

**Staff Training to Improve Pain Care in Dementia:
A Feasibility Study in Care Homes**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This thesis examines the problem of pain under-treatment in older adults, particularly those with dementia, and explores the role of staff training in improving pain care practices. Part 1 is a literature review of educational interventions to improve pain management in residential care settings. This review explores the impact of educational interventions on pain care at three levels: staff competence; clinical practice; and patient outcomes. There is also consideration of the relevant barriers to implementation of staff training interventions.

The main body of the thesis is Part 2, which is an empirical study examining the feasibility of a training intervention for care staff. The training focuses on enhancing beliefs of personhood in dementia alongside education in current best practice for assessing pain. The effects of the intervention on pain care practices and residents' pain are examined, in addition to evaluating the influence on staff knowledge and beliefs. Acceptability of the intervention design and feasibility of study processes are also explored.

The empirical paper is followed by Part 3, which is a critical appraisal of the work undertaken. A reflection on the process of delivering the training intervention is provided, with further consideration given to the barriers to change in pain care practices and wider challenges to conducting research in care homes. Successful strategies for mitigating barriers are discussed, and recommendations for future research are provided.

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Part 1: Literature Review

Can Educational Interventions for Care Home Staff Improve Pain Management in Older Adults? A Systematic Review.

Abstract

Background: Pain is under-recognised and under-treated among older adults living in care homes. Knowledge, beliefs and attitudes of caregivers can significantly affect pain care provision. Therefore, educating care staff on pain assessment and treatment is potentially valuable. This review aimed to establish the effectiveness of educational interventions on pain management for staff in care settings, and any barriers to implementation.

Method: A systematic literature search identified 1069 potentially relevant publications. Ten studies, published between 2000 and 2014, met the inclusion criteria and were included in the final review. Quality of studies was rated using pre-specified criteria.

Results: Overall the quality of studies was found to be poor. Nine studies reported a significant change in at least one domain, with the main focus on increasing staff knowledge or change in pain care practice. Only two studies reported a significant decrease in resident pain. No clear pattern between intensity and content was observed, but multifaceted studies may be more successful in achieving change in clinical practice. Four categories of barriers to implementation were observed: 1) resource constraints, 2) organisational culture, 3) communication, and 4) attitudes and beliefs.

Conclusions: Staff education can improve aspects of pain care for older adults in residential care settings, although effects of interventions were variable and methodological limitations negated clear conclusions. A greater emphasis should be placed on obtaining outcomes of residents' pain in future research.

Pain in Older Adults

Pain is common among older adults, with between 20-46% of older people in the community estimated to be experiencing pain at any one time (Abdulla et al., 2013). Among older adults in care settings the prevalence estimates are much higher, ranging from 28–73% for current pain (McClean & Higginbotham, 2002; Tsai, Lai, & Chu, 2004; Asghari, Ghaderi, & Ashory, 2006; Boerlage, van Dijk, Stronks, de Wit, & van der Rijt, 2008; Reis, Torres, & Reis, 2008; Achterberg et al., 2010) and 83-93% for chronic (i.e. persistent) pain (Weiner, Peterson, Ladd, McConnell, & Keefe, 1999; Boerlage et al., 2008; Zanolchi et al., 2008).

It is widely acknowledged that pain is under-recognised and under-treated in older adults, particularly those living with dementia (Hadjistavropoulos et al., 2014; Horgas & Tsai, 1998; Sengstaken & King, 1993). The degree of under treatment can be substantial, with one survey of over 13,000 nursing home residents finding that over a quarter of those with daily pain received no analgesics (Bernabei et al., 1998). Another study in a hospital setting found that most elderly patients received inadequate pain treatment, and even in a postoperative context where pain is a predictable outcome, a quarter had no standing prescription for analgesia (Morrison & Siu, 2000).

The consequences of untreated pain in older adults are wide-reaching and include greater limitations in activities of daily living (Cadogan et al., 2008; van Herk et al., 2009), poorer appetite (Bosley, Weiner, Rudy, & Granieri, 2004), sleep disturbance (Giron et al., 2002) and reduced quality of life (Asghari et al., 2006; Zanolchi et al., 2008; Torvik, Kaasa, Kirkevold, & Rustøen, 2010). Pain has also been found to be strongly associated with depression and anxiety (Bartels et al., 2003; Jongenelis et al.,

2004; Smalbrugge, Jongenelis, Pot, Beekman, & Eefsting, 2007), and with behavioural disturbances in older adults with dementia (Husebo, Ballard, Sandvik, Nilsen, & Aarsland, 2011); Sampson et al., 2015).

Although the problem of under-detection of pain in this population has been widely documented and discussed, the Care Quality Commission (CQC), which is the government regulatory body for care homes, currently has no standards for pain care and it is not part of their current inspection. Therefore, pain care can vary greatly across care homes in the UK, the majority of which are independently owned (Napp, 2014).

Challenges of assessing and treating pain in residential settings

There are numerous reasons why effective pain management is a problem in care settings. Self-report is held up as the gold standard of pain assessment, but relying on self-report can be problematic when assessing pain in older adults due to the high prevalence of sensory and cognitive impairments, and pervasive attitudes that may lead to under-reporting. Other barriers to adequate pain care in these settings include caregivers' inability to perceive and accurately assess pain due to inadequate staffing, gaps in knowledge, and unhelpful beliefs about pain and aging.

Under-report by residents

There is evidence that older adults are often reluctant to report or discuss their pain due to stoicism and beliefs that pain is a natural and inevitable part of aging (Hess, 2004; Schofield, 2006; Boerlage et al., 2008). Other barriers to self-report cited by older adults include concerns that reporting pain may result in admission to hospital (Brockopp, Warden, Colclough, & Brockopp, 1996), and not wanting to take medication

for fear of addiction (Hadjistavropoulos & Craig, 2004; Martin, Williams, Hadjistavropoulos, Hadjistavropoulos, & MacLean, 2005). Societal attitudes can also influence decisions not to report pain, as pervasive beliefs about pain being part of old age lead to perceptions that older people are expected to simply endure pain and that expressions of pain are seen as analogous to ‘whining’ (Martin et al., 2005).

One study of over 2000 nursing home residents found that more than half of those reporting pain had not requested medication (Jones et al., 2006); residents reported not requesting medication due to concerns about how staff may respond, or perceptions that they were too busy. Qualitative research into attitudinal barriers has also shown that residents may not report pain for fear of being labelled a ‘bad patient’, and highlights the role of specific pain beliefs, for example that chronic pain has little potential to change (Cairncross, Magee, & Askham, 2007; Weiner & Rudy, 2002; Higgins, Madjar, & Walton, 2004). In a recent collaborative project between the British Pain Society and Help the Aged these sorts of beliefs, as well as evidence of internalised ageism, were highly apparent in older people’s accounts of their experiences of pain (Kumar & Allcock, 2008).

Influence of caregiver attitudes and beliefs

Inaccurate beliefs of caregivers may be one reason for under-detection and under-treatment of pain. One study found a large proportion of nurses in residential homes thought that it was more appropriate for residents to be prescribed analgesics on an *as-needed* basis, rather than a fixed schedule (Cramer, 2000). This approach is likely to lead to under-treatment, especially in dementia, if people are less able to report pain or request medication. Similarly, another study reported evidence of key deficits in

nurses' knowledge of effective pain care, despite staff reporting being satisfied that pain was accurately assessed and treated in their nursing home (Zwakhale, Hamers, Peijnenburg, & Berger, 2007).

Health care professional attitudes about pain can significantly influence their provision of care (Darlow et al., 2012). Myths about pain and aging are prevalent among care staff (Martin et al., 2005; Sloman, Ahern, Wright, & Brown, 2001). In one study 26% of nurses said they did not think residents should necessarily be in a pain free state (Mrozek & Werner, 2001). Such attitudes, which are in line with older adult's beliefs that pain is an unavoidable part of aging, are likely to greatly increase the risk of under-detection of pain.

Another important factor is that caregivers' ratings of residents' pain do not always correlate significantly with administration of pain medications (Kaasalainen et al., 1998). An experimental study (Katsma & Souza, 2000) using unambiguous vignettes of pain found that less than half of long-term care staff indicated that they would advocate increasing analgesic dosage, even though most assessed pain correctly. Possible reasons for under-treatment of pain include a lack of confidence in the reliability of the pain assessment (Clark, Fink, Pennington, & Jones, 2006), reluctance to administer medications due to concerns about side-effects, overdose or addiction (Kaasalainen et al., 2007; Tarzian & Hoffmann, 2005) and empathy burnout (Katsma & Souza, 2000).

Organisational factors

Poor pain management practices may also be due to the environment and culture of residential care settings. Homes rarely have a standardised organisational approach to pain management (Allcock, McGarry, & Elkan, 2002; Tarzian & Hoffmann, 2005), and there is often poor communication across disciplines (Martin et al., 2005). Most residential facilities do not have a dedicated physician, and residents report that they see their GP infrequently and often do not feel involved in decisions about their pain care (Cairncross, et al., 2007).

Inconsistent care due to high staff turnover and staff shortages are cited by staff as a key barrier to effective pain care in this setting (Kaasalainen et al., 2007; Weiner & Rudy, 2002). Lack of time and staff shortages may mean that reports of pain can often go undocumented or residents are not asked about pain (Cairncross, et al., 2007; Cohen-Mansfield & Lipson, 2002). One UK study in 24 nursing homes found that less than half of residents reported staff asking about their pain and perceived time pressures on care assistants to be the main cause (Cairncross, et al., 2007).

The majority of direct resident care is conducted by care or nursing assistants, who have little or no training in pain management (Allcock, et al., 2002; Mozley et al., 2004). One of the few UK based studies found that 44% of nurses and 85% of care assistants had received no training on pain management in older people and, despite there being several observational pain assessment tools available, 75% of homes reported that they did not utilise any (Allcock et al., 2002). Managers in care homes are often unaware of current evidence-base practice in pain care, and their decisions and policies may be influenced by outdated or inaccurate beliefs (Barry, Parsons, Peter Passmore, & Hughes, 2012).

Educational programmes to improve pain care

Given the evidence that gaps in knowledge and caregiver attitudes and beliefs act as a barrier to effective pain care in residential homes there have been many calls for focused educational interventions for staff (Katsma & Souza, 2000; Tsai, Lai, & Chu, 2004; McConigley, Toye, Goucke, & Kristjanson, 2008; Alexis, Talusan, & Chen, 2009; Tse, Leung, & Ho, 2012). Improved education is identified by caregivers as key to improving pain care practices (Martin et al., 2005), and even health care professionals who have significant experience working in care settings identify pain assessment as a significant educational need (Tousignant-Laflamme et al., 2012).

Educational programmes have the potential to challenge ageist notions (Cowan, Roberts, Fitzpatrick, & While, 2003) and modify attitudinal barriers (Dobbs, Baker, Carrion, Vongxaiburana, & Hyer, 2014). They can also correct misinformed beliefs, target gaps in knowledge, and promote use of the available pain assessment tools (Achterberg et al., 2013). However, formats of educational interventions can differ greatly, from the provision of written information to long-term individually tailored programmes, and have varying degrees of effectiveness on behaviour change (Grimshaw et al., 2001). A recent Cochrane review, which examined 81 educational training interventions for healthcare professionals, found mixed interactive and didactic methods were more effective in improving both clinical practice and patient outcomes, compared with interventions that used either alone (Forsetlund et al., 2009).

It is also useful to distinguish between the different levels at which interventions can be implemented in order to effect change: staff competence; clinical practice; and patient outcomes, such as pain (Forsetlund et al., 2009). Multifaceted interventions,

which act at different levels, have been shown to be the most effective (Grimshaw et al., 2001).

Existing literature reviews

Two existing reviews have examined the effectiveness of pain interventions in residential care settings. Herman, Johnson, Ritchie and Parmelee (2009) examined the literature on pain management interventions delivered in nursing homes, including therapeutic interventions for residents and staff programmes. The review of 21 studies reported that fourteen targeted staff and twelve involved an educational component. The heterogeneity of interventions and outcomes measures, alongside widespread methodological weaknesses, made it difficult to draw clear conclusions regarding effectiveness. It was noted that many studies measured process endpoints, such as improved documentation of pain assessment or staff knowledge. Whilst these outcomes can be useful indicators of effective pain care they should ideally be used in addition to direct measures of residents' pain levels and not as a substitute.

Similarly, Swafford, Miller, Tsai, Herr & Ersek (2009) reviewed many of the same studies as Herman et al. (2009), but focused on the improvement of pain care processes, such as implementing new frameworks or decision support tools. Of 10 studies reviewed, the majority were classified as quality improvement (QI) initiatives, which are usually smaller-scale projects using a research-audit cycle design. All studies had an educational component, but these varied considerably in terms of format, intensity and target audience and were generally one part of a multicomponent

intervention. Findings suggested that implementation of organisational changes and decision-support algorithms can be effective, particularly in the context of continuous evaluation and feedback of the targeted outcomes.

Both existing reviews highlighted the difficulty in establishing the effectiveness of individual components such as education and raised methodological concerns. Also, while the existing reviews provide useful information about interventions targeting care staff, neither examined the barriers or facilitators to implementation of interventions in residential settings.

Current literature review

There has been no review to date which has specifically investigated educational training programmes for increasing the skills of care staff in providing effective pain care in residential settings, and potential barriers. The current review aims to update the previous reviews, which only included studies published up until 2007, but will focus specifically on educational interventions targeting care staff.

Literature review questions

This review addresses the following research questions:

- (1) Can staff education improve pain care for older adults in care settings?
- (2) Do the effects of interventions vary according to the content, intensity, or format of the educational programme?

(3) What are the barriers and facilitators to implementation of staff education interventions focusing on pain management in care settings?

Method

Search strategy¹

A systematic literature search was conducted using PsychINFO, PubMed (MEDLINE), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the Cochrane Library in February 2015. In addition, citation searching was conducted using Web of Science. Text words (or ‘keywords’) and Subject Headings (i.e. MeSH terms) for the following were combined:

Pain: (“Pain”[mesh:exp] OR pain[tw] OR pain*[tw] OR discomfort[tw] OR analgesic OR analgesic*)

Educational interventions: (“Training”[mesh:exp] OR “Education”[mesh:exp] OR intervention*[tw] OR training[tw] OR education[tw] OR program?[tw] OR ‘quality improvement’[tw])

In residential care homes: (nursing home*[tw] OR care home*[tw] OR assisted living residence[tw] OR residential care[tw] OR residential home[tw] OR long-term care[tw] OR skilled nursing facility[tw])

¹ [tw] indicates text word; [mesh:exp] denotes subject heading where search exploded (i.e. inclusion of all subsidiary heading terms); * denotes truncation and ? wildcard usage to detect alternate spellings.

Titles, abstracts and excerpts were reviewed according to the inclusion and exclusion criteria. Reference lists were also reviewed to identify additional publications.

Inclusion- and exclusion criteria

Studies were included if they met the following criteria:

- Interventions focused on education designed to help care staff assess or treat pain in older adults
- The setting was a nursing or residential care home
- Studies published in English, in peer-reviewed journals
- Pain care (i.e. staff or resident endpoints) was evaluated as a primary outcome measure
- Randomised controlled trials (RCTs), quasi-experimental or interrupted time-series designs and Quality Improvement (QI) projects

Studies were excluded if:

- they involved informal or non-paid carers
- interventions targeted residents (i.e. provision of pharmacological or non-pharmacological treatments)
- interventions targeted pain as part of the provision of palliative care, as this is a specific context where awareness of pain would be expected to be much higher
- the main focus of the intervention was on the introduction of new protocols (including decision-support algorithms) or organisational policies, rather than staff education

- they used qualitative or case study designs

Quality analysis

The most relevant quality indicators and risks of bias in educational/staff training interventions were identified a priori through consultation of the guidelines produced by The York Centre for Systematic Reviews (University of York, 2009) and PRISMA (Liberati et al., 2009), and are discussed as part of the results. A component approach, where risks of bias are considered individually without calculation of a composite score, allows consideration of context and the relative importance of the various dimensions of quality (Jüni, Altman, & Egger, 2001).

The key components of quality considered to potentially have a bearing on the results of this review were: (a) choice of outcomes measures (i.e. appropriateness, reliability and validity); (b) method of data analysis (i.e. sampling informed by power analysis, significance testing or analysis of clinical significance if appropriate or Intention-to-treat (ITT) analysis in cluster randomised controlled trials (CRCTs)); (c) attrition (i.e. dropout rate low or not likely to have introduced bias); (d) Follow-up period (i.e. long enough to identify changes in outcomes and demonstration of maintained benefits beyond intervention period); and (e) appropriate blinding of assessors (i.e. outcome assessment blind to treatment changes, or in CRCTs appropriate blinding to treatment status).

Results

Overview of results

As illustrated in Figure 1., the initial literature searches yielded 1439 hits: 1407 from database searches and 32 from citation searching, either by hand or using the Citation Index of Web of Science. After duplicates were removed, careful analysis of the 1069 unique hits by title and abstract identified 63 full-text papers that were screened for inclusion. Twelve papers describing 10 interventions met the inclusion criteria and were included in the final review (see Figure 1. and Table 1); one paper described data from the same study and another was a pilot of the intervention, the data from which was analysed as part of the main study. Sixteen full-text articles were not published as primary empirical data and the remaining full-text articles were excluded if the intervention focused on the introduction of new protocols or organisational policies (12), targeted residents (11), targeted pain as part of palliative care (7), or involved the development or evaluation of a specific pain assessment tool (5).

The majority of studies were conducted in the US (70%), with two from Canada (20%) and one from China (10%). Six studies were conducted in nursing homes and four described the setting as long-term care, which is generally used to describe residential settings without round-the-clock nursing input, but terms are often used interchangeably. Although no limits were applied to the searches, all studies included were published in 2000 or later.

Half of the studies included (Baier et al., 2004; Horner, Hanson, Wood, Silver, & Reynolds, 2005; Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004;

Stevenson, Dahl, Berry, Beck, & Griffie, 2006; Weissman, Griffie, Muchka, & Matson, 2000) were also included in both previous reviews (Herman et al., 2009; Swafford et al., 2009).

Design and methodological quality

There was wide heterogeneity of study designs. Only one RCT was included (Ghandehari et al., 2013), with the majority of studies using quasi-experimental designs. Two studies included non-randomised control groups: one was comparative (Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004), and the other was a non-equivalent natural control group (Baier et al., 2004). Seven studies were non-controlled: two used a pre-test/post-test design (Gagnon, Hadjistavropoulos, & Williams, 2013; Tse & Ho, 2014); and the remaining five studies were QI projects, three of which used an interrupted time series design (Fine et al., 2014; Long, 2013; Long et al., 2010; Weissman, et al., 2000), and two pre-test/post-test (Horner, et al., 2005; Stevenson, et al., 2006).

Overall methodological quality appeared weak, although this was often difficult to differentiate from poor quality reporting, particularly in QI projects. None of the studies used a power analysis to inform sample size, only one study employed appropriate blinding of assessors, out of six where it would have been appropriate. Also, many studies did not report or account for possible bias due to attrition, and few used validated outcome measures.

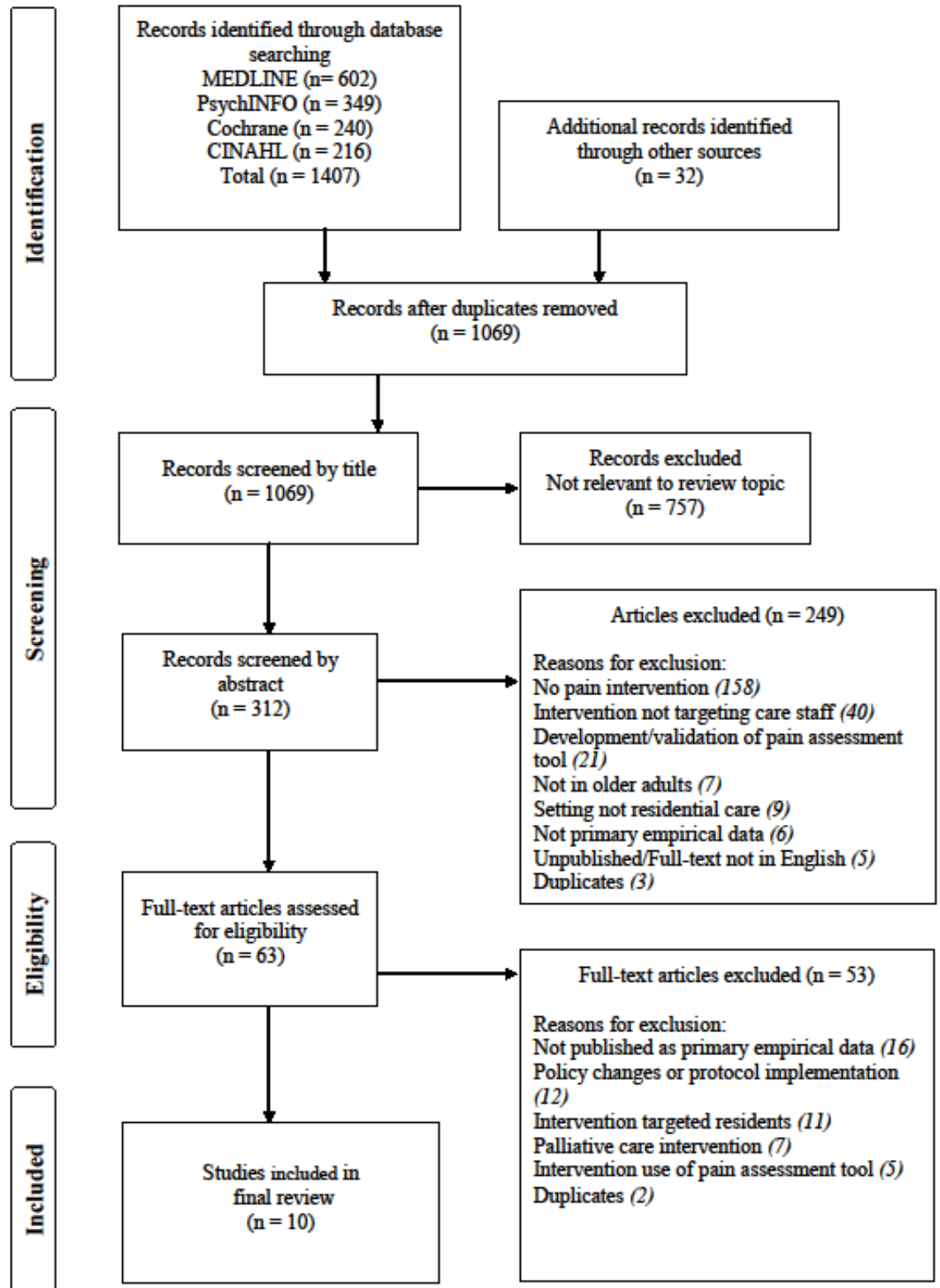


Figure 1: Flow chart of study selection process

Table 1

Summary of included studies

Author, year, country	Design, setting	N	Intervention, format, duration and intensity	Results	Quality components
Baier et al., 2004 US	Quasi-experimental Quality Improvement (QI) project with non-equivalent control group design (natural control group, 72 sites) <i>Setting:</i> Nursing homes	<u>Sites</u> 17 <u>Staff</u> Not specified <u>Residents</u> 284 at baseline, 276 at follow-up	Six bi-monthly workshops for MDTs; audit and feedback; consultation; resources for staff; between-site information sharing <i>Target audience:</i> MDT <i>Format:</i> Mixed <i>Duration:</i> 15 months <i>Intensity:</i> 12hrs	<u>Process outcomes</u> Sig. increase in assessment of pain and use of non-pharmacological treatments No change in prescription of any pain meds <u>Resident outcomes</u> Sig. reduction in prevalence of pain	<u>Strengths:</u> Appropriate outcome measures used; large sample size; process outcomes well operationalised <u>Weaknesses:</u> Only sampled residents with pain; sampling not informed by power analysis; no blinding of assessors; no follow-up
Fine et al., 2014 US	Quasi-experimental (QI project using interrupted time series design) <i>Setting:</i> Long-term care facilities	<u>Sites</u> 8 <u>Staff</u> 51 <u>Residents</u> 50 charts (25 at baseline and 25 at follow-up)	Nominated 'pain team' conducted audit of pain care practices followed by one-off 3hr workshop targeting specific needs; resources for staff; consultation. <i>Target audience:</i> All staff <i>Format:</i> Mixed <i>Duration:</i> 8 weeks <i>Intensity:</i> 3hrs	<u>Process outcomes</u> Random selection of charts showed: non-sig. improvements in 3/5 performance indicators Sig. increase in the percentage of residents with documented care plan for acute or chronic pain	<u>Strengths:</u> Appropriate outcome measure used; process outcomes well operationalised; 6wk follow-up; low attrition <u>Weaknesses:</u> Sampling not informed by power analysis; no blinding of assessors;

Gagnon et al., 2013 Canada	Quasi-experimental (one-group pre-test/post-test design) <u>Setting:</u> Long-term care facilities	<u>Sites</u> 2 health care regions <u>Staff</u> 148 <u>Residents</u> n/a	One 45 min video training session <u>Target audience:</u> Direct care staff <u>Format:</u> Didactic <u>Duration:</u> Follow-up at 4weeks post-intervention <u>Intensity:</u> 45mins	<u>Staff outcomes</u> Sig. increase in staff knowledge of pain assessment <u>Process outcomes</u> No change in clinical practice evident from self-report	<u>Strengths:</u> Outcome measures appropriate to intervention aim; Appropriate statistical analysis of quantitative data; some reliable and valid outcome measures; 4 week follow-up <u>Weaknesses:</u> Level of attrition not reported; sampling not informed by power analysis; some unvalidated outcome measures; possible biased reporting of outcomes ^a
Ghande-hari et al., 2013 Canada	RCT Constructivist education vs. attention control group <u>Setting:</u> Long-term care facilities	<u>Sites</u> 2 health care regions <u>Staff</u> 131 <u>Residents</u> n/a	Three weekly educational sessions led by experts, focussing on pain assessment and management. <u>Target audience:</u> Direct care staff <u>Format:</u> Mixed <u>Duration:</u> 5 weeks <u>Intensity:</u> 9hrs	<u>Staff outcomes</u> Sig. larger gains in pain knowledge and positive changes in some pain beliefs in intervention group compared to control. No sig. differences in organic beliefs about pain.	<u>Strengths:</u> Outcome measures appropriate to intervention aim; Appropriate statistical analysis of quantitative data; reliable and valid outcome measures <u>Weaknesses:</u> Level of attrition not reported; sampling not informed by power analysis; method of randomisation not specified

^a Table 3 refers to a measure not reported

Horner et al., 2005 US	Quasi-experimental (QI project with pre-test/post-test design) <u>Setting:</u> Nursing homes	<u>Sites</u> 9 <u>Staff</u> Not specified <u>Residents</u> 265	Two workshops and two teleconferences; conference call to agree action plans; audit and feedback; between-site information sharing <u>Target audience:</u> All staff (role specific content) <u>Format:</u> Mixed <u>Duration:</u> 5 months <u>Intensity:</u> ~ 12hrs	<u>Process outcomes</u> Sig. increase in no. of residents being assessed for pain Sig. increase in non-pharmacological treatment No change in pharmacological treatments	<u>Strengths:</u> Outcome measures appropriate to intervention aim; Appropriate statistical analysis; process outcome assessors blinded and reliability established <u>Weaknesses:</u> Only sampled residents with pain; level of attrition not reported; sampling not informed by power analysis; no follow-up
Jones, Fink, Vojir et al., 2004 & Jones, Fink, Pepper et al., 2004 US	Quasi-experimental (non-randomised controlled trail) <u>Setting:</u> Nursing homes	<u>Sites</u> 12 (6 case, 6 control) <u>Staff</u> 378 <u>Residents</u> 2033	Four 30min educational sessions, one every 5weeks; separate seminar for prescribers; staff training video; educational resources for staff and residents; pain team; consultation <u>Target audience:</u> Direct care staff <u>Format:</u> Mixed <u>Duration:</u> 9 months <u>Intensity:</u> 2.5hrs	<u>Staff outcomes</u> No sig. increase in staff knowledge No sig. improvements in attitudes and beliefs <u>Process outcomes</u> No diff. between treatment and control in pain assessments and reassessments (both showed sig. improvement) <u>Resident outcomes</u> No sig. reduction in residents reporting pain	<u>Strengths:</u> Outcome measures appropriate to intervention aim; appropriate statistical analysis; <u>Weaknesses:</u> some attrition and no comparison between completers and drop-outs; sampling not informed by power analysis; no follow-up; no blinding of assessors

Long et al., 2010 & Long, 2013	Quasi-experimental (QI project using interrupted time series design)	<u>Sites</u> 2 <u>Staff</u> 91 (convenience sample) <u>Residents</u> 24 completed measures) Not specified	5 didactic training modules delivered over 6 months; pain team oversaw changes in policies; consultation	<u>Staff outcomes</u> Sig improvement in staff knowledge and attitudes <u>Process outcomes</u> Staff reported barriers (e.g. reluctance to administer analgesics) mitigated after training <u>Resident outcomes</u> MDS data showed reduction in chronic and acute pain, maintained at 1yr (no significance testing conducted)	<u>Strengths:</u> Outcome measures appropriate to intervention aim; no attrition <u>Weaknesses:</u> Sampling not informed by power analysis and small <i>n</i> in some groups; convenience sample used; no follow-up; some unvalidated outcome measures; inappropriate statistical analysis ^b ; poor quality reporting of method/results
US	<u>Setting:</u> Nursing homes in a continuing care retirement community				
Stevens-on et al., 2006	Quasi-experimental (QI project using pre-test/post-test design)	<u>Sites</u> 49 LTCFs (113 total sites) <u>Staff</u> 94 pre, 45 post <u>Residents</u> 260 pre, 254 post	Two educational conferences, 3-days over 5months; consultation; pain team oversaw changes in policies; audit and feedback	<u>Staff outcomes</u> Sig. increase in pain knowledge <u>Process outcomes</u> Sig. increase in structural elements indicating quality of pain assessment <u>Resident outcomes</u> Sig. decrease in prevalence of pain according to self-report	<u>Strengths:</u> Large sample size; process outcomes well operationalised; diff's between completers and drop-outs examined <u>Weaknesses:</u> High attrition in resident data; use of unvalidated measure of pain; sampling not informed by power analysis; no blinding of assessors
US	<u>Setting:</u> Long-term care facilities (LTCFs)		<u>Target audience:</u> Pain team <u>Format:</u> Mixed <u>Duration:</u> 10 months <u>Intensity:</u> ≈ 21hrs		

^b t-tests performed on individual scale items and no correction for Type I error

Tse & Ho 2014	Quasi-experimental (One group pre-test/post-test design)	<u>Sites</u> 4 <u>Staff</u> 88 <u>Residents</u> n/a	Eight weekly educational sessions <u>Target audience:</u> Direct care staff <u>Format:</u> Mixed <u>Duration:</u> 8 weeks <u>Intensity:</u> 8hrs	<u>Staff outcomes</u> Sig. increase in knowledge and attitudes re: pain management	<u>Strengths:</u> Outcome measures appropriate to intervention aim; appropriate analysis of data; reliable/valid outcome measures <u>Weaknesses:</u> Attrition not reported; sampling not informed by power analysis; follow-up period not specified; possible selective reporting of outcomes ^c ; internal pilot data included in analysis unacknowledged
Weissman et al. 2000	Quasi-experimental (QI project using interrupted time series design)	<u>Sites</u> 87 <u>Staff</u> Not specified <u>Residents</u> ≈ 5 charts per site	Four education workshops, one every 3 months; pain team oversaw changes in policies; educational resources for staff; audit and feedback <u>Target audience:</u> MDT <u>Format:</u> Mixed <u>Duration:</u> 1 year <u>Intensity:</u> 20hrs	<u>Process outcomes</u> Sig. increase in facility pain process indicators and adequate resident pain documentation	<u>Strengths:</u> Outcome measures appropriate to intervention aim; appropriate analysis of data; 2 month follow-up <u>Weaknesses:</u> Level of attrition not reported; sampling not informed by power analysis; no blinding of assessors

^c Qualitative themes not presented

Outcomes

Staff knowledge and attitudes

Four studies primarily evaluated the effect of educational training on staff knowledge and beliefs (Gagnon et al., 2013; Ghandehari et al., 2013; Long, 2013; Tse & Ho, 2014), and two included it as one aspect of the evaluation (Jones, Fink, Pepper, et al., 2004; Stevenson et al., 2006). Most studies used a standardised questionnaire measure, such as the Pain Beliefs Questionnaire or Pain Knowledge and Beliefs Questionnaire (Gagnon et al., 2013; Ghandehari et al., 2013; Tse & Ho, 2014), and some also developed an intervention specific measure of knowledge (Gagnon et al., 2013; Ghandehari et al., 2013; Stevenson et al., 2006).

