Pain Assessment and Management for Patients with Advanced Dementia Nearing the End of Life

SHORT REPORT

Bannin De Witt Jansen
Kevin Brazil
Hilary Buchanan
Doreen Maxwell
Sonja McIlfatrick
Sharon Morgan
Peter Passmore
Max Watson
Carole Parsons

Contents

EVIDENCE BRIEF

Why did we start?

Pain assessment and management for people with advanced dementia nearing the end of life is highly challenging and complex. Patient self-report is often unavailable or unreliable. Debate regarding the reliability, validity and clinical utility of observational pain assessment tools is ongoing. Evaluation and exploration of whether and how health professionals use these tools and their impact on patient outcomes remains a critical gap in current evidence. No studies have been conducted to date which examine health professionals' or carers' experiences and perspectives of pain assessment and management in patients with advanced dementia approaching the end of life.

What did we do?

We conducted qualitative interviews to determine the issues in pain assessment and management in people with advanced dementia nearing the end of life in primary, secondary, nursing home and palliative care settings. We interviewed 3 bereaved carers, 23 doctors, 24 nurses and 14 healthcare assistants. Analysis of these interviews identified a need for healthcare professional training and professional development in pain assessment and management in advanced dementia. Participants expressed a strong desire for case-based learning led by a health professional with clinical experience and specialist expertise. This provided the evidence for adoption of the Project ECHO© Model for this intervention. A series of five TEAM Pain AD teleECHO clinics were developed, delivered and evaluated.

What answer did we get?

The interview data highlighted, and the teleECHO clinic evaluations reinforced, the importance of developing networks for knowledge exchange across specialties and care settings, and between physicians, nurses and healthcare assistants. Healthcare assistants were frustrated at their perceived exclusion from multidisciplinary care teams. Evaluations demonstrated the value of the teleECHO clinics in enhancing healthcare professional knowledge and self-efficacy in assessing and managing pain for people with advanced dementia, and the potential for this type of educational intervention in other clinical areas.

What should be done now?

Policy and practice initiatives should cross specialisms and care settings, involving all members of the multidisciplinary healthcare team, patients' families and other key health and social care staff. Training should be needs-driven, available on a regular basis, and involve those who require the training in co-design of the curriculum. Policy and practice initiatives should also make provision for an expanded role for healthcare assistants. The ECHO© Model should be adopted for healthcare professional training and education in pain in dementia, and is translatable to other clinical areas. Further work is required to evaluate its impact on service delivery and patient outcomes, in addition to healthcare professional knowledge and self-efficacy.

Background

Advanced stages of dementia are characterised by immobility, severe cognitive deficit, loss of communication skills and physical frailty, and are often accompanied by a number of distressing and/or painful symptoms including: respiratory infection, delirium, anorexia, dysphagia, incontinence and sleep disturbance (Smith et al., 2003; Chang et al., 2005; Anthierens et al., 2010; Thune-Boyle et al., 2010). Untreated pain in people with dementia is associated with the presence, onset or exacerbation of depression, delirium, sleep disturbance, cognitive decline, resistive behaviour and neuropsychiatric symptoms (Cervo et al., 2007; Hadjistavropoulos et al., 2007; Kaasalainen et al., 2007; Khachiyants et al. 2011; Krishnamoorthy et al., 2011; Pieper et al., 2013; Ahn et al., 2015). Studies suggest that, depending on the stage of dementia and the method of ascertainment, between 20% and 50% of people with dementia report some form of pain in the course of their illness progression (Sampson, 2010), with higher proportions affected towards the end of life (Mitchell et al., 2009; van der Steen, 2010; Pinzon et al., 2013). Addressing the palliative care needs of people with dementia, including pain and symptom management, is therefore a critical healthcare priority.

