

The landscape of pain management in people with dementia living in care homes: A qualitative study

Running head: Pain management in dementia in care homes

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Key points

- Pain is common in people with dementia living in care homes, yet there is no specific guidance or care programme to address pain management in this setting
- Care home staff appear to lack the confidence, training and support to take a stance on pain management
- Despite an extensive literature base, existing pain management guidance is not appropriate or feasible for implementation in care home settings
- A number of existing treatments, including COX-2 inhibitors and dextromorphan, warrant investigation as potential alternative analgesics for use in people with dementia

Word Count

Abstract

Objectives: This study sought to establish the current landscape of pain management in people with dementia living in care home settings. Pain is extremely common in this patient group, yet there is very limited guidance to support healthcare professionals and nothing comprehensive focussing on pain associated with dementia.

Methods: A mixed methods study utilising group stakeholder consultation in combination with a quality review of pain management guidance. Focus groups were held with care home staff (n=12) and family carers (n=10), in addition to an online survey (n=16). Data were subjected to thematic analysis to identify key themes and categories. A review of existing pain management guidance was conducted using published quality criteria adapted for the field. Outcomes were also reviewed by an expert panel which gave recommendations for practice and research.

Results: Thematic analysis revealed six major themes: the importance of person-centredness, the current lack of pain awareness in staff, communication as a core element of pain management, disparities in staff responsibility and confidence, the need for consistency of care and the current lack of staff training, indicating a need for evidence-based guidance and training. 14 existing guidelines were identified, of which three were designed for use in dementia and none were tailored for care home settings. In addition to the needs for practice, the expert panel identified promising pharmacological treatment candidates which warrant clinical evaluation.

Conclusions: The findings of this study clearly articulate a need for an evidence-based pain management programme for care homes which is informed by stakeholder input and based within a conceptual framework for this setting. There are novel opportunities for clinical trials of alternative analgesics for use in this patient group.

Introduction

Two major health issues facing older people are the increasing prevalence of dementia and widespread experience of pain. Dementia is a devastating neurodegenerative condition that affects 800,000 people in the UK, and this figure is set to rise (2009a). People with dementia have extremely complex needs for their care and treatment, compounded by frequent co-morbidities, many of which are associated with chronic pain (Ballard et al., 2011b). Treatment and care decisions often represent a delicate balance between pharmacological and psychosocial treatments, and the need for an individualised approach to care. The process of decision-making is further complicated by the loss of communication inherent in dementia that hinders the individuals' self-report and insight into their condition (Ballard et al., 2011a).

One third of people with dementia in the UK currently reside in care homes, and 80% of care home residents have a diagnosis of dementia (2013a). Pain is a major factor, affecting 80% of these individuals (Achterberg et al., 2013). The most common causes of pain include musculoskeletal conditions, recent or previous injuries and chronic pain underlying co-morbidity. Pain is usually persistent, and its severity correlates with functional impairment (Corbett et al., 2014). Pain is a subjective experience, meaning that self-report is by far the most effective means of assessing the pain experience. However, this ability is impaired, or absent, in dementia. Caregivers and physicians must rely on observation of 'pain behaviours' in order to detect pain (Lichtner et al., 2014). Whilst severe pain is usually identified and treated, moderate pain frequently is not, leaving patients in discomfort and distress (Husebo and Corbett, 2014). Untreated pain results in reduced mobility, muscle weakness and falls, and has a major detrimental impact on quality of life (Corbett et al., 2012a). Importantly, pain is a key underpinning factor in behavioural and psychological symptoms of dementia (BPSD) such as agitation, aggression and mood disorders (Ballard et al., 2011c).

Care homes present a unique challenge for the implementation and embedding of evidence-based care (Corbett et al., 2013). They require an effective balance of individualisation and institutionalised care, a close relationship with primary care and a motivated and well-trained workforce. However, care homes often do not meet UK Care Quality Commission (CQC) standards (2013b). Training is often inconsistent and not based on robust evidence. A recent review showed that of 27 training packages for person-centred care in care homes, only three were supported by evidence from randomised controlled trials (RCT) (Fossey et al., 2014). There is extremely limited evidence supporting training in pain management for care home

staff, although one small study reported improvements in staff knowledge and removal of barriers to care following education in pain (Long, 2013). There is a clear need to address this gap in practice through evidence-based, user-led guidance. Several programmes are underway to examine paradigms for person-centred care and theoretical frameworks for other key themes within care. However, there is no current guidance, care programme or validated training package to enable the effective management of pain (Corbett et al., 2012a).

The nature of the complex decision-making and the spectrum of individuals involved in dementia care in care homes highlights the importance of involving key stakeholders in the development of any real-life approach to pain management. In addition to a prescribing physician, care home staff at various levels and family members are critical informants to the process.

Methods

Study Design

This mixed methods study combined stakeholder consultation with a quality review of pain management guidance. The overall aim was to establish the current landscape of pain management and identify areas requiring evidence-based guidance and research. This study received ethical approval from the National Research Ethics Committee Harrow (REC Reference 14/LO/1693).

