

Feasibility of a staff training and support programme to improve pain management in people with dementia living in care homes

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Key points

- Pain is common in people with dementia yet current pain management guidance is limited and is not focused around the needs of a care home setting.
- The PAIN-Dem pain management training and support programme for care staff has shown good feasibility in a preliminary study with changes in staff behaviour, awareness and confidence in pain management
- Feasibility and impact on staff behaviour is heavily dependent on the contextual setting of training delivery, with major reliance on manager buy-in and involvement of the full staff team.
- Ongoing challenges for future research include the need to integrate family members as active contributors and the need to develop a training delivery model to maximise impact

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Abstract

Objectives: To establish the feasibility and initial effectiveness of a training and support intervention for care staff to improve pain management in people with dementia living in care homes (PAIN-Dem)

Methods: PAIN-Dem training was delivered to care staff from three care homes in South London, followed by intervention support and resources to encourage improved pain management by staff over four weeks. Feasibility was assessed through fidelity to intervention materials and qualitative approaches. Focus group discussions with staff explored the use of the PAIN-Dem intervention and interviews were held with six residents and family carers. Pain was assessed in all residents at baseline, three and four weeks and goal attainment scaling was assessed at four weeks.

Results: Delivery of training was a key driver for success and feasibility of the PAIN-Dem intervention. Improvements in pain management behaviour and staff confidence were seen in homes where training was delivered in a care home setting across the team demographic with good manager buy-in. Family involvement in pain management was highlighted as an area for improvement. Goal attainment in residents was significantly improved across the cohort, although no significant change in pain was seen.

Conclusions: This study shows good initial feasibility of the PAIN-Dem intervention, and provides valuable insight into training and support paradigms that deliver successful learning and behaviour change. There is a need for a larger trial of PAIN-Dem to establish its impact on resident pain and quantifiable staff behaviour measures.

Introduction

80% of people residing in UK care homes have a diagnosis of dementia (Alzheimer's Society, 2013). These individuals represent a patient group with complex medical and care needs due to the combined impact of cognitive impairment, medical comorbidity and frailty. Pain is common in this group, with up to 80% of residents experiencing persistent pain associated with musculoskeletal complaints such as osteoarthritis and chronic conditions leading to neuropathic pain (Corbett et al., 2014). The impacts of pain in the context of dementia are well documented, with evidence linking untreated pain with worsening cognitive decline, emergence of behavioural symptoms and reduced quality of life (Corbett et al., 2012, Kolanowski et al., 2015, Chibnall et al., 2005). Importantly, pain severity is associated with severity of functional impairment (Ahn and Horgas, 2013, Kolanowski et al., 2015), which raises a major issue in care home settings where dementia severity is disproportionately higher than in people living in the community. Management of pain is therefore a major issue in provision of treatment and care in these settings.

Pain management in dementia is complex. Detection and assessment of pain is hampered by the lack of self-report and insight into subjective experiences which are frequently seen in people with late-stage dementia. Assessment therefore relies on a skilled, knowledgeable workforce to identify behavioural cues and changes in individuals that indicate pain. Several simple assessment measures exist, yet there is no standardised approach for pain assessment in care home residents, and approaches vary considerably between homes (Corbett, 2016) (Lichtner et al., 2014). Mild and moderate pain is therefore frequently not identified and audits have raised concerns regarding the risk of pain (Husebo and Corbett, 2014, Monroe et al., 2014) (Care Quality Commission UK, 2014). The effectiveness of treatment of pain through analgesia is well documented, and there are suggestions of value in the use of non-pharmacological approaches such as massage, music and heat/cold

therapies (Park, 2010, Abdulla et al., 2013). There is a considerable body of evidence supporting the use of a stepped approach to treatment, particularly in improving proxy measures of pain such as agitation (Pieper et al., 2013, Husebo et al., 2011, Sandvik et al., 2014, Corbett et al., 2012). However, there is a lack of specificity in guidance for the dementia group, particularly when considering treatment for mild and moderate pain. Our recent review identified 15 pain management guidelines, of which only three were tailored to dementia and none were suitable for care home settings (Corbett, 2016).

Qualitative work has indicated a lack of confidence amongst care staff in assessing and managing pain, a reluctance to participate in decision-making and an over-reliance on prescribers and nursing staff to provide pharmacological solutions without considering non-drug approaches (Corbett, 2016). This is in direct contrast to published recommendations which highlight the need to take a person-centred approach to addressing the cause of pain through needs assessment and non-drug approaches before recourse to pharmacological agents (American Geriatric Society, 2002). Care staff are ideally placed, as primary caregivers of people with dementia in care homes, to play a role in this pathway. Our work in this field, in agreement with previous studies, has directly highlighted the need for training, and a structured approach, to empower care staff and provide them with the skills, knowledge and confidence to play an active role in pain management (Corbett, 2016) (Burns and McIlpatrick, 2015) (Wilson et al., 2015).