Pain assessment for people with dementia is challenging and complex. Patient self-report, the gold standard for diagnosing pain, is often unavailable or unreliable in the more advanced stages of dementia as profound deficits of memory, language, executive and cognitive function manifest, leaving this patient population at risk of under-assessment, under-diagnosis and under-treatment of pain (Hadjistavropoulos et al., 2007; Husebo et al., 2008; Park et al., 2010; Lints-Martindale et al., 2012). In the absence of reliable patient self-report, healthcare professionals must use other means to diagnose pain, and often employ observation and interpretation of behavioural and non-verbal indicators of pain such as: crying; shaking; frowning; agitation; vocalisations; sweating; resistive behaviour; increased immobility or mobility; changes in personality or demeanour; and guarding (Herr et al., 2006a; Zwakhelen et al., 2006; Van Herk et al., 2007; Lichtner et al., 2014; van der Steen et al., 2014). Much of the research undertaken to date on pain assessment in people with advanced dementia has consisted of identifying behavioural and non-verbal indicators of pain and developing pain assessment tools to aid healthcare professionals with observation and interpretation of these indicators (Warden et al., 2003; Abbey et al., 2004; Fuchs-Lacelle and Hadjistavropoulos, 2004; Herr et al., 2006b; Hølen et al., 2007; Lichtner et al. 2014). These assessments, collectively known as observational pain tools (OPTs), typically work on a similar principle; health professionals observe patients for a number of behavioural and non-verbal indicators of pain, attribute a numerical score representing estimated severity for each indicator/cue observed, and aggregate scores to produce an overall score of estimated pain severity (Warden et al., 2003; Abbey et al., 2004; Fuchs-Lacelle and Hadjistavropoulos, 2004; Herr et al., 2006b; Hølen et al., 2007; Lichtner et al. 2014).

However, there is ongoing debate regarding the reliability, validity and clinical utility of OPTs due to the widely varying methods, participants, disease severities and settings

in which these tools were developed, and the limited evidence for their use and impact on patient outcomes (Herr et al., 2006b; Corbett et al., 2012; Lichtner et al., 2014; Husebo et al., 2016). In addition there are questions regarding whether OPTs are able to distinguish between pain and non-pain related distress (Regnard et al., 2007; Brörson et al., 2014; van der Steen et al., 2015). A number of studies have reported challenges experienced by health professionals when using OPTs in practice including: difficulties differentiating between pain and non-pain related distress; insufficient training and support in conducting pain assessments in people with severe cognitive impairment; inconsistency in attributing pain scores; over- or under-estimation of pain; workload and other organisational and institutional pressures; and attitudes towards pain and pain assessment in cognitive impairment (Kovach et al., 2000; Nygaard & Jarland, 2005; Kaasalainen et al., 2007; Zwakhelen et al. 2007; Ballard et al. 2011; Barry et al., 2012; Ghandehari et al., 2013; Brörson et al., 2014. Despite these challenges and debates, health policies and clinical guidelines widely recommend the use of OPTs when assessing pain in people with dementia and many private healthcare providers mandate their use as part of pain assessment protocols (Department of Health, 2009; Department of Health, Social Services and Public Safety, 2011; World Health Organization, 2012, van der Steen et al., 2014). However, evaluation and exploration of whether, to what extent and how health professionals are integrating and applying these tools in clinical practice and the impact of their use on clinical outcomes for patients remains a critical gap in current evidence.

Pain assessment outcomes have serious consequences for pain management; selecting appropriate management relies on accurate diagnosis and understanding of the pain experience. Previous studies indicate numerous challenges faced by health professionals when addressing pain in older adults with dementia. Inconsistent approaches to pain management for people with dementia are primarily due to difficulty assessing and diagnosing pain, and lack of clinical data to guide prescribing for patients approaching the end of life (Bell, 1997; Morrison & Sui, 2000; De Souto Barreto et al., 2013; Bruneau, 2014; Krumm et al., 2014; Tan et al., 2015).

