aging and Mental Health*, 2, 6.
- Rabin, R. and de, C. F.** (2001). EQ-5D: a measure of health status from the EuroQol Group. *Ann.Med.*, 33, 337-343.
- Rapaport, P., et al.** (2018). How do care home staff understand, manage and respond to agitation in people with dementia? A qualitative study. *BMJ Open*, 8, e022260.
- Sampson, E. L., et al.** (2018). Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med*, 32, 668-681.
- Sampson, E. L., et al.** (2019). Agitation near the end of life with dementia: An ethnographic study of care. *PLoS one*, 14, e0224043.
- Schepers, A. K., Orrell, M., Shanahan, N. and Spector, A.** (2012). Sense of competence in dementia care staff (SCIDS) scale: development, reliability, and validity. *Int.Psychogeriatr.*, 24, 1153-1162.
- Skills for Care** (2019). *National Minimum Dataset for Social care United Kingdom*.
- Sleeman, K. E., Davies, J. M., Verne, J., Gao, W. and Higginson, I. J.** (2016). The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. *Palliat Med*, 30, 45-53.
- Smets, T., et al.** (2018). Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the 'PACE Steps to Success' intervention in seven countries. *BMC Palliat Care*, 17, 47.
- Smith, S. C., et al.** (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychol Med*, 37, 737-746.
- Spencer, L., Ritchie, J., Lewis, J. and Dillon, L.** (2003). *Quality in qualitative evaluation: A framework for assessing research evidence*.
- StataCorp** (2015). *Stata Statistical Software: Release 14*. College Station, TX StataCorp LP.

- Van den Block, L., et al.** (2019). Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries: The PACE Cluster-Randomized Clinical Trial. *JAMA Intern Med*, 1-10.
- van der Steen, J. T. and Goodman, C.** (2015). What research we no longer need in neurodegenerative disease at the end of life: the case of research in dementia. *Palliat Med*, 29, 189-192.
- van der Steen, J. T., et al.** (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*, 28, 197-209.
- Warden, V., Hurley, A. C. and Volicer, L.** (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J.Am.Med.Dir.Assoc.*, 4, 9-15.
- Weiner, M. F., Martin-Cook, K., Svetlik, D. A., Saine, K., Foster, B. and Fontaine, C. S.** (2000). The quality of life in late-stage dementia (QUALID) scale. *J.Am.Med.Dir.Assoc.*, 1, 114-116.
- World Health Organisation** (1990). Cancer Pain Relief and Palliative Care. Geneva.
- World Health Organisation** (2017). Global Health Observatory (GHO) data; mortality and global health estimates.
- Xie, J., Brayne, C. and Matthews, F. E.** (2008). Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ*, 336, 258-262.

FIGURE LEGENDS

Figure 1. Intervention content and delivery

Figure 2. Recruitment flow chart

APPENDIX

Appendix 1: Mean health and social care resource use and cost per resident at baseline and follow-up and mean total cost including intervention

(appendix 1 published as supplementary material online attached to the electronic version of this paper at <https://www.cambridge.org/core/journals/international-psychogeriatrics>)

Table 1: Characteristics of participating nursing homes

	Site 1	Site 2	Site 3
Ownership and registration			
Ownership	Charity	Private	Private
Dementia specialist	N	Y	Y
Mental health registered	N	Y	N
Physical disability registered	N	Y	Y
CQC rating - overall	Good	Good	Good
Nursing home size and type of residents			
Number of beds	215	22	52
Number of residents present in home	184	22	51
Number of residents with dementia in the home	110	22	25
Number of residents in hospital	1	0	1
New residents with dementia are cared for in a specialist area	Y	N	Y
Special unit for residents with dementia and behavioural disturbances	Y	N	N
Home has a specific team for dementia care	Y	Y	Y
Residents are moved as their needs change	Y	N	N
Number of nursing staff rostered on during the day in the last 24 hours	3	1	2
Number of care staff rostered on during the day in the last 24 hours	36	5	10
Number of nursing staff rostered at night in the last 24 hours	3	1	2
Number of care staff rostered on during the night in the last 24 hours	36	2	4
Number of staff in the last 24 hours who were agency or bank	8	0	0
Number of permanently registered nursing staff	14	6	11
Number of permanently registered care staff	168	17	44
Number of permanently registered nursing staff on leave	-	1	1
Number of permanently registered care staff on leave	-	0	0
Number of registered nurses joined as permanent staff in last 4 months	0	0	3
Number of other care staff joined as permanent staff in last 4 months	4	4	3
Nursing home provided dementia training in the last six months	Y	Y	Y
Recruitment at baseline			
Residents	14	7	7
Staff	29	12	12
Family carers	5	2	6
Training delivered			
Number of intervention training groups in the care home	4	2	2