Care homes present a unique challenge for the integration of novel interventions and training paradigms due to a perfect storm of complex care needs, limitations in staff skills and financial restrictions (Corbett et al., 2013). For any approach to be considered as realistic it requires evidence of both feasibility and cost-effectiveness in addition to overall effectiveness. An evidence-based pain management intervention (PAIN-Dem) was developed following a series of qualitative and meta-synthesis phases, with the aim of

providing a feasible programme to improve pain management in care homes. This paper describes the feasibility testing of the PAIN-Dem intervention in UK care homes.

Methodology

Study Design

This was a four-week feasibility study with nested resident case studies. The objective was to establish the feasibility of a novel pain management programme for care home settings. The study was conducted in three care homes in South London, sampled purposively to represent different home structures. The study received ethical approval from the NRES Committee London-South East (Reference 15/LO/1167).

Participants and Eligibility

Eligible care homes provided care for at least ten people with dementia, had at least two members of staff who were available to attend a training session and at least three people with identifiable pain at baseline, as measured using the Abbey and Mobilisation-Observation-Behavioural-Identification-Dementia-2 (MOBID-2) pain scale (Abbey et al., 2004, Husebo et al., 2007). Homes were invited to take part through the Maudsley Biomedical Research Centre Care Home Research Network hosted at King's College London. The decision for a home to take part was made by home management. Residents had an established diagnosis of dementia or probable dementia. Nested case studies were identified as consenting residents who had established pain at baseline, as defined by a score of three or above on the Abbey Pain Scale. Dyads of residents and their next-of-kin were approached for their involvement in an end-of-study interview. Staff selected for end-of-study focus groups had received the PAIN-Dem training.

Approaches to all participants were made through the care home manager, after which informed consent was obtained. In people lacking capacity to consent a consultee was nominated to support the process, as per Mental Capacity Act regulations.

Sample Size

The study included 19 people with dementia across three care homes. Six residents and their family carers were selected as case studies. Ten care staff were invited to end-of-study focus groups.

Intervention

All homes received the PAIN-Dem intervention. The intervention consisted of one half-day interactive training session for all care home staff which provided information about the importance, impact and prevalence of pain, simple principles for assessing pain through non-verbal cues and suggestions for non-drug approaches to alleviate pain within a person-centred framework. Training also comprised a series of practice scenarios to encourage participants to develop new behaviour for improved pain management. The overall intervention was framed within an acronym PAIN (Figure 1). Following training two Pain Monitors were nominated per home. This role involved taking responsibility for disseminating and implementing the training amongst their colleagues with the support of a trained researcher. Dedicated resources including posters, pain profile templates, flash cards and monitor folders were provided to each home. A researcher contacted each home at least once a week to provide support and advice.

Outcome measures

Qualitative outcomes

The primary outcome measure was feasibility of the PAIN-Dem intervention for use in care homes. Feasibility was analysed through collation of all paperwork completed as part of the four-week intervention, which was interrogated for completeness and fidelity. End-of-study focus group discussions (FGD) were coordinated with staff from all homes. Staff were asked for their experience and feedback on the PAIN-Dem training and intervention. Discussions

focussed on any changes in practice, what staff felt had been helpful, and any difficulties they had faced. Interviews were conducted with care home managers pre- and post-intervention at each home to establish their opinion of the intervention and its impact. Six nested case study dyads of residents and their next of kin were invited for end-of-study interviews. Interviews were conducted either separately or together, depending on the capacity and wishes of the participants. Case study interviews focussed on the experience of the resident and how they felt their pain had been managed, as well as ascertaining the extent of involvement of the relative. All FGD and interviews were audio recorded, anonymised and transcribed verbatim prior to thematic analysis.

Quantitative outcomes

Quantitative outcome measures were completed at baseline, three and four weeks to gather preliminary indications of the impact of the PAIN-Dem intervention. Pain was measured through the Abbey Pain Scale (Abbey et al., 2004), a well-validated brief observational six-item scale that records informant-rated pain behaviours and intensity. Pain was also measured through the MOBID-2 pain scale (Husebo et al., 2014), a validated tool that records location and intensity of pain based on pain behaviours in response to guided movements. A novel Pain Interference Scale for Dementia (PIS-D) was also used, which was adapted from the well established Pain Interference Scale in use for adults in the UK (Tyler et al., 2002). The PIS-D was developed as part of the PAIN-Dem intervention in response to stakeholder and expert consultations (Corbett, 2016) and was included to provide preliminary validity data. Goal Attainment was measured through Goal Attainment Scaling, a validated tool which has been successfully used in trials in Alzheimer's Disease (Rockwood et al., 2006). A trained researcher supported care staff and residents at baseline to define up to three personal goals for the resident which were related to their pain management. Goal Attainment was reviewed and scored at 0, 25, 50, 75 or 100% attainment at four weeks.