One study developed surveys based on pain management guidelines (Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004) and another utilised these newly developed survey scales (Long, 2013; Long et al., 2010). Whilst the knowledge scales developed by Jones, Fink, Pepper, et al. (2004) have the advantage of being in line with guidelines, and specific to the care environment, they are unvalidated and the internal reliability of the nurses' survey was marginal (.61).

Studies which focused on knowledge enhancement all employed appropriate paired statistical analyses (Gagnon et al., 2013; Ghandehari et al., 2013; Long, 2013; Tse & Ho, 2014) to assess pre-post change, and two also included detailed qualitative analysis of intervention acceptability and changes in clinical practice (Gagnon et al., 2013; Ghandehari et al., 2013). Both multifaceted studies which included knowledge change as an adjunct were unable to conduct paired analyses, as participants varied across time-points (Jones, Fink, Pepper, et al., 2004; Stevenson et al., 2006).

Assessment and treatment practices

The most common type of outcome assessed was change in pain assessment and treatment practices, which was measured by eight studies (Baier et al., 2004; Fine et al., 2014; Gagnon et al., 2013; Horner et al., 2005; Jones, Fink, Vojir, et al., 2004; Long, 2013; Long et al., 2010; Stevenson et al., 2006; Weissman et al., 2000). These process outcomes were most commonly measured through identification of key indicators of good pain care practice, based on national guidelines (Baier et al., 2004; Fine et al., 2014; Horner et al., 2005; Stevenson et al., 2006; Weissman et al., 2000). One study operationalised good practice indicators, but no rationale was given for inclusion/choice (Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004) and the remaining two used self-report of staff obtained through questionnaire or interview (Gagnon et al., 2013; Long, 2013).

Of the six studies which identified quality indicators, five measured adherence through reviewing documented practice in residents' charts, referred to as chart abstraction (Baier et al., 2004; Fine et al., 2014; Horner et al., 2005; Jones, Fink, Vojir, et al., 2004; Weissman et al., 2000), but only one study employed appropriate blinding of assessors (Horner et al., 2005). There was a lack of standardisation of good practice indicators as, even though many studies operationalised the same guidelines, there were subtle differences in content and emphasis (Baier et al., 2004; Fine et al., 2014; Horner et al., 2005; Stevenson et al., 2006; Weissman et al., 2000).

Residents' pain levels

Only three studies included a direct measure of residents' pain levels (Baier et al., 2004; Jones, Fink, Vojir, et al., 2004; Stevenson et al., 2006), all of which were

multi-component interventions. Three types of pain measurements were used, the Minimum Data Set (Centers for Medicare and Medicaid Services, 2013), self-report, and observation. Baier et al. (2004) used the Minimum Data Set (MDS) to calculate pain prevalence pre- and post-intervention, but only sampled residents already identified as having pain. The MDS is a questionnaire measure of residents' pain, which is regularly collected as part of the US healthcare insurance system.

Stevenson et al. (2006) developed a self-report measure called the *One Minute Pain Questionnaire* which assessed the presence of pain in the last 24 hours in a random sample of 10 residents in each home pre- and post-intervention. It was not stated, but presumably non-verbal residents were excluded, as no information was given about alternative methods of assessment.

The third study (Jones, Fink, Vojir, et al., 2004) used a combination of data from the MDS, self-report and observation. A 20% sample of residents was interviewed at each time point, but no information was provided on how residents were selected. Also, the authors state that residents unable to self-report were observed for signs of pain, but formal observational tools were not employed and no information is provided on the behavioural signs of pain assessed.

Description and evaluation of educational programmes

Educational intervention alone

Three studies purely provided education to a target audience of direct care staff, all of which primarily aimed to modify staff knowledge and beliefs (Gagnon et al., 2013; Ghandehari et al., 2013; Tse & Ho, 2014). Gagnon et al. (2013) reported that a one-off video training session significantly increased knowledge of pain assessment

among a sample of 148 care staff, but effects were not maintained at four week follow-up. Despite an increase in knowledge, thematic content analysis of focus group data indicated no changes in clinical practice. Also, although a validated measure of pain beliefs (PBQ: Edwards, Pearce, Turner-Stokes, & Jones, 1992) was included, this was used in an analysis of possible contributors to evaluation of the training, rather than a measure of pre-post change. The authors propose implementation of a model of practice change with pervasive managerial support to achieve sustained change. Findings from this well designed study indicate that a short video intervention can increase staff knowledge, but the absence of a control group means findings are not necessarily attributable to the intervention.

In the only RCT included, Ghandehari et al. (2013) compared expert-led training, taking a constructivist approach to education, with an attention control group. Nine hours of training delivered in three weekly sessions was found to significantly increase knowledge and beliefs on standardized measures and staff in the intervention group were four times more likely to report implementing pain management strategies than those in the control group.

A quasi-experimental pre-post design study examined the effectiveness of an 8-week educational programme using mixed interactive and didactic methods (Tse & Ho, 2014). Study outcomes showed significant improvement in staff knowledge and attitudes post-interventions. However, poor quality reporting of methodology and lack of control group undermine confidence in these findings.

Education with additional interventions

Target audience of direct care staff

A non-randomised controlled study explored the benefits of a multifaceted intervention, with education based on national guidelines, delivered over nine months (Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004). In addition to educational sessions, the intervention included formation of a pain team to drive forward practice change, expert consultation, and a separate seminar targeting prescribers. The educational component was relatively low intensity, with four 30min sessions delivered over six months, and authors report lack of prioritisation and high staff turnover resulted in low attendance. Overall outcomes were poor, with no significant improvement in staff knowledge or attitudes and no difference in process or resident outcomes between intervention and control sites. However, considerable attention was given to what could be learnt from the challenges encountered.

Education targeting all staff

Similarly to Jones, Fink, Pepper, et al. (2004) and Jones, Fink, Vojir, et al. (2004), another multifaceted study (Long, 2013; Long et al., 2010) provided consultation and nominated teams of staff to form working groups alongside an educational programme. However, this intervention had more of a focus on changing pain policies, educational content was longer and training targeted all care and ancillary staff. A significant improvement in staff knowledge and attitudes was seen from 8.5hr of didactic education. Pain prevalence also showed a reduction according to MDS data, which was maintained at one-year follow-up. However, no significance testing was conducted and there was no control group.

Another non-controlled QI project also involved consultation, but instead of nominating a team, a single pain champion volunteered to oversee the project at each home (Fine et al., 2014). Pain champions also conducted an audit which informed the educational component. Education consisted of a one-off 3hr workshop targeting direct care staff, physicians, and administrative staff, using a mixed interactive and didactic method. Staff were also provided with written educational resources. The intervention showed promising results, with a significant increase in pain care indicators across eight homes, but this was based on self-report of clinicians so should be interpreted cautiously.

A third QI project used a multifaceted approach, with audit and feedback (Horner et al., 2005). Approximately 12hrs of education was provided through two workshops and two teleconferences, with content targeted to professional roles. Findings showed an increase in number of residents being assessed for pain and in non-pharmacological treatments, but no overall increase in analgesic use. Authors suggested the lack of change in pharmacological treatment may have been due to poor attendance of prescribers.

Education provided to nominated pain team only

Three studies used a different approach, similar to the popular train-the-trainer model (Levine et al., 2007), choosing to deliver training to a designated team of representatives from each home. Baier et al. (2004) recruited staff from various disciplines, including some in leadership positions, to attend six educational workshops on pain management and receive training in QI methods. The intervention also employed audit and feedback, but this was conducted subsequent to receiving the educational intervention. Assessment and non-pharmacological treatment of pain

increased and there was reduction in residents' pain, but no change in prescribing practices.

A similar QI project also reported increased knowledge and better pain care practices, leading to lower prevalence of pain according to residents' self-report (Stevenson et al., 2006). A small group of staff from 49 care homes attended two educational conferences and oversaw policy changes directed by audit findings. Weissman et al. (2000) also reported an increase in pain care quality indicators using an intervention of similar design and length, but the educational component was not specifically tailored to facilities' needs. However, neither study included a control group, and bias may have been introduced by a lack of blinding of assessors.

Impact of intensity, format and content

Intensity of education varied greatly from one 45min video to 20hr over the period of one year. No clear relationship was observed between intensity and impact on outcome. However, less intense interventions were mostly targeted at the level of competence and did not aim to change pain care practices.

It is not possible to draw firm conclusions from a sample of ten studies, but it did appear that multifaceted interventions were more successful in achieving change in clinical practice. However, this may be because single interventions did not target change at this level. Most studies (80%) used a mixture of didactic (e.g. lectures) and interactive (e.g. role play, discussions) methods, which is likely to reflect an awareness of evidence that this format is most effective (Grimshaw et al., 2001). However, both studies using mainly didactic methods showed some positive impact (Gagnon et al., 2013; Long, 2013; Long et al., 2010).

Educational content was mainly derived from national guidelines in pain management for older adults (Baier et al., 2004; Fine et al., 2014; Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004), or developed by experts in the research team (Horner et al., 2005; Tse & Ho, 2014; Weissman, et al., 2000). One study based the content of their intervention on expert consensus guidelines (Gagnon et al., 2013), one derived content from previous research (Ghandehari et al., 2013), and two modified existing training programmes (Long, 2013; Long et al., 2010; Stevenson et al., 2006). There appeared to be no impact of content on study outcomes.

Barriers and facilitators to educational programmes

All studies made some reference to the challenges encountered when delivering an intervention in care homes. Three studies included a dedicated section on the barriers and/or facilitators (Baier et al., 2004; Gagnon, et al., 2013; Ghandehari et al., 2013) and one research group published a separate paper covering the topic in detail (Jones, Fink, Pepper, et al., 2004; Jones, Fink, Vojir, et al., 2004). Barriers fell in four broad categories: 1) resource constraints, 2) organisational culture, 3) communication, and 4) attitudes and beliefs.

Constraints on resources due to high staff turnover, high workload, staff shortages and poor attendance were the most common barriers reported (Baier et al., 2004; Gagnon et al., 2013; Ghandehari et al., 2013; Jones, Fink, Pepper, et al., 2004; Long, 2013; Tse & Ho, 2014). Attempted solutions included videotaping sessions, running training more than once, and offering make-up sessions (Jones, Fink, Vojir, et al., 2004; Tse & Ho, 2014). Stable staffing and high motivation among staff were

highlighted as particularly helpful. Some studies mentioned the use of incentives (Jones, Fink, Vojir, et al., 2004) but these were not effective in encouraging attendance.

In terms of organisational barriers, some studies suggested the hierarchical culture in these settings resulted in the least qualified staff feeling ignored (Gagnon et al., 2013; Ghandehari et al., 2013; Jones, Fink, Pepper, et al., 2004), and no strategies for improvement were suggested. Staff feeling empowered by the training was listed as a facilitator (Ghandehari et al., 2013; Weissman et al., 2000), but again no direct link was drawn to any aspects of the training which may have achieved this. Staff in one study (Fine et al., 2014) reported that improved documentation of pain assessments gave them the confidence to proactively discuss treatment options.

Reports of difficulties in communication between carers and physicians were common (Baier et al., 2004; Fine et al., 2014; Ghandehari et al., 2013; Jones, Fink, Pepper, et al., 2004), and some studies that included physicians in the training reported poor attendance (Fine et al., 2014; Horner et al., 2005; Jones, Fink, Vojir, 2004). One study included targeted outreach for physicians, but found this unsuccessful (Horner et al., 2005). Poor communication with prescribers can result in under-treatment if there are delays in speaking with prescribers or caregivers' reports are insufficient to inform prescription changes (Baier et al., 2004; Jones, Fink, Pepper, et al., 2004).

Finally, three studies reported staff attitudes and beliefs as a barrier to change. Baier et al. (2004) found that staff hesitated to make pharmacological changes due to feared potential side effects of pain medications. Other studies reported that some staff were resistant to changing ways of working (Gagnon et al., 2013) and that unhelpful attitudes were difficult to shift, particularly in less

qualified staff (Long, 2013). Only one study reported a facilitator in this area, which was staff directly observing the benefits of implementation of the training (Gagnon et al., 2013).

Summary of findings

A total of nine studies reported a significant change in at least one domain. Four studies reported an increase in staff knowledge following training as the primary finding (Gagnon et al., 2013; Ghandehari et al., 2013; Long, 2013; Tse & Ho, 2014), five reported it to be process changes (Baier et al., 2004; Fine et al., 2014; Horner et al., 2005; Stevenson et al., 2006; Weissman et al., 2000), and only two reported a significant decrease in residents' levels of pain (Baier et al., 2004; Stevenson et al., 2006).

Educational interventions appear to be effective in increasing the knowledge and attitudes of staff, but this effect may not be maintained with less intense interventions. Also, education alone is unlikely to influence the clinical practice of staff. Overall, multifaceted interventions were more successful in achieving behaviour change, and the main process changes observed were in improved pain assessment and documentation, whereas pharmacological treatment behaviours appeared more difficult to shift. Few studies used direct measures of residents' pain and those which saw an improvement were higher intensity interventions which targeted nominated pain teams.

Discussion

The current review provides a comprehensive summary of educational interventions designed to improve pain management in care homes. Although no time limits were applied, all of the studies included were published from 2000 onwards, demonstrating that research in this area has developed relatively recently and is slow to progress, with only ten studies being published in this time. Overall, results indicate that pain care education can enhance staff knowledge and modify unhelpful attitudes. It also appears that multifaceted interventions and those targeting all disciplines may have greater capacity to mitigate barriers in this setting and show promising results in improving pain care practices. However, few interventions were effective in shifting pharmacological treatment behaviours and only two studies saw a statistically significant reduction in actual pain levels for residents.

Findings are in line with previous reviews, as may be expected given the significant overlap in the included studies. Swafford et al. (2009) reported that multifaceted interventions which targeted organisational change were more effective at changing clinical practice. Also, in line with the findings of Herman et al. (2009), it was found that process measures were often used as a proxy measure of residents' pain.

Methodological limitations

A number of common methodological limitations were identified. There was a high prevalence of factors likely to introduce bias, such as high attrition or lack of attention to drop-outs, and lack of blinding of assessors. There was no use of power analysis to inform sample size, which is problematic as overpowered studies make it

more difficult to maintain intervention fidelity, whereas underpowered studies increase the risk of Type II error. Also, 60% of studies obtained post-intervention data immediately after the end of the programme, and those that included follow-up periods were typically short. Change in clinical practice may not be immediate and therefore null findings could be the results of inadequate follow-up.

Many studies developed outcome measures specifically for the intervention and reliability or validity were rarely assessed. This may introduce bias through factors such as low test-retest reliability, poor sensitivity to change, or ceiling effects. Also, the non-standardised nature and heterogeneity of measures makes direct comparison difficult. Four studies used the MDS, presumably as it is readily available as regular data reporting is mandated as part of the US healthcare insurance system. A recent review of pain prevalence in nursing homes found that studies using the MDS showed the most variation and reported the lowest prevalence, suggesting that it reflects assessment error (Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010). Research has suggested the MDS is not as sensitive as proxy report by carers (Fisher et al., 2002) or self-report (Lin, Lum, Mehr, & Kane, 2006), and others have questioned its suitability for use in research (Wang, Kane, Eberly, Virnig, & Chang, 2009). Although some authors acknowledge the limitations (Baier et al., 2004), use of measures which are inherently biased by observer factors highlights the relative lack of importance placed on this significant factor in pain under-treatment (Hadjistavropoulos et al., 2014).

Recommendations for research

Due to substantial challenges in conducting research in care home settings, small clinically driven research projects are much more common than experimental studies

(Maas, Kelley, Park, & Specht, 2002; Murfield, Cooke, Moyle, Shum, & Harrison, 2011), meaning that overall, the available evidence is weak due to poor methodological quality. Higher quality CRCTs are obviously needed, but it is also useful to consider how the methodological rigour of clinically-driven research could be improved. QI projects are highly valuable, but there is often confusion between QI or audit and formal research, and the presentation of these projects as research leads to poor designs and misinterpretation of results (Newhouse, Pettit, Poe, & Rocco, 2006). Clearer differentiation and improvements in quality of reporting would aid development of practice-based evidence. This could be achieved through better engagement with ethical review boards or research and development departments (or equivalents), and through adherence to guidelines designed to improve quality of reporting of primary research such as TREND and CONSORT (Armstrong et al., 2008).

This review also highlights that ongoing managerial support and commitment from those in leadership positions is key to overcoming some of the barriers encountered during research in these settings. None of the studies included a measure of organisational support and a lack of attention to this important factor in care home research has been raised previously (Elliott, Scott, Stirling, Martin, & Robinson, 2012). Development of empirical measures for known barriers, such as organisational support, would enable development of an evidence base in this area and facilitate more effective interventions.

Another important development would be the introduction of theory-informed interventions, as only 20% of studies in the current review provided any theoretical rationale for their intervention (Ghandehari et al., 2013; Tse & Ho, 2014). There are many psychological theories of health behaviour change, and experts in

implementation science have put forward a theoretical framework designed for use in research (Cane, O'Connor, & Michie, 2012; Michie et al., 2005).

Finally, none of the included studies were conducted in the UK, demonstrating a need for investigation of promising interventions in UK care homes, which have important differences in organisation and financing to care settings in other countries (Ribbe et al., 1997).

Clinical implications

It is important that behaviour change is not assumed following education or training and that the impact on residents' pain is assessed in several different ways. The current review highlights the many barriers to effective pain care that are present in care homes, and this information can inform policies and clinical practice guidelines.

Although increased staff knowledge alone is unlikely to be sufficient in bringing about changes in clinical practice, it may have positive impact on staff outcomes such as competence and indirect effects on resident care. Previous research has shown that levels of knowledge are closely associated with job satisfaction and wellbeing in care staff (Elliott et al., 2012), and that improvements in knowledge can positively impact upon attitudes and behaviour (Elliott et al., 2012; Zimmerman et al., 2010).

Using a model where a small number of staff are trained, and both transfer this learning to other staff and implement practice change, is more cost effective than providing training for all staff and may have similar results. However, audit cycles should be implemented to ensure effectiveness, and resident outcomes should be the main target of change.

Strengths and limitations of the current review

Some limitations of the current review should be considered. Although the databases employed were carefully considered, due to the scope of the current review a limited number were chosen, which could have resulted in some studies being overlooked. Publication bias should also be considered when interpreting the results, as one consequence of the underreporting of non-significant results is that reviews can report overly positive findings (Petticrew & Roberts, 2006).

One of the main strengths of this review was the consideration of barriers and facilitators reported in this research and specific recommendations for how clinically driven research might contribute meaningfully to the evidence base through addressing current weaknesses. When overall methodological quality is poor, reviews should aim to clearly identify gaps in the research and provide concrete suggestions for improvements, rather than merely concluding that findings were inconclusive (Petticrew & Roberts, 2006).

Another strength was the use of a component approach to quality rating. Quality rating tools can be problematic as many are not based on empirical evidence (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004), and summary scores can vary significantly depending on the tool employed and often weight risks of bias equally (Brouwers et al., 2005). A component approach allows consideration of context and the relative importance of the various dimensions of quality in different research settings and overcomes many of these limitations (Jüni et al., 2001).

Conclusion

Overall, it appears that staff education can improve aspects of pain care for older adults in residential care settings. However, there are few high quality studies examining effectiveness at all three levels (i.e. staff competence, clinical practice and patient outcomes), and due to the methodological limitations of the current studies findings should be interpreted cautiously. Also, many studies excluded non-verbal residents and those with cognitive impairments, often for the reason that it poses additional challenges, and therefore findings may not be applicable to pain care for these populations. Higher quality clinically-driven research, and well-designed controlled studies (e.g. CRCTs), are needed to determine effectiveness of promising educational interventions for care staff, and greater emphasis should be placed on obtaining outcomes of residents' pain.

References

- Abdulla, A., Adams, N., Bone, M., Elliott, A. M., Gaffin, J., Jones, D., ... British Geriatric Society. (2013). Guidance on the management of pain in older people. *Age and Ageing*, 42 Suppl 1, i1–i57.
- Achterberg, W. P., Gambassi, G., Finne-Soveri, H., Liperoti, R., Noro, A., Frijters, D. H. M., ... Ribbe, M. W. (2010). Pain in European long-term care facilities: cross-national study in Finland, Italy and The Netherlands. *Pain*, 148, 70–74.
- Achterberg, W. P., Pieper, M. J., van Dalen-Kok, A. H., de Waal, M. W., Husebo, B. S., Lautenbacher, S., ... Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interventions in Aging*, 8, 1471–1482.
- Alexus, L., Talusan, L., & Chen, K. (2009). Evaluation guideline for managing chronic pain. *Perspectives (Gerontological Nursing Association)*, 33, 15–17.
- Allcock, N., McGarry, J., & Elkan, R. (2002). Management of pain in older people within the nursing home: a preliminary study. *Health & Social Care in the Community*, 10, 464–471.
- Armstrong, R., Waters, E., Moore, L., Riggs, E., Cuervo, L. G., Lumbiganon, P., & Hawe, P. (2008). Improving the reporting of public health intervention research: advancing TREND and CONSORT. *Journal of Public Health*, 30, 103–109.
- Asghari, A., Ghaderi, N., & Ashory, A. (2006). The prevalence of pain among residents of nursing homes and the impact of pain on their mood and quality of life. *Archives of Iranian Medicine*, 9, 368–373.
- Baier, R. R., Gifford, D. R., Patry, G., Banks, S. M., Rochon, T., DeSilva, D., & Teno, J. M. (2004). Ameliorating Pain in Nursing Homes: A Collaborative

- Quality-Improvement Project. *Journal of the American Geriatrics Society*, 52, 1988–1995.
- Barry, H. E., Parsons, C., Peter Passmore, A., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry*, 27, 1258–1266.
- Bartels, S. J., Horn, S. D., Smout, R. J., Dums, A. R., Flaherty, E., Jones, J. K., ... Voss, A. C. (2003). Agitation and depression in frail nursing home elderly patients with dementia: treatment characteristics and service use. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 11, 231–238.
- Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., ... Mor, V. (1998). Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA: The Journal of the American Medical Association*, 279, 1877–1882.
- Boerlage, A. A., van Dijk, M., Stronks, D. L., de Wit, R., & van der Rijt, C. C. D. (2008). Pain prevalence and characteristics in three Dutch residential homes. *European Journal of Pain*, 12, 910–916
- Bosley, B. N., Weiner, D. K., Rudy, T. E., & Granieri, E. (2004). Is chronic nonmalignant pain associated with decreased appetite in older adults? Preliminary evidence. *Journal of the American Geriatrics Society*, 52, 247–251.
- Brockopp, D., Warden, S., Colclough, G., & Brockopp, G. (1996). Elderly people's knowledge of and attitudes to pain management. *British Journal of Nursing*, 5, 556–558, 560–562.

- Brouwers, M. C., Johnston, M. E., Charette, M. L., Hanna, S. E., Jadad, A. R., & Browman, G. P. (2005). Evaluating the role of quality assessment of primary studies in systematic reviews of cancer practice guidelines. *BMC Medical Research Methodology*, 5, 8.
- Cadogan, M. P., Edelen, M. O., Lorenz, K. A., Jones, M., Yosef, J., Hascall, T., ... Saliba, D. (2008). The relationship of reported pain severity to perceived effect on function of nursing home residents. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 63, 969–973.
- Cairncross, L., Magee, H., & Askham, J. (2007). *A Hidden Problem: pain in older people: a qualitative study*. Oxford: Picker Institute Europe
- Cane, J., O'Connor, D., & Michie, S. (2012). Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implementation Science*, 7, 37.
- Centers for Medicare and Medicaid Services. (2013). *Minimum Data Set, 2.0 Public Quality Indicator and Resident Reports*. Retrieved May 19, 2015, from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-systems/MDSPubQIandResRep/index.html?redirect=/MDSPubQIandResRep>
- Clark, L., Fink, R., Pennington, K., & Jones, K. (2006). Nurses' Reflections on Pain Management in a Nursing Home Setting. *Pain Management Nursing*, 7, 71–77.
- Cohen-Mansfield, J., & Lipson, S. (2002). Pain in cognitively impaired nursing home residents: how well are physicians diagnosing it? *Journal of the American Geriatrics Society*, 50, 1039–1044.

- Cowan, D. T., Roberts, J. D., Fitzpatrick, J. M., & While, A. E. (2003). The need for effective assessment and management of pain among older people in care homes. *Reviews in Clinical Gerontology, 13*, 335–341.
- Cramer, B. S. G. (2000). A drug use evaluation of selected opioid and nonopioid analgesics in the nursing facility setting. *Journal of the American Geriatrics Society, 48*, 398–404.
- Darlow, B., Fullen, B. m., Dean, S., Hurley, D. a., Baxter, G. d., & Dowell, A. (2012). The association between health care professional attitudes and beliefs and the attitudes and beliefs, clinical management, and outcomes of patients with low back pain: A systematic review. *European Journal of Pain, 16*, 3–17.
- Dobbs, D., Baker, T., Carrion, I. V., Vongxaiburana, E., & Hyer, K. (2014). Certified nursing assistants' perspectives of nursing home residents' pain experience: communication patterns, cultural context, and the role of empathy. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 15*, 87–96.
- Edwards, L. C., Pearce, S. A., Turner-Stokes, L., & Jones, A. (1992). The Pain Beliefs Questionnaire: an investigation of beliefs in the causes and consequences of pain. *Pain, 51*, 267–272.
- Elliott, K.-E. J., Scott, J. L., Stirling, C., Martin, A. J., & Robinson, A. (2012). Building capacity and resilience in the dementia care workforce: a systematic review of interventions targeting worker and organizational outcomes. *International Psychogeriatrics, 24*, 882–894. 1
- Fine, P. G., Bradshaw, D. H., Cohen, M. J., Connor, S. R., Donaldson, G., Gharibo, C., ... Tselentis, H. N. (2014). Evaluation of the performance improvement

- CME paradigm for pain management in the long-term care setting. *Pain Medicine*, 15, 403–409.
- Fisher, S. E., Burgio, L. D., Thorn, B. E., Allen-Burge, R., Gerstle, J., Roth, D. L., & Allen, S. J. (2002). Pain assessment and management in cognitively impaired nursing home residents: association of certified nursing assistant pain report, Minimum Data Set pain report, and analgesic medication use. *Journal of the American Geriatrics Society*, 50, 152–156.
- Forsetlund, L., Bjørndal, A., Rashidian, A., Jamtvedt, G., O'Brien, M. A., Wolf, F., ... Oxman, A. D. (2009). Continuing education meetings and workshops: effects on professional practice and health care outcomes. *The Cochrane Database of Systematic Reviews*, 2, CD003030.
- Gagnon, M. M., Hadjistavropoulos, T., & Williams, J. (2013). Development and mixed-methods evaluation of a pain assessment video training program for long-term care staff. *Pain Research & Management: The Journal of the Canadian Pain Society*, 18, 307–12.
- Ghandehari, O. O., Hadjistavropoulos, T., Williams, J., Thorpe, L., Alfano, D. P., Bello-Haas, V. D., ... Lix, L. M. (2013). A controlled investigation of continuing pain education for long-term care staff. *Pain Research & Management: The Journal of the Canadian Pain Society*, 18, 11–18.
- Giron, M. S. T., Forsell, Y., Bernsten, C., Thorslund, M., Winblad, B., & Fastbom, J. (2002). Sleep problems in a very old population: drug use and clinical correlates. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 57, M236–240.