Participants

Stakeholder consultation was performed through focus group discussions, supplemented by online surveys. Two stakeholder groups were involved - care home staff and family carers. Each group was consulted independently to enable freedom of expression and a tailored approach. Care home staff were recruited through the Maudsley Biomedical Research Centre Care Home Research Network in South London. Care home managers nominated staff with responsibility for dementia care. Family carers were recruited through UK Alzheimer's Society's Research Network Volunteers via email invitation. Participants were current or former carers of a person with dementia who had experienced pain. Focus group discussions were presented as an opportunity to share experiences, contribute to the future improvement of care, and to give input into shaping a new.

Focus group discussions

Focus groups were held at the Wolfson Centre for Age-Related Diseases in London, or at participating care homes. Three care staff groups (Total n = 12) and two family carer groups

(Total n = 10) were coordinated. Care staff groups included junior care assistants, senior carers, nurses and care home managers. Discussions aimed to explore current pain management practice and followed an overall structure which involved first discussing the challenges of pain management, then identifying the elements that characterise good practice, and finally discussing practical solutions. The detail and flow of the discussions was flexible in order to gather the richest and most relevant data. Participants were encouraged to explore both positive and negative experiences, and were supported in applying their views to the research question. Focus groups were audio recorded and transcribed verbatim, with edits made to ensure anonymity. Observations were noted at the end of each discussion.

Additional stakeholder consultations

In addition to the focus group activity, family carers were also invited via email to complete an online survey. 16 carers participated. Survey questions were designed to specifically interrogate the discussion points arising in the focus groups, with the aim of providing additional clarity to the key emerging themes. The survey consisted of ten questions, with a mix of definitive Yes / No and free text answers (Supplementary Table 1).

Thematic analysis of qualitative data

Thematic analysis of focus group transcripts and online survey responses was undertaken to identify themes and interpret the data. The analysis framework was based on the overall research question 'What is the current state of pain management in people with dementia in care homes?', and the sub-question, 'What are the barriers and opportunities for improvement?'. Themes were defined according to their relevance to these questions. Data were separated into meaningful fragments and labelled with codes. The constant comparison method (Glaser, 1978) was used to delineate similarities and differences between codes and to develop categories. These elements were refined and validated as the analysis proceeded. Analysis was performed by a group of the authors through an iterative process, including group meetings and email communications, to ensure themes were clearly defined and agreed. Alternative interpretations were discussed in the context of the whole set of transcripts to enable a consensus to be reached.

Quality review of existing pain guidance resources

Currently available pain management guidance documents were identified by electronic searches on the NCBI Pubmed library and through Google. Search terms were 'pain' AND 'management' OR 'assessment' AND 'guideline' OR 'pathway' OR 'guidance' AND/OR 'older' AND/OR 'dementia'. The search was conducted on 20th February 2015. Bibliographies in identified documents were searched for additional relevant resources. Guidance was also

identified by experts in the field. Guidance documents were included if they were presented as a guidance or care pathway for assessment and / or management of pain in adults, written in English and published since 2000. Documents were excluded if they were designed for sole use in specialist non-geriatric settings and if they were scoping documents. Quality was assessed using published quality indicators established (Shaneyfelt et al., 1999), expanded to include items relating to use in older people, dementia and care homes. An additional indicator was also added to identify documents with supporting evidence of effectiveness in managing pain. A traffic light system was employed to grade the quality of each item, as per the Cochrane quality grading process (Corbett et al., 2012b). Guidance documents were also reviewed by an expert panel to identify key elements and gaps within existing resources.

Results

Current pain management pathways

A consistent, yet often incompletely applied, pain management structure emerged from discussions (Figure 1, Table 1). Identification of pain in a resident is made by a care assistant or in some cases by a visiting family member. Pain is reported to the nurse on duty who may conduct a specific pain assessment. The most commonly used assessment is the Abbey Pain Scale, a six-item scale of common pain indicators and their intensity (Abbey et al., 2004). First-line treatment in almost all cases is administration of paracetamol. Participants reported that the majority of residents have an existing as-needed prescription. In cases where this is absent the nurse would contact the resident's GP to request a prescription. Staff are most familiar with buprenorphine patches as an escalated treatment where paracetamol is not effective. Follow-up and monitoring of pain was described as an ad-hoc process, relying on recording of events and prescriptions in resident charts for discussion at staff handover meetings and GP visits.

Inclusion of pain in care planning varied across homes and participant experiences. Roughly half of the homes had care plans that included a specific item on pain. There was consensus across participants that information within medical notes and resident charts would provide sufficient information regarding the likelihood of pain arising in an individual, and the most appropriate treatment method. However, there was a lack of clarity regarding how these sources are proactively used to identify and treat pain in day-to-day care.

Perceived value of non-pharmacological treatment approaches

There was an interesting disparity between the opinions of care staff and family members regarding the use of non-drug approaches (Table 1). Family members highlighted the

importance of these treatments as a first-line step, with participants suggesting the use of hot and cold, massage, aromatherapy and music as approaches they had found successful. Conversely, the use of non-drug treatments was not raised by care staff. When questioned participants readily recognised the value of trying a comfort approach. However, this was not seen as being a part of usual practice, and an inherent reliance on nursing staff and medications was a strong theme.