A substantial body of compelling evidence has identified deficits in nurses' knowledge of pain assessment, pharmacology, side-effects and dosing schedules of analgesia, and misguided perceptions regarding the use of opioids and regularly prescribed analgesics, suggesting that nursing staff are inadequately educated on the use of analgesics in palliative care for people with dementia (Kovach et al., 2000, Auret & Schug, 2005, Barry et al., 2012, Ghandehari et al., 2013). Nurses have been reported to be uncertain about the reliability of pain reported by people with dementia (Cook et al., 1999) and to be concerned about use of opioid analgesics (Closs, 1996; Plaisance & Logan, 2006; Barry et al., 2012). Nursing home managers in Northern Ireland (NI) identified difficulties associated with accurate pain assessment, lack of knowledge about the experience of pain in dementia and the lack of a standardised treatment approach as hindrances to managing pain in residents with dementia (Barry et al., 2012). Nursing staff also reported that reluctance on the part of general practitioners (GPs) to prescribe alternative formulations of analgesics (including liquid formulations and transdermal patches) presented an obstacle to optimal pain management. A further study examining perceptions of Finnish nursing staff regarding barriers to postoperative pain management in hip fracture patients with dementia reported

physicians' reluctance to prescribe adequate pain relief due to fear of over-medication and lack of knowledge about prescribing analgesics (Rantala et al., 2012). This reluctance to prescribe analgesia and poor communication between physicians and nurses is consistent with previous work examining pain management in older people in general (not specific to patients with dementia) (Titler et al., 2003; Coker et al., 2010). Additionally, qualitative work undertaken by Brörson et al. (2014) reported that nurses experienced frustration associated with prescribing for patients; for instance, prescribed doses being sub-therapeutic. Some nurses felt that physicians did not consider their views when making prescribing decisions.

Research into communication between healthcare professionals and bereaved carers of patients with advanced dementia regarding medication use in end of life care undertaken in the School of Pharmacy (QUB) identified pain management as one of the main themes arising from qualitative interviews examining medication use (De Witt Jansen, 2014). Nursing staff reported that prescribing decisions for appropriate pain management were challenging for doctors who were unfamiliar with the unique physical, psychological, pharmacological and communication needs of patients with dementia, and believed that doctors, particularly GPs, could benefit from additional training in the pharmacology and pharmacotherapy of pain management, including dose equivalents for analgesia and in the range of formulations available as an alternative to tablets (patches, liquid formulations). Furthermore, there was recognition by GPs that care settings could impact on the efficacy of pain management; it was felt that managing pain in nursing home residents was significantly easier to achieve than in patients who were being cared for in their own homes. GPs and physicians across secondary care and hospice care settings acknowledged that further training in assessing pain, pain management and prescribing for pain would be beneficial. They did not find pain assessment tools such as the Abbey Pain Scale (Abbey et al., 2004) to be particularly helpful. Nursing staff suggested that antipsychotics and opiates are often prescribed to manage challenging behaviours which they felt originated from and were attributable to pain. Pain was also identified by carers as an issue (De Witt Jansen, 2014). Similarly, a study undertaken by Oliver et al. (2013) examining the experiences of family members whose care-recipients were being cared for in hospice reported clear concerns related to pain management including difficulties with administration of medications, concerns regarding side-effects, lack of clarity with regards to assessing pain, frustrations with poor communication among healthcare professionals and memories of unrelieved pain in loved ones (Oliver et al., 2013). A small qualitative study by Brörson and colleagues (2014) explored the experiences of nurses working in a Swedish hospital dedicated to the care of patients with neuropsychiatric disorders including dementia. Barriers to pain management identified included difficulties obtaining analgesic prescriptions, anxiety regarding use of morphine, and problems with nurse-physician communication (Brörson et al. 2014). Previous studies have focused on nurses' experience of pain management prior to the end of life but little is known about attitudes of and competence in pain management in the final weeks.

As physicians and nurses continue to shoulder the burden of an increasingly pressurised NHS system, time spent with patients is gradually reducing as