- Grimshaw, J. M., Shirran, L., Thomas, R., Mowatt, G., Fraser, C., Bero, L., ...
O'Brien, M. A. (2001). Changing provider behavior: an overview of
systematic reviews of interventions. *Medical Care*, 39, II2–45.
- Hadjistavropoulos, T., & Craig, K. D. (Eds.). (2004). *Pain: Psychological
perspectives*. Mahwah, NJ: Lawrence Erlbaum.
- Hadjistavropoulos, T., Herr, K., Prkachin, K. M., Craig, K. D., Gibson, S. J., Lukas,
A., & Smith, J. H. (2014). Pain assessment in elderly adults with dementia.
The Lancet. Neurology, 13, 1216–1227.
- Herman, A. D., Johnson, T. M., Ritchie, C. S., & Parmelee, P. A. (2009). Pain
Management Interventions in the Nursing Home: A Structured Review of the
Literature. *Journal of the American Geriatrics Society*, 57, 1258–1267.
- Hess, P. (2004). Pain and Comfort. In P. Ebersole, P. Hess, & S. Luggen (Eds.),
Toward healthy aging: Human needs and nursing response (6th ed., pp. 279–
305). St. Louis: Mosby.
- Higgins, I., Madjar, I., & Walton, J. A. (2004). Chronic pain in elderly nursing home
residents: the need for nursing leadership. *Journal of Nursing Management*,
12, 167–173.
- Horgas, A. L., & Tsai, P. F. (1998). Analgesic drug prescription and use in
cognitively impaired nursing home residents. *Nursing Research*, 47, 235–242.
- Horner, J. K., Hanson, L. C., Wood, D., Silver, A. G., & Reynolds, K. S. (2005).
Using Quality Improvement to Address Pain Management Practices in
Nursing Homes. *Journal of Pain and Symptom Management*, 30, 271–277.
- 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–d4065.
- Jones, K. R., Fink, R. M., Clark, L., Hutt, E., Vojir, C. P., & Mellis, B. K. (2006). Nursing Home Resident Barriers to Effective Pain Management: Why Nursing Home Residents May Not Seek Pain Medication. *Journal of the American Medical Directors Association*, 7, S21–S28.
- Jones, K. R., Fink, R., Pepper, G., Hutt, E., Vojir, C. P., Scott, J., ... Mellis, K. (2004). Improving Nursing Home Staff Knowledge and Attitudes About Pain. *The Gerontologist*, 44, 469–478.
- Jones, K. R., Fink, R., Vojir, C., Pepper, G., Hutt, E., Clark, L., ... Mellis, B. K. (2004). Translation research in long-term care: improving pain management in nursing homes. *Worldviews on Evidence-Based Nursing*, 1 Suppl 1, S13–20.
- Jongenelis, K., Pot, A. M., Eisses, A. M. H., Beekman, A. T. F., Kluiter, H., & Ribbe, M. W. (2004). Prevalence and risk indicators of depression in elderly nursing home patients: the AGED study. *Journal of Affective Disorders*, 83, 135–142.
- Jüni, P., Altman, D. G., & Egger, M. (2001). Assessing the quality of controlled clinical trials. *BMJ*, 323, 42–46.
- Kaasalainen, S., Coker, E., Dolovich, L., Papaioannou, A., Hadjistavropoulos, T., Emili, A., & Ploeg, J. (2007). Pain management decision making among long-term care physicians and nurses. *Western Journal of Nursing Research*, 29, 561–580; discussion 581–588.

- Kaasalainen, S., Middleton, J., Knezacek, S., Hartley, T., Stewart, N., Ife, C., & Robinson, L. (1998). Pain and cognitive status in the institutionalized elderly: perceptions & interventions. *Journal of Gerontological Nursing*, 24, 24–31.
- Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Kumar, V. S., & Grimmer, K. A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology*, 4, 22.
- Katsma, D. L., & Souza, C. H. (2000). Elderly pain assessment and pain management knowledge of long-term care nurses. *Pain Management Nursing*, 1, 88–95.
- Kumar, A., & Allcock, N. (2008). *Pain in Older People: Reflections and Experiences from an Older Person's Perspective*. Help the Aged. London. Retrieved from:
<http://www.scie-socialcareonline.org.uk/pain-in-older-people-reflections-and-experiences-from-an-older-persons-perspective/r/a11G00000017z2vIAA>
- Levine, S. A., Brett, B., Robinson, B. E., Stratos, G. A., Lascher, S. M., Granville, L., ... Barry, P. P. (2007). Practicing Physician Education in Geriatrics: Lessons Learned from a Train-the-Trainer Model. *Journal of the American Geriatrics Society*, 55, 1281–1286.
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., ... Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ*, 339, b2700.
- Lin, W. C., Lum, T. Y., Mehr, D. R., & Kane, R. L. (2006). Measuring pain presence and intensity in nursing home residents. *Journal of the American Medical Directors Association*, 7, 147–153.

- Long, C. O. (2013). Pain management education in long-term care: it can make a difference. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 14, 220–227.
- Long, C. O., Morgan, B. M., Alonzo, T. R., Mitchell, K. M., Bonnell, D. K., & Beardsley, M. E. (2010). Improving Pain Management in Long-term Care: The Campaign Against Pain. *Journal of Hospice & Palliative Nursing*, 12, 148–155.
- Maas, M. L., Kelley, L. S., Park, M., & Specht, J. P. (2002). Issues in conducting research in nursing homes. *Western Journal of Nursing Research*, 24, 373–389.
- Martin, R., Williams, J., Hadjistavropoulos, T., Hadjistavropoulos, H. D., & MacLean, M. (2005). A Qualitative Investigation of Seniors' and Caregivers' Views on Pain Assessment and Management. *Canadian Journal of Nursing Research*, 37, 142–165.
- McClellan, W. J., & Higginbotham, N. H. (2002). Prevalence of pain among nursing home residents in rural New South Wales. *The Medical Journal of Australia*, 177, 17–20.
- McConigley, R., Toye, C., Goucke, R., & Kristjanson, L. J. (2008). Developing recommendations for implementing the Australian Pain Society's pain management strategies in residential aged care. *Australasian Journal on Ageing*, 27, 45–49.
- Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D., & Walker, A. (2005). Making psychological theory useful for implementing evidence based practice: a consensus approach. *Quality and Safety in Health Care*, 14, 26–33.

- Morrison, R. S., & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain and Symptom Management*, 19, 240–248.
- Mozley, C., Sutcliffe, C., Bagley, H., Cordingley, L., Challis, D., Huxley, P., & Burns, A. (2004) *Towards Quality Care: Outcomes for Older People in Care Homes*, Ashgate: Aldershot.
- Mrozek, J. E., & Werner, J. S. (2001). Nurses' attitudes toward pain, pain assessment, and pain management practices in long-term care facilities. *Pain Management Nursing*, 2, 154–162.
- Murfield, J., Cooke, M., Moyle, W., Shum, D., & Harrison, S. (2011). Conducting randomized controlled trials with older people with dementia in long-term care: Challenges and lessons learnt. *International Journal of Nursing Practice*, 17, 52–59.
- Napp (2014). *Pain in People with Dementia: A Silent Tragedy*. London, UK: Napp Pharmaceuticals Limited. Retrieved from <http://www.scie-socialcareonline.org.uk/pain-in-people-with-dementia-a-silent-tragedy/r/a11G0000005Xy4BIAS>
- Newhouse, R. P., Pettit, J. C., Poe, S., & Rocco, L. (2006). The slippery slope: differentiating between quality improvement and research. *The Journal of Nursing Administration*, 36, 211–219.
- Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences: a practical guide*. Malden, MA: Blackwell Publishing.
- Reis, L. A. dos, Torres, G. de V., & Reis, L. A. dos. (2008). Pain characterization in institutionalized elderly patients. *Arquivos De Neuro-Psiquiatria*, 66, 331–335.

- Ribbe, M. W., Ljunggren, G., Steel, K., Topinkova, E., Hawes, C., Ikegami, N., ... Jonnson, P. V. (1997). Nursing Homes in 10 Nations: A Comparison Between Countries and Settings. *Age and Ageing*, 26, 3–12.
- Sampson, E. L., White, N., Lord, K., Leurent, B., Vickerstaff, V., Scott, S., & Jones, L. (2015). Pain, agitation, and behavioural problems in people with dementia admitted to general hospital wards: a longitudinal cohort study. *Pain*, 156, 675–683.
- Schofield, P. (2006). Talking to older people in care homes : perceptions of their pain and their preferred management strategies. Results of a pilot study. *International Journal of Disability & Human Development*, 5, 53-59.
- Sengstaken, E. A., & King, S. A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41, 541–544.
- Sloman, R., Ahern, M., Wright, A., & Brown, L. (2001). Nurses' knowledge of pain in the elderly. *Journal of Pain and Symptom Management*, 21, 317–322.
- Smalbrugge, M., Jongenelis, L. K., Pot, A. M., Beekman, A. T., & Eefsting, J. A. (2007). Pain among nursing home patients in the Netherlands: prevalence, course, clinical correlates, recognition and analgesic treatment – an observational cohort study. *BMC Geriatrics*, 7, 3.
- Stevenson, K. M., Dahl, J. L., Berry, P. H., Beck, S. L., & Griffie, J. (2006). Institutionalizing Effective Pain Management Practices: Practice Change Programs to Improve the Quality of Pain Management in Small Health Care Organizations. *Journal of Pain and Symptom Management*, 31, 248–261.

- Swafford, K. L., Miller, L. L., Tsai, P.-F., Herr, K. A., & Ersek, M. (2009). Improving the Process of Pain Care in Nursing Homes: A Literature Synthesis. *Journal of the American Geriatrics Society*, 57, 1080–1087.
- Takai, Y., Yamamoto-Mitani, N., Okamoto, Y., Koyama, K., & Honda, A. (2010). Literature Review of Pain Prevalence Among Older Residents of Nursing Homes. *Pain Management Nursing*, 11, 209–223.
- Tarzian, A. J., & Hoffmann, D. E. (2005). Barriers to Managing Pain in the Nursing Home: Findings From a Statewide Survey. *Journal of the American Medical Directors Association*, 6, S13–S19.
- Torvik, K., Kaasa, S., Kirkevold, O., & Rustøen, T. (2010). Pain and quality of life among residents of Norwegian nursing homes. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 11, 35–44.
- Tousignant-Laflamme, Y., Tousignant, M., Lussier, D., Lebel, P., Savoie, M., Lalonde, L., & Choinière, M. (2012). Educational needs of health care providers working in long-term care facilities with regard to pain management. *Pain Research & Management: The Journal Of The Canadian Pain Society*, 17, 341–346.
- Tsai, H. H., Lai, Y. H., & Chu, T.-L. (2004). Pain prevalence, experiences and management strategies among the elderly in Taiwanese nursing homes. *Journal of Pain and Symptom Management*, 28, 579–84.
- Tse, M. M. Y., & Ho, S. S. K. (2014). Enhancing knowledge and attitudes in pain management: a pain management education program for nursing home staff. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 15, 2–11.

- Tse, M., Leung, R., & Ho, S. (2012). Pain and psychological well-being of older persons living in nursing homes: an exploratory study in planning patient-centred intervention. *Journal of Advanced Nursing*, 68, 312–321.
- University of York. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: Centre for Reviews and Dissemination, University of York.
- Van Herk, R., Boerlage, A. A., van Dijk, M., Baar, F. P. M., Tibboel, D., & de Wit, R. (2009). Pain management in Dutch nursing homes leaves much to be desired. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 10, 32–39.
- Wang, J., Kane, R. L., Eberly, L. E., Virnig, B. A., & Chang, L.-H. (2009). The Effects of Resident and Nursing Home Characteristics on Activities of Daily Living. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 64A, 473–480.
- Weiner, D., Peterson, B., Ladd, K., McConnell, E., & Keefe, F. (1999). Pain in nursing home residents: an exploration of prevalence, staff perspectives, and practical aspects of measurement. *The Clinical Journal of Pain*, 15, 92–101.
- Weiner, D. K., & Rudy, T. E. (2002). Attitudinal barriers to effective treatment of persistent pain in nursing home residents. *Journal of the American Geriatrics Society*, 50, 2035–2040.
- Weissman, D. E., Griffie, J., Muchka, S., & Matson, S. (2000). Building an Institutional Commitment to Pain Management in Long-Term Care Facilities. *Journal of Pain and Symptom Management*, 20, 35–43.
- Zanocchi, M., Maero, B., Nicola, E., Martinelli, E., Luppino, A., Gonella, M., ... Molaschi, M. (2008). Chronic pain in a sample of nursing home residents:

prevalence, characteristics, influence on quality of life (QoL). *Archives of Gerontology and Geriatrics*, 47, 121–128.

Zimmerman, S., Mitchell, M., Reed, D., Preisser, J.S., Fletcher, S., Beeber, A.S., ...

Sloane, P.D. (2010). Outcomes of a dementia care training program for staff in nursing homes and residential care/assisted living settings. *Alzheimer's Care Today*, 11, 83-99.

Zwakhlen, S. M., Hamers, J. P., Peijnenburg, R. H., & Berger, M. P. (2007).

Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research & Management : The Journal of the Canadian Pain Society*, 12, 177–184.

Part 2: Empirical Paper

Staff Training to Improve Pain Care in Dementia: A Feasibility Study in Care Homes

Abstract

Background: Pain is under-recognised and under-treated in people with dementia. Recent research (Hunter et al., 2013) has shown a relationship between care staff's beliefs about personhood and increased willingness to provide an appropriate pain intervention.

Aims: To develop a training intervention for dementia care staff focusing on enhancing beliefs of personhood alongside education in current best practice for assessing pain in dementia. This feasibility study tested the acceptability of the intervention design, examined recruitment and drop out, and can be used to establish a sample size for future more complex hypothesis-testing studies.

Design: A within-subjects pre/post design was used to evaluate the impact of the intervention on the assessment and management of pain in two UK care homes. Primary outcome variables were behavioural observation of residents' pain levels, and analgesic administration. Staff beliefs about personhood, and knowledge and beliefs about pain in dementia were also measured.

Results: Changes in pharmacological treatment practice were classified as 'improved' for 53% of residents, and residents with no analgesic prescription at baseline were significantly more likely to have an 'as needed' prescription at follow-up, but there were no significant differences in residents' overall pain levels. Care staff knowledge and beliefs about pain in dementia increased significantly following training, and a small but non-significant improvement was seen in staff beliefs about personhood in dementia.

Conclusion: Training was found to be acceptable to staff and proved feasible to implement. The promising findings should now be assessed further in a quasi-experimental controlled study.

Pain management in dementia

Although pain is increasingly common with age, it is not an inevitable part of the aging process. In the UK more than half of those over 65 years old report pain or discomfort (Office for National Statistics, 1997), and among older adults in institutional care the prevalence estimates range from 45–83% of respondents reporting at least one current pain problem (Ferrell, Ferrell, & Osterweil, 1990; Helme & Gibson, 2001). It is widely recognised that pain is under-recognised and under-treated in older adults and to the largest degree in people living with dementia (PwD) (Bernabei et al., 1998; Hadjistavropoulos et al., 2014; Horgas & Tsai, 1998; Sampson et al., 2015).

Self-report ratings of pain appear to be negatively correlated with degree of cognitive impairment (Cohen-Mansfield & Lipson, 2002), and nursing home residents with dementia often receive significantly less pain medication than cognitively intact residents with similar disorders (Feldt, Ryden, & Miles, 1998; Husebo et al., 2008; Kaasalainen et al., 1998; Morrison & Siu, 2000). In hospital settings patients with dementia who had surgery following hip fracture received one third of the pain medication of those without dementia (Morrison & Siu, 2000). Also, despite equal prevalence of potentially painful conditions, cognitively impaired residents are less likely to have fixed-schedule (FSC) prescriptions for analgesics, instead being given medications on an as-needed (PRN) basis, which increases the risk of under-treatment (Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008).

Untreated pain leads to reduced quality of life (QoL) (Asghari, Ghaderi, & Ashory, 2006; Torvik et al., 2010; Zancocchi et al., 2008), poorer appetite (Bosley, Weiner, Rudy, & Granieri, 2004), sleep disturbance (Giron et al., 2002) and greater

limitations in activities of daily living (Cadogan et al., 2008; van Herk et al., 2009; Won et al., 1999). Pain in dementia is strongly associated with depression and anxiety (Bartels et al., 2003; Jongenelis et al., 2004; Smalbrugge, Jongenelis, Pot, Beekman, & Eefsting, 2007), and with increased behavioural disturbances (Husebo, Ballard, Sandvik, Nilsen, & Aarsland, 2011; Sampson et al., 2015). In addition, the behavioural signs associated with pain are often interpreted as a psychological symptom of dementia and inappropriately treated with psychotropic medications (Haasum, Fastbom, Fratiglioni, Kåreholt, & Johnell, 2011), leading to a cycle of unmet need and inadequate pain care.

Although the problem of under-detection of pain in this population has been widely documented, there is little national emphasis on improving pain care, and only recently has the issue been raised by campaigns such as the ‘See Change: Think Pain’ campaign (Down, Wikström, & Siddorns, 2014). The most recent NICE guidelines (NICE, 2006) only discuss pain in the context of palliative care, and the issue of best practice in pain care for people with dementia is not addressed. Also, the Care Quality Commission (2014), the regulatory body for care homes, currently has no standards for pain care.

Pain assessment in dementia

Pain is a largely subjective experience, therefore the task of judging another’s pain is a complex process. Self-report is seen as the gold standard of pain assessment, which presents an obvious problem for assessing pain in patients with a limited ability to communicate. Clinicians rely heavily on people’s verbal reports when judging pain severity and when this is lacking there is a greater degree of underestimation (Kappesser, Williams, & Prkachin, 2006). Difficulties with abstract thought and lack

of language associated with cognitive impairment makes self-report of pain problematic, and presents a substantial barrier to pain assessment (Ferrell, Ferrell, & Rivera, 1995).

Although recommendations encourage the use of self-report scales, especially during mild stages of dementia (Corbett et al., 2012), cognitively impaired residents have much greater difficulty using these instruments accurately, and many are unable to do so at all (Pautex et al., 2006; Wynne, Ling, & Remsburg, 2000). There is also evidence that PwD report pain less often than those without (Parmelee, Smith, & Katz, 1993). Therefore, much research has focussed on the development of observational measures of pain for use in this population, but although a plethora of tools have been developed, many require further validation in people with dementia and are unsuitable or impractical for clinical use due to length or extensive training requirements (Achterberg et al., 2013; Herr, Bjoro, & Decker, 2006; Qi, Brammer, & Creed, 2012). A recent meta-review emphasised that despite several systematic reviews examining the psychometric properties and clinical utility of the 28 available tools, clear recommendations cannot be drawn (Lichtner et al., 2014).

Pain management in residential care settings

In the UK there are over 750,000 people living with dementia and approximately one third live in residential care homes (Alzheimer's Society, 2007) where there are numerous barriers to effective pain care. Direct resident care is provided predominantly by care or nursing assistants with little or no training in pain management (Allcock, McGarry, & Elkan, 2002; Mozley et al., 2004). In the UK, up to 85% of care assistants receive no training on pain management in older adults (Allcock et al., 2002), and more than two thirds of all care staff feel more training on

pain in dementia is needed (Napp, 2014). Also, care home managers are often unaware of current evidence-based practice in pain care (Barry, Parsons, Passmore, & Hughes, 2012), and homes rarely have a standardised organisational approach to pain management (Allcock et al., 2002; Tarzian & Hoffmann, 2005).

Lack of training and gaps in knowledge result in a lack of competence and confidence in pain assessments (Clark, Fink, Pennington, & Jones, 2006), and reluctance to administer medications due to concerns about side-effects, overdose, or addiction (Kaasalainen et al., 2007; Tarzian & Hoffmann, 2005). Unhelpful attitudes and inaccurate beliefs, such as that pain is a natural or inevitable part of aging, or dementia causes people to be insensitive to pain, are common and contribute to under-treatment (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010). Staff may be highly uncertain about pain in dementia (Gilmore-Bykovskyi & Bowers, 2013) and concerned about the authenticity or reliability of reports of pain in people with dementia (Sengstaken & King, 1993).

Staff cite high turnover and staff shortages as key barriers to effective pain care in this setting (Kaasalainen et al., 2007; Weiner & Rudy, 2002). Lack of time and staff shortages may mean that pain is not assessed or reports of pain go undocumented (Cairncross, Magee, & Askham, 2007; Cohen-Mansfield & Lipson, 2002), and residents who can self-report are reluctant to, as they believe staff are too busy (Cairncross, et al., 2007).

Interventions to improve pain management in dementia

Whilst there has been much written about the challenges of pain assessment in older adults with cognitive impairments and the problem of pain under-treatment, there is

a dearth of research into strategies for improvement, and published guidelines and recommendations cite limited evidence (Royal College of Physicians, British Geriatrics Society, & British Pain Society, 2007; Hadjistavropoulos et al., 2007). A number of interventional studies have focussed on improving pain care in residential settings (see Part 1: Literature review) (Herman, Johnson, Ritchie, & Parmelee, 2009; Swafford, Miller, Tsai, Herr, & Ersek, 2009). However, few studies have focused on dementia populations and many exclude residents with cognitive impairment, often for the reason that it poses additional challenges (Tse & Ho, 2013; Tse, Vong, & Ho, 2012; Weissman, Griffie, Muchka, & Matson, 2000).

Some interventions have shown promising results in reducing residents' observable pain behaviours, either through systematic use of observational tools (Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008), or algorithms advocating pain intervention use (Kovach et al., 2006; Kovach, Weissman, Griffie, Matson, & Muchka, 1999). However, when such interventions are not part of a rigorously implemented RCT they may fail to be as effective. For example, Cohen-Mansfield (2014) reported that in one study (Zwakhalen, van't Hof, & Hamers, 2012), even with 90% adherence to an observation protocol, pain-relieving interventions were still not adequately implemented.

Personhood and pain

Tom Kitwood (1997) defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being... impl[ying] recognition, respect, and trust” (p. 8). This idea of personhood-as-status

builds upon the philosopher Buber's (1970) interpersonal theory which posits that personhood is established by the way in which people relate to one another. Buber (1970) described two distinct ways of relating to others, depicted using the word pairs 'I-It' and 'I-Thou'. The I-It mode of relating implies a detached way of being which does not seek to acknowledge the individuality of the other, and instead the other is objectified. In contrast, the I-Thou mode involves engaging the other and relating to them in a genuine way.

The idea that perceptions of personhood influence approaches to pain management has been put forward several times. Kitwood (1997) talked about paying attention to pain as an integral part of the provision of person-centred care, and more recently a model of person-centred care which highlights the importance of paying attention to pain was proposed (Buron, 2008). The strongest case for the hypothesis that beliefs about personhood play a key role in pain under-treatment in dementia was provided by Malloy and Hadjistavropoulos (2004), who asserted that perceptions of personhood in PwD, regardless of the degree of cognitive impairment, would increase caregivers' awareness of pain and willingness to address it.

Recent research (Hunter et al., 2013) has shown that there is a relationship between beliefs about personhood and intended approaches to pain care among dementia care staff. This study found that staff who held stronger beliefs about the personhood of PwD were more likely to respond to vignettes in ways which indicated greater awareness of pain and increased willingness to provide an appropriate intervention.

One way in which personhood beliefs may influence approaches to pain management in PwD could be through influencing the amount of empathy caregivers feel for the patient. Decety and Lamm (2006) present a model of empathy as a

complex interplay of both bottom-up (emotional reactions) and top-down (executive control) information processing. When applied to the perception of pain in others (Craig, Versloot, Goubert, Vervoort, & Crombez, 2010; Goubert et al., 2005), this model explains empathy as the product of automatic reactions to the painful reactions of others (bottom-up information), to which meaning is attached through use of top-down information (i.e. application of the prior knowledge, experience, beliefs, attitudes and biases of the observer).

Empathy plays an important role in pain treatment biases. For example, Drwecki, Moore, Ward, & Prkachin (2011) found empathy biases predicted disparities in pain treatment, and participants who engaged in an brief exercise designed to enhance empathy, showed at least a 55% reduction in pain treatment bias compared to controls. Qualitative research with care staff found that empathy was related to greater realisation of the importance of appropriate pain care, such as the advantages of fixed schedule prescriptions over prn schedules (Dobbs, Baker, Carrion, Vongxaiburana, & Hyer, 2014), and that empathy achieved through role-taking was associated with descriptions of good clinical practice in palliative care (Schell & Kayser-Jones, 2007).

Communication of pain as a social transaction

Currently, the emphasis on development of behavioural observation tools reflects the fact that the problem of pain under-treatment is conceptualised as one of inability to identify pain in those with cognitive impairments. Therefore, the approach taken is facilitation of a more accurate or systematic assessment of pain. This conceptualisation neglects to pay sufficient attention to the pain assessment as a judgement, and the complexities involved. Measuring and assessing pain accurately

is of great importance. However, the observer must first be aware of, and willing to treat pain, in order to be motivated to assess it.

Experts in the field have advocated that pain assessment should be understood as social transaction rather than an objective process (Schiavenato & Craig, 2010; Tait, 2013). The communications model (Hadjistavropoulos & Craig, 2002) states that expressions of pain are messages which need to be decoded by observers. Non-verbal behaviours are more difficult to decode than verbal, so the transaction is vulnerable to all the complexities of interpersonal judgements that influence observers' decisions, such as attitudes and beliefs. Even the most objective and reliable observational assessment tool could not eradicate all of the subjective elements of this social transaction. Therefore, an approach which seeks to enhance providers' empathy and willingness to make positive pain judgements could also play a valuable role in bringing about behaviour change in dementia care staff.

Current study

There are currently no pain management interventions focusing on personhood or empathy reported in the literature. The current project aims to design a intervention for dementia care staff, building on the work of Hunter et al. (2013), by aiming to enhance beliefs of personhood through assisting dementia care staff to develop what Malloy and Hadjistavropoulos (2004) refer to as authentic relationships with PwD. It is proposed that this will be as effective in reducing residents' pain as the existing interventions which focus on systematic assessment, either through use of observational tools use or algorithms advocating analgesic use.

Aims

- a) To develop a brief staff intervention which aims to:
 - i. train dementia care staff in the application of guidelines on current best-practice (based on expert consensus) for assessing pain in older adults with cognitive impairment
 - ii. increase awareness of pain in PwD, especially those with limited capacity to communicate, as evident in improved pain assessment and treatment strategies
 - iii. increase perceptions of personhood in dementia
- b) To examine its feasibility in a small pilot study and generate data to enable calculation of effect size to inform a larger trial

Hypotheses

The staff training intervention will:

- i. Increase perceptions of personhood in dementia among care staff
- ii. Improve dementia care staff's knowledge of pain in dementia
- iii. Improve pain assessment and treatment strategies.

Method

Design

A quasi-experimental one group pre/post design was used to examine the feasibility of implementing a person-centred pain management programme in UK care homes and the impact on the assessment and management of pain in PwD.

In line with the Medical Research Council Guidance (MRC, 2008), the study was designed as a feasibility (pilot) study to test out the acceptability of the intervention design, examine recruitment and drop out, and establish sample size for future more complex hypothesis-testing studies. It also aimed to examine whether the intervention was associated with improvements in pain assessment and treatment practices and/or a reduction in residents' pain levels.

Setting

Recruitment of Care Homes

Using the Care Quality Commission (2014) care directory, a specified geographical area within acceptable travel distance of the researcher was screened to identify suitable care homes. To increase the likelihood of recruiting enough participants, only those homes with more than 35 residents and those that specified provision of dementia care were contacted. Also, from previous research overseen by her supervisor, the researcher was provided with the details of two care home contacts who had expressed an interest in participating in further research. Sixty eight homes were invited to participate (see Appendix A), of which six replied expressing interest. Managers of the six care homes were contacted to provide more detailed

information; one manager did not reply to contact attempts and this was assumed to indicate insufficient commitment. Of the remaining five homes, three declined to take part as the study time-line did not suit them; they had thought the research offered a pharmacological intervention for residents (1), or were unable to provide cover for staff to participate (1). The researcher visited the remaining two homes, which were selected to take part.

Description of sites

Care home A was an independent privately-owned home that provided residential care for up to 39 residents, overseen by one full time manager and a deputy manager. The majority of residents had a diagnosis of dementia, although they also provided care for people with physical health problems. The home had a total of 37 residents, with 7 staff on each day shift, providing an overall staff/resident ratio of 1:5. All staff, including ancillary staff, had received training in dementia care as part of their induction.

Care home B was also privately-owned and accommodated 48 residents in one unit providing residential care, overseen by one general manager. There were 9 care staff working each day shift, so the staff/resident ratio was also 1:5. Most residents were diagnosed with dementia, although the home also provided intermediate and long-term care for people with severe and enduring mental health problems and brain injury.

Quality of care provision was assessed through consulting the most recent inspection reports published by the Care Quality Commission (2014), an independent regulatory body for health and social care services. Both homes were reported to be compliant with the five quality rating standards: 1) Treating people with respect and

involving them in their care, 2) Providing care, treatment and support that meets people's needs 3) Caring for people safely and protecting them from harm, 4) Staffing, 5) Quality and suitability of management. In addition to meeting the minimum inclusion criteria in terms of care quality, both homes had also been awarded a Gold Standard Framework (GSF) in Care Homes Quality Hallmark Award, which is a national training programme and award for palliative care.

Ethics

Ethical approval was obtained from Camberwell St Giles National Research Ethics Service (NRES) Committee London (Appendix B), which is a flagged NHS Research Ethics Committee (REC) for approving research carried out under the Mental Capacity Act (2005).

Research involving staff can raise ethical issues around risk of undue influence from employers to participate. To reduce the risk of this, the researcher ensured managers were aware that participation must be voluntary and asked them to disseminate information sheets to staff who were asked to opt in to the research. Also, the participant information sheet stated that there would be no adverse effects on their employment should staff decline to participate, and this message was reinforced by the researcher during the consent process.

All prospective participants in the resident sample were assessed for their capacity to consent to take part in the study. Procedures for assessing capacity adhered to the Mental Capacity Act Code of Practice (2007) and followed the guidelines published by the British Psychological Society for conducting research with participants who lack capacity to consent (BPS: Dobson, 2008). If the

assessment indicated that a resident did not have the capacity to consent, the research team identified a personal consultee (usually the person's next of kin) in line with the MCA (2005), who was asked to consider the wishes and interests of the person who lacks capacity and advise the researcher about their participation. Full details of the consent procedure for residents is provided in Appendix C and copies of the information sheets and consent form in Appendix D.

Participants

Inclusion criteria

Site:

- within Greater London
- sufficient cover to allow at least 50% of fulltime day staff to attend training
- compliance with all 5 Care Quality Commission (CQC) quality rating standards
- managerial assurance of adequate resources allowing staff participation
- at least 21 residents who meet DSM-IV criteria for dementia

Residents:

- Meet diagnostic criteria for dementia according to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV; APA, 2000)
- Residents who have a painful disorder, PRN prescription for analgesia or other breakthrough pain medication documented in their medical notes or care plan

Staff:

- Working as a nurse (registered nurses of any grade including student nurse) or care assistant (health care assistants and nursing assistants)
- Working at least 4 shifts per week

Exclusion criteria

Site:

- Participation in any other pain management or quality improvement intervention
- Use of an existing pain assessment/management protocol (as this would be unrepresentative of UK care homes)

Residents:

- None

Staff:

- Lack of availability on training or assessment dates

Power analysis

Residents

The study was powered on resident outcomes, as these were identified as the primary outcome variables. As a feasibility study, reaching statistical power was not necessary. However, a power analysis was carried out using G*Power 3.1.7 software (Faul, Erdfelder, Lang, & Buchner, 2007) to inform sampling procedures. Estimating an effect size of 0.56 (obtained by Kovach, Weissman, Griffie, Matson, & Muchka,

1999) and specifying $\alpha = 5\%$ and desired power = 80%, the minimally desired resident sample size was 28.

Staff

Due to lack of research looking at changes in scores across time on either staff outcome measure, it was difficult to determine the size of effect that might be expected, and therefore to estimate a minimum desired sample size for staff. However, the aim was to recruit 30 staff, which would enable the detection of medium ($d=0.5$) effect sizes, according to a sensitivity power analysis specifying α ($p < .05$) and desired power (80%).