'Knowing the person'

An overwhelmingly strong theme was the importance of 'knowing the person' in order to provide the most suitable treatment and care. A person-centred approach was universally acknowledged as essential for identifying unique individual pain behaviours and for detecting and interpreting changes in a resident which may indicate pain (Table 1). Participants also championed an individualised approach to treatment, highlighting specific challenges such as intolerance to specific medication, impaired swallowing and personal preferences, such as a lifelong avoidance of pills or dislike of needles as reasons for treatment resistance. There was a consensus regarding the key role of family members, although participants highlighted the challenges involved in this relationship (Table 1). Care staff identified instances where a family member's recommendations conflicted with their own experience and observations. Family members reported mixed experiences of contributing to care planning, with many expressing frustration at 'not being heard'.

Communication at the core of pain management

There was a consensus amongst all focus groups that communication is central to pain management, and yet that communication is often challenging within the context of dementia. The central communication types were verbal and non-verbal cues from residents where cognitive and communicative impairments were raised as major barriers (Table 1). A complex network of communication channels in care homes also emerged. In the majority of homes the clearest communication framework for pain reporting was from care assistant to nurse. This route appears to function effectively in a unidirectional manner. It was less clear whether information flows as readily from nurses to care assistants. Staff clearly identified that their most critical communication forum was the handover meeting, involving verbal and written exchanges. The extent of ad-hoc communication amongst staff during a shift was less clear-cut. The importance of communication with primary care was also raised, predominantly in the context of requesting an analgesic prescription (Table 1).

Family members were key players within the pain management communication network, with participants highlighting events that required close working between family and care staff.

These included family reporting of pain and instances where family was involved in treatment and care decisions. Discussions highlighted that this relationship can often be fraught where miscommunication leads to confusion or misunderstandings.

Awareness of pain and the need for staff training

An emerging theme was the importance of pain awareness amongst care home staff, and a consensus that this is currently inconsistent (Table 1). Family members gave accounts of having prioritised pain as an issue, and one which occurred regularly. There was an impression amongst family members that this level of awareness was absent in care homes. Care home staff reports were consistent with this, with few participants feeling able to describe detailed pain assessment protocols or instances where pain was a high priority. A strong message arising from all discussions was the need for training in pain management in order to raise awareness amongst care staff (Table 1). No participants had received training in pain, either in a general setting or in the context of dementia, with the exception of nursing qualifications held by the nurses.

Responsibilities for pain management and staff confidence

Care staff groups appeared to agree that there was a finite role for care assistants, extending only to reporting pain in the first instance, at which point the responsibility devolved to the care home nurse. Nurse reports concurred with this where discussions were heavily focussed on pharmacological treatment. However, there appeared to be a gap in responsibility for ongoing monitoring and follow-up. Family members felt they played a key role in addressing areas where they felt care staff input was lacking, particularly in reporting pain, seeking follow-up and changes in treatment, and in providing non-drug treatment (Table 1).

All participants described a lack of confidence among care staff, particularly those in more junior roles, to take a proactive stance on pain. There was a particular subtlety in this issue since many care staff were able to describe how they might identify pain but appeared to lack the confidence to take ownership. There was an overall consensus that in addition to training, there was a need for more leadership and structure within the home to encourage and support staff to take more responsibility for pain management.

Consistency of care

Family members reported a concern regarding the inconsistency of care, both within individual homes and across the care sector (Table 1). Participants reported having witnessed examples of excellent pain management in rapid succession to instances of poor practice. Participants

agreed that the training, leadership and proactive stance on pain would be essential factors in ensuring greater consistency.

Interestingly, discussions with care staff often revealed other areas with clear protocols and consistency. Participants agreed that there was a need to include pain as a key outcome for homes to monitor in order to reach this status. Many felt that the motivation to accomplish this would best be achieved through the CQC and inclusion of pain in national care home standards.

Quality review of existing pain guidance

14 guidance documents were identified that fulfilled the inclusion criteria (Table 1). Six provided brief pathways for pain management, often restricted to pharmacological treatment of a specific pain type (2013c, 2013e, 2013, 2012b, 2013d, Horgas, 2012, Flaherty, 2012). Seven provided extensive policy-based guidance, focussed on a specialist audience (2007, Rasmussen, 2014, 2002, 2009b, Abdulla et al., 2013, 2005, 2012a). When subjected to quality analysis there were clear areas of weakness (Table 2). Of the 14, three were designed for use in dementia, and none for care home settings. None reported robust evidence of effectiveness in managing pain. Three did indicate some preliminary evaluations, including an implementation programme in five Australian care centres with staff-related outcomes but no assessment of pain (2005), an unreferenced statement of effectiveness (2012b) and reports of validation work for non-pain-related sections of a more general report (2012a).

Expert panel recommendations

There was consensus amongst the expert panel on the need for training and accessible guidance for care homes. The panel also identified gaps in pharmacological pain management and recommended candidates for evaluation in clinical trials. The panel focussed on the lack of alternative analgesics in cases where paracetamol is not effective, and where escalation to an opioid is not advisable. Preliminary literature was cited for the safety of COX-2 inhibitors namebutone and celecoxib in people with established inflammatory pain where there are no contraindications of gastric sensitivity (Everts et al., 2000) and for dextromethorphan, currently licensed as a cough suppressant (Weinbroum et al., 2000).

Discussion

This study provides novel perspectives and data illustrating the current landscape of pain management in people with dementia living in care homes. Thematic analysis revealed the subtleties and challenges involved, with six major themes emerging: the importance of person-

centredness, the need for pain awareness in staff, miscommunication among staff and carers, lack of confidence and responsibility, inconsistency of care and need for staff training (Figure 2). Despite several examples of good practice focus group discussions clearly revealed inconsistencies in each of these areas, with a lack of formal structure and support for staff, a severe lack of staff confidence and awareness, insufficient communication networks and disparities in priority-setting and motivations, particularly between staff and family members. A need for structure and training was clearly articulated.