Data Analysis

Thematic analysis of FGD and interview transcripts was undertaken to identify themes and interpret the data. The constant comparison method (Glaser, 1978) was used to delineate similarities and differences between codes and to develop sub-themes. These elements were refined and validated as the analysis proceeded. Initial coding and theme identification was performed by author AC. The coding framework was further developed through an iterative process involving a group of the authors (AP, AC, KN, VL, MK), including group meetings to ensure themes were defined and agreed. The analysis framework was based on the overall research question 'What is the feasibility of the PAIN-Dem intervention in care homes?', and the sub-question, 'What improvements are required to improve feasibility?'. Themes were defined according to their relevance to these questions. Data were separated into meaningful fragments and labelled with codes. Alternative interpretations were discussed in the context of the whole set of transcripts to enable a consensus to be reached.

Quantitative data was analysed as descriptive statistics. The three pain assessment scales were recorded as change from baseline. The GAS was analysed as a percentage achievement at four weeks.

Results

Intervention Fidelity

Attendance at training sessions varied between the three homes. In the session provided at a care home location there were two and eight staff from each home respectively, including care assistants, nurses and managers. Training for the third home, which was run at an external location, was attended by three care assistants. All participants completed the four-week study, and all three homes remained engaged and in contact with the therapist.

Analysis of intervention materials showed a high level of fidelity to the PAIN-Dem approach. Pain profiles were made available for nine of the 19 participants. One home utilised their own note-taking format for five participants, and no paperwork was available for the remaining five. Of the profiles recovered staff completed an average of 98.9% of the 19 sections. An additional optional 'Talking With Families' document, which provides a template for discussing pain with families, was used for 47% of participants.

Feasibility Analysis: Focus Group Discussions

Two FGD were completed with seven staff members. FGD1 was attended by junior and senior care assistants, team leaders and nurses from two care homes and was conducted in a study home. FG2 was conducted with a smaller group of care assistants from one home. There was considerable discrepancy between the major themes emerging from these FGD (Table 1).

Analysis of transcripts from FGD1 indicated an increased confidence and awareness in staff, who described a more proactive approach to pain management. There were several examples of staff employing non-verbal facial and behavioural cues to assess pain and make treatment decisions. Participants described using person-centred non-drug approaches including music, social interaction and heat/cold. Staff spoke positively about having worked within their team to make decisions for individual residents, and some described the value of discussing these issues with next-of-kin. They also gave positive feedback about the PAIN-Dem materials, particularly the Pain Profile document and the flash cards which many staff used to communicate with residents. In contrast however, when asked about the impact of the training programme participants stated that there had been no change, indicating a possible lack of insight into their changed behaviour. When asked about challenges the group described frustrations and communication barriers with family members, and particularly found it difficult to keep conversations focussed on pain instead of

general care. Despite perceived additional workload there was a consensus that the extra work was worth the benefit to themselves and their residents (Table 1).

Analysis of FGD2 transcripts showed a markedly negative experience, with staff expressing a lack of time and motivation to implement non-drug approaches. Participants did not independently discuss any detail regarding the PAIN-Dem intervention, and expressed a belief that the intervention was focussed solely on the use of non-drug approaches, which they described as time-consuming and ineffective. There was an apparent lack of understanding of the inherent person-centredness of the intervention, with one staff member describing their reluctance to use heat treatment for all residents. Participants did not appear to understand the pathway concept of the PAIN-Dem approach and acronym, and the group did not describe any attempts to integrate pain assessment into their daily routine. This appeared to indicate a lack of learning and understanding of the PAIN-Dem intervention. The discussion was largely dominated by one staff member, but it was noted that two care assistants expressed a desire to play a role in pain management, and recognised its importance in care, although they were unable to describe what their role might be. An overriding theme from the FDG2 discussion was the passing on of responsibility to more senior members, and the impression that dissemination of learning from PAIN-Dem training had failed (Table 1).