Measures

Resident outcome measures

Analgesic use

Administration of medications for pain was measured through analysis of the Medication Administration Records (MAR charts). MAR charts are a list of the person's current prescriptions for all medications, and are provided on a monthly basis by the pharmacist. Staff record each dose of medication administered on this form, including any non-prescription medication which are used for short-term management (i.e. less than 48hrs) of minor ailments, for example use of paracetamol to treat a headache.

Treatment changes

It is difficult to assess changes in dosage or analgesic class in a relatively small sample, as wide heterogeneity in medications prevents direct comparison. Therefore, changes in pharmacological treatment practice were classified as either 'improved',

‘no change’ or ‘deteriorated’. Improvement in treatment was defined as either a) an increase in prescribed dose b) an increase in the number of doses administered c) prescription of a stronger class of analgesic⁵ d) a change from no prescription (NIL) to an ‘as-needed’ prescription (PRN), or from PRN to a fixed-schedule (FSC) prescription (provided dose and class of analgesic remain the same or increase), or e) a combination of any of the previous criteria.

Residents’ pain levels

The primary outcome of residents’ pain levels was measured using the Pain Assessment in Advanced Dementia (PAINAD) scale (Warden, Hurley, & Volicer, 2003), which is a behavioural observation tool developed for the measurement of pain in people with dementia who cannot verbalise their experience. Staff received brief training in administration of the PAINAD from the researcher.

Observations on the PAINAD are made across five domains of pain-related behaviour; change in breathing, negative vocalisations, facial expression, change in body language, and consolability. Each domain is rated by severity from 0 to 2 according to specific descriptions of behaviours for each level of pain. Total scores range from 0 to 10 and provide an overall assessment of pain intensity. A cut-off score of ≥ 2 on the PAINAD was used to indicate possible pain (Jordan, Hughes, Pakresi, Hepburn, & O’Brien, 2011; Zwakhalen, van der Steen, & Najim, 2012).

The PAINAD tool was developed through adaptation of two existing longer scales, the discomfort scale for patients with dementia of the Alzheimer type (DSDAT; Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992) and the face, legs, activity, cry, consolability, infant pain scale (FLACC; Merkel, Voepel-Lewis,

⁵ Medications such as anti-epileptics (i.e. Gabapentin and Carbamazepine) were also included in the analysis if the GP confirmed that they were prescribed for the treatment of pain.

Shayevitz, & Malviya, 1997), alongside review of the literature and expert consensus. The psychometric properties of the PAINAD have been shown to be comparable with other available tools designed to assess pain in older people (Herr et al., 2006; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). Warden et al., (2003) reported high levels of inter-rater reliability (Pearson $r = .82-.97$), but only moderate internal consistency ($\alpha < .70$). However, further research using a sample more similar to that in the current study (Schuler et al., 2007) showed good internal consistency (Cronbach's $\alpha = 0.85$). It also has good content and construct validity (Warden et al., 2003; Zwakhalen et al., 2006), and shows the ability to detect decreased pain after treatment with analgesics (Jordan et al., 2011; Warden et al., 2003).

There are multiple behavioural observational tools available, each with strengths and limitations (Herr et al., 2006), and no consensus on which is the best (Hadjistavropoulos et al., 2007). This measure was chosen as it is quick and easy to use, requires minimal training (Lane et al., 2003), and is recommended by various bodies, such as The American Medical Directors Association (Warden et al., 2003) and The National Nursing Home Pain Collaborative (Herr, Bursch, Ersek, Miller, & Swafford, 2010), as clinically useful.

Staff outcome measures

Staff perceptions of Personhood in Dementia

Staff perceptions of personhood were measured using the Personhood in Dementia Questionnaire (PDQ: Hunter et al., 2013). The PDQ is a measure of beliefs about the personhood status of people living with dementia. It was developed through operationalisation of Kitwood's (1997) definition of personhood, as a tool to explore whether beliefs about patient status influence care provision. It contains 20 items,

formatted as brief statements e.g. *'Most residents with dementia feel the same range of emotions as I do'*; *'Residents with very advanced dementia are so low-functioning that they are no longer persons'*. Agreement with statements is measured on a 7-point response scale ranging from 'disagree strongly' to 'agree strongly', with higher scores indicating more person-centred attitudes towards people with dementia. The PDQ shows good reliability (Internal consistency $\alpha = 0.81$), good discriminant validity against another physician attitude scale, and resistance to socially desirable responding (as shown by non-significant correlation with the Balanced Inventory of Social Desirability Responding; Paulhus, 1991).

Staff knowledge and beliefs about pain

The Pain Knowledge and Belief Questionnaire (Zwakhalen, Hamers, Peijnenburg, & Berger, 2007) was used to evaluate staff knowledge and beliefs about pain in care home residents with dementia. The PKBQ was developed through review of the literature, identifying which gaps in knowledge and inaccurate beliefs act as a barrier to effective pain care in dementia. It is a 17-item questionnaire, containing statements about pain and residents' experience of pain e.g. *'Dementia patients experience less pain than non-dementia patients'*; *'A dementia patient should first report pain before receiving the next dose of pain medication'*. Items are rated on a 5-point scale (1 = completely disagree, 5 = completely agree), with lower scores indicating more accurate knowledge and beliefs. Face validity was established through review by pain experts and nurses. It was found to have satisfactory internal consistency (Cronbach's $\alpha > 0.7$) and clear underlying factor structure, but as a newly developed scale its validity has not yet been established.

Changes in clinical practice

Following completion of training, staff took part in a semi-structured interview (see Appendix E for schedule), designed by the researcher to:

- 1) provide further information about the acceptability of the training intervention; and
- 2) to examine changes in the clinical practice of pain care, in particular increased frequency and/or scope of pain assessment practices, such as regular pain assessment and use of appropriate assessment practices (i.e. use of observation methods, involving familiar carers, attempts at facilitating self-report wherever possible).

Dementia screening tool

The Clinical Dementia Rating scale (CDR; Hughes, Berg, Danziger, & Martin, 1982) was used to screen for probable dementia as part of assessment of eligibility, and to ascertain the severity of participants' level of cognitive impairment. This global measure of dementia (Hughes et al., 1982; Morris, 1993) is usually completed by a professional with detailed knowledge of the individual. The CDR uses a semi-structured interview protocol with six domains of cognitive and functional performance; memory, orientation, judgment and problem solving, community affairs, home functions, and personal care rated on a five-point scale. Global scores, which range from 0 to 3 and indicate the degree of cognitive impairment; none (0), questionable/very mild (0.5.), mild (1), moderate (2) or severe (3), are calculated using an algorithm weighted towards the memory domain (Morris, 1993). It has been shown to be a reliable and valid diagnostic and staging tool in dementia (Morris, 1997).

Procedure

Pre-intervention site visit

Following recruitment of the sites, the researcher visited both care homes to discuss how training could be supported and whether any organisational changes could be implemented to facilitate this. This discussion was informed by a review of the barriers and facilitators to implementing research in care homes, as detailed below.

Staff

Care home managers disseminated information sheets to the staff, who were invited to meet the principal researcher to ascertain whether they were eligible and obtain informed consent. Written informed consent was obtained from the individual staff within the teams participating in the research, and from their managers.

Staff completed a set of questionnaires and some brief demographic details. The PDQ and the PKBQ were completed at baseline (two week period prior to delivery of the training intervention) and repeated at follow-up. The follow-up period differed slightly across homes, with care home B completing post-intervention measures at week 8 and care home A at week 9, due to the Christmas holiday period.

Following completion of training, the researcher conducted semi-structured interviews with staff, focusing on changes in clinical practice, specifically pain assessment and treatment. Staff were provided with refreshments during the workshops and a £5 gift certificate upon study completion as incentives to participate.

Residents

The direct care team identified potential participants from the residents of their care homes using the inclusion and exclusion criteria. They also completed the Clinical Dementia Rating scale (CDR; Hughes et al, 1982) for all residents identified as potential participants. Most residents (93%) had a formal diagnosis of dementia, but for those without (n=2) the CDR was used to ensure they met the DSM-IV (APA, 2000) diagnostic criteria.

Staff were asked to observe residents for approximately five minutes and to complete the PAINAD (Warden et al., 2003) on four occasions (two at rest and two during movement). For the movement condition, staff were asked to identify a standard care procedure, during which movement is necessary (e.g. washing, dressing, etc.), when pain assessment can be carried out and to observe during the same procedure at baseline and post-intervention.

The principal researcher reviewed residents' MAR charts to obtain a measure of administration of pain medications at baseline and during the follow-up periods.

Intervention development

Phase one: Collation and review of existing guidelines

Key guidelines and consensus recommendations for pain assessment and treatment in older adults with dementia were identified, through an informal review of the literature. The main points of agreement were identified and formed the basis of the educational component of the intervention.

Key guidelines and consensus recommendations reviewed included:

- Royal College of Physicians, British Geriatrics Society and British Pain Society. National guidelines in the assessment of pain in older people (BGS & BPS, 2007)
- An interdisciplinary expert consensus statement on assessment of pain in older persons (Hadjistavropoulos et al., 2007)
- American Geriatrics Society Panel on Persistent Pain in Older Persons (AGS, 2002) and American Geriatrics Society Panel on the Pharmacological Management of Persistent Pain in Older Persons (AGS, 2009)
- Pain in residential aged care facilities (Australian Pain Society, 2005)
- American Medical Directors' Association Pain Management Guidelines (AMDA, 2012)
- National Council for Palliative Care information guide on pain in dementia (NCPC, 2012)
- National Nursing Home Pain Collaborative: expert consensus recommendations for use of pain-behavioural assessment tools in the nursing home (Herr et al., 2010)
- Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011)

Under guidance of expert consultants, clinical implications and recommendations were also drawn from the most recent research, which has given more weight to the importance of facial expressions of pain as part of effective observational assessment (Kunz, Scharmann, Hemmeter, Schepelmann, & Lautenbacher, 2007; Prkachin, 2009).

Phase two: Addition and integration of personhood component

The limited literature on personhood and pain was used to inform the content of the intervention. Malloy & Hadjistavropoulos (2004) claim that perspective taking aids the development of authentic relationships where personhood is respected. There is

also evidence that perspective taking increases empathy (Drwecki et al., 2011; Schell & Kayser-Jones, 2007). Therefore, several exercises were developed with the aim of encouraging staff to take the perspective of residents with dementia. Second, Malloy & Hadjistavropoulos (2004) suggest that caregivers should conduct a self-audit considering the ontological variables that influence the nature and quality of relationships with residents. A list of possible self-audit questions is provided in the article (Malloy & Hadjistavropoulos, 2004), and these were modified for use with care staff as part of group discussions (e.g. What is a person/personhood? Does a human ever cease to be a person worthy of respect, dignity and authenticity?).

In line with Kitwood's (1997) definition of personhood, group discussions were designed to invite staff to consider how they could foster relationships with residents which involve recognition, respect, and trust, and the particular applications of these values to pain care. Also, Hunter et al. (2013) suggest that sensitivity to residents' personhood can be enhanced through teaching person-centred approaches. Therefore, the researcher sought to promote the principles of person-centred care throughout all training activities. As there is no universally accepted model of person-centred care, the VIPS framework (Røsvik, Brooker, Mjorud, & Kirkevold, 2013) was employed as a useful heuristic. The VIPS model aims to summarise Kitwood's (1997) key ideas: recognising and respecting the value (V) of each person as an individual; providing individualised care (I); paying attention to the perspectives (P) of residents; and promoting positive social psychology (S). Also, the unmet needs model of challenging behaviour (James & Stephenson, 2007) was chosen as a framework for case discussions, as it allows for consideration of the various individual factors which influence pain expression.

Phase three: Consideration of barriers and facilitators

Key barriers and facilitators in care home research implementation were identified through review of the literature (for full details see Part 1: Literature Review). Six additional papers were also reviewed which were not included in Part 1, as they were not specific to educational interventions, but were relevant to research in this setting (Clark et al., 2006; Corazzini et al., 2010; Maas, Kelley, Park, & Specht, 2002; Montes & Tripp-Reimer, 2002; Murfield, Cooke, Moyle, Shum, & Harrison, 2011; Tarzian & Hoffmann, 2005).

The four categories of barriers identified in Part 1: 1) resource constraints, 2) organisational culture, 3) communication, and 4) attitudes and beliefs, were also the most prevalent in the additional papers reviewed, with a particular emphasis on the first two. The predominant facilitating factor identified was managerial support. As such, the pre-intervention site visit was focused upon obtaining a clear commitment from managers and identifying ways of demonstrating support to staff.

Strategies designed to overcome barriers due to resource constraints included running the training twice in each home, and problem-solving challenges, such as lack of time and high workload, as part of intervention (i.e. action plan formation). The intervention also specifically targeted staff beliefs and attitudes most commonly reported to be barriers to change. Finally, a GP was asked to act as an expert consultant during intervention development to advise on effective communication with prescribers.

Phase four: Expert consultation and piloting

A multidisciplinary group of seven experts provided consultation during development of the intervention. Experts included four clinical psychologists (three with expertise in dementia and one with expertise in pain), a consultant nurse specialist in dementia, an old age psychiatrist, and a general practitioner. The psychiatrist and GP also held positions as senior clinical lecturer, and senior research associate respectively, at the Marie Curie Palliative Care Research Unit and had a special interest in pain in dementia. Experts provided input during development meetings and made comments and suggestions on successive drafts of intervention materials.

Training materials were piloted with nine direct care staff who provided written feedback and took part in informal focus groups. The group consisted of four nurses (44.4%), three health care assistants (33.3%), one nursing assistant (11.1%) and one student nurse (11.1%), with a mean experience of 7.25 (3.97) years in dementia care. Most staff ($n=5$, 55%) also had several years' experience of working in care homes ($M = 3.12$, $SD = 1.92$), and were able to advise on the amount of general dementia training needed and the appropriate level to pitch this. Feedback was then integrated and an overview of the finalised training programme is presented in Table 1. (see Appendix F for training materials).

Intervention delivery

The training intervention was delivered at both care homes over a period of five weeks as two half-day workshops and a group case discussion lasting one hour. In

order to allow for different staff shifts, the training workshops were run twice in both homes, with three case discussion sessions offered, at least one of which was at the beginning or end of a night shift.

Both the workshop and case discussion sessions were delivered by the researcher, under the supervision of an experienced clinical psychologist working in dementia care (Dr Aimee Spector). As far as possible, staff attended the training during their normal working hours, but where this was not possible they were paid for their attendance outside these hours.

Table 1

Overview of the staff training programme

Main Topics	Format
Workshop 1 (4hrs)	
Personal experiences of pain	Group discussion
The problem of pain in dementia	Quiz, video, didactic education, small group discussion (brainstorm)
‘Myth busting’: addressing erroneous beliefs	Small group exercise, group discussion
Pain assessment in dementia, behavioural signs	Didactic education, case/vignette based discussion, quiz, role-play
Pain treatment and the roles of care staff	Didactic education, group discussion
Non-verbal communication of pain	Role-play, group discussion
Workshop 2 (4hrs)	
Communication of pain	Vignette, group discussion, didactic education
Attitudes and beliefs as barriers to effective pain management	Self-audit exercise, group discussion (brainstorm)
Person-centred pain assessment	Role-play, demonstration/modelling, vignette, case discussion
Personhood in dementia	Individual exercises, small-group discussion, didactic education, group discussion
Applying principles of person-centred care to pain assessment	Case discussion
Implementing the training	Action plan formation
Case discussion session (1hr)	Staff members led discussions on their assigned resident

Data Analysis

Data were analysed using The Statistical Package for the Social Sciences (SPSS) version 21.0.

Treatment of missing data

Individual values of missing data on staff measures data were pro-rated (i.e. the scale mean was used). Pro-rating was considered inappropriate if more than 10% of items were missing and case-wise deletion was performed.

Staff were asked to observe residents using the PAINAD under two conditions, at rest and during movement, on two separate days, to generate a baseline mean and follow-up mean of pain level. However, a high percentage of missing Day 2 data (16% overall, >33% at baseline), and obtained observations often of questionable reliability (e.g. no date and identical scores to Day 1) or collected after the allotted measurement period, led to the decision to use only Day 1 PAINAD scores in the analysis. The PAINAD showed high test-retest reliability ($r = .90$) in a similar sample (Schuler et al., 2007), therefore it is hoped that this decision will have little impact on the results.

Significance testing

Staff data from the PKBQ and PDQ were found to be normally distributed and paired t-tests were carried out to evaluate the change in scores over time. Resident data on the PAINAD violated assumptions of normality, therefore the Wilcoxon signed ranks test was used. Categorical data was analysed using the Related Samples Marginal Homogeneity test, which is an extension of the McNemar test. Where statistical

significance was achieved, effect sizes were calculated for the magnitude of change. To control for the risk of Type I error, due to multiple testing, a Bonferroni corrected alpha was used where appropriate.

Reliable and clinically significant change

Reliable Change Indices (RCI)⁶ were calculated for each resident's PAINAD score. Change is considered reliable when it is greater than might be expected by chance, given the reliability (Cronbach's α) of the measure. If the RCI ratio was greater than ± 1.96 , change is considered to be reliable at the $p = 0.05$ level (Jacobson & Truax, 1991).

Clinical significance of change in pain ratings was also calculated. Criterion C of Jacobson and Truax (1991) was used, which defines clinical significance as a score moving from the clinical range pre-treatment to below the clinical cut-off post-treatment. A cut-off score of ≥ 2 was used to indicate potential pain on the PAINAD (Jordan et al., 2011; Zwakhalen, van der Steen, & Najim, 2012).

Analysis of staff interview data

Due to the scope of the current project it was not possible to undertake qualitative analysis of data from semi-structured feedback interviews with staff. Instead, a brief quantitative analysis of content was conducted (Berelson, 1952; Weber, 1990). The manifest content of staffs' answers was examined and explicit

⁶ RCI ratio is calculated as the difference between pre- and post-test scores $[X_1 - X_2]$, divided by the standard error (SE) $[X_1 - X_2 / s_{diff}]$; $s_{diff} = \sqrt{2(SE)^2}$.

categories were identified and tallied. This basic deductive approach was judged to be appropriate as an adjunct the main analysis, and sufficient to address research questions about change in clinical practice and acceptability of the intervention to staff.

Results

Participants

Staff sample

Twenty eight care staff took part in the training and demographic information is presented in Table 2. All staff were female, and the majority were from countries outside the UK and spoke English as a second language (71%). Twenty three members of staff (82%) had a qualification relevant to care work, such as an NVQ or non-UK nursing qualification. One member of staff dropped out as she left her post; it was not possible to obtain follow-up measures for two staff due to sickness and unplanned leave. No staff reported receiving any training in pain in dementia previously.

Table 2

Demographic characteristics of staff participants

Characteristic (n = 28)	N	%	Mean (SD)	Range
Gender: Female	28	100		
Language:				
English as first language	8	29		
English as second language	20	71		
Time working at Care Home (years)			4.6 (6.2)	0.1-23yrs
Total experience in Care (years)			7.7 (7.0)	0.1-25yrs
Qualifications:				
No relevant qualification	5	18		
NVQ2	4	14		
NVQ3	7	25		
NVQ4	2	7		
Non-UK Nursing qualification	8	29		
Other (managerial)	2	7		
Currently studying:				
NVQ2	3	11		
NVQ3	1	4		
NVQ4	1	4		
Other (not stated)	1	4		
Not currently studying	22	79		
Job title:				
Care Assistant	15	54		
Senior Care Assistant	8	28		
Care Team Leader	3	11		
Deputy Manager	1	4		
Manager	1	4		

Staff outcomes

Knowledge and beliefs

At baseline, staff showed good overall knowledge about pain in dementia, with scores clustered towards the lower end of the scale on the PKBQ ($M = 31.3$, $SD = 9.7$), indicating more accurate knowledge and beliefs. An increase in knowledge was observed at follow-up ($M = 27.1$, $SD = 9.3$), which was significant using a corrected alpha of $p < 0.025$, $t(24) = 2.64$, $p = .014$, with a small effect size ($d = 0.4$).

Perceptions of personhood in dementia

Care staff reported strong positive beliefs about personhood on the PDQ at baseline ($M = 95.5$, $SD = 17.4$). There was a small increase in scores at follow up ($M = 100.4$, $SD = 17.2$), but this was not statistically significant $t(24) = -1.89$, $p = .072$.

Self-report of change in clinical practice

Staff were interviewed about changes in their clinical practice at follow-up. In total, 90% ($n=18$) of staff were able to provide at least one example of how the training had influenced their practice. The dominant themes, shown in Table 3, indicated increased frequency and scope of pain assessment practices, in particular observing for behavioural signs of pain during care tasks. Staff reports also suggested an increase in effort to facilitate self-report when possible.

A bias towards pharmacological treatment for pain was found, as all staff who spoke about changes in treatment referred to analgesic use, whereas only six staff members mentioned the use of non-pharmacological treatments for pain: four mentioned repositioning, one spoke about the use of massage, and one gave an idiosyncratic example. Six members of staff (30%) spoke about re-assessment being

an important part of good pain management, but this was lacking from most accounts. Also, there was no mention of involvement of family members or informal carers.

Several staff spoke about barriers to implementing changes in clinical practice, which are presented in Table 4. Care assistants (i.e. junior staff) spoke about being uncertain about their role in pain management, resulting in a poor uptake of the available pain assessment tools. Reports of major changes in pain treatment plans (i.e. a change in prescription type) were mostly provided by senior staff. Managers and senior staff spoke about difficulties organising case discussions and lack of time making pain assessment difficult to prioritise. Some staff thought the fact that new practices were not yet routine made implementing them more challenging. Another perceived barrier to implementing change was difficulties with communication, and most staff appeared unaware of what had been discussed in the other case discussion groups.

Table 3

Feedback from staff (n = 20): Reported change in clinical practice

Themes	N	<i>Quotations</i>⁷ (participant identifier)
Increased frequency of pain assessment	13	<i>'...we need to come back a couple of times, come again to ask about pain and some of them might start to show or tell you if you keep asking' (109)</i>
Increased effort to obtain self-report	13	<i>'...he didn't tell me [about pain] until I and sat down with him on the same level, make eye contact and make him understand that I am here for him' (110)</i>
Use of informal observation during care tasks	11	<i>'If we have to move a resident from one position to another it gives me the opportunity of knowing if the person is in pain or not, because you can know from the kind of utterances coming out, probably moaning, groaning or that kind of reaction tells you something is wrong' (118)</i>
Scope of pain assessment increased beyond self-report	10	<i>'I look in different ways, it might be body language, facial expression or if they withdraw [...] clues they might be in pain' (100)</i>
Heightened awareness leading to greater detection of pain	8	<i>'We had a lady with a chest infection and normally they [care assistants] don't pick up on things like that, but because they're now more aware, that was picked up on...because of her facial expression and body language' (112)</i>

⁷ An ellipsis in parenthesis indicates the quotation has been edited.

Increased persistence to treat	7	<i>'...some of our ladies with their medication they can be very difficult [...] instead of going over and giving it to them and if they refuse just leaving it [...] it's just actually sitting down with them and taking your time with them' (135)</i>
Increase in frequency of re-assessment following treatment	6	<i>'I know we are too busy, but we can find ample time to re-assess, if not we ask someone else or ask the person in charge to give ample time for this person because I think she is in pain' (123)</i>
Use of non-pharmacological treatments	6	<i>'I knew she had the arthritis, but we didn't realise the extent [...]so she should be being massaged in the Namaste room now' (105)</i>
Asking the GP to review residents' medications	5	<i>'we were talking about it [possibility of review by GP] last week and when I said it they'd already asked the doctor'(126)</i>
Use of perspective taking to aid pain assessment	5	<i>'Let's say I have a headache and I can't verbalise, I think 'ok, what would I do to show people around me I'm in pain?'...that helps, and I wouldn't do that if I didn't have the training' (135)</i>
Consideration of pain as a possible explanation for agitation or confusion	4	<i>'...before this training I never thought it [agitation]could be a sign of pain' (124)</i>
Increase in use of pain treatment plans	4	<i>'I leaned more strategies or systems, we have action plans now for those we think they are in pain' (121)</i>

Table 4

Feedback from staff (n = 20): Barriers to change

Themes	N	<i>Quotations</i>⁸ (participant identifier)
Uncertainty about role in terms of pain management (<i>Junior staff</i>)	5	<i>'I think they're done by seniors [...] I need to find out whether or not we would do it or whether I would need to refer it to a senior' (106)</i>
Communication between staff difficult in busy environment	4	<i>'...you can quite easily slip under the loop if you're off for a day or something' (105)</i>
New practices not part of routine	3	<i>'If we were told we would, if not then we come and do the routine things and the time is going and then the shift is finished' (117)</i>
Organisation difficult due to lack of time (<i>Managers/senior staff</i>)	3	<i>'Time is of the essence really here [...] trying to find enough time when you've got the maximum amount of people available when you're doing it is hard' (120)</i>

⁸ An ellipsis in parenthesis indicates the quotation has been edited.

Resident sample

Thirty six residents were identified as eligible to participate. Consent was obtained for 30 residents, with four having capacity to consent themselves and next of kin acting as a personal consultee for the remaining residents. Reasons for non-participation included personal consultees stating that they did not think their relative would wish to take part (3), not being able to contact a suitable personal consultee (2) and resident declining to take part (1).

Characteristics of the resident sample are described in Table 5 below. The majority had dementia at the moderate or severe stage. Most residents (n = 28) had been given a formal diagnosis of dementia and two were included on the basis that carers considered them to have probable dementia and they were rated as having a moderate level of cognitive impairment on the CDR. No residents dropped out or were withdrawn from the study, but there was some missing data for one resident due to being hospitalised during the follow-up period.

Table 5

Demographic characteristics of resident participants

Characteristic (n=30)	Mean (SD) Range	N	%
Age	88.7 (5.1) 78.0 - 98.1		
Gender:			
Female		27	90
Male		3	10
Cognitive impairment:			
Mild		5	17
Moderate		13	43
Severe		12	40
Pain-related conditions:			
Arthritis		13	43
Back/joint pain (inc. scoliosos, sciatica)		7	23
Previous fractures		3	10
Urinary tract infections		2	7
Gallstones		1	3
Neuralgia		1	3
Contractures		1	3
Cancer		1	3
Angina		1	3

Resident outcomes*Analgesic use**Prescription type*

Analgesic prescription rates at baseline were 37% NIL, 23% PRN and 40% FSC, whereas at follow-up rates were 10% NIL, 50% PRN and 40% FSC. Of those without any analgesic prescription at baseline, 72% (n=8) were prescribed analgesic at least PRN post-intervention. The Marginal Homogeneity test revealed that this difference was significant $X^2(2) = 11.0$, $p = 0.021$, with a medium effect size ($r = .42$). As shown in Figure 2, residents with no prescription for analgesic (NIL) at

baseline were significantly more likely to have a PRN or ‘as needed’ prescription at follow-up.

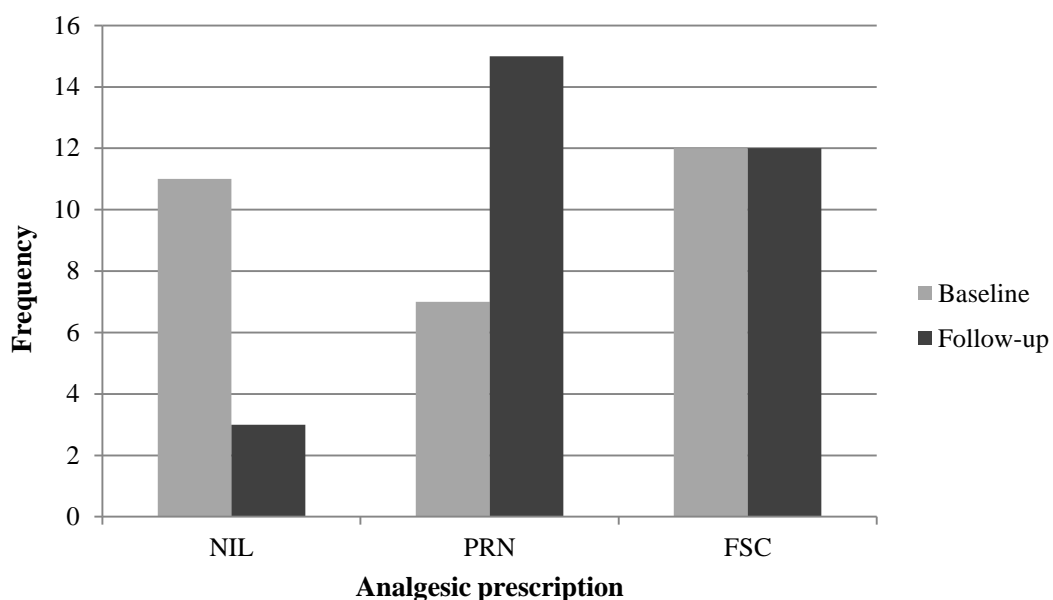


Figure 2. Frequency of analgesic prescriptions at baseline and at follow-up

Improvement in pharmacological treatment

Overall, changes in pharmacological treatment were classified as either improved, no change or deteriorated. More than half of the participants (53%) had an improvement in their treatment. Forty three percent ($n = 13$) of residents had no changes in their pharmacological treatment and one resident's treatment was classified as deteriorated (3.3%), as his/her PRN paracetamol dose was reduced.

Of the changes categorised as improvements, nine represented change in prescription type ($n = 9$), as shown in Figure 2. Frequency of analgesic prescriptions at baseline and at follow-up. However, this category also included residents whose

prescription dosage was increased ($n = 2$) or who were administered more doses on a PRN prescription ($n = 5$). In the latter case, these residents were described as often being offered but refusing medication during case discussions. The increase in number of doses taken corresponded with staff reports of better treatment practices, such as a change from solid to soluble tablets, which are easier to take, and more time spent identifying the individual needs of residents in order to enhance the likelihood of them taking medications: *“She would take them [tablets] and just leave them in her mouth or sometimes spit them out [...] I gave her a bottle to drink out of instead of glass and she was able to take the water better” (P126)*

Staff observations of residents’ pain

Prevalence of pain

Pain was found to be highly prevalent at baseline. Forty percent of residents ($n=12$) had a PAINAD score indicating a clinically significant level of pain (above cut-off ≥ 2) at rest, and 73% ($n=22$) on movement.

Changes in pain levels

There were no significant differences in residents’ overall pain levels between baseline and follow-up. PAINAD scores at rest were clustered at the lower end of the scale ($M = 1.4$, $SD = 1.7$), and although there was a small decrease in scores between baseline ($Mdn = 1.0$) and follow up ($Mdn = 0$) this was not significant, $z = -.739$, $p = .460$. Scores during movement were also within the lower range of the scale, but the mean baseline score was within the clinically significant range ($M = 3.6$, $SD = 2.2$). Again, there was a small but non-significant decrease between scores at baseline ($Mdn = 3.0$) and follow-up ($Mdn = 2.5$), $z = -1.724$, $p = .085$.