These findings are consistent with the outcome of the review of existing guidance, which highlighted the absence of evidence-based, accessible guidance for pain management in care homes. Detailed policy- and clinically-focussed documents provide valuable in-depth accounts of the field but are largely inaccessible to non-specialist audiences and lack practicality for implementation of their recommendations. Several brief, user-friendly pathways primarily focus on pharmacological treatment and specific pain types, such as neuropathic or cancer-related pain and are best suited to clinical use in acute care settings. Conversely, one public-facing campaign provides guidance and resources for pain assessment but does not consider treatment. Critically, although several guidance documents are designed for older people, only three were specifically tailored for people with dementia, and none were for use in care home settings.

The findings of this study clearly highlight the need for a tailored, evidence-based guidance package to support pain management in care homes, which is accessible to all key stakeholders, but particularly for care staff. In order to embed any guidance in practice there is also a call for evidence-based training for staff. These initiatives would require evaluation through complex trial methodology to ensure they resulted in improved overall pain management. Importantly, in order to avoid replication of the failings of existing resources, any intervention will need to be both based on stakeholder input and embedded in a conceptual framework that considers the specific care home environment and the unique challenges of dementia. This study revealed considerable lack of confidence and culturally engrained beliefs and behaviours amongst care home staff. For any intervention to be successful it must also consider behaviour change theory in order to empower and motivate this workforce.

The study highlights the current limited nature of pain treatment in this patient group. Despite recognition of the value of non-drug approaches and advocacy of these interventions by family members, these are not routinely used. This is of additional concern since pain is an established underlying cause of many BPSD which may be preventable through prompt use of simple measures. Stakeholder consultation clearly revealed a reliance on administration of

paracetamol in the majority of cases, without consideration of actions that could address pain without recourse to pharmacological intervention. This is a particularly critical issue given the risk of polypharmacy in dementia.

In cases where pharmacological intervention is warranted the options available to prescribing physicians is clearly limited. Beyond the first-line use of paracetamol prescribers usually escalate to the opioid derivative buprenorphine and other opioids. The expert panel highlighted a number of potential candidates to fill this gap which warrant further investigation. Preliminary work has shown promising outcomes from the use of dextromorphan in older adults, and a number of COX-2 inhibitors raise the possibility of an anti-inflammatory treatment that avoids the most common adverse effects of these agents. Future research should consider the potential value of these and other less commonly used analgesics.

This study has provided clear indications of the challenges and opportunities for pain management in people with dementia in care homes, with a valuable mix of qualitative analysis, literature review and consensus finding. One limitation should be highlighted. This was a small study with limits on the number of participants involved. However, the addition of an online survey ensured redundancy was reached in the emerging themes and the authors are confident that major themes and sub-categories were captured. In addition, it should be noted that some outcomes may be specific to the regional location of the focus group discussions, particularly the use of specific pain assessment scales. However, the overall themes and findings are likely relevant across UK care home settings. There may have been bias in the nomination process used to identify care staff participants by managers. Future work is needed to build on these findings and establish how pain management functions in real-life settings, in addition to exploring the effectiveness and feasibility of an evidence-based pain management programme.

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Table 1: Illustrative quotes of key emerging themes from care staff and family carer focus groups