Feasibility Analysis: Manager Interviews

Interviews were conducted with managers from each of the homes. Themes were consistent with the FGD conducted for each home. Managers from homes involved in FGD1 expressed a positive experience and described changes in team behaviour and dynamics. Examples were given of improved pain management including regular assessment and joint decision-making. These managers described minimal burden on the team and a positive impact of the structure imposed by the intervention. In contrast, the manager from the home involved in FGD2 was unable to describe the objective or content of the PAIN-Dem intervention and

expressed negativity, particularly with regard to the perceived burden associated with the programme.

Feasibility Analysis: Case Studies

Six interviews were conducted with dyads of residents and family members. The main theme emerging was a lack of communication between family members and care staff and an unfulfilled desire to be more involved in decision making. Several family members described ways in which they could contribute pain management and questioned how decisions were made. One family member reported having been involved with an initial conversation as part of the PAIN-Dem study but had not received any further involvement. However, relatives also acknowledged the time pressures experienced by care staff and expressed the need for realism in expectations for communication.

Goal Attainment Scaling in residents

Analysis of Goal Attainment Scaling at four weeks showed significant achievement of goals. Recording of goal attainment in the primary goal at four weeks showed achievement of 73.6%. Of the 11 participants who set additional secondary goals, achievement at four weeks ranged from 62% to 80% (Figure 2). Completion of goal attainment scaling by care staff was 100%, indicating good feasibility for this subjective outcome measure.

Pain outcomes in residents

No significant change was seen in resident pain. A numerical increase was seen in the Abbey Pain Scale score, while a numerical decrease in pain was recorded on the MOBID-2 and PIS-D scales. The relative changes recorded on the new PIS-D were in agreement with the MOBID-2, indicating good preliminary validity for this new measure (Table 3)

Discussion

This study provides insight into the feasibility of a dedicated training and support intervention to improve pain management in care homes. Short-term implementation of the PAIN-Dem programme revealed important findings regarding the impact of the method of training delivery and the role of support and staff networks in the feasibility of this approach. In two of the three homes involved in the study the PAIN-Dem intervention resulted in a change in behaviour amongst staff, leading to increased awareness of pain, higher staff confidence and proactive, informed decision-making across the staff team. This builds on the small existing evidence which also reports learning effects following training in pain (Long, 2013). However, the study also revealed key contextual barriers which must be addressed if future evaluation and implementation are to be successful.

Examination of the environment and situation of the intervention delivery across the three homes reveals stark contrasts between homes where the training was successful and those where learning was not achieved. One major driver of success is the profile of staff attending the training and acting as the PAIN-Dem monitors. Successful implementation was seen in homes where the full staff team were encouraged to attend the training, with attendees ranging from care assistants to managers. This appears to have led to a joint commitment across the home to implement change and to pass learning on to other staff. In particular, this manifested as buy-in from the manager, ensuring staff had support and encouragement to develop new skills. The opposite situation was seen following training where only a small number of junior staff attended. There was a clear outcome showing no onward transference of learning, no proactive support for behaviour change and no manager buy-in. An additional factor may also be the location of training delivery. In homes receiving training at their, or another, care home, uptake and learning was high. However, where staff travelled to training at an academic venue this resulted in low turnout and a failure of the training objectives. It is important to note that across the whole study there was a clear message that staff at all levels, and particularly more junior staff, are willing and interested in learning new skills to

support their role, but that in some cases homes do not provide a nurturing environment to encourage this process.

Regarding the PAIN-Dem intervention itself, the study showed good levels of engagement and feasibility when training was delivered using the paradigm for success. Completion of pain profiles was high and there was evidence that staff used these personalised documents to guide discussions and decision-making. There was also evidence that staff performed regular pain assessments and increased the use of non-drug treatments. These two behaviours were primary objectives of the PAIN-Dem training. The proactive use of non-drug approaches is in particular contrast to usual practice as defined in published studies, and indicates a clear pathway from learning to practice (Corbett, 2016). The impact of the intervention on residents is less clear although the study showed significant impact on achievement of personal goals. Given the subjective experience and impact of pain, this outcome is extremely relevant. However, this study was not powered or designed to investigate quantitative outcomes and no significant change was seen in the Abbey, MOBID-2 or Pain Interference Scales. Of note, the Pain Interference Scale showed good agreement with the MOBID-2, indicating promising preliminary validity for this new scale.

One aspect of the intervention that requires attention is in promoting the involvement of families in pain management. Despite a moderately high usage of the 'Talking with Families' document, both staff and family members reported challenges with communicating and making joint decisions. This disconnect is frequently acknowledged in care homes, and is a known barrier to holistic dementia care (Corbett, 2016). Staff are aware of the potential value of family input but meaningful interactions are hampered by ad hoc communication and a lack of structure and resource (Alzheimer's, 2013). Future development of PAIN-Dem will need to consider this and build a structured format for family involvement. One potential emerging route to addressing this issue may be through technology to enable family members to contribute to decision-making remotely.