Individual level analyses of changes in pain

Reliable change in pain levels

As shown in Table 6, none of the residents identified as having probable pain from baseline scores at rest showed a deterioration in their pain levels; the majority showed no change (58%), and 42% (n = 5) showed reliable improvement. Pain during movement was more prevalent, and 16 of the 22 residents whose scores indicated likely pain at baseline showed no improvement at follow-up. There was a reliable improvement for five residents (23%) and deterioration in one resident who sustained a fractured pelvis during a fall that was misdiagnosed in hospital leading to untreated pain. The pain scores for this resident showed reliable deterioration in both conditions.

For most of the residents whose scores indicated no pain at baseline, this was also true at follow-up across both rest and movement conditions. However, for three residents (10%), they developed pain at rest. For one of these residents the development of pain at rest was due to a misdiagnosed fracture, as discussed above, and staff reported being aware of pain but unable to provide treatment as pain was not being recognised by prescribers. The two other residents both had a change in treatment, classified as an improvement; one received more analgesic and the other went from no analgesic to a PRN prescription.

Table 6

Reliable change in residents' pain scores on the PAINAD

Baseline scores	Deterioration	No change	Improvement
At rest			
No pain <Cut-off of 2 (n=18)	3	15	0
Probable pain >2 (n=12)	0	7	5
Total (n=30)	3 (10%)	22 (73.3%)	5 (16.7%)
During movement			
No pain <Cut-off of 2 (n=7)	0	7	0
Probable pain >2 (n=22)	1	16	5
Total (n=29)	1 (3.4%)	23 (79.4%)	5 (17.2%)

Clinical significance of change in pain levels

Further analyses were carried out to determine what percentage of reliably improved scores could also be considered clinically significant. All five residents whose pain showed reliable improvement at rest were also below the clinical cut-off at follow-up (17%). However, for pain during movement, only 7% (n = 2) showed improved levels of pain which were both reliable and clinically significant.

Acceptability of the training programme

Acceptability of the intervention was assessed as part of the semi-structured interview at follow-up. To reduce potential bias, all staff were invited to take part, including those who only partially completed the training, 25% (n = 5) of respondents.

Overall, the training programme was well received by staff. As shown in Table 7, staff reported that training heightened their awareness of pain and increased

their confidence in their assessment skills. Reports also indicated that the training enhanced knowledge, dispelled unhelpful myths, and helped staff develop more positive attitudes towards PwD.

Staff thought the most helpful aspect of training was education around the behavioural signs of pain, as shown by the themes presented in Table 8. They also reported that the exercises requiring more active participation (i.e. case discussions and role play) were useful. Senior staff in particular said they valued the introduction of new tools, mostly referring to the self-report scales, as opposed to behavioural observational tools, for which uptake appeared limited.

Workshops were well received, but some staff needed significant encouragement to take part in the role play, and the exercise was modified in one group to support less confident members. Also, during case discussions, frequent requests were made for direct advice from the researcher, implying that the supervisory style employed was unfamiliar to staff. However, staff responded well when asked to think about how they might use certain aspects of the training and were able to generate appropriate suggestions.

As shown in Table 9, around half of the staff stated there were no aspects of the training which they thought could be improved. Of those who suggested improvements, the most common feedback was that the training was too long. When prompted further there were no suggestions for material which could be removed; some suggested that didactic content could be condensed and most thought that the training should be provided in more frequent but shorter sessions. Others suggested making the training more active.

Table 7

Feedback from staff (n = 20): Experience of training in general

Themes	N	Quotations⁹ (participant identifier)
Training heightened awareness of pain	14	<i>'It makes you think more [about pain], because you do get complacent' (105)</i>
Training increased confidence in pain assessment skills	5	<i>'My confidence has grown [...] with the course it teaches you the facial signs and things ...gives you more confidence in what you're looking for' (113)</i>
Learning that people may hide pain was a new and useful idea	5	<i>'We usually think they will express that they are in pain, but I found out some interesting things ...some people don't express pain and we need to find out' (110)</i>
Training dispelled myths about pain in dementia	4	<i>'People used to think 'people with dementia they don't feel pain', and that was my concept' (124)</i>
Training helped staff develop a more positive attitude towards people with dementia	4	<i>'It changes stereotypes that old people they just moan all the time' (100)</i>
Training developed greater understanding of residents	4	<i>'After the case discussion I know why she feels like that...sometimes she's very agitated with me, so I know now [...] I understand her [...] you feel it, you really feel it for her' (117)</i>
Training increased perception of reliability of self-report/ reduced suspicion	3	<i>'Instead of dismissing it, you know that a lot of it might be attention seeking, you've still got to be very aware' (105)</i>

⁹ An ellipsis in parenthesis indicates the quotation has been edited.

Table 8

Feedback from staff (n = 20): Aspects of the training that were helpful

Themes	N	Quotations
Knowing behavioural signs to look out for	16	<i>'I found it very useful to know if people are in pain who can't speak [...] we can recognise by facial expressions, physical movements, or gesture, posture [...] it's useful...like people will be wandering or crying not just because of the mental illness but here could be pain' (125)</i>
Case discussions	11	<i>'I enjoyed discussing about different persons [...] I know more information about the residents, so it's really helpful so I can communicate with them differently' (109)</i>
Role-play	7	<i>'I could put myself into their shoes and see how difficult it is [...] it must be horrible. Now I look at them from a different point of view' (135)</i>
Introduction of new tools	7	<i>'...the new tools for self-assessment [...] we're inclined to forget for people with dementia ... if we have a nurse or doctor come in we can show them we've been doing this' (111)</i>

Table 9

Feedback from staff (n = 20): Aspects of the training that could have been improved

Themes	N	Quotations
No aspects needed improvement	9	<i>'Nothing. It was different than I expected, it was better. I didn't expect that we'd be involved so much in it. I just found it all really helpful' (126)</i>
Session were too long	8	<i>'Instead of two four hours, it could've been split into three two hours' (106)</i>
Training could have been more active	3	<i>'I would get people up and moving about a bit more' (120)</i>

Feasibility of the current study

Study processes

The recruitment strategy proved to be feasible, as although the recruitment rate for sites seems low at 3% (2/68 sites), the recruitment process of a mailshot was low cost and the recruitment phase was short (<2 months). Recruitment rates for residents were high, with 83% of all eligible participants recruited and the desired sample size exceeded. As expected, rates for the staff sample were lower, with 50% of eligible participants recruited, and sample size falling just short of the desired number (28/30).

The overall time-frame of training was feasible in both homes, with training taking place over five weeks. However, as both homes required sessions to fit around other training commitments, the interval between workshops differed across homes (Home A: 3 weeks vs. Home B: 1 week). Overall there was good retention (100% residents; 96% staff) and follow-up rates (97% residents; 89% staff).

Training intervention

Workshop sessions

The overall attendance rate was 93% (n=26) for both workshops; absences were due to illness and child care difficulties. Each workshop was run twice, to suit different shift patterns and allow staff to make-up missed sessions. Staff mostly engaged well in the workshop sessions, making active contributions. However, staff who attended after working a full shift, especially night staff, were noticeably less engaged.

Case discussion sessions

Attendance at case discussions was 71% (n=20), which was much lower than workshops. Lack of attendance was partly attributable to poor organisation and communication, but may have been due to a belief that this was an optional adjunct to the training and therefore not as highly prioritised. Some staff also mentioned during informal feedback that they felt anxious about presenting a case in a small group.

The usefulness of case discussions was sometimes limited by staff's lack of knowledge of residents' social and medical histories, and current pain treatment plans. This was more often the case when the group did not include a senior member of staff. In some instances staff were able to obtain this information, but this sacrificed discussion time.

Resource and management considerations

As shown in Table 4, there was some feedback that the logistical aspect of organising the training was challenging, as staff work different shift patterns and adequate cover is required. This feedback was congruent with the researcher's observations, as some staff who expressed an interest were unable to take part as they were needed to cover shifts and it was necessary to offer four case discussion sessions to accommodate all participants.

Although it was possible to deliver the training within the project timeline, in Home B there was a two month delay after the original commitment as the home needed to undertake an inspection to maintain their GSF accreditation and this was

prioritised. Delays and organisational issues were also encountered in both homes during the follow-up period due to managers taking leave.

In terms of resources, one home had all of the required technology for delivering training, but additional equipment (e.g. projector, laptop) needed to be brought to the second home. Training space was adequate, but off-site training might have been preferable as there were frequent interruptions from residents, and senior staff sometimes got called away for short periods to deal with clinical issues. However, offsite training might be less accessible to some staff.

During the pre-intervention site visits, both managers readily engaged with discussions around avoiding potential barriers to change and implementing training principles. However, during the final stage of the training where action plans were discussed, one manager was unable to attend and the other appeared disengaged and eager to end the session. All the barriers to change presented in Table 4 were anticipated and discussed as part of this action planning stage, but there were no reports of the possible solutions being attempted.

Feasibility of outcome measures

There were low rates of missing data and multiple answers (<3%), and no qualified answers on completed questionnaires, indicating that these measures were well understood and acceptable to staff.

Data regarding residents' medication was readily available and easily obtained. However, the quality of record keeping was not sufficient for detailed analysis (e.g. average daily dose). For example, it was often unclear whether one or

two paracetamol were administered where the prescription was ‘one or two tablets, as needed’. Also, when assessing pain care practice it is useful to know whether medication was not taken because it was refused, or because it was not offered, and this information is often not recorded for PRN prescriptions as it is not a requirement.

The amount of missing and unreliable data on the PAINAD suggests that the burden of data collection procedures for resident data was too great for staff to manage. Also, the same members of staff were asked to complete the measure at both baseline and post-intervention for each resident. This consistency was achieved in the majority of cases (n= 26, 87%), but was not possible for four residents (13%, n=2 in each care home), due to staff drop-out and sickness.

Non-pharmacological treatment is an important aspect of effective pain care and it was originally planned to collect data on this. However, although both managers indicated this data was available during the pre-intervention visit, it transpired that records at both homes were incomplete and inconsistent, and therefore unusable.

Discussion

Summary of findings

As hypothesised, the results indicate that the training significantly increased the accuracy of care staff’s knowledge and beliefs about pain in dementia. Staff also demonstrated stronger beliefs about personhood in dementia post-intervention, but this did not reach statistical significance. Training was successful in improving aspects of pain assessment and treatment strategies, but this only translated into

clinically meaning reduction of pain for a minority of residents, suggesting further improvements in pain care were needed. Overall, the staff training intervention was found to be feasible to implement in care homes, but key challenges and threats to validity were identified, which are discussed when considering implications for future research.

Interpretation of findings

The high prevalence of pain in this sample is broadly consistent with estimates in this setting (Ferrell et al., 1990; Helme & Gibson, 2001), and illustrates the need for effective pain care. Self-report of staff was consistent with previous research which has found that many care staff hold inaccurate beliefs and unhelpful attitudes, and can be suspicious about reports of pain when residents have a dementia diagnosis (Kaasalainen et al., 2007; Sengstaken & King, 1993; Tarzian & Hoffmann, 2005).

Changes in staff knowledge and beliefs

Self-report of staff was congruent with a reduction in inaccurate beliefs and development of understanding in this area, and attempts were made to correct for Type I error which increases confidence in this finding. Although unsurprising that training increased knowledge, it is clinically meaningful given that gaps in knowledge contribute to reluctance to administer analgesics (Kaasalainen et al., 2007; Tarzian & Hoffmann, 2005).

Reviews of staff training highlight that there is often a short-term increase in knowledge, but this is not always accompanied by changes in practice and effects may dissipate over time (Aylward, Stolee, Keat, & Johncox, 2003). Previous research has also found that educational interventions can increase knowledge but,

unlike the current study, have not examined implementation of knowledge or resident end points (Gagnon, Hadjistavropoulos, & Williams, 2013; Ghandehari et al., 2013; Tse & Ho, 2014), as discussed in Part 1.

The finding that beliefs about personhood did not increase significantly is surprising, given that this was a key aim of the training. As Hunter et al. (2013) found that stronger beliefs about personhood were predictive of increased willingness to treat pain, it was expected that with an increase in pain assessment and treatment practices we would see an associated increase in perceptions of personhood.

It is possible that the null finding regarding beliefs about personhood represents Type II error, due to a lack of sufficient statistical power. A lack of research on change across time on the PDQ complicated estimation of possible effect size. The study was powered to enable the detection of medium ($d=0.5$) effect sizes, but a smaller effect would not have been detected. Null findings should be interpreted cautiously in small pilot studies due to small sample sizes (Thabane et al., 2010) and viewed as inconclusive as opposed to evidence of an absence of effect (Altman & Bland, 1995). Also, it is likely that there were ceiling effects on the PDQ, as staff scores were clustered towards the upper end of the range at baseline leaving little room for improvement.

The concept of personhood is difficult to define and is likely to be multidimensional, which poses a challenge to measurement. A measure of beliefs about personhood as status was chosen in the current study as this had the strongest evidence for association with pain care practices (Hunter et al., 2013). An observational measure, such as Dementia Care Mapping (Innes & Surr, 2001), would

be an alternative way of measuring personhood through assessing the care environment (Kitwood, (1997) .

It could also be that the content of the training was not adequate to change beliefs about personhood. Despite the popularity of models of person-centred care, there is little empirical evidence (Dewing, 2004), and an absence of research into methods for enhancing beliefs about personhood in dementia. Therefore, the training components designed to enhance personhood beliefs were based on expert recommendations (Malloy & Hadjistavropoulos, 2004) and related theory, as opposed to direct evidence.

Another possibility is that the follow-up period was too short to detect change in personhood. Beliefs about personhood are likely to be developed through person-centred interactions where carers create an environment characterized by respect and support (Kitwood, 1997). Kitwood used the term person-centred in reference to the Rogerian psychotherapeutic approach which emphasises authentic contact and communication (Brooker, 2007). There were several accounts from staff which were characteristic of this, but the formation or further development of authentic relationships with people with dementia may be a process that occurs over a longer period of time.

Finally, it should be considered that lack of change indicates that beliefs about personhood may not be an important factor in pain care. The positive changes in clinical practice could have been due to others factors, such as increased sense of competency or a shift in more general attitudes about people with dementia or the nature of pain. However, due to the multi-faceted nature of the intervention, the study design did not allow for the association between beliefs about personhood and

outcomes to be directly tested. This has been noted to be a common problem in person-centred interventions (Edvardsson & Innes, 2010) and should be investigated further in future research.

Changes in pain care and residents' pain levels

Staff reported increased awareness and changes in clinical practice, which was reflected in the fact that residents with no analgesic prescription at baseline were significantly more likely to have at least a PRN prescription at follow-up, and improvements in pain treatment were observed in 53% of residents. However, improved treatment practices did not translate into an improvement in residents' pain levels as might be expected.

It is possible that using a crude measure of improvements in treatment might have led to an inflation in estimate of effect. Effective pain care is much more complex than an increase in analgesics; it should balance the risks associated with side-effects and polypharmacy against those of under-treated pain (BGS & BPS, 2007; AGS, 2002). Although classification of changes is sufficient in a feasibility study, cautious interpretation is warranted and any further research should use a measure which is able to take this complexity into account. Ideally, to assess whether pain care is effective, the interference of pain on function and activities of daily living should also be measured.

Although there was a small decrease in overall pain levels this was non-significant. Also, individual level analyses revealed that change in scores on the PAINAD were only likely to represent a clinically meaningful reduction in pain for a

small percentage of residents (7-17%), and a small number showed reliable deterioration on the measure whilst at rest (10%). This could reflect either development of pain, or alternatively, it could be that staff were more aware of and sensitive to pain and the increase represented detection of existing pain. In this way, it is possible that increased assessment of pain could resemble an increase in pain.

Lack of change in residents' pain levels could be due to insufficient changes in pain treatment. Although there was positive change in analgesic use, PRN prescriptions are likely to lead to under-treatment in dementia, as this type of prescription relies on the person being able to report pain and request medication, or being regularly assessed and re-assessed for behavioural signs of pain (Reynolds et al., 2008). Therefore, the lack of increase in *fixed-schedule* (FSC) prescriptions might mean many residents had under-treated pain.

Limited information was collected about the type and nature of pain, meaning it was not possible to determine what proportion of residents might have had difficult-to-treat or intractable pain. However, this is unlikely to be a large factor, as it would have been expected to be indicated in staff reports. More likely is that the improvements seen were due to increased awareness and willingness to treat, but greater consistency and systematic use of assessment tools, better communication, and more re-assessment was needed for pain care to be effective. Assessment over time, and especially before and after analgesic treatment, is integral to effective pain assessment in dementia (Hadjistavropoulos et al., 2014). Therefore, with staff reports suggesting a general lack of re-assessment, it is unlikely staff would have been able to detect when the first line treatment (i.e. paracetamol) was ineffective and stronger analgesia was needed.

Alternatively, lack of change could have been due to measurement error, as behavioural observation measures of pain have associated conceptual and methodological issues (Jordan, Regnard, & Hughes, 2007). The PAINAD has poor specificity of 61% (Jordan et al., 2011), meaning it generates a high proportion of false positive results. It is notoriously difficult to differentiate pain from psychological distress in dementia as, apart from facial expression, there are no behaviours which are specific to pain (Regnard et al., 2007), and behaviours resulting from untreated pain can be identical to those resulting from other unmet needs or psychological symptoms (Snow & Shuster, 2006). This difficulty was often mentioned in case discussions, so it is possible that some of the scores indicating pain reflected false positives.

Methodological limitations

A number of methodological limitations should be considered when interpreting the findings of this study. As a feasibility study, the aim was not to investigate effectiveness and therefore the study did not include a control group. However, this clearly reduces the certainty with which any effects can be ascribed to the intervention.

Several aspects of study design could have introduced bias, for example, it is possible that the researcher's frequent presence at the home raised awareness of pain or that changes are due to the effect of being observed as part of a study, known as the Hawthorne effect (McCarney et al., 2007). Also, there may have been selection bias in the recruitment of staff participants, as staff who already held strong beliefs about personhood in dementia and were sensitive to residents' pain may have been more likely to see the training as worthwhile and volunteer to take part. A key

threat to the internal validity of the study was the lack of blinding of assessors. Observational measures of residents' pain were conducted by staff, and ratings could have been biased by either a motivation to show reductions in pain to demonstrate implementation of training, or alternatively to minimise any change to evidence that the home was providing good pain care pre-training. Using an independent assessor or obtaining several ratings from different staff and calculating inter-rater reliability would have reduced risk of bias, but was beyond the resources of the current study and care homes. Also, ideally self-report should be used for all residents who have the ability and inclusion of this would have improved validity of pain assessments (Hadjistavropoulos et al., 2014).

Bias might also have been a problem in the semi-structured interviews with staff, as feedback was gathered by the same researcher who delivered the training. Therefore, it is likely to have introduced some degree of social desirability bias. Using a questionnaire to gather feedback might have reduced the risk of bias, but on the other hand it would not have allowed the flexibility to explore barriers as they emerged.

Clinical implications

The current study demonstrates that staff training interventions informed by psychological theory can be acceptable to, and valued by, care home staff. Aside from the educational component, staff found the case discussions particularly useful. These sessions provided space for reflection in contrast to the heavily task-oriented environment of care homes (Brooker, 1995). Understanding and decoding behaviours in dementia can be challenging as people often have multiple complex needs (Chenoweth et al., 2009). Application of psychological models can aid more

accurate assessment of pain and help carers choose the most appropriate treatments through a focus on formulation and individual needs-led interventions. This can be achieved through the provision of training, supervision, or staff consultation by clinical psychologists.

The National Dementia Strategy (Department of Health, 2009) recommends specialist dementia care training for all care staff, and reduction in inappropriate use of anti-psychotic medication. Clinical psychologists are well placed to deliver training to care staff as they can utilise skills in supervision, staff consultation, interdisciplinary working and cultural competency. Successful psychological intervention can challenge the dominance of the medical model in dementia care (Finnema, Dröes, Ribbe, & van Tilburg, 2000), and could reduce inappropriate use of anti-psychotic medication (Margallo-Lana et al., 2001) through provision of effective alternative approaches. Training in person-centred care and psychological management of challenging behaviour has shown ability to reduce anti-psychotic use in nursing homes (Fossey et al., 2006), and approaches tackling pain could have similar effects.

Implications for future research

The current study has demonstrated the feasibility and acceptability of the staff training intervention and shown promising results in terms of improvements in pain care. Effectiveness should now be explored across a larger number of care homes using a quasi-experimental design with a control arm, and, if appropriate, proceed to a well-designed CRCT including three arms (control, intervention with educational content only, and intervention with educational and personhood components) in order to tease apart whether the personhood component has additional benefits.

Any future study should ideally include additional measures of residents' pain, including self-report where possible, and independent blind assessors for observational scales to reduce bias. Examination of results over a longer follow-up period would allow assessment of whether benefits are maintained. Also, more detailed qualitative analyses would allow exploration of mechanisms of change and factors associated with implementation of knowledge.

Future research should also explore possible additional benefits of the intervention, such as a reduction in the use of anti-psychotics for residents, and staff factors such as sense of competence. It would also be beneficial if the research design allowed the association between personhood and approaches to dementia care to be tested further, for example through obtaining data on the behaviour change of individual staff and determining predictors through use of a regression model.

The current study demonstrates that even with an awareness of probable barriers and a concerted effort to develop individualised solutions, research in this environment is challenging. Future research should include more directive strategies to overcome barriers, such as an inclusion of pain as an agenda item in handovers, and obtain firm commitments from management about their application.

Conclusions

The current study was the first staff training intervention based on integrating the principles of person-centred care with best practice in pain management. As a feasibility study the main objectives of considering requirements for successful implementation and possible threats to validity for a full trial were achieved, and

effectiveness should now be assessed across several sites. The intervention was successful in increasing the knowledge of care staff and showed promising improvements in pain care practices. However, it was indicated that further improvements were needed to achieve meaningful reductions in residents' pain levels. Surprisingly, the intervention did not significantly increase staff beliefs about personhood in dementia, but due to the methodological limitations inherent in small pilot studies it was not possible to draw clear conclusions about the meaning of this finding.

References

- Achterberg, W. P., Pieper, M. J., van Dalen-Kok, A. H., de Waal, M. W., Husebo, B. S., Lautenbacher, S., ... Corbett, A. (2013). Pain management in patients with dementia. *Clinical Interventions in Aging*, 8, 1471–1482.
- AGS Panel on Persistent Pain in Older Persons. (2002). The management of persistent pain in older persons. *Journal of the American Geriatrics Society*, 50, S205–224.
- Allcock, N., McGarry, J., & Elkan, R. (2002). Management of pain in older people within the nursing home: a preliminary study. *Health & Social Care in the Community*, 10, 464–471.
- Altman, D. G., & Bland, J. M. (1995). Absence of evidence is not evidence of absence. *BMJ: British Medical Journal*, 311, 485.
- Alzheimer's Society. (2007). *Home from home*. London.
- American Geriatrics Society Panel on Pharmacological Management of Persistent Pain in Older Persons. (2009). Pharmacological management of persistent pain in older persons. *Journal of the American Geriatrics Society*, 57, 1331–1346.
- American Medical Directors Association (2012). *Pain management in the long term care setting*. Retrieved from <http://www.guideline.gov/algorithm/3522/NGC3522.pdf>
- APA (2000). *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR Fourth Edition* (4th ed.). Virginia: American Psychiatric Publications.
- Asghari, A., Ghaderi, N., & Ashory, A. (2006). The prevalence of pain among residents of nursing homes and the impact of pain on their mood and quality of life. *Archives of Iranian Medicine*, 9, 368–373.

- Aylward, S., Stolee, P., Keat, N., & Johncox, V. (2003). Effectiveness of continuing education in long-term care: a literature review. *The Gerontologist*, 43, 259–271.
- Barry, H. E., Parsons, C., Peter Passmore, A., & Hughes, C. M. (2012). An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. *International Journal of Geriatric Psychiatry*, 27, 1258–1266.
- Bartels, S. J., Horn, S. D., Smout, R. J., Dums, A. R., Flaherty, E., Jones, J. K., ... Voss, A. C. (2003). Agitation and depression in frail nursing home elderly patients with dementia: treatment characteristics and service use. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 11, 231–238.
- Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., ... Mor, V. (1998). Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *JAMA: The Journal of the American Medical Association*, 279, 1877–1882.
- Bosley, B. N., Weiner, D. K., Rudy, T. E., & Granieri, E. (2004). Is chronic nonmalignant pain associated with decreased appetite in older adults? Preliminary evidence. *Journal of the American Geriatrics Society*, 52, 247–251.
- Brooker, D. (1995). Looking at them, looking at me. A review of observational studies into the quality of institutional care for elderly people with dementia. *Journal of Mental Health*, 4, 145–156.
- Brooker, D. (2007). *Person-centred Dementia Care: Making Services Better*. Jessica Kingsley Publishers.

- Buber, M. (1970) *I and thou*. New York: Scribner.
- Buron, B. (2008). Levels of Personhood: A Model for Dementia Care. *Geriatric Nursing*, 29, 324–332.
- Cadogan, M. P., Edelen, M. O., Lorenz, K. A., Jones, M., Yosef, J., Hascall, T., ... Saliba, D. (2008). The relationship of reported pain severity to perceived effect on function of nursing home residents. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 63, 969–973.
- Cairncross, L., Magee, H., & Askham, J. (2007). *A Hidden Problem: pain in older people: a qualitative study*. Oxford: Picker Institute Europe
- Care Quality Commission. (2014). Care Quality Commission. Retrieved February 18, 2014, from <http://www.cqc.org.uk/>
- Chenoweth, L., King, M. T., Jeon, Y., Brodaty, H., Stein-Parbury, J., Norman, R., Haas, M. & Luscombe, G. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster randomised trial. *The Lancet Neurology*, 8, 317–325.
- Clark, L., Fink, R., Pennington, K., & Jones, K. (2006). Nurses' Reflections on Pain Management in a Nursing Home Setting. *Pain Management Nursing*, 7, 71–77.
- Cohen-Mansfield, J. (2014). Even with regular use of an observational scale to assess pain among nursing home residents with dementia, pain-relieving interventions are not frequently used. *Evidence Based Nursing*, 17, 24–25.
- Cohen-Mansfield, J., & Lipson, S. (2002). Pain in cognitively impaired nursing home residents: how well are physicians diagnosing it? *Journal of the American Geriatrics Society*, 50, 1039–1044.

- Corazzini, K. N., McConnell, E. S., Anderson, R. A., Reed, D., Champagne, M. T., Lekan, D., ... Zimmerman, S. (2010). The Importance of Organizational Climate to Training Needs and Outcomes in Long-term Care. *Alzheimer's Care Today*, 11, 109–121.
- 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. *Nature Reviews. Neurology*, 8, 264–274.
- Craig, K. D., Versloot, J., Goubert, L., Vervoort, T., & Crombez, G. (2010). Perceiving pain in others: automatic and controlled mechanisms. *The Journal of Pain: Official Journal of the American Pain Society*, 11, 101–108.
- Decety, J., & Lamm, C. (2006). Human empathy through the lens of social neuroscience. *The Scientific World Journal*, 6, 1146–1163.
- Department of Health (2009). *Living Well With Dementia: A National Dementia Strategy*.
- Dewing, J. (2004). Concerns relating to the application of frameworks to promote person-centredness in nursing with older people. *Journal of Clinical Nursing*, 13, 39–44.
- Dobbs, D., Baker, T., Carrion, I. V., Vongxaiburana, E., & Hyer, K. (2014). Certified nursing assistants' perspectives of nursing home residents' pain experience: communication patterns, cultural context, and the role of empathy. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 15, 87–96.
- Dobson, C. (2008). *Conducting research with people not having the capacity to consent to their participation : a practical guide for researchers*. Leicester: British Psychological Society.

- Down, R., Wikström, H., & Siddons, A. (2014). Pain in people with dementia. See Change: Think Pain. *Pain News*, 12, 84-87.
- Drwecki, B. B., Moore, C. F., Ward, S. E., & Prkachin, K. M. (2011). Reducing racial disparities in pain treatment: the role of empathy and perspective-taking. *Pain*, 152, 1001–1006.
- Edvardsson, D., & Innes, A. (2010). Measuring Person-centered Care: A Critical Comparative Review of Published Tools. *The Gerontologist*, 50, 834–846.
- Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175–191.
- Feldt, K. S., Ryden, M. B., & Miles, S. (1998). Treatment of pain in cognitively impaired compared with cognitively intact older patients with hip-fracture. *Journal of the American Geriatrics Society*, 46, 1079–1085.
- Ferrell, B. A., Ferrell, B. R., & Osterweil, D. (1990). Pain in the nursing home. *Journal of the American Geriatrics Society*, 38, 409–414.
- Ferrell, B. A., Ferrell, B. R., & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management*, 10, 591–598.
- Finnema, E., Dröes, R. M., Ribbe, M., & van Tilburg, W. (2000). A review of psychosocial models in psychogeriatrics: implications for care and research. *Alzheimer Disease and Associated Disorders*, 14, 68–80.
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ: British Medical Journal*, 332, 756–761.

- Fuchs-Lacelle, S., Hadjistavropoulos, T., & Lix, L. (2008). Pain assessment as intervention: a study of older adults with severe dementia. *The Clinical Journal of Pain*, 24, 697–707.
- Gagnon, M. M., Hadjistavropoulos, T., & Williams, J. (2013). Development and mixed-methods evaluation of a pain assessment video training program for long-term care staff. *Pain Research & Management: The Journal of the Canadian Pain Society = Journal de La Societe Canadienne Pour Le Traitement de La Douleur*, 18, 307–12.
- Ghandehari, O. O., Hadjistavropoulos, T., Williams, J., Thorpe, L., Alfano, D. P., Bello-Haas, V. D., ... Lix, L. M. (2013). A controlled investigation of continuing pain education for long-term care staff. *Pain Research & Management: The Journal of the Canadian Pain Society*, 18, 11–18.
- Gilmore-Bykovskyi, A. L., & Bowers, B. J. (2013). Understanding nurses' decisions to treat pain in nursing home residents with dementia. *Research in Gerontological Nursing*, 6, 127–138.
- Giron, M. S. T., Forsell, Y., Bernsten, C., Thorslund, M., Winblad, B., & Fastbom, J. (2002). Sleep problems in a very old population: drug use and clinical correlates. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 57, M236–240.
- Goubert, L., Craig, K. D., Vervoort, T., Morley, S., Sullivan, M. J. L., de C Williams, A. C., ... Crombez, G. (2005). Facing others in pain: the effects of empathy. *Pain*, 118, 285–288.
- Haasum, Y., Fastbom, J., Fratiglioni, L., Kåreholt, I., & Johnell, K. (2011). Pain treatment in elderly persons with and without dementia: a population-based

study of institutionalized and home-dwelling elderly. *Drugs & Aging*, 28, 283–293.