administrative burdens steadily increase, with much of the direct care now being carried out by healthcare assistants (HCAs) (Spilsbury & Meyer, 2004; Kessler et al., 2010; Department of Health, 2013). HCAs (who may also be known as nurse auxiliaries, healthcare support workers, and personal or clinical support workers) work in health and social care settings providing physical and psychosocial care to patients under the supervision of Registered Nurses (RNs). Their typical duties, which include: providing personal care, maintaining patient hygiene, assisting patients with eating and toileting, providing social interaction and psychological support, and basic housekeeping, bring them into direct, prolonged contact with patients (Spilsbury & Meyer, 2004; Stacey, 2005; Wilson et al., 2009; Kessler et al., 2010; Ingleton et al., 2011; Lloyd et al., 2011; Morgan et al., 2016). Over time, HCAs often develop detailed knowledge of patients' preferences, routines, and normative patterns of behaviour, mood, appetite and disposition, and they are often the first within the healthcare team to recognise changes in patients' physical and cognitive functioning (Morgan et al., 2016). Previous work has explored the impact of HCAs on patient care and outcomes in the context of the care of older adults, palliative care and dementia (Stacey, 2005; Wilson et al., 2009; Lloyd et al., 2011; Ingleton et al., 2011). However, no previous work has examined HCAs' experiences and perspectives of and contributions to pain assessment and management in nonverbal patients with dementia approaching the end of life.

Whilst it has been reported that physicians prescribe less palliative medication for patients with dementia than for cognitively intact individuals (Afzal et al., 2010), no studies have been conducted to date which examine physicians' or carers' views or experiences of the assessment and management of pain in patients with advanced dementia who are approaching the end of life. This represents a gap in the research literature in an important and under-researched area. Comprehensive research in this area is therefore required to determine the issues in assessment and management of pain in patients with advanced dementia who are approaching the end of life. This research should include the perspectives of healthcare professionals and carers in order to develop a model/models of practice by which the assessment and management of pain may be optimised and thus contribute to the drive to improve the quality of care that people with dementia receive. It is in the context of this research gap that the research team successfully obtained funding to address this issue.

Aims and Objectives

The aims for this 36-month funded project were as follows:

1. To identify the main issues in the assessment and management of pain in patients with advanced dementia nearing the end of life from the perspective of carers and healthcare professionals

2. To develop and test a model/models to improve assessment and management of pain in patients with advanced dementia nearing the end of life

The specific objectives for this study were:

1. To explore and understand the issues that arise in the assessment and management of pain in patients with advanced dementia nearing the end of life in primary, secondary and palliative care settings

2. To develop a model/models for assessment and management of pain nearing the end of life tailored to these settings

3. To present this model/these models to key stakeholders for feedback and subsequent revision

4. To pilot the finalised model(s) in primary, secondary and palliative care settings

Methods

This study was set within the Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Craig et al., 2008). The development stage comprised a review of the literature on pain assessment and management in patients with advanced dementia approaching the end of life, and qualitative interviews with healthcare professionals and bereaved carers (Phase I). This informed the development and implementation of the intervention, which was presented to key stakeholders at a one-day workshop for feedback and subsequent revision (Phase II). The finalised model was then tested in a pilot study (Phase III).

Phase I Qualitative Interviews

This study adopted a qualitative approach to data collection via the use of semi-structured interviews conducted with two key informant groups: bereaved carers and healthcare professionals (physicians, nurses and HCAs). This approach was selected to facilitate comprehensive discussion of the core clinical issues in pain assessment and management and how these impact on healthcare professionals and carers.

A purposive approach to sampling was applied to recruit a maximum variation sample of bereaved carers who had provided care for a person with dementia who had since died in hospice, a nursing home, hospital or at home. We aimed to recruit carers from both rural and urban locations across NI. Bereaved carers were recruited through carer support groups co-ordinated and hosted by the Alzheimer's Society NI.

To guide participant recruitment the following eligibility criteria were applied:

Inclusion criterion:

- Carers were eligible for participation if they had provided care on an informal (i.e. unpaid) basis for a minimum of once a week for a minimum of two years prior to the patient's death

Exclusion criteria:

- Carers bereaved for a period of less than 6 months OR exceeding 24 months (two years) from the date of initial contact about the study

- Carers participating in any other research study.

We aimed to recruit a maximum variation sample (with regards to clinical experience, educational attainment, age, setting, etc.) of physicians, nurses and HCAs from general practice surgeries, hospitals, hospices and nursing homes across NI. Recruitment procedures varied slightly between settings of care. A nominated sampling approach (also referred to as 'snowballing') was applied to identify primary care healthcare professionals for inclusion in this study. In secondary care settings governed by the five Health and Social Care Trusts across NI, an initial approach of Trust-employed healthcare professionals was conducted by local collaborators, senior clinicians within the Trusts who had agreed to facilitate the study. Within the hospice setting, the Medical and Nursing Directors of participating hospices acted as local collaborators, and suggested healthcare professionals within their organisations who met the eligibility criteria and who could be approached for participation. In the nursing home setting, homes which had an existing collaborative relationship with the School of Pharmacy, QUB, were approached in the first instance. Nursing home managers who agreed to allow staff within the home to be approached for participation were asked to suggest nurses and HCAs who met the eligibility criteria for the study.