Theme	Quote
Assessment of pain by staff and family through observation of behaviour	<p>"You can feel the pain with the way they express it non-verbal. Perhaps when you try to lift the hand, the... that they could be having pain in their hand, or things like that."</p> <p>"She became very challenging and then I got complaints about your mother's challenging behaviour. Okay... this? And when they told me how they were dealing with it. I said, "Well if you keep doing it like that you're... behaviour because she's in pain." "But how do you know that?" I said "Well, because I know her. She's m..."</p>
Importance of knowing the person	<p>"So there are different ways, but you have to know your residents - that's the major key - apart from using... however, you still need to know them."</p> <p>"First you want to see what she wants, because she's the one who can feel the pain. It has to be what she..."</p> <p>"But I think if you're used to being with someone, and you're used to watching someone, you can pick up..."</p> <p>"I think finding out the person's history with pain. How have they dealt with pain during their life?"</p> <p>"The biggest obstacle is lack of time given to patients whether home carers or in a care home setting. Ge... will expedite the best options to offer including non-drug approaches."</p>
Family carer reports of use of non-pharmacological approaches to address pain	<p>"Well, I'm thinking for people who have been sat in one position for a long period of time, they've got a sti... something - all you need to do is get them up and walk them around when it hasn't occurred to the patient... because he couldn't."</p> <p>"Maybe it's more important that the person who's struggling to give you this drug, to spend more back time... you got a headache but it's all right. It's going to get better."</p> <p>"Maybe paracetamol, maybe wandering around, maybe putting on some music - as a sort of calming influ..."</p> <p>"Some things like when they're enjoying their music, the level of pain reduces. It can help"</p>
Care staff recognition of value of non-drug approaches	<p>"I think it will help to a certain degree, but not 100%. Like this lady, she always have it like once or twice a... patch as well. She'll hardly take her medication. It will be a force. We'll do all kinds of-- and when she refu... think maybe with the massage, maybe it's helping her a bit"</p> <p>"Exercise, yeah. Maybe a dentist. It's not necessarily prescribing anything, but it's more specific than just... comfortable"</p> <p>"Some of our residents, they use aromatherapy and massaging. It relaxes them "</p>
An individualised approach to treatment and challenge of treatment resistance	<p>"Sometimes the pain management is very different as well because some of them, they don't want to take... them to take it."</p> <p>"They can be lashing out, and if you've got a needle-- you can end up with a needle sticking through-- so... easy."</p> <p>"We all need to find a way to provide medication in a way it's acceptable to people - but also a way to cor... it is that they take it."</p> <p>"It's called loving. I ground them down and put them in some honey or something sweet. She had a sweet..."</p> <p>"She would often hid them in her mouth and then hide them under the bed, down sides of a chair or in a c... what the pill is for and some people with dementia become suspicious of medication, especially if they ha... medication before dementia."</p>
Reliance on pharmacological treatments	<p>"You can only give so much painkiller... you can only give so much paracetamol in a day. Usually I find it's... next lot of painkillers, that is when it kicks in - that's when it will kick in."</p>
The key role of family members in pain management	<p>"We asked the son, "Your mum, any time she tries to drink she's always coughing. Is that how she is?" or... anything wrong?" She said, "No. If she coughs, then there must be something that is wrong"</p> <p>"Often he'd been sat like that holding in front of his head, so then that would alert me to go to the nurse a... have his analgesia?" It had often not been given with the regularity that it was necessary, so the staff mig... physical signs that I could recognise, because he couldn't always tell us."</p> <p>"It's vital that they do know and work with us relatives so that they can notice changes in behaviours and... change in the behaviour."</p>
Care staff reporting conflict between their experience and family's opinions	<p>"I know that they know their loved ones better than we do, but in this situation we feel that going into hosp... interests."</p> <p>"It's a bit complicated. They come and tell you something now. Then another family member comes and t... tricky when it's like that because you don't know which one to pick. We listen to whatever they tell us. We... with them as much as we can. "</p> <p>"You're a completely different person, than when you are with the family, and that's what family's forget. T... is now with carers, even though it's not jealousy, and also relatives will think, that you can't look after my..."</p>

Family members expressing frustration at 'not being heard'.	<p>"They asked me, "Tell me about your mother." "She played golf." "Oh yes, we have one of the sisters who all this went down, and I thought, "That's nice , they'll be able to chat to her about golf" and she was in bu it was completely ignored."</p> <p>"Yeah not believing families when they tell you they know that your loved one better than the care home p</p> <p>"You could get my mother to do anything if you made her laugh. And I kept saying this, but of course they</p>
Close working between family and care staff.	<p>"A simple thing like that, and that's why she ended up coming in, because she kept forgetting a simple thi nothing written in her papers at all, but that's a good example of listening to the relatives, and they really. her shoes, or she'll fall over, and she did"</p> <p>"Does touch come in, do they have touch--- that seems to be an area where potentially carers could help some stranger but if it's somebody you love"</p>
Cognitive and communicative impairments as major barriers.	<p>"Most of them, they can't express because they don't talk, so you don't know where is really painin them from"</p> <p>"Mostly, the person is not able to communicate and express them. So that's the agitation coming out, rea frustrated."</p> <p>"I'd say it would be nonverbal communication, because if you actually speak to them, they may tell you so they're not cognitively aware."</p> <p>"We had a huge problem of, "Where does it hurt?" And describing that because the vocabulary had gone to work out-- the connected thinking had gone."</p>
Communications patterns between care home staff	<p>"The nurse is the one who will make the ultimate decision because it's a clinical issue... So they [the staff observed"</p> <p>"They would come and report it not write it down."</p> <p>"These carers they really know their residents. And we work together. She is fairly new but she's working notes, reading the handover, she picks up what is happening"</p>
The importance and differing experiences of communication with GPs	<p>"I think our GPs are very, very good. You can sit with them. We know the residents more than they do, so they with their professional level will then let us know if this is the right measures or not the right measure</p> <p>"If the GP knows the resident, they will trust the staff"</p> <p>"My biggest challenge was getting through to the GP, the GP to change the prescription for the care hom prescription and my father to be given his meds three or four times a day, whatever"</p>
Family carers believe pain awareness is lacking in care home staff	<p>"Too often, the person that has dementia, the carer dealing with them will put whatever they are going thr behaving, down to the dementia. And not even think that it could be pain problem."</p> <p>"They said he had no abnormal behaviour and yet he was sitting there - I've never seen anyone grind the</p>
The need for training in pain management	<p>"Every training helps, doesn't it? For us to be more knowledgeable. I'm just trying to think back, to when y They do the types of dementia, but I don't think they actually cover pain within dementia."</p> <p>"I'm wondering whether there is a need to-- probably not train everyone in the neuroscientific subtleties of people understand these different types of pain, and what might cause them. So when you see people or go up in your mind, thinking, oh actually that could be linked to pain, even if it's not immediately obvious"</p> <p>"So they've got to be trained because they're at the front of everything"</p> <p>"Trained to observe. That's the point - training."</p> <p>"I think it should be a requirement that all care assistants in care homes for dementia are trained in all asp to look for and how to approach and deal with it with someone who has dementia."</p>
Responsibilities and confidence amongst care home staff	<p>"If somebody is in pain and they're lashing out. The person who's in charge, we'll call them, and maybe th</p> <p>"Even in residential care homes, they don't have peer support. They to go in and do an eight hour shift. T actually chew over "How do we feel about what happened today?", "How do I feel about how aggressive her fault"</p>
Family members playing an active role in pain management	<p>"Yes, and how I would be able to tell that he needed something and to what level. But I felt a duty to chec time I visited, because the different staff on, insufficient staff to even be checking. So I would check his m</p> <p>"I used to get a phone call, "He isn't taking his medication this morning," so then I had to go in and talk to from me because he knew and trusted me."</p> <p>"Control of medication was poor. She was often in pain but not given any pain relief until I arrived and der</p>
Family carer reports of inconsistency of care in care homes	<p>"If we could find one of this good ones, they would be an absolute joy, but they don't exist everywhere. I t country where there's nothing."</p> <p>"In this home I'm talking about, there were some excellent carers and I could go home and sleep at night unfortunately they need a break like everybody else."</p> <p>"The fact that there was so much variability of the carers and the way that they give care"</p>