This study has provided valuable insights into the feasibility of PAIN-Dem, and highlights key elements of successful pain management programmes in care homes. However, there are limitations. This was a small feasibility study with no control group so no conclusions can be drawn regarding impact on residents, despite initial indications of benefit. Also, evidence of behaviour change in staff relies on self-reported activity as pain assessment and treatment was not routinely gathered. These aspects are a priority for the future. A larger randomised controlled trial of the PAIN-Dem intervention is now warranted to explore the value of different non-drug treatment approaches within the intervention framework, and to gather more in-depth data on staff behaviour. It will also be important for future studies to consider longer term embedding of learning across the care home sector, and the potential role of peer support and online-based learning tools to enable staff to develop and retain skills.

Figure 1: The PAIN-Dem acronym used to encourage staff to think proactively about pain in their residents

“See Change Think PAIN”

P – Profile: Create a pain profile for each resident based on their needs

A – Assessment: Assess pain regularly and look out for signs of pain

I – Intervention: Use non-drug approaches first and work with GPs if drug treatment is needed

N – Now: It is essential that pain is managed as soon as possible

Figure 2: Goal Attainment at four weeks in residents receiving pain management via the PAIN-Dem intervention

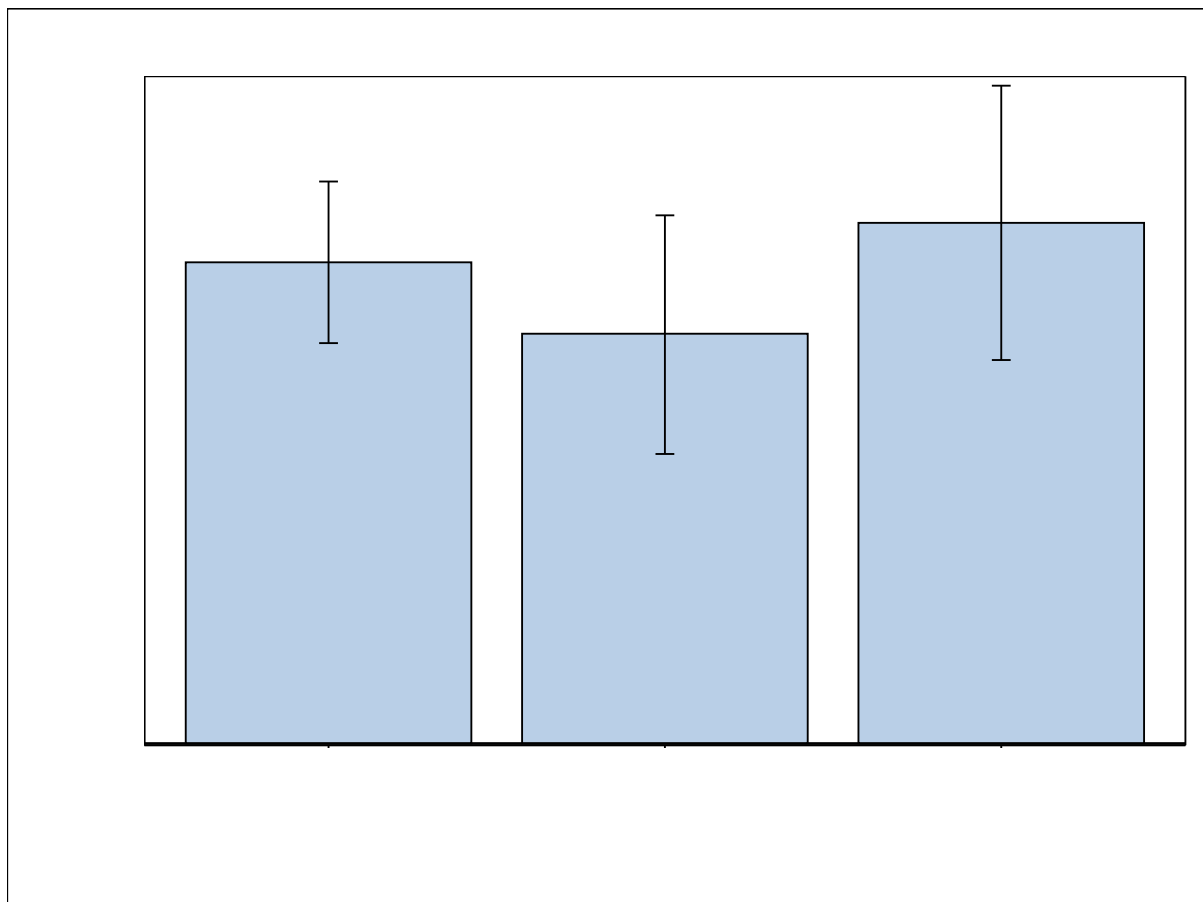


Table 1: Key themes emerging from focus groups with care home staff

Theme	Quote	Source
Increased confidence and awareness following use of PAIN-Dem	It is useful, both for us and the relatives, because they understand better, I would say, how pain can be managed	FG1
	I am more aware of that, and I always go back and write it. I think it's a good way to monitor the outcome, also for other people to look at and see if that particular medication did work.	FG1
	We are encouraged, I would say, to have a better understanding, to engage with them better, so that if there is a possibility of the resident being in pain, we can do something about it.	FG1
	I think everybody who works in the care, I think they would benefit from the information.	FG1
More productive approach to pain management	at some point, we decided to change the tablets into liquid medication and now she's taking it regularly. All of a sudden, she's going to music therapy. She's going to activities. She's eating like never-- she's like a totally different person.	FG1
	one of the residents we have monitored for pain, according to him. He didn't look okay. I asked him what was wrong. He said he was not feeling well. I asked him whether it was anything that he could not come, even though he's sick. Was he hurting anywhere as well? I'll give you some painkillers. He said, No. And then I just gave him a cup of tea with biscuit, and [?] actually to give some chocolate. I wrote on the chart, and by the time I finished, I asked him again how he was feeling, and he was fine.	FG1
	I think it's good for people to know that there's someone keeping an eye on it	FG1
Discussion with other team members	We discuss the problem and what's going on. That's how teamwork is going on.	FG1
	We had a meeting with the manager, and I was asked to share the information I had received from here so they're all aware.	FG1
Employing non-verbal assessments & observations	it's important that you really get to know that resident, know their behaviour, and know how they used to be	FG1
	throughout the day when you're working with them, you observe them	FG1