Healthcare professionals were recruited using the following eligibility criteria:

Inclusion criterion:

- Healthcare professionals who have been, or still were, responsible for treatment provided to patients in the advanced and final stages of dementia who have died, or were likely to die, in one of four healthcare settings: their own home, in hospice, in secondary care or in a nursing home.

Exclusion criterion:

- Healthcare professionals participating in any other research study

Bereaved carers were interviewed in their own homes, and healthcare professionals were interviewed in a suitable private room and/or personal office at their workplace. The guiding questions proposed for healthcare professional and carer interviews were developed from a review of the published literature regarding assessment and management of pain in geriatric populations, refined to suit the context of end of life stages of dementia and reviewed by the Project Management Group (PMG).

Interviews were digitally recorded using a Sony ICD-UX533 digital recorder (Sony Corp., Tokyo, Japan). All participants provided written informed consent to participate in the interviews and for the interviews to be digitally recorded. Ethical approval for the study was obtained from the Office for Research Ethics Committees Northern Ireland (ORECNI); reference 14/NI/0013. Interviews were conducted between June 2014 and September 2015.

Demographic data were entered into a Microsoft Word Excel spreadsheet and basic descriptive statistics conducted to report the sample characteristics. All interviews were digitally recorded and transcribed verbatim into Microsoft Word documents. Transcripts were anonymised to protect the identities of participants, patients, healthcare professionals, individual institutions and other organisations. Anonymised transcripts were uploaded into N-Vivo (QSR International) software and analysed on an iterative and inductive basis using thematic analysis.

Phases II and III: Intervention Development and Piloting

In consideration of the evidence base, current trials and the findings of Phase I, the PMG discussed and agreed that the Project ECHO© (Extension for Community Healthcare Outcomes) Model provided a suitable model from which to develop and pilot an intervention aimed at bringing together physicians, nurses and HCAs to engage in interactive real patient case-based learning and to address the health professionals' clinical knowledge and self-efficacy needs identified in Phase I. This is a model of telementoring which uses teleconferencing technology (a computer/tablet/phone with broadband internet, speakers, computer screens and a camera) to connect a diverse group of health professionals across multiple settings and disciplines in real-time clinics (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014). It uses a 'hub and spoke' model', in which the 'hub' is the central physical location from which a specialist team hosts the clinic and the 'spokes' are health professionals who dial in remotely from their workplace. ECHO clinics have a standardised structure comprising twenty minutes of didactic teaching on a specific clinical area and one hour and 40 minutes of case-based discussion. Cases are (anonymised) real patient cases presented by the clinician(s) responsible for the patient's care and management. Each case is discussed with input from the hub and spoke members and the information formulated into a suggested treatment plan/approach. Physicians retain primary responsibility for treatment decisions for their patients.

ECHO clinics are evaluated pre- and post-intervention with purpose-designed knowledge and self-efficacy evaluation forms and/or continuing medical education (CME) evaluations. Post-intervention evaluation also requires a retrospective pre-ECHO evaluation to be completed; in this case, participants rate their knowledge and self-efficacy prior to participation in ECHO with the benefit of knowing what they did not know before ECHO (i.e. the benefit of hindsight).

Previous participants from Phase I, other health and social care teams in primary, secondary, nursing home and hospice care settings and other key stakeholders were invited to attend the **TE**lementoring for **A**ssessment and **M**anagement for **Pain** in **A**dvanced **D**ementia (TEAM Pain AD) teleECHO workshop to familiarise participants with the model, enable trust relationships between the spokes and the hub to form and provide an opportunity for participants to design the curriculum. The pre-ECHO workshop is not seen as a formality but rather as a critical and important part of developing the 'community of care' on which the model relies.