Family carer views on drivers of change and improvement	<p>"So, it must be on the care plan checklist on a daily basis instead of, "Has so and so had a bath? Has so and so had their dinner?" It should also be are they in pain?"</p> <p>"And, what's expected and get it integrated into the CQC or whoever it is, DP. It should be part of the assessment."</p> <p>"And I suppose another another way of doing it would be actually making sure that the public know about it. In care home, you chose the ones that are using the right method... So if people know about it and are choosing it, then eventually it's going to potentially get people to think that it's worth having."</p>
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Table 1: Summary of existing pain management guidance documents

Document	Publisher	Target population	Setting	Summary of content	Development process and evidence
Assessment of Pain in Older People 2007 (2007)	Royal College of Psychiatrists British Pain Society British Geriatric Society	Older People including cognitive impairment	All	Comprehensive guidance and pain assessment pathway. Stepped assessment according to cognitive impairment. Recommended Abbey scale and various self-report Visual Analogue / Numerical Rating scales. No treatment or overall care guidance.	Developed by experts to RCPsych guidelines. Full systematic review, evidence-based clinical review.
Neuropathic Pain Guidance 2014 (2013c)	National Institute of Clinical Excellence	Neuropathic Pain	Non-specialist and specialist settings	Pain management pathway for treatment of neuropathic pain. Accompanying in-depth guidance. No guidance on	Full NICE expert panel review, systematic clinical review.

				assessment, dementia or care homes.	
The Management of Persistent Pain in Older Persons / Update for Pharmacological Treatment 2002 / 2009 (2002, 2009b)	American Geriatric Society	Older Adults	All	Systematic review and guidance for assessment and treatment. Includes stepped, rated guidance according to quality of underlying evidence.	Full review referencing
Guidance on the management of pain in older people 2013 (Abdulla et al., 2013)	British Geriatrics Society	Older Adults	Any care setting	Extensive systematic review of epidemiology of pain in older adults, assessment and treatment options. Full review of pharmacological and non-drug approaches. No summary guidance for use by practitioners	Full system with external referencing
Guidance on the recognition, assessment and management of pain in people with dementia 2014 (Rasmussen, 2014)	MGP & Napp pharmaceuticals	Dementia	Primary care, community & carers	Extensive review and guidance with a focus on practical aspects of management. Recommendations for entire pathway, including several assessment scales and escalating pharmacological treatment	Fully referenced developed
Pain in Residential Aged Care Facilities: Management Strategies 2005 (2005)	The Australian Pain Society	Older adults including non-communicative individuals	Long-term care / nursing home	Extensive overview of pain management issues and strategy in care settings. Recommendation for use of Abbey / PAIN-AD or CNPI with self-report. Review of pharm and non-pharm approaches including physical therapy / complementary therapy / psychological-educational. 27 overall guidance points	Written by panel Informed by best practice guidelines resources Focus on studies and guidelines
Pain Patient Pathways 2013 (2013e)	British Pain Society	General	Primary & Secondary Care	Stepped management pathway with detailed guidance for clinicians. No inclusion of people with dementia / care homes but basic info on working with cognitive impairment. Each includes specific differential diagnoses, medical history factors, red flags and recommended assessment tools for the pain type. Neuropathic pathway has close similarity with NICE guidelines for assessment but key additions to treatment recommendations incl	Developed by Medicine and independent reviewers practice-based from clinical