	Something has changed when you take care is looking at people's faces.	FG1
	you can see on the face reaction, how she's talking the person like this	FG2
Non-drug approaches	try different ways of managing it with non-drug therapies. That's the part I found fascinating, a non-drug approach, what you could try	FG1
	Well, from what I've seen, massage and music therapy works very well.	FG1
	We have lots of external people coming in to do the music therapy. People externally come in to do stuff like that.	FG1
	The change is actually for us to understand how it works and how we can contribute to it	FG1

	I think with music and TV, you can turn it on and leave and get on with anything else you need to do. Stuff like going for walks and stuff if you have other stuff to do, that's a bit harder, but there's definitely	FG1
Value of discussion with family members	She gave me more details, because I'd spoken to the daughter. So, I found that really helpful	FG1
	I have some feedback from the relative that used [?] and they're like, I've been talking to this person, and they said, 'Oh, we can actually try something else to see if we can manage with the pain.'	FG1
	I think it's very interesting and I'm quite sure family members would like to come and hear	FG2
	I think most of the family members will be very interested in it. Yeah, it's good to discuss with them.	FG2
Challenges with communicating with family members	when it comes to diagnosis and the actual medical conditions, they don't really know. They have a vague idea.	FG1
	the relatives don't always know the actual medical condition, so most of the times the medical summary is more relevant than what you get from the family	FG1
Reasons for lack of implementation	I have to cover the office for a very long time and most of the time I was in the office. So, it didn't give me that opportunity to sort of be with the residents.	FG1
	actually we don't really have the time dedicated to do all these activities with them.	FG2
	I don't even have time to see her. I think I saw her in a flash maybe two days ago - just in a flash - as she was coming up and I was going down. It's a time factor. Even for us to have break is difficult	FG2
	Actually some of them are not filled which I still need time to fill, because once I complete--it's a lot of paperwork to do, it's a lot.	FG2
	They are very helpful, they are very helpful. It's actually pinpoint the way you can alleviate pain, the way you can manage pain. But like I said, it's doing it as it is, that is a problem. The time for it, that's a problem.	FG2
	the cards have not been given, no	FG2
Challenges between staff members	The problem is the communication between a lot of things. We have time but we don't have enough time, and it's bad communication between us, like carers.	FG2
	it's not enough staff.	FG2
Lack of understanding of	To me the thing is this, because this medication can go hand in hand. This one with the medication can go hand in hand, in the sense that the nurses could be the ones practicing this.	FG2

intervention	What is like a hot water bottle the family members can provide, and then bath which I know most of the residents will not go in, and then pillow cases we're already using it, pillows.	FG2
	There's always a follow-up. If a resident is in pain and then you call the nurse, they come to assess the pain and then they know what to give. If it's above them, they refer them to GP	FG2
	She will see as in like ask the reaction of them. She will be available to take responsibility of this, and to respond to us what we have to do	FG2
	most of the questions what you put it, I think these questions you will be better to put it forward on nurse which are in charge	FG2