The workshop commenced with presentations that covered the following:

- the findings of Phase I
- an explanation of how these findings informed the choice of the ECHO model as a potential intervention to address the issues and concerns regarding pain assessment and management in advanced dementia
- an overview of the ECHO model, its philosophy and application in healthcare
- specific examples of how the ECHO model matched the specific learning requirements identified by participants in Phase I
- specific examples of how ECHO meets considerations of clinical utility, feasibility and other organisational constraints such as finances

Participants then discussed the following topics in small groups:

- Timing: days, dates, times and length of clinics
- Curriculum: were the topics indicated in the findings of the Phase I interview study still relevant? Any topics to be added, removed or changed?
- Active participation: volunteers for facilitator, didactic and case presenter roles

A whole-group discussion followed this small group work, the purpose of which was to collate information and feedback from the small group discussions. The curriculum for the TEAM Pain AD pilot was agreed.

TEAM Pain AD teleECHO clinics were facilitated by the principal investigator (CP). Clinics began with participant sign-ins after which participants were individually welcomed and introduced by the facilitator. A 20-minute didactic lecture was delivered on the specific topic area identified in the curriculum (e.g. off-label prescribing for pain at end of life) and participants were given an opportunity to ask questions. Patient case presentations then followed. These were presented by a physician/nurse responsible for the care and/or management of the patient. Following the case presentation, the facilitator opened case discussion to all members of the clinic. Case discussion continued until a proposed treatment plan has been outlined and/or sufficient guidance to address the clinical questions posed was provided. At the close of discussion, the facilitator summarised the proposed treatment plan/guidance. On completion of patient case discussions, participants were reminded of the date, time and topic of the next session and thanked for their participation. Clinics were digitally recorded using video with audio. Informed consent was deemed to have been given on participation in the clinic.

The impact of the TEAM Pain AD teleECHO curriculum and telementoring model on participants' clinical knowledge and professional self-efficacy in pain assessment and management in people with advanced and end-stages of dementia was evaluated, and the utility of the teleECHO Pain Clinic to cover pain management across health conditions and patient populations examined.

A census approach to sampling was undertaken; all physicians, nurses and HCAs who participated in the TEAM Pain AD teleECHO clinics were approached to complete the evaluation forms and focus group discussion. All those who agree to participation were included in the final sample. Prior to the first TEAM Pain AD teleECHO clinic,

physicians, nurses and HCAs registered for participation in the clinics were sent an email containing a link to complete the pre-teleECHO online evaluation using Survey Monkey software (https://www.surveymonkey.co.uk/). This clinical knowledge and self-efficacy evaluation was developed using adapted material from the KnowPain-50 and KnowPain-12 questionnaires (Gordon et al., 2014; Harris et al., 2008), evaluations used by the original developers of Project ECHO© (Arora et al., 2010) and items from the Palliative Care Evaluation Tool Kit: A compendium of tools to aid in the evaluation of palliative care projects (Eagar et al., 2004). Three versions of this evaluation were designed to reflect the knowledge and self-efficacy domains of physicians, nurses and HCAs. Submission of completed evaluation forms was deemed to constitute consent to participate in the evaluation.

A TEAM Pain AD teleECHO evaluation was also completed post-ECHO. This post-teleECHO evaluation contained questions relating to participants' experiences and perceptions of the utility of the teleECHO model. A third measure, known as the retrospective, pre-ECHO (retro-pre-ECHO) evaluation was also completed. This was identical to the pre-teleECHO evaluation but required participants to reflect retrospectively on their knowledge and self-efficacy prior to the intervention with the benefit of knowing what they did not know at the outset of the study (i.e. with the benefit of hindsight). Post-teleECHO and retrospective-pre-teleECHO online evaluations were disseminated at the end of the final teleECHO clinic. Mann Whitney U tests were used to explore differences in pre- and retro-pre-teleECHO evaluations and p-values reported to provide an indication of the impact of the model on self-reported clinical knowledge and self-efficacy. Statistical significance was set *a-priori* at p=0.05.