Hadjistavropoulos, T., & Craig, K. (2002). A theoretical framework for understanding self-report and observational measures of pain: a communications model. *Behaviour Research and Therapy*, 40, 551–570.

Hadjistavropoulos, T., Fitzgerald, T. D., & Marchildon, G. P. (2010). Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities. *Physiotherapy Canada*, 62, 104–113.

Hadjistavropoulos, T., Herr, K., Prkachin, K. M., Craig, K. D., Gibson, S. J., Lukas, A., & Smith, J. H. (2014). Pain assessment in elderly adults with dementia. *The Lancet. Neurology*, 13, 1216–1227.

Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., Helme, R., ... Williams, J. (2007). An interdisciplinary expert consensus statement on assessment of pain in older persons. *The Clinical Journal of Pain*, 23, S1–43.

Helme, R. D., & Gibson, S. J. (2001). The epidemiology of pain in elderly people. *Clinics in Geriatric Medicine*, 17, 417–431.

Herman, A. D., Johnson, T. M., Ritchie, C. S., & Parmelee, P. A. (2009). Pain Management Interventions in the Nursing Home: A Structured Review of the Literature. *Journal of the American Geriatrics Society*, 57, 1258–1267.

Herr, K., Bjoro, K., & Decker, S. (2006). Tools for Assessment of Pain in Nonverbal Older Adults with Dementia: A State-of-the-Science Review. *Journal of Pain and Symptom Management*, 31, 170–192.

Herr, K., Bursch, H., Ersek, M., Miller, L. L., & Swafford, K. (2010). Use of pain-behavioral assessment tools in the nursing home: expert consensus

- recommendations for practice. *Journal of Gerontological Nursing*, 36, 18–29; quiz 30–31.
- Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 12, 230–250.
- Horgas, A. L., & Tsai, P. F. (1998). Analgesic drug prescription and use in cognitively impaired nursing home residents. *Nursing Research*, 47, 235–242.
- Hughes, C. P., Berg, L., Danziger, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *The British Journal of Psychiatry*, 140, 566–572.
- Hunter, P. V., Hadjistavropoulos, T., Smythe, W. E., Malloy, D. C., Kaasalainen, S., & Williams, J. (2013). The Personhood in Dementia Questionnaire (PDQ): Establishing an association between beliefs about personhood and health providers' approaches to person-centred care. *Journal of Aging Studies*, 27, 276–287.
- Hurley, A. C., Volicer, B. J., Hanrahan, P. A., Houde, S., & Volicer, L. (1992). Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing & Health*, 15, 369–377.
- 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–d4065.
- Husebo, B. S., Strand, L. I., Moe-Nilssen, R., BorgeHusebo, S., Aarsland, D., & Ljunggren, A. E. (2008). Who Suffers Most? Dementia and Pain in Nursing

- Home Patients: A Cross-sectional Study. *Journal of the American Medical Directors Association*, 9, 427–433.
- Innes, A., & Surr, C. (2001). Measuring the well-being of people with dementia living in formal care settings: the use of Dementia Care Mapping. *Aging & Mental Health*, 5, 258–268.
- Jacobson, N. S., & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*, 59, 12–19.
- James, I., & Stephenson, M. (2007). Behaviour that challenges us: the Newcastle support model. *Journal of Dementia Care*, 15, 19.
- Jongenelis, K., Pot, A. M., Eisses, A. M. H., Beekman, A. T. F., Kluiters, H., & Ribbe, M. W. (2004). Prevalence and risk indicators of depression in elderly nursing home patients: the AGED study. *Journal of Affective Disorders*, 83, 135–142.
- Jordan, A., Hughes, J., Pakresi, M., Hepburn, S., & O'Brien, J. T. (2011). The utility of PAINAD in assessing pain in a UK population with severe dementia. *International Journal of Geriatric Psychiatry*, 26, 118–126.
- Jordan, A. I., Regnard, C., & Hughes, J. C. (2007). Hidden pain or hidden evidence? *Journal of Pain and Symptom Management*, 33, 658–660; author reply 660.
- Kaasalainen, S., Coker, E., Dolovich, L., Papaioannou, A., Hadjistavropoulos, T., Emili, A., & Ploeg, J. (2007). Pain management decision making among long-term care physicians and nurses. *Western Journal of Nursing Research*, 29, 561–580; discussion 581–588.
- Kaasalainen, S., Middleton, J., Knezacek, S., Hartley, T., Stewart, N., Ife, C., & Robinson, L. (1998). Pain and cognitive status in the institutionalized elderly:

- perceptions & interventions. *Journal of Gerontological Nursing*, 24, 24–31; quiz 50–51.
- Kappesser, J., Williams, A. CdeC., & Prkachin, K. M. (2006). Testing two accounts of pain underestimation. *Pain*, 124, 109–116.
- Kitwood, T. M. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press.
- Kovach, C. R., Logan, B. R., Noonan, P. E., Schlidt, A. M., Smerz, J., Simpson, M., & Wells, T. (2006). Effects of the Serial Trial Intervention on Discomfort and Behavior of Nursing Home Residents With Dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 21, 147–155.
- Kovach, C. R., Weissman, D. E., Griffie, J., Matson, S., & Muchka, S. (1999). Assessment and Treatment of Discomfort for People with Late-Stage Dementia. *Journal of Pain and Symptom Management*, 18, 412–419.
- Kunz, M., Scharmann, S., Hemmeter, U., Schepelmann, K., & Lautenbacher, S. (2007). The facial expression of pain in patients with dementia. *PAIN*, 133, 221–228.
- Lane, P., Kuntupis, M., MacDonald, S., McCarthy, P., Panke, J. A., Warden, V., & Volicer, L. (2003). A pain assessment tool for people with advanced Alzheimer's and other progressive dementias. *Home Healthcare Nurse*, 21, 32–37.
- 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 Geriatrics*, 14, 138.

- Maas, M. L., Kelley, L. S., Park, M., & Specht, J. P. (2002). Issues in conducting research in nursing homes. *Western Journal of Nursing Research*, 24, 373–389.
- Malloy, D. C., & Hadjistavropoulos, T. (2004). The problem of pain management among persons with dementia, personhood, and the ontology of relationships. *Nursing Philosophy: An International Journal for Healthcare Professionals*, 5, 147–159.
- Margallo-Lana, M., Swann, A., O'Brien, J., Fairbairn, A., Reichelt, K., Potkins, D., ... Ballard, C. (2001). Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry*, 16, 39–44.
- McCarney, R., Warner, J., Iliffe, S., van Haselen, R., Griffin, M., & Fisher, P. (2007). The Hawthorne Effect: a randomised, controlled trial. *BMC Medical Research Methodology*, 7, 30.
- Medical Research Council. (2008). *Developing and evaluating complex interventions: new guidance*. London: MRC.
- Mental Capacity Act (2005). London: Stationery Office.
- Mental Capacity Act (2007). *Mental Capacity Act 2005 : Code of Practice*. London: TSO.
- Mentes, J. C., & Tripp-Reimer, T. (2002). Barriers and facilitators in nursing home intervention research. *Western Journal of Nursing Research*, 24, 918–936.

- Merkel, S. I., Voepel-Lewis, T., Shayevitz, J. R., & Malviya, S. (1997). The FLACC: a behavioral scale for scoring postoperative pain in young children. *Pediatric Nursing*, 23, 293–297.
- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412–2414.
- Morris, J. C. (1997). Clinical Dementia Rating: A Reliable and Valid Diagnostic and Staging Measure for Dementia of the Alzheimer Type. *International Psychogeriatrics*, 9, 173–176.
- Morrison, R. S., & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain and Symptom Management*, 19, 240–248.
- Mozley, C., Sutcliffe, C., Bagley, H., Cordingley, L., Challis, D., Huxley, P., & Burns, A. (2004) *Towards Quality Care: Outcomes for Older People in Care Homes*, Ashgate: Aldershot.
- Murfield, J., Cooke, M., Moyle, W., Shum, D., & Harrison, S. (2011). Conducting randomized controlled trials with older people with dementia in long-term care: Challenges and lessons learnt. *International Journal of Nursing Practice*, 17, 52–59.
- National Council for Palliative Care (2012). ‘How would I know? What can I do?’: *How to help someone with dementia who is in pain or distress*. Retrieved June 12, 2014, from <http://www.ncpc.org.uk/publication/how-would-I-know>
- NICE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. Retrieved from <http://www.nice.org.uk/CG42>

Office for National Statistics (1997). National Statistics Online. Self-reported health problems: by gender and age, 1996–97: social trends dataset. Retrieved October 20, 2013, from

www.statistics.gov.uk/StatBase/xsdataset.asp?More=Y&vlnk=670&All=Y&B2.x=86&B2.y=13

Parmelee, P. A., Smith, B., & Katz, I. R. (1993). Pain complaints and cognitive status among elderly institution residents. *Journal of the American Geriatrics Society*, 41, 517–522.

Paulhus, D. L. (1991). Measurement and control of response bias. *Measures of Personality and Social Psychological Attitudes*, 17–59.

Pautex, S., Michon, A., Guedira, M., Emond, H., Le Lous, P., Samaras, D., ... Gold, G. (2006). Pain in severe dementia: self-assessment or observational scales? *Journal of the American Geriatrics Society*, 54, 1040–1045.

Prkachin, K. M. (2009). Assessing pain by facial expression: Facial expression as nexus. *Pain Research & Management: The Journal of the Canadian Pain Society*, 14, 53–58.

Qi, N. S., Brammer, J. D., & Creedy, D. K. (2012). The psychometric properties, feasibility and utility of behavioural-observation methods in pain assessment of cognitively impaired elderly people in acute and long-term care: A systematic review. *The JBI Database of Systematic Reviews and Implementation Reports*, 10, 17.

Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication

- difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*, 51, 277–292.
- Reynolds, K. S., Hanson, L. C., DeVellis, R. F., Henderson, M., & Steinhauser, K. E. (2008). Disparities in Pain Management Between Cognitively Intact and Cognitively Impaired Nursing Home Residents. *Journal of Pain and Symptom Management*, 35, 388–396.
- Røsvik, J., Brooker, D., Mjorud, M., & Kirkevold, Ø. (2013). What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS practice model. *Reviews in Clinical Gerontology*, 23, 155–163.
- Royal College of Physicians, British Geriatrics Society and British Pain Society.(2007) *The assessment of pain in older people: national guidelines*. Concise guidance to good practice series, No 8. London: RCP.
- Sampson, E. L., White, N., Lord, K., Leurent, B., Vickerstaff, V., Scott, S., & Jones, L. (2015). Pain, agitation, and behavioural problems in people with dementia admitted to general hospital wards: a longitudinal cohort study. *Pain*, 156, 675–683.
- Schell, E. S., & Kayser-Jones, J. (2007). “Getting into the skin”: Empathy and role taking in certified nursing assistants’ care of dying residents. *Applied Nursing Research*, 20, 146–151.
- Schiavenato, M., & Craig, K. D. (2010). Pain assessment as a social transaction: beyond the “gold standard.” *The Clinical Journal of Pain*, 26, 667–676.
- Schuler, M. S., Becker, S., Kaspar, R., Nikolaus, T., Kruse, A., & Basler, H. D. (2007). Psychometric properties of the German “Pain Assessment in

- Advanced Dementia Scale” (PAINAD-G) in nursing home residents. *Journal of the American Medical Directors Association*, 8, 388–395.
- Sengstaken, E. A., & King, S. A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41, 541–544.
- Smalbrugge, M., Jongenelis, L. K., Pot, A. M., Beekman, A. T., & Eefsting, J. A. (2007). Pain among nursing home patients in the Netherlands: prevalence, course, clinical correlates, recognition and analgesic treatment – an observational cohort study. *BMC Geriatrics*, 7, 3.
- Snow, A. L., & Shuster, J. L. (2006). Assessment and treatment of persistent pain in persons with cognitive and communicative impairment. *Journal of Clinical Psychology*, 62, 1379–1387.
- Swafford, K. L., Miller, L. L., Tsai, P.-F., Herr, K. A., & Ersek, M. (2009). Improving the Process of Pain Care in Nursing Homes: A Literature Synthesis. *Journal of the American Geriatrics Society*, 57, 1080–1087.
- Tait, R. C. (2013). Pain assessment-an exercise in social judgment. *Pain*, 154, 625–626.
- Tarzian, A. J., & Hoffmann, D. E. (2005). Barriers to Managing Pain in the Nursing Home: Findings From a Statewide Survey. *Journal of the American Medical Directors Association*, 6, S13–S19.
- Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., ... Goldsmith, C. H. (2010). A tutorial on pilot studies: the what, why and how. *BMC Medical Research Methodology*, 10, 1.

- The Australian Pain Society. (2005). *Pain in residential aged care facilities: Management strategies*. Retrieved from <https://www.apsoc.org.au/publications>
- Torvik, K., Kaasa, S., Kirkevold, O., & Rustøen, T. (2010). Pain and quality of life among residents of Norwegian nursing homes. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 11, 35–44.
- Tse, M. M. Y., & Ho, S. S. K. (2013). Pain management for older persons living in nursing homes: a pilot study. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 14, e10–21.
- Tse, M. M. Y., & Ho, S. S. K. (2014). Enhancing knowledge and attitudes in pain management: a pain management education program for nursing home staff. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 15, 2–11.
- Tse, M. M. Y., Vong, S. K. S., & Ho, S. S. K. (2012). The effectiveness of an integrated pain management program for older persons and staff in nursing homes. *Archives of Gerontology and Geriatrics*, 54, e203–212.
- Van Herk, R., Boerlage, A. A., van Dijk, M., Baar, F. P. M., Tibboel, D., & de Wit, R. (2009). Pain management in Dutch nursing homes leaves much to be desired. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*, 10, 32–39.
- Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association*, 4, 9–15.
- Weber, R. P. (1990). *Basic content analysis*. Beverly Hills, CA: Sage.

- Weiner, D. K., & Rudy, T. E. (2002). Attitudinal barriers to effective treatment of persistent pain in nursing home residents. *Journal of the American Geriatrics Society*, 50, 2035–2040.
- Weissman, D. E., Griffie, J., Muchka, S., & Matson, S. (2000). Building an Institutional Commitment to Pain Management in Long-Term Care Facilities. *Journal of Pain and Symptom Management*, 20, 35–43.
- Won, A., Lapane, K., Gambassi, G., Bernabei, R., Mor, V., & Lipsitz, L. A. (1999). Correlates and management of nonmalignant pain in the nursing home. SAGE Study Group. Systematic Assessment of Geriatric drug use via Epidemiology. *Journal of the American Geriatrics Society*, 47, 936–942.
- Wynne, C. F., Ling, S. M., & Remsburg, R. (2000). Comparison of Pain Assessment Instruments in Cognitively Intact and Cognitively Impaired Nursing Home Residents. *Geriatric Nursing*, 21, 20–23.
- Zanocchi, M., Maero, B., Nicola, E., Martinelli, E., Luppino, A., Gonella, M., ... Molaschi, M. (2008). Chronic pain in a sample of nursing home residents: prevalence, characteristics, influence on quality of life (QoL). *Archives of Gerontology and Geriatrics*, 47, 121–128.
- Zwakhlen, S. M., Hamers, J. P., Abu-Saad, H. H., & Berger, M. P. (2006). Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools. *BMC Geriatrics*, 6, 3.
- Zwakhlen, S. M., Hamers, J. P., Peijnenburg, R. H., & Berger, M. P. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research & Management: The Journal of the Canadian Pain Society*, 12, 177–184.

Zwakhallen, S. M. G., van der Steen, J. T., & Najim, M. D. (2012). Which score most likely represents pain on the observational PAINAD pain scale for patients with dementia? *Journal of the American Medical Directors Association, 13*, 384–389.

Zwakhallen, S. M., van't Hof, C. E., & Hamers, J. P. (2012). Systematic pain assessment using an observational scale in nursing home residents with dementia: exploring feasibility and applied interventions. *Journal of Clinical Nursing, 21*, 3009–3017.

Part 3: Critical Appraisal

Overview

Attention to the barriers and facilitators to research in care home settings has been an overarching theme in this thesis, as it is an important area to address if research is to progress (Maas, Kelley, Park, & Specht, 2002; Menten & Tripp-Reimer, 2002; Murfield, Cooke, Moyle, Shum, & Harrison, 2011). Perceptions of barriers to research results in an avoidance of research in this area, leading to the problems facing older adults in care homes being understudied (Maas et al., 2002).

Using the four categories of barriers identified in Part 1: 1) organisational culture, 2) resource constraints, 3) communication, and 4) attitudes and beliefs, I will reflect upon the degree of impact of each on implementation of changes in pain care practice and on study processes. I will also discuss how these barriers influenced methodological considerations and my reflections on these decisions following completion of the project.

Organisational culture

Organisational culture will be discussed firstly, as this exerts a significant influence on all other types of barriers. Organisational culture is defined as “*A pattern of shared assumptions learned by a group as it solved its problems of external adaptation and internal integration which has worked well enough to be considered valid and, therefore to be taught to new members as the correct way to perceive, think and feel in relation to those problems.*” (Schein, 1985, p. 36).

In line with previous research (Brooker, 1995), the culture of the care homes was observed to be heavily task-focused, with the assumption that the primary role of carers is to take care of the physical and practical needs of residents. Also, there was

a clear hierarchical power structure in homes, where management assumed all responsibility and senior staff assigned tasks to care assistants (CAs), who had very little autonomy. Observations germane to these two key aspects of the organisational culture of care homes will be discussed in this paper.

Hierarchical power structure

Coercion of staff

Protecting staff against coercion can be challenging in care home settings, due the inherent power imbalance in staff relationships and lack of control over the actions of managerial or senior staff, and is an important responsibility of the researcher (Lingler, Jablonski, Bourbonniere, & Kolanowski, 2009). Although it was emphasised to managers that consent must be completely voluntary, with no repercussions for staff declining to take part, there were some instances of coercion witnessed in one home. For example, on one occasion a staff member said she was too tired to attend the training after working a night shift and the deputy manager expressed disapproval and asked her to stay. Also, coercion was suspected in the other home, as when staff were unable to attend a session they appeared anxious about potential repercussions.

Due to these concerns, it was necessary to intervene on some occasions and to regularly reiterate the following: the importance of consent being freely and voluntarily given; staffs' right to withdraw at any time; and managerial assurance that non-participation would not compromise employment in any way. It is possible that senior staff, who are used to training being mandatory, held an assumption that if staff were being paid for their time they could be instructed to attend. As staff were

being paid to attend by their employer, training could be seen to assume a dual role, as both a research and an employment activity, which further complicated the issue.

This serious ethical issue has been noted to be a challenge in previous research in this setting (Lingler et al., 2009; Nelson & Merz, 2002). Attempts to protect against coercion have included staff being allowed to attend training sessions without participating in the study, but researchers reported that even with safeguards in place there were attempts to mandate attendance (Nelson & Merz, 2002). With hindsight, it would have been useful to have explicitly addressed this issue during the pre-intervention site visit. Advance discussion would have allowed clarification of these complex issues, and enabled provision of information on what constitutes coercion and how it can be avoided.

Disempowerment of care assistants

During my time at the homes I observed that CAs (i.e. the most junior staff) would regularly state the limitations of their role, for example, *'I can't do an assessment, my job is to report any observations to someone more senior'*. CAs also tended to be less vocal during workshop discussions and I often needed to specifically invite their feedback to ensure active participation. Also, during case discussions senior staff tended to answer questions posed to CAs, and sometimes attempted to take over case presentations.

Disempowerment of care staff in junior positions occurs due to factors such as low pay, lack of training and support, and a lack of recognition of the demands of their role and it can have a significant impact on dementia care (Beck, Ortigara, Mercer, & Shue, 1999). For example, one study found that staff empowerment,

through structures such as access to training and recognition, was significantly associated with the provision of individualised care (Caspar & O'Rourke, 2008).

It is possible that the lack of report of re-assessment of pain, as detailed in Part 2, could be due to disempowerment. For example, if a CA notices behavioural signs of pain in a resident, according to them they must inform a senior staff member, who would verify their assessment and make a decision about appropriate treatment. However, if in this time the care assistant is needed elsewhere they may be unaware of the treatment plan. It is easy to see how the hierarchical structure and rigid practices have the potential to lead to confusion over whose responsibility it is to assess the effectiveness of the treatment. Unfortunately, I was unable to explore this idea during the feedback interviews, as I was only aware that lack of re-assessment was a pervasive issue afterwards, but it could be important to explore in further research.

In order to avoid potential barriers due to diffusion of responsibility the training included discussions about the various roles of staff in providing effective pain care and managers were asked to endorse the message that assessing pain is the responsibility of all staff. During workshop discussions managers were asked whether use of observational assessment tools was appropriate for all staff, and both managers agreed that it was. However, it was clear from staff feedback that this did not occur, as uptake of observational measures was limited to a few senior members of staff. It was perhaps naïve to presume that merely discussing these principles would be enough to bring about change in this area, especially considering that any increase in CA's responsibility would be incongruent to other care processes.

The rationale for assigning the responsibility of re-assessment to CAs was to show respect for their skills in pain assessment, as previous research has suggested that training can have a powerful role in empowering staff (Beck, et al., 1999; Caspar & O'Rourke, 2008). However, it is likely that this approach did not fit with the existing organisational culture. Many homes have a culture which is more status-oriented where recognition and reward is based on status afforded by job title, rather than merit (Corazzini et al., 2010). Upon reflection this approach was too alien to the organisational culture and conflicted with the entrenched ways of working. In terms of achieving effective pain care practices it might have been more useful to have established clearly defined roles which fit with the current culture.

Managerial style and subcultures

In reflecting on my observations of CA disempowerment I considered the impact of management style. There were key differences across homes: in one home the manager invested a lot of time in training and often reminded staff who described themselves as 'only' a CA, that all staff roles were important and valued, whereas the other manager took a much more hands-off approach and their behaviour maintained the hierarchical power structure, for example holding meetings with only senior staff. Despite these different management styles, the issue of disempowerment of CAs appeared to be just as prevalent across both homes. This was somewhat surprising, as previous research has found that management practices directly influence staff relationships and can contribute to disempowerment (Beck et al., 1999; Corazzini et al., 2010)

Some research has suggested that the culture in care homes is best understood in terms of subcultures, with administrative and managerial staff forming one

subculture and direct care staff another (Maas et al., 2002). This fits with some of my observations of senior staff adopting a more blaming leadership style, often using an accusatory tone and seeking to locate blame rather than establish an understanding in response to problems. For example, in one case discussion session a carer reported that she might have overlooked a resident's report of pain due to her own attitudes towards pain. My praise of her reflective capacity and ability to recognise how attitudes can act as barriers to pain care was quickly undercut by a senior member of staff, who reprimanded her for not reporting the resident's pain immediately. Therefore, it could be that even a supportive and person-oriented managerial style may not be enough to overcome a blaming leadership style in the care staff subculture.

Culture of blame and scrutiny

Care homes are highly scrutinised environments, with regular inspections by the CQC who can conduct impromptu visits and have the power to issue fines, mandate changes, or prosecute facilities (Care Quality Commission, 2015), which could be one reason why a punitive and blaming response to errors is common (Hughes & Lapane, 2006; Scott-Cawiezell et al., 2006). A blaming leadership style is likely to result in care staff feeling under scrutiny, and it is possible that participating in a research study increased this effect. Some research has suggested that staff may be suspicious about whether the true intent of a study is to allow their managers to evaluate their job performance (Lingler et al., 2009).

Fear of blame or scrutiny may be one reason that some staff were initially reluctant to take part in role-play activities. The role-play exercise was modified in one group, due to some staff expressing discomfort at being observed by senior staff

and asking to opt out. The modification agreed upon was that instead of each pair taking it in turns to role-play in front of the group, all pairs would do the exercise simultaneously and then feed back to the wider group. Although this format still allowed for sharing of learning points, the opportunity for positive feedback from, and in front of, other staff was lost.

During the planning stage, I discussed the different aspects of the training with managers, who assured me role-play was a usual format for training and would be acceptable to staff. This is an example of how there may be two different cultures in care homes which both need to be understood in order to maximize study processes. Care staff appreciate being involved in the planning of interventions and this can maximise chances of successful implementation (Kaasalainen et al., 2010). Although some direct care staff were consulted as part of piloting the training materials, they may have been working in a different organisational culture. Therefore, future developments of the training programme should include consultation specifically with care assistants.

Influence of organisational culture on self-report of clinical practice

Staff often appeared quite anxious during the feedback interviews and this may have been due to feeling their performance was being scrutinised. Staff were more forthcoming with examples of clinical practice change during informal conversations and case discussion sessions. For example, one member of staff gave an account of how attending the training had given her the confidence to advocate for a resident, which ultimately resulted in diagnosis of a fracture which had been missed by the hospital on two occasions.

I considered whether to report on these observations as part of the results. As a researcher it is important to reflect upon personal investment in a project and, having spent considerable time developing and running the training programme, I was very invested in the outcome. Also, I was aware that both authorship of an intervention and not having an active control are also seen to increase the risk of bias due to allegiance, which can impact study outcomes (Gaffan, Tsaousis, & Kemp-Wheeler, 1995; Leykin & DeRubeis, 2009). Employing reflexivity helped me to realise that any reports would be at high risk of confirmation bias (Nickerson, 1998), as I was likely to have paid specific attention to conversations where staff gave examples I interpreted as supporting my hypothesis (i.e. that the training positively impacted pain care practices). Therefore, I decided against making any additions to the results.

Task-focused culture

Although staff clearly appreciated the value of good relationships with residents, the focus of caregiving was still primarily on the completion of care tasks. This was summarised well by one carer who said: *“If we were told [to do something] we would, if not then we come and do the routine things and the time is going and then the shift is finished” (P117)*. One of the managers also spoke about it being challenging to find the time for reflective practice. She described the amount of time spent on the case discussions as ‘luxurious’ and stated that she appreciated the value of reflection and was thinking about ways that this could be incorporated into routine practice.

The task-focused approach to care in residential settings has been posited to be the result of an under-appreciation of the challenging nature of caring for people

with dementia, demonstrated by the inadequate levels of training, support and supervision, alongside a high workload (Mentes & Tripp-Reimer, 2002).

Implementation of principles of person-centred care

As discussed in Part 2, the usefulness of case discussions was sometimes limited by staffs' lack of knowledge of residents' social and medical histories, and current pain treatment plans. One possible reason for this lack of knowledge could be the task-focused culture, which left little time for implementation of person-oriented approaches, such as familiarisation with the information kept in residents' notes. For example, it was particularly evident in the accounts of new staff that they knew where they could find this information, but they had not read the notes due to lack of time, prioritisation, or both.

My observations from discussions around person-centred care (PCC) were that, although many staff had prior training in this area, most had only really engaged with PCC principles at a superficial level. For example, the most common definitions of PPC were 'treating people as individuals' and 'recognising that everyone is unique', and it was often equated with respecting and accommodating individual preferences, rather than developing a full understanding of people through an awareness of their social history or promoting independence and autonomy.

Using the VIPS framework of PCC (Røsvik, Brooker, Mjorud, & Kirkevold, 2013), which aims to summarise Kitwood's (1997) key ideas, staff demonstrated good awareness and competence in the first two areas; recognising the value (V) of each person as an individual, and providing individualised care (I). However, there was a lack of attention to the perspectives (P) of residents with dementia or to the importance of positive social psychology (S). This observations fits with qualitative

research showing that although many CAs describe good clinical practice which is implicitly in line with some of the principles of PCC, many lack a clear understanding and further training is needed to ensure full adherence to these principles in practice (Colomer & de Vries, 2014).

Communication

Communication can be difficult in busy care environments as there are constant demands on carers' time and opportunities for team discussions are limited. I observed that handovers are generally very short, and there is little time for discussion. Also, staff meetings were held relatively infrequently (<1 per week) and other channels of communication appeared to be very limited. There were some small bulletin boards in staff areas, but these did not seem to be in regular use, no email circulation lists in use and there were no pigeon holes. The main channel of communication was face-to-face at handovers and staff meetings.

Problems in communication with and between staff had two main impacts on the study. Firstly, a lack of communication between staff limited the usefulness of the case discussion sessions. When conducting the feedback interviews with staff it became clear that most staff were unaware of what had been discussed in other groups. Also, CAs were uncertain about whether or not they should be using pain assessment tools, and attributed this to a lack of clear guidance. This lack of sharing of ideas from discussions is likely to be largely due to the task-focused working culture.

Communication difficulties also impacted upon data collection. Although a clear data collection plan was agreed with managers and senior staff, outcome

measures were often not complete by the deadlines set. This ultimately resulted in a large amount of missing data on the observational measure of residents' pain (PAINAD). Care staff stated that they had not been informed about deadlines or had been given unclear instructions. However, it should also be considered that not completing outcome measures could be communicating to the researcher or management that the study demands were too great, or that staff did not consider it to be a priority. It has been observed that managers may agree to taking part in a study without consulting care staff or providing them with adequate support (Maas et al., 2002). It would have been useful to explore the barriers to data collection as part of the staff feedback process, as both managers assured me that staff would be supported in completing study processes during the pre-intervention site visit.

In order to facilitate communication, particularly when coordinating data collection processes I used several strategies. Those that proved unsuccessful included: sending emails with minutes of meetings and designated action points; creating checklists or summary sheets to post on bulletin boards or in the study folder; and putting contact details on all study documents and actively encouraging staff to contact me with any queries or should they need any help. The most successful strategies were direct face-to-face meetings with managers and senior staff, attending handovers and staff meetings and regular phone calls. Successful strategies were also the most time-consuming, so researchers may want to consider allowing extra time in order to maintain effective communication in this setting, which is key to maintaining fidelity and ensuring internal validity of a study.

Resource constraints

Constraints on resources due to high staff turnover, high workload, staff shortages and poor attendance were the most common barriers to educational interventions found in Part 1. In the current study, small incentives of food / gift certificates were offered to staff participants. This strategy has been suggested to facilitate attendance by some authors (Maas et al., 2002), but others have reported it to be largely ineffective (Jones, Fink, Vojir, et al., 2004; Robinson, Dennison, Wayman, Pronovost, & Needham, 2007). In the current study it was difficult to tell whether the incentives provided had any impact upon attendance, but staffs' comments suggested they served to acknowledge the sacrifice of time and conveyed a sense of respect and value for their time.

It was decided to run the training twice in both homes and to vary the dates and times of case discussion sessions. This approach definitely facilitated attendance, as it allowed staff to attend the most convenient sessions and some opportunities to make up missed sessions. Other strategies such as videotaping workshops or offering 1:1 catch-up sessions were considered, but decided against as they could negatively impact upon intervention fidelity and might have discouraged attendance at workshops.