Table 2: Key themes emerging from dyads case study interviews

Theme	Quote	Source
Communication challenges	I never quite know how successful it's been	CS3
	I don't know that she has anyone specific at the moment	CS3
	I come in everyday in the afternoon and I always make sure that things I've asked to be put in place are actually put in place. Because there's a big turnover of staff, and you can't expect everyone to have that in their mind of what's got to be done.	CS1
	They've obviously got their reasons, but they've not really discussed it with me	CS1
	I haven't had any conversations with anybody.	CS1
	She has had massage in the past but not in this period as far as I know. Unless it's happened without me knowing.	CS1
	There's been no working together. And, Families and carers can use this to record changes to care and treatment. As I say, it was given to me two days ago.	CS1
	one or two carers I didn't feel had been informed enough	CS6
	Although apparently it had been picked up, but hadn't been relayed further down the line, I don't know.	CS6
	I wouldn't say involved in decisions. They certainly do, or have, told me if the GP has changed anything.	CS6
	No, not really. I think the carers get ongoing training. How often, I don't know, but probably as the regulations tell them to.	CS6
	Some are very good at, if they could do anything they would. And some others, don't want to know.	CS2
Positive communication: Next of Kin and staff	from previous discussions I think we've come to the conclusion that everything that can be done has	CS2
	I do talk to him occasionally about it.	CS2
	I think it's good, but is it followed up?	CS6
	I've not been told what they're doing. I have not been looking out for it	CS1
	If I had realized that, I probably would've asked a few questions. But really it's not my place. They should be telling me.	CS1
Current practices	if I happened to coincide with a visit from the GP on a Tuesday, I would perhaps speak to them directly.	CS2
Positive understanding	I think they did everything they could have done.	CS6
	They've got their job to do, and they follow the routines	CS6
	Well they are always very keen to help with pain but, and that everybody is very aware that my mum suffers	CS2

Table 3: Impact of the PAIN-Dem intervention on pain outcomes

	Baseline (n = 19)	Week 3 (n = 19)	Week 4 (n = 19)
	Mean (SD)	Mean (SD)	Mean (SD)
Abbey Pain Scale	4.74 (2.79)	5.26 (3.72)	5.47 (3.82)
MOBID-2	4.19 (2.71)	3.44 (1.92)	3.82 (2.24)
PIS-D (total score)	16.74 (9.24)	13.16 (8.67)	17.63 (10.33)

References

- ABBEY, J., PILLER, N., DE BELLIS, A., ESTERMAN, A., PARKER, D., GILES, L. & LOWCAY, B. 2004. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *Int J Palliat Nurs*, 10, 6-13.
- ABDULLA, A., ADAMS, N., BONE, M., ELLIOTT, A. M., GAFFIN, J., JONES, D., KNAGGS, R., MARTIN, D., SAMPSON, L. & SCHOFIELD, P. 2013. Guidance on the management of pain in older people. *Age Ageing*, 42 Suppl 1, i1-57.
- AHN, H. & HORGAS, A. 2013. The relationship between pain and disruptive behaviors in nursing home residents with dementia. *BMC Geriatr*, 13, 14.
- ALZHEIMER'S, S. 2013. Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes. http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=270.
- ALZHEIMER'S SOCIETY 2013. Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes. http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=270.
- AMERICAN GERIATRIC SOCIETY. 2002. *The management of persistent pain in older persons* [Online]. <http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.50.6s.1.x/abstract>: American Geriatrics Society. [Accessed 23rd September 2015].
- BURNS, M. & MCILFATRICK, S. 2015. Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. *Int J Palliat Nurs*, 21, 479-87.
- CARE QUALITY COMMISSION UK. 2014. *Cracks in the Pathway: People's experiences of dementia care as they move between care homes and hospitals* [Online]. http://www.cqc.org.uk/sites/default/files/20141009_cracks_in_the_pathway_final_0.pdf. [Accessed 14th October 2015].
- CHIBNALL, J. T., TAIT, R. C., HARMAN, B. & LUEBBERT, R. A. 2005. Effect of acetaminophen on behavior, well-being, and psychotropic medication use in nursing home residents with moderate-to-severe dementia. *J Am Geriatr Soc*, 53, 1921-9.
- CORBETT, A., HUSEBO, B., MALCANGIO, M., STANILAND, A., COHEN-MANSFIELD, J., AARSLAND, D. & BALLARD, C. 2012. Assessment and treatment of pain in people with dementia. *Nat Rev Neurol*, 8, 264-74.