Table 1 legend: Y= yes, N=no

Table 2: Characteristics of participants

Characteristic	Frequency/N (%) unless stated otherwise
STAFF (N=53)	
Female	48/53 (91%)
Age mean (SD)	46 (14)
Ethnicity (N, %)	
White	5/52 (10%)
Black	26/52 (50%)
Asian	14/52 (27%)
Mixed or other	7/52 (13%)
Educational attainment	
No qualifications/ O levels/ GCSEs/ CSEs/ NVQ/ Level 1 or 2	14/53 (26%)
A levels/ NVQ Level 3-5	15/53 (28%)
Degree/ Postgraduate	19/53 (36%)
Other	5/53 (9%)
English is first language	
Years working in any nursing home mean (SD)	6 (6)
Years working in current nursing home mean (SD)	3 (4)
Full time work (N, %)	47/53 (89%)
Part time work (N, %)	6/53 (11%)
Shift pattern (N, %)	
Days	38/52 (73%)
Days and nights	14/52 (27%)
UK recognised nursing qualification	
Registered general nurse	7/10 (70%)
Registered mental health nurse	2/10 (20%)
Enrolled nurse	1/10 (10%)
RESIDENTS (N=28)	
Female Residents	19/28 (68%)
Age mean (SD) (N=27)	87 (9)
Ethnicity	
White	26/27 (96%)
Non-white	1/27 (4%)
Educational attainment	
No qualifications	2/15 (13%)
Degree/ postgraduate	11/15 (73%)
Other	2/15 (13%)
English is first language	19/23 (83%)
Marital status	
Married	12/27 (44%)
Separated/ divorced	3/27 (11%)
Widow/ widower	12/27 (44%)
FAMILY CARERS (N=13)*	
Female	10/11 (91%)
Age mean (SD)	62 (7)
Relationship to resident	
Spouse	3/11 (27%)
Child	7/11 (64%)
Other	1/11 (9%)
Visits per month median (IQR)	13 (7, 22)

IQR – interquartile range. SD = Standard deviation

*2 family carers did not provide demographic information

Table 3: Study measures

	Baseline		Follow up		Difference (Follow up – baseline)		
	N	Mean (SD)	N	Mean (SD)	N	Mean difference	95% Confidence interval
STAFF SCIDS	53		44				
Professionalism	51	18 (2)	44	19 (1)	43	0.3	(-0.2, 0.9)
Building Relationships	53	13 (2)	44	14 (2)	44	0.7	(0.1, 1.3)
Care Challenges	52	14 (2)	44	15 (2)	43	0.8	(0.2, 1.4)
Sustaining Personhood	52	15 (1)	44	15 (1)	43	0.5	(-0.0, 1.0)
Overall	50	60 (6)	44	63 (5)	42	2.4	(0.5, 4.2)
RESIDENTS	28		26				
CMAI*	23	44 (20) Median (IQR): 34 (30, 57)	26	42 (13) Median (IQR): 37 (31, 52)	21	-4.9 Median difference: -2	(-10.4, 0.7) (-8, 0)
PAIN-AD at rest	22	1 (4)	19	1 (2)	21	-0.2	(-2.3, 2.0)
PAIN-AD at movement	19	1 (2)	19	1 (1)	15	0.1	(-0.9, 1.2)
Quality of life in late stage dementia (QUALID)	27	22 (7)	26	23 (8)	25	0.9	(-2.7, 4.4)
SMEOLD	27	27 (10)	26	33 (8)	25	5.7	(1.4, 9.9)
DEMQOL proxy	28	107 (12)	26	113 (9)	26	4.5	(0.0, 9.1)
FAMILY CARERS	13		6				
Carer SWCEOLD	12	29 (3)	6	28 (4)	6	-1.7	(-5.3, 1.9)

SD= standard deviation, IQR = interquartile range, * median and median difference also given as the score has a skewed distribution