As detailed in Part 2, staff who attended workshops after their shifts were noticeably less engaged during discussions. Also, recruitment was hindered by the need to provide adequate staff cover and managers reported that the logistical aspect of organising the training sessions was difficult. The need for provision of 24-hour care is a challenge to research in this area as managers can find it difficult to release staff (Maas, et al., 2002; Menten & Tripp-Reimer, 2002). It would be worth

exploring the feasibility of holding the training over one day somewhere off-site on several occasions.

Constraints on managers' time also had an impact on study processes. On several occasions I arranged meetings with managers and team leaders in order to build relationships and ensure there was a clear understanding of the research commitment. However, meetings were often cancelled or interrupted by unexpected demands on managers' time, such as urgent matters relating to resident care. Therefore, I adopted a different approach and wherever possible I spent the whole day at the home, which allowed me to eat meals and spend time with staff informally and fit conversations around the demands of their workload.

Beliefs and attitudes of staff

As beliefs and attitudes of staff are known barriers to effective pain care (Hadjistavropoulos, Fitzgerald, & Marchildon, 2010), the training was designed to help staff develop awareness of their own attitudes, encourage self-reflexivity and modify inaccurate beliefs. Exercises designed to meet these objectives included group discussions of beliefs about and attitudes towards pain and their origins (e.g. through familial, cultural and societal influences). Also, a small group exercise was designed for staff to rate their agreement with common unhelpful and erroneous beliefs about pain in dementia.

An awareness of the importance of creating a safe space for discussion influenced my decisions about the design of these exercises. Holding a large group discussion beforehand allowed me to model a curious and non-judgemental stance towards attitudes and beliefs, drawing on my training on creating a good therapeutic

alliance (Beck, 2005). Also, the rationale for asking staff to rate beliefs was to draw attention to the fact that beliefs do not fall into a dichotomy of right or wrong. Finally, the aim of doing the exercise in small groups was so that if any less helpful beliefs were shared they were not attributable to any one individual which, given the organisational culture discussed above, was an important factor in encouraging open discussion.

Although not explicit in the training design, I found myself drawing on my own teaching and experience of self-reflexivity when facilitating discussions. Also, I found it very helpful to draw upon the skills in cultural competency developed through training, particularly drawing upon the of Co-ordinated Management of Meaning model (CMM: Pearce, 2004). Staff came from a variety of different cultural backgrounds and it was important to explore their cultural values and beliefs in a sensitive and respectful manner, especially where they could potentially contribute to pain under-treatment (e.g. religious or cultural beliefs that suffering pain builds personal strength).

Staff commented during these sessions that talking about their beliefs and attitudes and the relative influences on practice was a novel task, and that they found it helpful and enjoyable. One reason this might not have been reflected in staff feedback is that they did not conceptualise these discussions as part of the formal training, which was more associated with the learning of new information. This would be congruent with one manager's report of a general lack of reflective practice.

Implications for future research

Given the significant impact of organisational culture on research implementation it would be useful to develop an evidence-base in this area. There are several existing measures of organisational culture (Scott, Mannion, Davies, & Marshall, 2003) that could be implemented, and qualitative research is especially needed to develop an more in-depth understanding (Maas et al., 2002). In pain care, the impact of organisational culture on prescribing practices has been little studied (Hughes, Lapane, Watson, & Davies, 2012) and could potentially have a significant effect.

It has been suggested that in order to overcome some of barriers in this research setting it is useful for researchers to spend considerable time in care homes (Maas et al., 2002). Spending entire days at the home was useful in understanding the culture of the care homes, but it would have been useful to explore potential barriers with managers in more detail prior to implementing the training.

It may be useful to use a community consent model in care homes research (Lingler et al., 2009), where residents and staff are involved in the agreement to act as a research site along with managers, to ensure full commitment to participation. Also involving care assistants in the planning and directly addressing cultures of blame may enhance success of interventions and empower staff.

Being flexible with study processes and running the training twice were found to be key facilitators in the current study. Future research should include more directive strategies to overcome barriers (e.g. inclusion of pain as an agenda item in handovers), and obtain firm commitments from management about their application. It is important to ensure that any suggested strategies fit with the organisation culture, or are significant enough to alter it.

Methodological considerations

The methodological decision to further investigate the influence of beliefs about personhood on pain care through staff training was largely based on considerations of potential barriers to research in care settings. Hunter et al. (2013) found that stronger beliefs about personhood were predictive of increased willingness to treat pain. However, it is well known that intentions only account for a relatively small amount of variance in behaviour change (i.e. the intention-behaviour gap: Sheeran, 2002). Therefore, given the early stage of this area of research it would have been preferable to conduct a further experimental study to explore the relationship between staff perceptions of personhood and pain management in dementia, focusing on actual clinical practice.

Employing a quasi-experiential staff training design, as opposed to a more experimental approach, was mainly based upon the rationale that this would be more attractive to care homes. Anecdotal reports from experienced researchers in this field, suggested that recruitment of care homes can be extremely challenging, unless there is a clear benefit to the care home. Also, I drew on my previous experience working on research trials, which taught me that recruitment is often the most challenging aspect of research and given the limited time frame for conducting doctoral research projects I was motivated to avoid potential pitfalls.

Reflecting on this decision with the benefit of hindsight, I still consider it to be appropriate, given the scope of DClinPsy projects and my observations in care homes. Based on my experience, I think it would have been incredibly challenging to have recruited to and conducted research with a similar level of demand on staff, but with less incentive for participation.

Conclusion

The current study demonstrates that even with an awareness of probable barriers and a concerted effort to develop individualised solutions, research in this environment is extremely challenging. In order for research to progress researchers should continue to reflect on learning points, and it would be useful for publications to cite facilitators to change and successful strategies to mitigate barriers.

References

- Beck, C., Ortigara, A., Mercer, S., & Shue, V. (1999). Enabling and empowering certified nursing assistants for quality dementia care. *International Journal of Geriatric Psychiatry, 14*, 197–211; discussion 211–212.
- Beck, J. (2005). Developing and using the Therapeutic Alliance. In *Cognitive therapy fo challenging problems: What to do when the basics don't work* (pp. 63-90). New York: Guilford.
- Brooker, D. (1995). Looking at them, looking at me. A review of observational studies into the quality of institutional care for elderly people with dementia. *Journal of Mental Health, 4*, 145–156.
- Care Quality Commission (2015). *Taking Action*. Retrieved April 21, 2015, from <http://www.cqc.org.uk/content/taking-action>
- Caspar, S., & O'Rourke, N. (2008). The influence of care provider access to structural empowerment on individualized care in long-term-care facilities. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 63*, S255–S265.
- Colomer, J., & de Vries, J. (2014). Person-centred dementia care: a reality check in two nursing homes in Ireland. *Dementia*. Advance online publication. Retrieved from <http://doi.org/10.1177/1471301214556132>
- Corazzini, K. N., McConnell, E. S., Anderson, R. A., Reed, D., Champagne, M. T., Lekan, D., ... Zimmerman, S. (2010). The Importance of Organizational Climate to Training Needs and Outcomes in Long-term Care. *Alzheimer's Care Today, 11*, 109–121.

- Gaffan, E. A., Tsaousis, I., & Kemp-Wheeler, S. M. (1995). Researcher allegiance and meta-analysis: the case of cognitive therapy for depression. *Journal of Consulting and Clinical Psychology, 63*, 966–980.
- Hadjistavropoulos, T., Fitzgerald, T. D., & Marchildon, G. P. (2010). Practice Guidelines for Assessing Pain in Older Persons with Dementia Residing in Long-Term Care Facilities. *Physiotherapy Canada, 62*, 104–113.
- Hughes, C. M., & Lapane, K. L. (2006). Nurses' and nursing assistants' perceptions of patient safety culture in nursing homes. *International Journal for Quality in Health Care, 18*, 281–286.
- Hughes, P. C. M., Lapane, K., Watson, M. C., & Davies, H. T. O. (2012). Does Organisational Culture Influence Prescribing in Care Homes for Older People? *Drugs & Aging, 24*, 81–93.
- Hunter, P. V., Hadjistavropoulos, T., Smythe, W. E., Malloy, D. C., Kaasalainen, S., & Williams, J. (2013). The Personhood in Dementia Questionnaire (PDQ): Establishing an association between beliefs about personhood and health providers' approaches to person-centred care. *Journal of Aging Studies, 27*, 276–287.
- Jones, K. R., Fink, R., Vojir, C., Pepper, G., Hutt, E., Clark, L., ... Mellis, B. K. (2004). Translation research in long-term care: improving pain management in nursing homes. *Worldviews on Evidence-Based Nursing / Sigma Theta Tau International, Honor Society of Nursing, 1 Suppl 1*, S13–20.
- Kaasalainen, S., Williams, J., Hadjistavropoulos, T., Thorpe, L., Whiting, S., Neville, S., & Tremeer, J. (2010). Creating bridges between researchers and long-term care homes to promote quality of life for residents. *Qualitative Health Research, 20*, 1689–1704.

- Kitwood, T. M. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press.
- Leykin, Y., & DeRubeis, R. J. (2009). Allegiance in Psychotherapy Outcome Research: Separating Association From Bias. *Clinical Psychology: Science and Practice*, 16, 54–65.
- Lingler, J. H., Jablonski, R. A., Bourbonniere, M., & Kolanowski, A. (2009). Informed Consent to Research in Long-Term Care Settings. *Research in Gerontological Nursing*, 2, 153–161.
- Maas, M. L., Kelley, L. S., Park, M., & Specht, J. P. (2002). Issues in conducting research in nursing homes. *Western Journal of Nursing Research*, 24, 373–389.
- Mentes, J. C., & Tripp-Reimer, T. (2002). Barriers and facilitators in nursing home intervention research. *Western Journal of Nursing Research*, 24, 918–936.
- Murfield, J., Cooke, M., Moyle, W., Shum, D., & Harrison, S. (2011). Conducting randomized controlled trials with older people with dementia in long-term care: Challenges and lessons learnt. *International Journal of Nursing Practice*, 17, 52–59.
- Nelson, R. M., & Merz, J. F. (2002). Voluntariness of consent for research: an empirical and conceptual review. *Medical Care*, 40, V69–80.
- Nickerson, R. S. (1998). Confirmation bias: A ubiquitous phenomenon in many guises. *Review of General Psychology*, 2, 175–220.
- Pearce, W. B. (2004). The Coordinated Management of Meaning (CMM). In W. Gadyjunt (Ed.), *Theorizing communication and culture* (pp. 35-54), Thousand Oaks, CA: Sage.

- Robinson, K. A., Dennison, C. R., Wayman, D. M., Pronovost, P. J., & Needham, D. M. (2007). Systematic review identifies number of strategies important for retaining study participants. *Journal of Clinical Epidemiology*, 60, 757.e1–757.e19.
- Røsvik, J., Brooker, D., Mjorud, M., & Kirkevold, Ø. (2013). What is person-centred care in dementia? Clinical reviews into practice: The development of the VIPS practice model. *Reviews in Clinical Gerontology*, 23, 155–163.
- Schein, E. (1985). *Organizational Culture and Leadership*. San Francisco: Jossey-Bass.
- Scott-Cawiezell, J., Vogelsmeier, A., McKenney, C., Rantz, M., Hicks, L., & Zellmer, D. (2006). Moving From a Culture of Blame to a Culture of Safety in the Nursing Home Setting. *Nursing Forum*, 41, 133–140.
- Scott, T., Mannion, R., Davies, H., & Marshall, M. (2003). The Quantitative Measurement of Organizational Culture in Health Care: A Review of the Available Instruments. *Health Services Research*, 38, 923–945.
- Sheeran, P. (2002). Intention—Behavior Relations: A Conceptual and Empirical Review. *European Review of Social Psychology*, 12, 1–36.

Appendix A

Care home invitation letter

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY



Care Home Manager
Address

Dear Care Home Manager,

Re: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

You are invited to take part in a research study being conducted at University College London. This research involves piloting a staff training programme designed to help improve the skills of care home staff in recognising and managing the pain of people with dementia. We will be selecting two suitable care homes in which to deliver this training programme and would like to give you the opportunity to take part.

What is the staff training programme?

The training will give staff the chance to improve their knowledge and skills about pain assessment and management in patients with dementia. We hope that it will also enhance resident's quality of life by leading to better detection and treatment of pain.

The training will run for approximately 6-8 weeks and will involve staff attending 2 half-day workshops, with some group supervision/case discussion sessions in between. The training programme will be open to all care home staff.

As a small token of appreciation for their time commitment we will also give each member of staff who participates a £5 gift voucher.

What will taking part involve?

We would ask for 10-15 members of care staff from each home to take part in the training programme and to fill out some questionnaires about themselves and their patients (this will take approximately 6-8 hours in total).

In order to study the effects of the staff training on pain in residents, we would ask that approximately 10-15 residents with dementia are also involved (residents will not have direct involvement with the research team, but we would ask to get some details from staff and to look at records of their pain medication).

If you think that the care home you manage may like to take part in this research or you would like to find out more please contact me by telephone or email on the details below.

Yours faithfully,

Faye Sweeney
Trainee Clinical Psychologist
Tel: [REDACTED]
Email: f.sweeney@ucl.ac.uk

Appendix B

Letter confirming favourable ethical opinion



Health Research Authority

NRES Committee London - Camberwell St Giles

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421391

07 August 2014
Amended 08 August 2014 (SSA exemption)

Dr Aimee Spector
Senior Lecturer in Clinical Psychology
University College London
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place
WC1E 7HB

Dear Dr Spector

Study title:	Staff Training Intervention for Pain Management in Dementia: A Pilot Study in Residential Care Homes
REC reference:	14/LO/1084
Protocol number:	n/a
IRAS project ID:	150893

Thank you for your letter of 30th July 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Assistant, Miss Elizabeth Hearn, nrescommittee.london-camberwellstgiles@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will

be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The committee noted your request for SSA exemption for non-NHS sites and have agreed to grant it.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Cover letter]	1.1	04 July 2014
Covering letter on headed paper [Further cover letter]		30 July 2014
Covering letter on headed paper [Cover letter]	1	26 May 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Certificate of confirmation of Insurance from Sponsor]	v1	26 July 2013
GP/consultant information sheets or letters [Letter to Nominated Consultee (GP)]	v1.2	08 May 2014
GP/consultant information sheets or letters [GP Information Letter]	v1.2	08 May 2014
Interview schedules or topic guides for participants [Semi-structured interview with care staff]	v1.2	08 May 2014
IRAS Checklist XML [Checklist_02062014]		02 June 2014
IRAS Checklist XML [Checklist_24072014]		24 July 2014
Letter from funder [Funding Confirmation Form]	v1.2	14 March 2014
Letters of invitation to participant [Care Home Invitation Letter]	v1.2	08 May 2014
Non-validated questionnaire [Personal & Demographic questionnaire for staff]	v1.1	23 April 2014
Participant consent form [Personal Consultee Declaration]	1.1	04 July 2014
Participant consent form [Nominated Consultee declaration form]	1.3	04 July 2014
Participant consent form [Personal Consultee Invitation]	1.1	04 July 2014
Participant consent form [Consent form for staff]	v1.2	08 May 2014
Participant consent form [Nominated Consultee invitation]	v1.2	08 May 2014
Participant consent form [Consent form for residents]	1.3	04 July 2014
Participant information sheet (PIS) [Information sheet for residents]	1.3	04 July 2014
Participant information sheet (PIS) [Information sheet for staff]	v1.2	08 May 2014
Participant information sheet (PIS) [Information sheet for Nominated Consultee]	1.3	04 July 2014
Participant information sheet (PIS) [Information & assent form]	v1.1	22 April 2014

for residents]		
Participant information sheet (PIS) [Personal Consultee Information Sheet]	1.1	04 July 2014
REC Application Form [REC_Form_02062014]		02 June 2014
Referee's report or other scientific critique report [Research Proposal Review Form]	v1	30 January 2014
Research protocol or project proposal [Protocol]	1.3	04 July 2014
Summary CV for Chief Investigator (CI) [Aimee Spector CV]	v1	30 September 2010
Summary CV for student [Faye Sweeney CV]	v1	06 March 2014
Summary CV for supervisor (student research) [Amanda Williams CV]	v1	23 April 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Summary Protocol]	v1.2	08 May 2014
Validated questionnaire [PAINAD]	v1.1	23 April 2014
Validated questionnaire [PDQ]	v1.1	23 April 2014
Validated questionnaire [Pain Knowledge & Beliefs Questionnaire]	v1.1	23 April 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/1084	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

*Enclosures: List of names and professions of members
who were present at the meeting and those who submitted written
comments
"After ethical review – guidance for
researchers"*

Copy to: Ms Suzanne Emerton

NRES Committee London - Camberwell St Giles

Attendance at Sub-Committee of the REC meeting on 01 August 2014

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>
Mr John Richardson	Retired Director of COREC; Ecumenical Officer for Churches Together in South London	Yes
Mr Jonathan Watkins	Independent Social Worker	Yes

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Elizabeth Hearn	REC Assistant

Appendix C

Consent procedure for residents

The following process for obtaining consent adheres to the Mental Capacity Act (2005), and the guidelines outlined in the document ‘Conducting research with people not having the capacity to consent to their participation: a practical guide’ (British Psychological Society, 2008).

Process for obtaining consent for residents

Throughout all interactions with potential participants the researcher used simple language, spoke slowly and clearly, repeated information where necessary and asked open-ended questions.

Potential participants received the Participant Information Sheet at least 24 hours prior to a discussion with the researcher. The researcher was introduced to residents by a member of staff and met with them to explain the project in more detail. The quality of the person’s decision to participate in the study was judged by asking the person about: the purpose of the study; the reason they arrived at their decision; and the reasons for and against participating in the study. If the person was able to reach a decision about agreeing or refusing to participate in the study this was accepted.

If a resident was not able to reach a decision about participating or refusing to participate in the study the researcher attempted to enhance the person’s decisional capacity by providing further information about the nature of research and providing more specific and accessible information. If the person was then able to make a decision about agreeing or refusing to participate in the study (as described above) the researcher accepted this decision.

If a resident decided to participate in the research and were judged as having the capacity to make this decision they were asked to sign the participant consent form. A caregiver was asked to witness the informed consent process whenever possible.

Procedure for assessing capacity to consent

If a resident was still unable to reach a decision after all efforts to increase their decisional capacity, the researcher assessed their capacity to consent. A potential participant was judged as not having the capacity to consent if they were unable to: understand the purpose of the study; recall information about the research (although if the person has memory difficulties this will not be sufficient to indicate a lack of capacity); and/or use or weigh up the information and communicate their decision. The researcher documented all decisions regarding whether or not a resident was judged to have capacity and the reasons for this judgement.

Procedure for decisions regarding participation for residents lacking capacity to consent

Where potential participants were not judged to have capacity to consent, the researcher used the additional safeguards provided by the Mental Capacity Act to inform decision making about whether to still include them in the study despite their inability to consent. In these instances assent was always sought from the potential participant, either verbally or in writing.

The researcher identified a personal consultee, such as a friend or relative, to advise on the person's participation. Consultees were asked to carefully consider the wishes of the person with dementia and any opinions they may hold about participating in research. Information sheets were provided and the researcher ensured all consultees demonstrated a good understanding of the project. The following information and advice was sought from consultees:

- Whether they have any personal or professional connections with the project or an interest in its outcome.
- What knowledge of they have of potential participant.
- Whether they have discussed involvement in this or any other research project with the person at any point.
- Their views about whether the participant may benefit from taking part.
- Their views about whether the person may object, be upset in any way or want to stop being involved, and if so, how this would be shown.
- Their views about whether participation may cause any problems or inconvenience for the potential participant.
- Whether, from their understanding of the person and the project, on balance the person should or should not take part.

Using the information provided by the consultee and the resident, the researcher appraised the benefits, burdens and risks of participating in the study for each prospective participant.

Appendix D

Resident information and consent forms

Resident information sheet

Resident information and assent forms

Resident consent form

Personal consultee letter

Personal consultee invitation

Personal consultee information sheet

Personal consultee declaration form

Staff information and consent forms

Staff information sheet

Staff consent form



PARTICIPANT INFORMATION SHEET

Study Title: Staff Training for Pain Management for People with Memory and/or Communication Problems: A Pilot Study (Student Study)

Invitation to participate in a research study

You are being invited to take part in a research study. The study will be conducted by Faye Sweeney, and will form part of a postgraduate degree in Clinical Psychology at University College London.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

This study is testing out new training for the staff who provide your care. The training is designed to help improve the skills of care home staff in recognising and managing pain for people with memory and communication problems.

Why have I been chosen?

You have been invited to take part because you are considered to be experiencing memory problems and/or communication difficulties.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you can change your mind and withdraw at any time without giving a reason. If you decide not to take part, at any time, this will not affect the standard of care you receive.

Participant Information Sheet for Residents, version 1.3 (04.07.14)

What will happen to me if I take part?

You will not have to do anything differently and you will receive your usual care.

A member of staff will observe you several times, for between 2-5 minutes, to see if you are in any pain. A researcher will also speak to a member of staff who knows you well and look through your medical notes to get information about you and your care.

What are the possible disadvantages and risks of taking part?

We believe that the risks involved in taking part in the research are minimal. However, you may find being observed, as part of staff assessing your pain, upsetting or distressing. If you do find any part of being in the research distressing, you are free to withdraw at any point.

What are the possible benefits of taking part?

If you do decide to take part in the study, we hope that staff will be more likely to detect and provide the treatment you need for any pain you have. Research has shown that when people get better treatment for their pain it can improve their overall quality of life, although we cannot promise this.

For all participants, the information we get from this study may help us to treat the pain of people with memory problems and/or communication difficulties better in the future.

Will my taking part in the study be kept confidential?

All information collected about you will be kept private unless there is a concern about risk; if we are concerned about your or another person's safety we may need to break confidentiality and share any relevant information.

All documents that leave the care home will have your name removed, with the exception of a consent form, which will be kept in a locked cabinet. Once the study has finished University College London will keep the study data in a secure location.

What happens when the study stops?

We hope that the staff who provide care for you will continue to assess and treat any pain you may have using the skills and knowledge they have learned from the training they get.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care you receive. We will need to use all data collected in the study, up to the point of withdrawal.

What if something goes wrong?

Every care will be taken in the course of this study. However, in the unlikely event that you are harmed by taking part, compensation may be available. If you are harmed and you think that this was caused through negligence by University College London, you should talk to the researcher and then contact Dr Aimee Spector. Dr Spector is the Chief Investigator for the research and is based at UCL, she will support you to make any claims in writing and pass it on to UCL's Insurers (if you take legal action you may have to pay the costs of this initially, and you should consult a lawyer about this).

If you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study or if you are unhappy with anything about your participation, you can make a complaint through UCL. Please ask the researcher if you would like more information about making a complaint.

Who is organising and funding the research?

The research is being organised and funded by University College London. The study will be conducted by Faye Sweeney, a Trainee Clinical Psychologist who is being supervised by Dr. Aimee Spector, who is a Clinical Psychologist.

What will happen to the results of the research?

The results will be published in journals for health care professionals and other scientists. No-one who takes part will be identified in any publication. Once the study has ended you will be invited to hear the

researcher present the study findings at your care home. If you would prefer to have a written report this is also be possible.

Who has reviewed the study?

All NHS research is looked at by a group of people, called a Research Ethics Committee to protect your safety, rights, and dignity. This study has been cleared by the Camberwell St. Giles Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Faye Sweeney

Department of Clinical, Educational and Health Psychology

UCL

Gower Street

WC1E 6BT

Email: f.sweeney@ucl.ac.uk

Or if you have any complaints about this study please contact:

Dr Aimee Spector

Department of Clinical, Educational and Health Psychology

UCL

Gower Street

WC1E 6BT

Email: a.spector@ucl.ac.uk

Tel: 0207 6791844

Thank you for thinking about taking part in this research study

Yours

Faye Sweeney

Trainee Clinical Psychologist

Dr Aimee Spector

Senior Lecturer in Clinical Psychology

Dr Amanda Williams

Reader in Clinical Health Psychology



Participant information and assent form Version 1.1 22.04.2014

PARTICIPANT INFORMATION AND ASSENT FORM

Study Title: Pain Management for People with Memory and/or Communication Problems in Care Homes: Developing and testing a new staff training programme

Invitation to participate in a research study

You are being invited to take part in a research study.

What is the purpose of the study?

This study is testing out new training for the staff who provide your care. The training is designed to help improve the skills of care home staff in recognising and managing pain for people with memory and communication problems.

What will happen if I take part?

You will not have to do anything differently and you will receive your usual care. A member of staff will observe you several times, for a short while, to see if you are in any pain. A researcher will also speak to a member of staff who knows you well and look through your medical notes to get information about you and your care.

Do I have to take part?

You do not have to take part in this study. If you do decide to take part you will be free to stop the study at any time, without giving a reason. Stopping the study will not affect the care you receive.

Will my taking part in the study be kept confidential?

The researcher will not tell other people (i.e. people not involved in your care) that you are taking part in the study or share any information about you unless we are concerned about your or another person's safety. We will keep some written information about you but this will be kept securely.

If you sign below, this means that you have read this form, or have had it read to you, and that you are willing to be in this study. A researcher will then speak to someone who will think about your best interests and advise whether they think it is ok for you to take part in this study.

Name of participant	Date	Signature
Name of person who has discussed the study and provided me with information	Date	Signature

If you are unable to sign your name, a member of staff can witness you telling the researcher that you are willing to be in this study.

Name of staff member witness	Date	I have witnessed that the participant has told the researcher they are willing to be in this study Signature to confirm the above
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You will keep a copy of this form. One copy will also be kept in your care records and one copy will be kept by the researcher.



PARTICIPANT CONSENT FORM

Study Title: Staff Training for Pain Management for People with Memory and/or Communication Problems: A Pilot Study (Student Study)

Name of Researcher: Faye Sweeney
Participant Number:

Please initial
boxes

1. I confirm that I have read and understand the information sheet dated 04/07/2014, version 1.3 for the above study and have had the opportunity to ask questions and have had these answered acceptably.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes (including my Medication Administration Records) and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records.	
4. I understand that my participation involves being observed by staff, as part of an assessment of pain and give my permission for this.	

Participant consent form for residents, version 1.3, 04.07.2014

5. I understand that all information given by me or about me will be treated as confidential by the research team.	
6. I agree to take part in the above study.	

Name of participant	Date	Signature
Name of person taking consent (if different from the principal researcher)	Date	Signature
Principal researcher	Date	Signature

Participant consent form for residents, version 1.3, 04.07.2014

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London WC1E 6BT
General Enquiries Tel: +44 (0)20 7679 1897
Fax: +44 (0)20 7916 1989
<http://www.ud.ac.uk/clinical-psychology/>



Dept of Clinical, Educational and Health Psychology
University College London
Gower Street
London
WC1E 6BT

DATE

LETTER TO PERSONAL CONSULTEE

Study Title: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

Dear Name

The XXXX care home is collaborating with University College London (UCL) in a student research project.

I (Faye Sweeney) am a Trainee Clinical Psychologist. I am completing this project as part of a doctoral course in Clinical Psychology at University College London. The project is called 'Staff Training for Pain Management in Dementia'.

An important aspect of the research project is that all participants have the choice about whether to volunteer or to refuse to take part. However some of the residents may not have the capacity to consent because of particular difficulties they are experiencing that affect how they make some decisions.

You have been approached as you are a partner, relative or friend of a resident of the XXX care home. The researchers would like to discuss with you your views about whether XXX may wish to participate in the research project. I attach some information about the project, who the researchers are, and in what ways you can help.

We would be grateful if you could have a look at the enclosed information and return the 'Invitation to Act as Personal Consultee' to me within two weeks of the date of this letter (my contact details are provided on enclosed the information sheet). A stamped addressed envelope is also provided. If you have any queries, please feel free to contact me to discuss this.

Thank you for your interest in the project and taking time to read the information.

(Signed)
Faye Sweeney
Researcher/Trainee Clinical Psychologist



INVITATION TO ACT AS PERSONAL CONSULTEE

Study Title: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

Patient Number:

Researcher: Faye Sweeney

I think that my partner, friend or relative may NOT like to take part in the project.	I agree with this statement Signed
I think that my partner, friend or relative may be interested in taking part and I would like to discuss this with the researcher. I have provided a contact number and the times I can be contacted below.	I agree to being contacted further about the study Signed
I think that my partner, friend or relative may like to take part in the project – but I do not wish to be consulted. I have provided information about an alternative contact person below (if possible).	I do not agree to being contacted further about the study Signed

Contact details:

Name:

Contact number:

Most convenient time(s) to be contacted:

Thank you for completing the form. Please return it in the stamped addressed envelope or leave it F.A.O Faye Sweeney at XXX care home.



PERSONAL CONSULTEE INFORMATION SHEET

Study Title: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

What is the purpose of the study?

Research shows that pain is under-recognised and under-treated in older adults and that this problem is worst for people with dementia. It can be very difficult to know whether a person with dementia is in pain because they may be unable to tell anyone even when asked. This study is developing and testing a new training programme for care home staff to help them improve their skills in recognising and managing pain in people with dementia.

The project has been approved by Camberwell St. Giles Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, the researchers need information from people who have known the participant for some time or those who have agreed to be consulted on such matters.

Why have I been contacted?

We are intending to recruit participants to this project who may not have the capacity to consent to their participation. This means that they may not be able to judge for themselves whether they would like to take part or refuse. The project includes such participants because we are studying the impact of an intervention for people with dementia, an illness which limits a person's ability to give consent.

Researcher/s in the project would like to discuss with you whether you think that your partner, friend or relative would like to take part. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. As you have known them for some time, you may be aware of any views they may have about taking part in such a project or whether they have made an 'Advance Decision'. If your partner, friend or relative has made an 'Advance Decision' this is important as it shows that they have ready made decisions for themselves. The researchers would like to respect the person's wishes.

Secondly, if you think that your partner, friend or relative may be interested in taking part in the project, you may be able to tell us about any possible difficulties they may have. You also may be able to tell us how they may communicate that they wanted to stop being involved.

What is required of each participant?

The intervention provided in this study is for dementia care staff and so residents of care homes will not be directly involved with the research team. However, in order to study the effects of the staff training on pain in residents, we would do the following:

- 1) The principal researcher will look at participant's medical records to obtain details about any relevant diagnoses and their pain medication.
- 2) Staff will be asked to observe residents in order to assess any behavioural signs of pain. They will be asked to do on several occasions, for around 2-5minutes, using a standardised observational measure.

This will help the researchers to assess whether any change has occurred over time.

Taking part in the study does not involve any lifestyle restrictions or changes. Participants will carry on with their everyday activities as normal while participating in the study.

What are the possible disadvantages and risks of taking part?

As pain assessment should be carried out as part of routine clinical practice the risk is seen to be minimal and equivalent to that encountered as part of daily care. However if participants find observations significantly distressing they may be withdrawn from the study. A decision to withdraw will be made where the participation is no longer judged to be in the person's best interests. Decisions will be made by the principal researcher through discussion with the Chief Investigator and the person's direct care team. We will need to use all data collected in the study, up to the point of withdrawal.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think your partner, friend or relative should be withdrawn.