				first-line gabapentin/ carbamazepine, use of topicals, judicious use of opioids.	
'Best care for older people everywhere: The Toolkit 2012' 2012 (2012a)	Australian Dept of Health (Victoria State)	Older adults	Acute care	259-page guide to old-age hospital care including a section on pain. Recommendations for self-report and observational assessment (PACSLAC, PAIN- AD, Abbey, NoPain) tools. Brief guidance on pharmacological treatment. No overall pathway for practice.	Developed hospital care through: - Litera - Surve staff a resou - Ident review - Final exper Pain asse guidance AGS Pan Australia guideline
Cancer Pain Ladder 2012 (2012b)	World Health Organisation	Cancer	All (acute)	Brief three-step analgesic ladder for cancer pain, recommending escalation from non-opioid (paracetamol, NSAID, aspirin) to weak opioid (codeine) to strong opioid (morphine). No assessment guidance or overall care. Not specific to older adults, dementia or care homes	Developed No details
Pain Management Documents 2013 (2013d)	Wiltshire Clinical Commissioning Group	Adults	Non- specialist	Stepped pathways for non- cancer and neuropathic pain. Recommendations for general pain assessment tools. Guidance for escalating pharmacological treatment including opioids, buprenorphine patch and neuropathic pain treatments. Also including brief non-drug approaches	Developed NICE gui BPS guid specific re
Assessing Pain in Older Adults with Dementia 2012 (Horgas, 2012)	Alzheimer's Association Hartford Institute	Dementia	Nursing	Brief summary of rationale and challenges of management in dementia. Recommended use of PAIN-AD tool with item descriptions. No guidance on treatment or overall care	Brief limit review for PAIN-AD on review methodolo design pr
Assessing Pain in Older Adults 2012 (Flaherty, 2012)	Hartford Institute for Geriatric Nursing	Older Adults	Nursing	A/A but for adults without cognitive impairment. Recommended self-report tools (VAS, NRS).	A/A
Neuropathic Pain Treatment 2013 (2013)	Gloucestershire Hospitals NHS Trust	Neuropathic Pain	Acute care	Stepped treatment pathway with online links to additional guidance on assessment and general pain treatment. First-line treatment Amitriptyline	Developed NHS Trus BPS and guidance
See Change Think Pain (2015)	Napp /Alzheimer's Society	Dementia	All	Commercially produced campaign promoting recognition of pain by all. Simple forms for completion by professionals and family. Mnemonic. No treatment recommendations. Dedicated website.	No clear process. indicates of indepe (Rasmus

Table 2. Summary of quality scores for existing pain management guidance for older adults. Items are scored according to whether guidance fulfils (green), partially fulfils (amber) or does not fulfil (red) the criterion

[illegible]

Method of data extraction is specified														
Expiration date / review date is specified														
Time period from which evidence is reviewed is specified														
Method for grading of classifying evidence / expert opinion are used and described														
Role of value judgments used by the guideline developers in making recommendations is discussed														
Recommendations are graded according to the strength of the evidence														
Effect on healthcare costs from specific health practices is specified														
Benefits and harms are quantified														
Costs are quantified														
General total (/24)	21	20	18.5	18	14	12.5	11.5	11	9.5	9.5	7.5	7	4.5	4.5
Targets older adults														
Targets people with dementia														
Targets care homes														
Published evidence of evaluation / implementation														
Study-specific total (/5)	0.5	2.5	1.5	1.5	2.5	0.5	2	1.5	0.5	2.5	0.5	1	2.5	1
Overall total (/29)	21.5	22.5	20	19.5	16.5	13	13.5	12.5	10.5	12	8	8	7	5.5

Supplementary Table 1 Online survey for family carers

	Question	Response type
1	Did / does the person you care for live in a care home?	Yes / No / Respite Care only
2	Did / does this person have known conditions or injuries that could cause pain? (for example: arthritis, diabetes, an old injury)	Yes / No
3	How well do you believe pain is managed in care homes, in your experience?	Very Well / Fairly Well / Not well at all
4	Why do you think this is?	Free Text
5	Assessment of pain is very difficult in people with dementia because they cannot communicate that they are in pain. What are the important signs to look for to know someone is in pain?	Free Text
6	A person who is in pain may be prescribed a regular painkiller. In your experience are there any practical problems or difficulties involved in giving analgesic drugs to a person with dementia? (Please note – we are not asking you to give medical details, but practical challenges you may have experienced)	Free text
7	In your experience should non-drug approaches (music, massage, social interaction) be used to address pain in people with dementia?	Yes / No
8	How do you think pain management should be included in overall treatment and care?	Free Text
9	How could family be involved in decisions around pain management in people with dementia?	Free text
10	Do you have any other comments or information you would like to contribute to the study?	Free Text