In addition, two focus groups were held after the final TEAM Pain AD teleECHO clinic (July 2016 and September 2016) using the same teleconferencing format as the TEAM Pain AD teleECHO clinics. A topic guide was used to guide discussion and covered the following:

- participants' reasons for participation in the TEAM Pain AD teleECHO clinics
- participants' perceptions of the efficacy of the curriculum (cases and didactic materials) in addressing participants' learning needs
- participants' application of learning gained through TEAM Pain AD teleECHO clinics to patient care
- the impact of participation in the TEAM Pain AD teleECHO clinics on participants' clinical teams
- how, when, and if participants share knowledge and skills from TEAM Pain AD teleECHO clinics with others
- participants' perceptions of future ECHO pain clinics (e.g. the sustainability and utility of a central ECHO pain clinic that would cover pain across all heath conditions and patient populations).

Educational governance was sought from the NI Hospice for permission to access the Project ECHO© NI superhub, ECHO© software and use of NI Hospice premises. The Southern Health and Social Care Trust (as lead trust on Phase I) and the Research Governance office of the Research and Enterprise Directorate (QUB) reviewed the protocol and confirmed that Trust permissions for the inclusion of secondary care health professionals in this study were not required. Written informed consent was obtained for participants. Focus group discussions were video-recorded and audio data were transcribed verbatim, checked and verified for accuracy and the video

permanently deleted. Transcripts were uploaded to N-Vivo (QSR International) software and analysed using Braun and Clarke's model of thematic analysis (Braun & Clarke, 2006).

Personal and Public Involvement (PPI)

This study benefited significantly from the involvement of the personal/patient and public involvement representative Dr Hilary Buchanan. As a carer for a person with dementia, Hilary provided unique insight which proved invaluable in the concept and design of the interview guides and in the search for alternative sources and methods to improve carer recruitment. Her assistance with transcript reviews was greatly appreciated and facilitated discussion of the core themes at later stages of the project. In addition, this study also employed a PPI approach in inviting healthcare professionals who were participants in earlier phases of the study to develop and design an educational intervention that would address the needs that many of them had themselves identified in interviews. Participants designed their own curriculum including number of sessions, topics for discussion, duration of sessions and choice of didactic trainers and case presenters. Furthermore, many participants offered verbal and written feedback in response to case presentations; this feedback was disseminated to case presenters via formal letters on behalf of the expert hub.

Findings

Phase I Qualitative Interviews

Despite significant efforts to problem-solve, encourage research participation and increase research visibility, with the collaboration and advice of local charities and organisations, we did not recruit the number of bereaved carers (10) anticipated at the outset of the study. In total, thirteen carers were approached for participation; eight declined at first approach and two declined participation after being booked for interview; three carer interviews were conducted. Recruitment and participation of healthcare professionals was greater than that proposed in the original study application, with a total of 61 interviews (23 doctors, 24 nurses, 14 HCAs) recruited to the study. This recruitment over and above the anticipated numbers was the result of analysis of preliminary findings during early data collection which suggested that further investigation of professionals to achieve data saturation by healthcare setting (primary care, secondary care, hospice and nursing home) would better inform the development of the proposed intervention.

The three carers described varying experiences of pain assessment and management towards the end of life. However, all three felt that training and education regarding caring for people with dementia, including recognising signs or potential signs of pain (such as resistive behaviour) was required particularly for those caring for people unable to express pain. The key themes emerging from the healthcare professional interviews are presented in Table 1.

Table 1. Key themes from doctor, nurse and HCA data.

Data set	Key themes
Pain assessment: **Physicians & Nurses**	(1) use of pain assessment tools in advanced dementia towards the end of life (2) barriers to the use of pain assessment tools and the importance of 'added value' (3) perspectives on practice development and training in pain assessment in advanced dementia in end of life care
Pain management: **Physicians**	(1) Diagnosing pain (2) Complex prescribing and treatment approaches (3) Side-effects and adverse events (4) Route of administration (5) Sharing knowledge (6) Training needs
Pain management: **Nurses**	(1) Challenges administering analgesia (2) The nurse-physician relationship (3) Interactive learning and practice development
Pain assessment and management: **Healthcare Assistants**	(1) Recognising pain (2) Reporting pain (3) Training and upskilling