What are the possible benefits of taking part?

We hope that participating in this research will lead to a direct benefit to participants through improved detection and treatment of pain, although this cannot be guaranteed. If pain is a problem for people the reduction or relief of pain is likely to enhance their quality of life. Also, previous research has found that when people with dementia receive effective pain treatment it is associated with a reduction in agitation and distress.

There is a lack of evidence-based intervention for pain management in dementia; therefore this study may also lead to changes in the way that care is provided in this population.

Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London. This project will be submitted by the researcher as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology.

Who has reviewed the study?

The study was reviewed in detail by the UCL Doctorate in Clinical Psychology. All research in the NHS is looked at by independent groups of people called a Research Ethics Committee to protect the safety, rights, wellbeing and dignity of participants. The X Research Ethics Committee has checked and approved this study.

Will participant's information be kept confidential?

All information collected about participants over the course of the study will be kept private unless there is a concern about risk. All documents that leave the care home will have participant's name removed with the exception of a consent form. This form will be kept securely. After the study has finished study data will be kept by UCL in a secure location.

No participants will be identified in any publication arising from the study. The results of the research study will be published in a report that will be available to you and in journals for medical professionals and other scientists. The researchers will also present the study findings to staff and interested parties at each care home. You are welcome to attend this presentation.

Will information that I give be kept confidential?

Information about yourself (name, address and telephone number) will be held by the Care organisation. Information that you disclose about the prospective participant will be held by the researcher.

What do I have to do now?

If you think that your partner, friend or relative would be interested and you are able to discuss this with the researcher, please fill in the attached 'Invitation to Act as Personal Consultee' form and include your name, contact number and a convenient time when the researcher can contact you. We would be grateful if you could return the 'Invitation to Act as Personal Consultee' within two weeks of the date of our letter. Please also retain the 'Personal Consultee Declaration' form and the spare

stamped addressed envelope as we may ask you to complete this once you have spoken to the researcher.

If you think that your partner, friend or relative would be interested but you are not sure about whether you would like to talk about this with the researcher, then please suggest who else could be approached.

If you think that they would **not** be interested in taking part, then it is important that you still complete the accompanying form entitled 'Invitation to Act as Personal Consultee'. A stamped addressed envelope is provided. We would be grateful if you could return the 'Invitation to Act as Personal Consultee' form no later than two weeks from the date of our letter.

Making a complaint

Any complaint about the way you have been dealt with during the study will be addressed. If you have any comments or concerns you may discuss these with the researchers. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should email the Joint Research Office at research-incidents@ucl.ac.uk or alternatively you may contact the Chief Investigator and they will forward your complaint on.

For more information about this research, please contact:

If you would like to know more, please contact the Researcher, Faye Sweeney on 07877834847 or f.sweeney@ucl.ac.uk. Alternatively you can contact the Chief Investigator Dr. Aimee Spector, on 020 7679 1897, or by writing to the address on the letterhead.

If you are unsure about taking the role of consultee and would like seek advice from an independent person who is not associated with the project, please contact:

Dr Chris Barker
Department of Clinical, Educational and Health Psychology
UCL
Gower Street
WC1E 6BT
Email: c.barker@ucl.ac.uk

Thank you for thinking about helping us with this research study

Faye Sweeney
Researcher/Trainee Clinical Psychologist

Dr Aimee Spector
Chief Investigator/Senior Lecturer in Clinical Psychology

Dr Amanda Williams
Academic Supervisor/Reader in Clinical Health Psychology



PERSONAL CONSULTEE DECLARATION

Study Title: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

Patient Number:

Researcher: Faye Sweeney

Please initial

1. I confirm that I have read and understood the Information for Personal Consultees (version 1.1, dated 04.07.14) for the study	
2. I confirm that I have had time and opportunity to ask questions about the study or my role as a Personal Consultee	
3. I understand the purpose of the project and what the participant's (my partner, friend or relative's) involvement would be. In my opinion, they would not object to taking part in the study	
4. I understand that participation in the project is voluntary and that the participant would be withdrawn if they do not wish to continue participating and the participant would not have to give a reason.	
5. I understand that if the participant were withdrawn from the project, this would not affect in any way the care or treatment they receive, or affect their legal rights.	

Name of Consultee	Date	Signature
Name of person who has discussed the study and provided me with information (usually principal researcher)	Date	Signature
Principal Researcher	Date	Signature

Please complete *both* copies of this form and keep one for yourself. Please send the other copy in the stamped addressed envelope provided, thank you.



Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

Information for staff about the research

You are invited to participate in a research project to help improve the skills of care home staff in recognising and managing the pain of people with dementia. The study will be conducted by Faye Sweeney, as part of her training at University College London and will be submitted as a thesis in partial fulfilment of the requirements for the postgraduate degree of Doctor of Clinical Psychology. Before you decide if you want to join, it's important to understand why the research is being done and what it would involve for you. So please consider this leaflet carefully and ask the researcher any questions you may have.

Why are we doing this research?

Research shows that pain is under-recognised and under-treated in older adults and that this problem is worst for people with dementia. It can be very difficult to know whether a person with dementia is in pain because they may be unable to tell anyone even when asked.

This study is developing and testing a new training programme for care home staff to help them improve their skills in recognising and managing pain in people with dementia.

Why have I been invited to take part?

You have been invited to join the study because you currently work at one of the care homes that has agreed to take part. Your manager has given permission for you to attend the training and to take part in other activities related to the research if you choose to do so.

Do I have to take part?

No: it's up to you. Please read through this information sheet and think carefully about whether you want to take part. We invite you to attend a meeting with a researcher at your workplace about the study. If you have any questions about the study, you can ask the researcher then. If you are willing to take part in the study, we will ask you to sign a consent form to show you have agreed to take part.

If you decide that you do not want to take part or you decide to withdraw from the study you do not have to tell us why, and any reason you do give will not be shared with your manager.

What will happen if I take part?

If you agree to take part you will be asked to do the following:

1. Complete some questionnaires about yourself (demographic information, qualifications, job details etc.) and your knowledge and attitudes towards dementia and pain in dementia. These will take approximately 20 minutes and will be paper and pen based.

2. Assess pain for some of the patients you care for who have dementia. These patients may be identified by you or by your manager. You will be asked to observe the patient at rest and during movement. You will be asked to assess pain both before and after taking part in the training programme. Each assessment should take around 5 minutes to complete.
3. Attend the training programme, which will be held at the care home where you work and involve two training workshops of approximately half a day in length each, over a 6-8 week period. Between workshops you will be asked to attend one or two group supervision sessions of approximately an hour, to support you in applying what was learned at the workshops to your clinical work with patients.

There will not be any test or quiz at the end of the training programme.

4. At the end of the training programme we will invite you to discuss your thoughts and ideas about the workshops you attended and how helpful they were for your day-to-day work. This will involve you taking part in a face-to-face interview lasting approximately 15 minutes. This will also be held at the care home where you work and will take place within a month of completing the training programme.

What are the possible benefits of taking part?

The potential benefits for you are improvement of skills and/or knowledge about pain assessment and management in patients with dementia. Also, we hope that undergoing the training will help you to provide the best care possible for your patients, potentially leading to better detection and treatment of pain, which may enhance their quality of life.

It is also hoped that this study will help us to improve pain management for people with dementia in general.

What are the risks of taking part?

We do not expect there to be any risks of taking part in this study over and above those which would be part of your normal job. However if being involved in this research really does not suit you, for example if you find it distressing, you are free to withdraw at any point.

Although it is not anticipated that the questionnaires or face-to-face will cause any stress or distress, this is a possibility. If, for any reason you do become distressed the researcher, who is a clinician with appropriate training, will be available to help you manage this in the most appropriate way (i.e. accompanying you to a private room).

Participating in the research involves a time commitment and you may experience some minimal inconvenience from attending training and answering questionnaire/completing observational measures. As a small token of appreciation for the time and effort involved in taking part we will provide you with a £5 high-street voucher.

What happens if I don't want to carry on with the study?

You can withdraw from the study at any time, without giving a reason. If you choose to withdraw from the study this will not affect your employment in any way.

What happens if I don't want to carry on with the study?

You can withdraw from the study at any time, without giving a reason. If you choose to withdraw from the study this will not affect your employment in any way.

Will our taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. It will be shared with associated university researchers who have a duty to you as research participants. However, if you or another member of staff were to disclose issues related to protection of vulnerable adults during the research, we might have to share this information with an appropriate person. We would discuss this with you before we notified anyone else.

We will let your manager know that you are taking part in the study so that s/he can authorise your attendance at the training days and provide any other time away from your clinical duties as needed.

What will happen to the information I give?

One of the requirements for taking part in the study is that you plan to be working at the care home throughout the study (until [date]). If you plan to leave your job before this date and so decide not to take part in the study we will not share this information with your manager.

The results of the research study will be published in a report that will be available to you and your workplace and in journals for medical professionals and other scientists. Your name or the name of your workplace will not appear in any report or publication.

Who is organising and funding the research?

The research is being organised and funded by the Research Department of Clinical, Educational and Health Psychology, part of University College London.

Who has reviewed this study?

The study was reviewed in detail by the UCL Doctorate in Clinical Psychology. All research in the NHS is looked at by independent groups of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The Camberwell ~~St.Giles~~ Research Ethics Committee has checked and approved this study.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, UCL complaints mechanisms are available to you. Please ask the researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr Aimee Spector who is the Chief Investigator for the research and is based at University College London. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Contact details

If you would like to know more, please contact the Researcher, Faye Sweeney or the Chief Investigator Dr Aimee Spector, on 020 7679 1897, or by writing to the address on the letterhead.

Thank you for reading this – please ask any questions you may have.

Yours

Faye Sweeney
Trainee Clinical Psychologist

Dr Aimee Spector
Senior Lecturer in Clinical Psychology

Dr Amanda Williams
Reader in Clinical Health Psychology

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

University College London Gower Street London

WC1E 6BT

General Enquiries Tel: +44 (0)20 7679 1897

Fax: +44 (0)20 7916 1989

<http://www.ucl.ac.uk/clinical-psychology/>



Participant identification Number:

Name of Researcher:

Title of project : Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

CONSENT FORM

Please *initial* box

1. I confirm that I have read and understand the information sheet dated 08/05/14 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my occupational status or legal rights being affected. ☐
4. I understand that data collected during the study may be looked at by members of the research team from University College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
5. I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Person Date Signature
taking consent

When completed, 1 for patient; 1 for researcher as part of the study documentation; 1 (original) for researcher site file

Appendix E

Staff feedback interview schedule

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY



Semi-structured interview with care staff

Study title: Staff Training for Pain Management in Dementia: A Pilot Study (Student Study)

Interview length: 15-20mins

Introduction: Thank you for agreeing to take part in an interview about the 'pain in dementia' training programme. I would like to ask you about your experience of the training and any effects you feel it has had on your clinical practice. I would like to assure you that your answers will remain completely anonymous and no records of the interview will be kept with your name on them. I also want to remind you that you do not have to take part and you are free to withdraw at any time, without giving a reason. Do you have any questions before we begin?

Questions

Interviewer instructions: Use open ended questions and neutral prompts to avoid asking leading questions. The researcher should focus on identifying *change*, therefore it is important to check whether examples are 'different or the same as before the training'.

1. What was your experience of attending the 'pain in dementia' training? (*Prompts: 'How helpful was it?', 'In what ways was it helpful/unhelpful?'*)
2. 'Do you feel the training has increased your knowledge about pain in people with dementia?'
If yes, 'In what ways?'


'Has your clinical practice changed since taking part in the 'pain in dementia' training?'
If yes, 'In what ways?'
(Neutral prompts, such as 'has anything else changed?', 'Is there anything else you are doing differently')
3. 'Can you tell me about one or more examples where you have put something you learned from the 'pain in dementia' training into practice'. (*Use neutral prompts to elicit as much detail as possible for each example given*)

If the staff member does not give examples after neutral prompts ask specifically about the following:
 - a) Assessment: 'How have you assessed pain in people?'
(*prompt: 'Have you used an observational tool?'*)
 - b) Treatment: 'Since receiving the training do you feel your treatment of pain in residents with dementia has changed?'
(*prompts: 'Have you provided any pain medication on an 'as needed' or PRN basis?', 'Have you provided any non-medical treatment for pain, such as heat/cold pads or massage?'*)
'How do you assess whether any treatments have been effective?'

N.B. The researcher should clearly record '(p)' to denote when prompts have been provided.

Appendix F

Staff training workshop presentations



Pain Management for people with Dementia

Dr Aimee Spector, UCL, Chief Investigator
Dr Amanda C de C Williams, UCL, Academic Supervisor
Faye Sweeney, UCL, Principal Researcher

A staff training intervention

UCL, RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Plan for today

Focus:
Today's session will focus on an introduction to 'Pain in Dementia' and 'Assessing Pain in Dementia'

Morning workshop:

- Training will run from 8.00am- 11.30am
- 15 min breaks at 9:00am and 10:15am

Workshop 2 : Tuesday 3rd March (TBC)

Pain experiences

Think about a personal experience of pain that you feel comfortable discussing

- Did you express this pain? If yes why and how?
- How did other people respond to your pain?
- How did you manage or cope with the pain?
- Where do your beliefs about how or when you should express pain come from?

What is dementia?

Dementia is a progressive deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing.

Problems with thinking or memory, include:

- day-to-day memory
- concentrating, planning or organising – e.g. difficulties making decisions
- language – e.g. difficulties finding the right word for something
- visual and spatial skills – e.g. problems judging distances
- orientation – e.g. becoming confused about where they are
- changes in mood or behaviour

How big is the problem of pain?

1) What percentage of elderly people have chronic pain?

10% 25% 50% 65% 80%

2) How many people living in residential care are thought to be in pain at any one time?

10% 25% 50% 75%

Why is pain such a problem in dementia?

- Pain is under-recognised and under-treated in older adults and to the largest degree in people with dementia

Dr Liz Sampson talks about pain in dementia

Problems pain can cause in dementia

- Reduced quality of life and disability
- Increased behavioural symptoms, such as Agitation
- Worsening of psychological symptoms e.g. confusion and depression

What are the difficulties in assessing pain in residents with dementia?

Brainstorm together as a group

What are the difficulties in assessing pain in residents with dementia?

- Language deteriorates in dementia
- Dementia affects people's understanding
- Behaviours seen as symptoms of 'the dementia'
- People with dementia may be reluctant to tell you about their pain

Common causes of pain in dementia

- Constipation
- Urinary tract infections (UTIs)
- Undiagnosed fractures from falls which no-one witnessed
- Sore mouth, toothache (less able to clean teeth properly) or ill-fitting dentures (often due to weight loss)
- Earache
- Being lifted or moved in an uncomfortable or painful way

Beliefs about pain and dementia

In groups of two consider the following statements.

Rate each statement from '0' (not at all true) to '10' (definitely true).

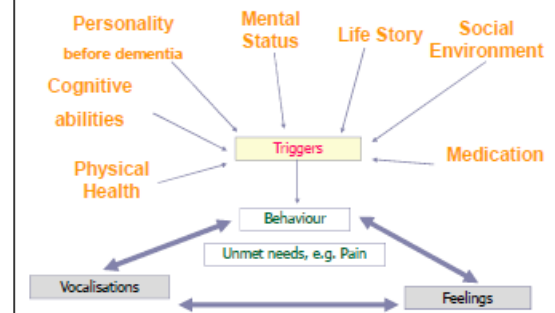
Please make a note of any previous knowledge, experiences or evidence that you consider in your decision.

Myth busting

- Which myths had you already become aware of?
- What sources do you most trust to learn about such things?
- What did you find most surprising in your discussions about these myths?
- What's the best way to address other people's mistaken ideas about dementia?
- What implications do these myths have for how you work?

'Challenging Behaviour': Communication of an 'unmet need'

- People's basic needs can go unmet in dementia:
 - people are less able to meet or communicate their own needs
 - it's difficult to meet needs in the care environment (i.e. freedom may be restricted to ensure their safety)
- 'Challenging Behaviour' can be seen as an attempt to either meet or communicate these unmet needs.
- The approach places the person with dementia at the centre of the assessment and intervention process



'Challenging Behaviour' due to Pain

Beryl

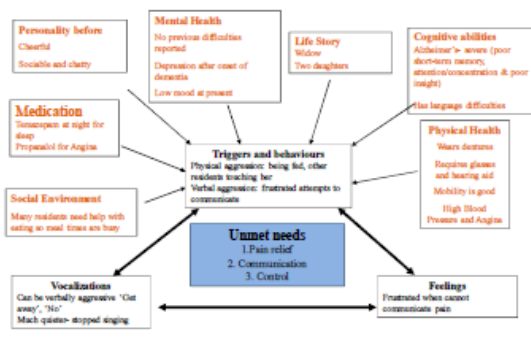
- Resident at Rose view Care Home for six years
- Diagnosis of Alzheimer's
- Well liked by staff and other residents- usually 'chirpy'
- Good mobility and requires minimal help with personal hygiene/care.

Beryl

Recent changes in Beryl's behaviour:

- Her mood seems low and she is not talking or singing as much as she used to
- Poor appetite and refusal to eat (particularly meat)
- Increased restlessness and moaning
- Disturbed sleep
- Refusal to take part in daily activities
- Aggressive behaviour

'Unmet needs' model: Case of Beryl



PAIN ASSESSMENT

If you see change or challenging behaviour think 'could it be pain?'

ASSESS, TREAT, RE-ASSESS

ASSESS

- Ask the person what the matter is
- Listen to them
- Observe their behaviour and what's going on

TREAT

- Act on what you've seen and heard

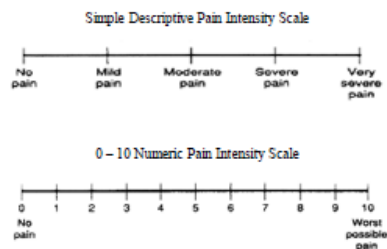
RE-ASSESS

- Check if the treatment is working

ASSESS

- Simple language
'how are you feeling?' or 'what's troubling you?'
- Use different phrases or expressions
'Are you feeling sad?', 'Are you cold?', 'Do you feel sick?'
- Try non-verbal ways to communicate
(i.e. gestures or facial expression)

ASSESS: Self-report scales



ASSESS: Self-report where possible

- Ask person if they have pain at rest or during movement
- Use alternative descriptors such as 'does it hurt?', 'is it sore?', 'do you have any aches?'
- If people seem to struggle with a numerical scale (0-10), you can ask them on a verbal scale ('no pain', 'mild pain', 'moderate pain' etc.)
- If you know the person well try and use their language, some older people may refer to a part of their body 'giving them gip or bother', or 'playing or acting up'

ASSESS

- Spend time with the person
- If they are confused listen for clues as to how you can reassure them
- Allow enough time for the person to do whatever it is they are trying to do
- Ask if they need help, without crowding them
- Avoid showing impatience

ASSESS: Observe

Record a description of the behavior (e.g. what and how often)

Consider doing/requesting a physical examination

Notice how they react to the environment (e.g. sights and sounds)

Could it be something simple? E.g. do they have appropriate clothing on

ASSESS: Facial expressions

- Nose wrinkles
- Eye lids tighten/close
- Lips tighten/parted
- Eye brow lowers
- Cheek area raised

Picture

quiz

Picture

quiz

ASSESS: Observe Behaviour

Look out for:

- Grimacing or grinding or clenching their teeth?
- Rubbing, pointing or pulling at a particular part of their body?
- Mood change, irritability or tearfulness
- Groaning, shouting or screaming?

ASSESS: Observe Behaviour cont.

- Movement- Are they less mobile, or moving differently? Are they pacing, unable to settle for long, restless or fidgeting?
- Body language - stiff, rocking or perhaps guarding part of their body?
- Physical changes- do they have a temperature, has their appetite or breathing pattern changed?

ASSESS- Gather more information

- Is there something that they like doing that will lift their mood or reassure them? Does this help?
- Are there familiar people, places, or objects that can help reassure them?
- If symptoms persist, who the best person is to ask for help and advice? E.g. a family member, GP or dentist.

TREAT: Pain treatment – the “analgesic ladder”

The “analgesic ladder” is the progression from weaker to stronger types of pain relief.

Giving painkillers such as paracetamol on an ‘as needed’ or *prn* basis can be very effective.

Evidence supports the use of paracetamol as a first-line treatment for pain in dementia

If the person is obviously already in significant discomfort you don’t need to start on the first rung of the “ladder”! Don’t get stuck there either if the problem is continuing.

TREAT: Pain treatment

Important things to bear in mind:

If medication is frequently given *prn* seek advice about a ‘fixed-schedule’ prescription.

Reassess and Monitor the person to see if the medicine is working.

How can I best communicate results of pain assessments to GPs

- Give a brief summary of the resident’s information
- Why are staff concerned?
- What do you think it might be and why?
- Physical observations
- Treatments already tried
- What medication is the resident on?

TREAT: Non-pharmacological treatments

What can I do other than talk to the GP about medication?

- Changing their position
- Touch or massage
- Cool compress, or heat pad

➤ *Non-pharmacological treatments can be effective but should only be provided where appropriate and you may need to consult with a nurse, doctor or physiotherapists to ensure this.*

Act as an advocate or supporter for the person with dementia to make sure other pain treatments are considered or tried.

Role- play (hand-out 1)

Please get into pairs

- One person to take the role of a resident who is unable to communicate verbally
- One person to be staff and try to assess their pain
- Each ‘resident’ will be given some information about a painful condition and they will have to act this out and try and communicate pain

Cont. Role-play

Feedback the results of your pain assessments to the wider group. ‘Residents’ read out the information you had.

- How close were you to the information the resident was trying to communicate?
- How easy was it assessing this? What made it difficult?

Key steps in pain assessment and treatment process

1. Be always on the look out for pain
2. Assess pain- verbally if possible and/or use observations of behaviour
3. Assess pain at rest and during movement
4. Use the knowledge you have about the patient or ask familiar caregivers for more information
5. Do a physical exam and check medical notes
6. Choose an appropriate treatment for the pain (pharmacological, non-pharmacological or both)
7. Check the effectiveness of the treatment- has it worked or do you need to do more?

Preparation for Workshop 2

- Spend 5-10 minutes thinking together about a resident with dementia whose care you think it would be useful to discuss next session.
- They may be new to the home or perhaps have lots of behaviours that are challenging and not fully understood.
- Please only choose one of the residents who is involved in the research.

WORKSHOP 2

Person-centred pain assessment

Plan for today

Focus:

Today's session will focus on implementing the principles of 'Person-centred Care' when assessing Pain in Dementia

Timings:

- Training will run from 1.30pm- 5.30pm
- 15 min breaks at 2:45pm and 3:45pm

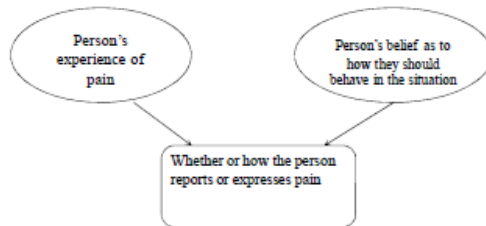
Recap from previous workshop

IMAGINE . . .

You are in a room you don't recognise, the people around you seem vaguely familiar but you're not sure who they are or how you know them. Most other people in the room are 'old people', but there are also women the same age as you, they are wearing blue uniforms and rushing around, they look busy. You decide you should investigate where you are and maybe ask someone, so you start to get up but notice a sharp pain in your leg, so you stay put. You wonder what could be wrong with your leg, have you had an accident? Is that why you're here? Has somebody hurt you? Where are your family? You start to feel very afraid and confused.

One of the women in uniforms come up and says "Eve it's time for your bath", gently taking hold of your arm and gesturing for you to get up. What do you do?

Communicating pain



What can get in the way of us recognising pain in residents with dementia?

What can get in the way of us recognising pain in residents with dementia?

Brainstorm together as a group

Pain Beliefs

Think about all the sorts of beliefs people have about pain

- What beliefs might older people hold about pain that might get in the way of them expressing pain?
- What beliefs might we have that might get in the way of us recognising the pain of others?

Pain Beliefs

Some examples:

- Pain is a necessary part of life
- Pain makes people stronger
- Pain is a punishment from God or God will only give me pain that I can handle
- Admitting I have Pain means people will think I'm weak/tolerating Pain shows strength of character

Person-centred pain management

What questions can you ask family and friends to help you understand how someone might cope with or express pain?

Person-centred pain management

"Life story" information is vital:

- What have they done in the past?
- What is important to them?
- How have they coped in difficult situations in the past?
- What might reassure, comfort or frighten them?
- Is there anything they can normally do for themselves that they can't do at the moment?

Talk to other people involved in their care, record their life story and use it to help support their care.

The example of Mr Jones

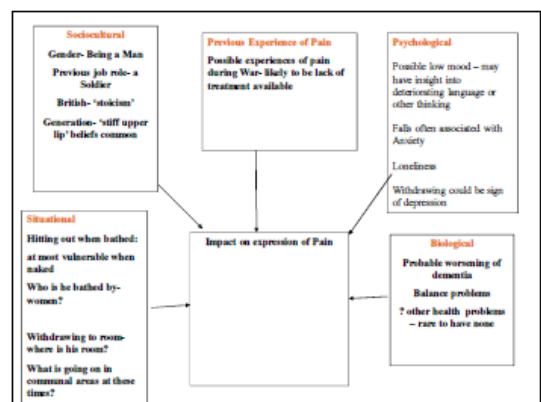
In small groups consider the case of Mr Jones, thinking about how the following factors might influence his experience and/or expression of pain

- Biological (e.g. his health, disabilities)
- Sociocultural (e.g. ethnicity, gender, culture)
- Psychological (e.g. fear/stress/anxiety, mood)
- Previous Experience (of pain or reporting pain)
- Situational (e.g. the effect of his current environment)

- What are the next steps you would take to assess his pain?
- What could you ask his sons?

Mr Jones

Mr Jones is a 79 year-old white British man with dementia and a history of falls. He has been living at Oak View care home for 3 years and is a widower. He has two sons who live quite far away, but visit him on his birthday and at Christmas. You know that Mr Jones used to be in the Army, but he has never spoken about this. In the past few months Mr Jones' communication has deteriorated and he is often no longer able to finish his sentences, but he often shouts phrases or single words and swears when he becomes frustrated. He used to pace around the home but has recently stopped doing this, preferring to stay in his room. He has started to hit out and shout at staff when he is bathed, but has no obvious physical injuries.



What next steps could you take to assess for pain?

- Stop bathing and see if reacts differently during washing?
- If possible see if bathing by male staff helps
- Observe during movement particularly or when sitting at different times
- Look for any guarding, bracing or rubbing of body parts
- Bath using a support so his weight is on a different area
- Try prn paracetamol before bathing
- Look in medical notes for any reasons for falls
- Ask another member of staff to observe his facial expressions
- Ask him about pain (use his language if possible)

What could you ask his sons?

- What was his previous personality?
- Any previous aggressive behaviour?
- Did he show pain in the past? If so, how?
- How would he cope in difficult or anxiety-provoking situations before?
- How was he with going to the Doctors previously?
- What might be the best way to help him 'save face' or to feel in control?
- Full medical history if possible

Personhood and person-centred care

Group discussion

Topic 1: Personhood

What does the term 'person-centred' care mean to people?

What is a person?

What is it to be a person?

Group discussion continued...

Topic 2: Quality of Life

What constitutes a high quality of life/what makes life worth living?

Who and what decides quality of life? Is the most important voice the carers, the family, or the patient?

Does quality of life change once a person is admitted to a care home?

Personhood and person-centred care

'Self-audit' exercise

- What are my ideas about getting older? How do I feel about frail older people?
- How do I perceive patients with dementia?
- Do I react differently when I believe that a patient with dementia has pain as compared to a patient without dementia?

Person-centred care

Initially developed by Tom Kitwood, who argued:

- viewing people with dementia in medical terms leads them to be seen as objects instead of people
- the approach highlights the importance of the person with dementia rather than the disease process itself

How can people's sense of 'personhood' be undermined?

Kitwood identified 17 different factors in how we relate to people with dementia which he argued can exacerbate the symptoms of dementia, such as:

Disempowerment: Not allowing a person to use their abilities

Infantilisation: Treating a person like a child

Outpacing: Acting / behaving at a rate too fast for a person to follow or understand

Can you think of examples of when you might have seen this in pain management?

Demonstration- person-centred pain assessment

What's wrong with this assessment?

Person-centred communication

A relationship which promotes viewing people with dementia as 'people first and foremost' involves three key things:

- Recognition
- Respect
- Trust

How do we show these things in our relationships with patients?

Person-centred communication during pain assessment

Recognition

- Seeking the attention of the person with dementia
- Speak to them face-to-face and establish eye contact
- Making an attempt to know about their history, beliefs and preferences can help you recognise their individual pain behaviours or ways of communicating

Person-centred communication during pain assessment

Respect

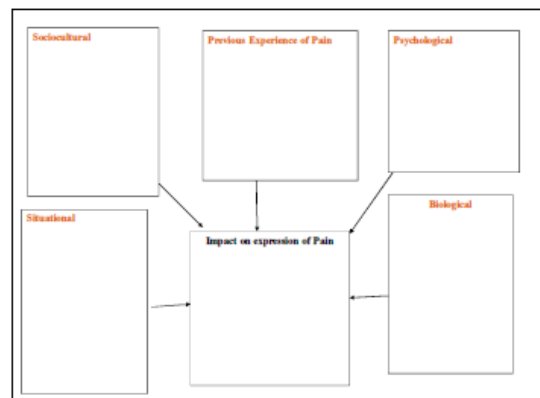
- Give the person your full attention and allow them enough time to respond
- Make it as likely as possible they will understand you; Use 'yes/no' questions, repeat or rephrase things, use appropriate gestures
- Show them that you are listening and paying attention to their responses
- Use simple language but not a patronising tone or 'infantilising' language

Person-centred communication during pain assessment

Trust

- Show them you are taking what they say seriously and act on any information they give you
- Be honest with them "I can see you are upset/distressed but I'm struggling to understand- I will do my best to try and help you"
- Provide reassurance by appropriate use of gentle touch or using a calm tone of voice

Case discussion



Summary of key points

ASSESS

- *Gather more information and consider life history*
- *Do behavioural observations*
- *Do a physical examination*

TREAT

- *Provide pharmacological, non-pharmacological treatment or both*

RE-ASSESS

- *Is the treatment working? If not, escalate!*

Reflections and Action Points

In small groups discuss:

- What changes could be made in your care home to support best practice for pain assessment and treatment in dementia? (i.e. using different forms or deciding to do things in a different way)
- What one thing will *you* try and focus on doing differently as a result of attending this training?