- CORBETT, A., HUSEBO, B. S., ACHTERBERG, W. P., AARSLAND, D., ERDAL, A. & FLO, E. 2014. The importance of pain management in older people with dementia. *Br Med Bull*, 111, 139-48.
- CORBETT, A., NUNEZ, K. & THOMAS, A. 2013. Coping with dementia in care homes. *Maturitas*, 76, 3-4.
- CORBETT, A., NUNEZ, K., SMEATON, E., TESTAD, I., THOMAS, A. J., CLOSS, S. J., BRIGGS, M., GJESTSEN, M., T., LAWRENCE, V 2016. The landscape of pain management in people with dementia living in care homes: A qualitative mixed methods study. *Int J Geriatr Psychiatry*, In Press.
- GLASER, B. G. 1978. *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*, California, United States, Sociology Press.
- HUSEBO, B. S., BALLARD, C., SANDVIK, R., NILSEN, O. B. & 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.
- HUSEBO, B. S. & CORBETT, A. 2014. Dementia: Pain management in dementia--the value of proxy measures. *Nat Rev Neurol*, 10, 313-4.
- HUSEBO, B. S., OSTELO, R. & STRAND, L. I. 2014. The MOBID-2 pain scale: Reliability and responsiveness to pain in patients with dementia. *Eur J Pain*, 18, 1419-30.
- HUSEBO, B. S., STRAND, L. I., MOE-NILSSEN, R., HUSEBO, S. B., SNOW, A. L. & LJUNGGREN, A. E. 2007. Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID): development and validation of a nurse-administered pain assessment tool for use in dementia. *J Pain Symptom Manage*, 34, 67-80.
- KOLANOWSKI, A., MOGLE, J., FICK, D. M., HILL, N., MULHALL, P., NADLER, J., COLANCECCO, E. & BEHRENS, L. 2015. Pain, delirium, and physical function in skilled nursing home patients with dementia. *J Am Med Dir Assoc*, 16, 37-40.
- LICHTNER, V., DOWDING, D., ESTERHUIZEN, P., CLOSS, S. J., LONG, A. F., CORBETT, A. & BRIGGS, M. 2014. Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools. *BMC Geriatr*, 14, 138.
- LONG, C. O. 2013. Pain management education in long-term care: it can make a difference. *Pain Manag Nurs*, 14, 220-7.
- MONROE, T. B., MISRA, S. K., HABERMANN, R. C., DIETRICH, M. S., COWAN, R. L. & SIMMONS, S. F. 2014. Pain reports and pain medication treatment in nursing home residents with and without dementia. *Geriatr Gerontol Int*, 14, 541-8.
- PARK, H. 2010. Effect of music on pain for home-dwelling persons with dementia. *Pain Manag Nurs*, 11, 141-7.
- PIEPER, M. J., VAN DALEN-KOK, A. H., FRANCKE, A. L., VAN DER STEEN, J. T., SCHERDER, E. J., HUSEBO, B. S. & ACHTERBERG, W. P. 2013. Interventions targeting pain or behaviour in dementia: A systematic review. *Ageing Res Rev*, 12, 1042-55.
- ROCKWOOD, K., FAY, S., SONG, X., MACKNIGHT, C. & GORMAN, M. 2006. Attainment of treatment goals by people with Alzheimer's disease receiving galantamine: a randomized controlled trial. *CMAJ*, 174, 1099-105.
- SANDVIK, R. K., SELBAEK, G., SEIFERT, R., AARSLAND, D., BALLARD, C., CORBETT, A. & HUSEBO, B. S. 2014. Impact of a stepwise protocol for treating pain on pain intensity in nursing home patients with dementia: A cluster randomized trial. *Eur J Pain*, 18, 1490-500.
- TYLER, E. J., JENSEN, M. P., ENGEL, J. M. & SCHWARTZ, L. 2002. The reliability and validity of pain interference measures in persons with cerebral palsy. *Arch Phys Med Rehabil*, 83, 236-9.
- WILSON, E., MORBEY, H., BROWN, J., PAYNE, S., SEALE, C. & SEYMOUR, J. 2015. Administering anticipatory medications in end-of-life care: a qualitative study of nursing practice in the community and in nursing homes. *Palliat Med*, 29, 60-70.