Figure 1 Current pain management pathway in UK care homes

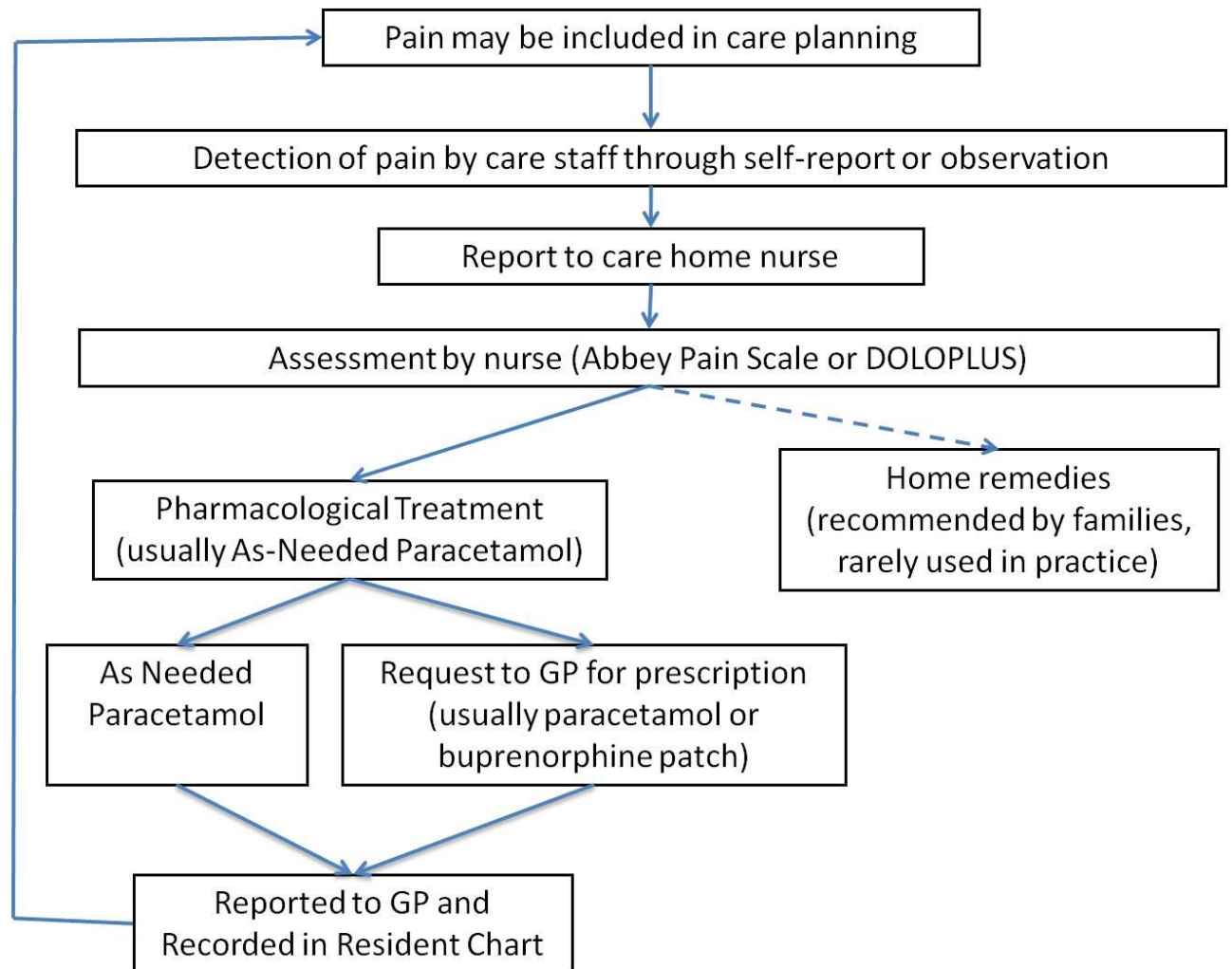
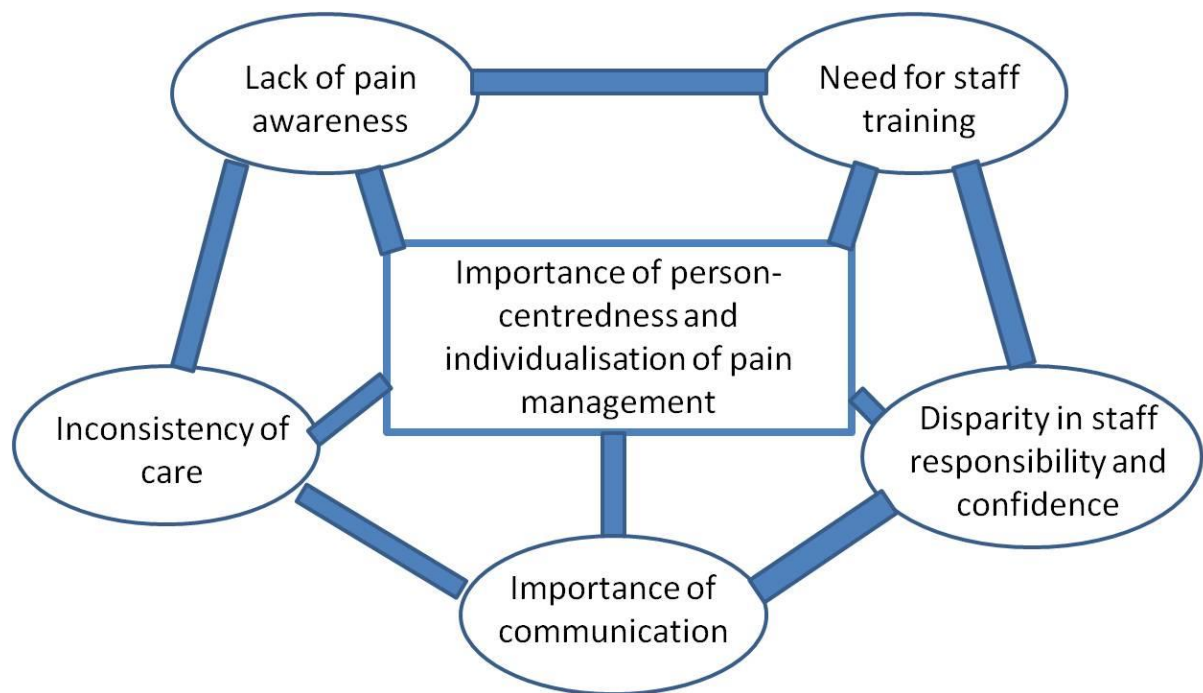


Figure 2 Six major pain management themes emerging from focus group discussions



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