The findings of this phase of the research may be summarised as follows:

- This study was the first to explore and describe the complexities and challenges experienced by physicians and nurses when assessing and managing pain in people with advanced dementia who are approaching the end of life. This included exploration of the impact of these challenges on prescribing and treatment approaches, and the strategies used by physicians and nurses to meet these challenges.
- A number of challenges in assessment and management of pain for people with advanced dementia were identified including: interpreting behavioural and non-verbal indicators of pain and differentiating these from the behavioural and psychological symptoms of dementia (BPSD), distinguishing pain from agitation and/or anxiety, complex prescribing in diagnostic uncertainty, limitations with

routes of administration, use of opioids, assessing treatment response and monitoring and identifying side-effects and adverse events in dying patients with altered consciousness.

- Physician data indicated that where possible, guidance was sought and knowledge shared with other physicians across specialties and care settings, and used to meet or mitigate the challenges of assessment and management of pain in patients dying with dementia. Knowledge exchange networks were particularly important for non-palliative care physicians (i.e. GPs and psychiatrists). Shared knowledge networks for nursing staff comprised the immediate nursing team within the care setting, specialist nurses from hospice and/or palliative care and patients' physicians.

- Observational pain assessment tools were not widely used to assess pain in people with advanced dementia approaching the end of life despite policy recommendations. Health professionals' pain assessment, prescribing and treatment approaches were shaped by holistic, collateral patient knowledge of their comorbidities, ageing physiology, existing medication regimens, physical and cognitive impairments and health status rather than on the use of pain assessment tools.

- Difficulties with implementing policy recommendations with regards to the use of observational pain assessment tools were identified. Translation of research innovations into clinical practice requires careful consideration before implementation.

- Gaps between health policy recommendations for pain assessment and management in palliative care and availability of resources to support nurses working in different healthcare settings in implementing these recommendations in clinical practice were identified.

- HCAs were among the first members of staff in every setting to recognise and report change in patient behaviours, including post-treatment; however, outside hospice settings, these staff had limited access to training and knowledge development to improve reporting quality.

- Promoting cross-speciality knowledge exchange and mentoring can empower non-palliative care physicians to confidently and effectively manage complex palliative care patients in their respective settings.

- Training and ongoing professional development was a strong, recurrent theme across datasets. All healthcare professionals described current training opportunities as restricted. Time and financial restrictions were primary barriers; however, respondents also observed that training opportunities were irregular and curricula often unreflective of current needs. Participants perceived training as being of low quality, poor validity and unlikely to promote change in clinical practice. They suggested it was not needs-driven, did not consider healthcare professional limitations with accessibility and was not

delivered by trainers with clinical patient experience in addition to substantive knowledge.

- Physicians and nurses identified professional mentoring (physician-to-physician/nurse-to-nurse) as an ideal method of delivering continuing professional development (CPD). Learning by experience, sharing disciplinary knowledge, and opportunities to co-manage complex patient cases were seen to be key elements of a highly dynamic and relevant form of clinical training capable of cultivating sustained practice change.

Phases II and III: Intervention Development and Piloting

The curriculum for the teleECHO workshops was agreed as follows:

Date	Topic, facilitator and didactic teaching details
01 June 2016	Managing challenges of routes of administration in pain management for people with advanced dementia (inc. managing non-compliance)
8 June 2016 (subsequently rescheduled to 6 July 2016)	Non-pharmacological aspects of pain management in advanced dementia (inc. working with families, managing BSPD and distress)
15 June 2016	Pain assessment in advanced dementia (inc. diagnosing pain, integrating pain assessment tools into clinical practice, clinical utility, limitations and practicality of assessment tools)
22 June 2016	Pharmacology in advanced dementia (inc. polypharmacy, drugs to avoid, identifying and managing side and adverse effects)
29 June 2016	Differentiating the behavioural indicators of pain from anxiety, agitation and other non-pain related behaviours in dementia

Workshop participants agreed that workshops should be scheduled for Wednesday lunchtimes on a weekly basis and should last one hour 15 minutes.

Key findings from questionnaire evaluations

Seven physicians completed the pre-teleECHO knowledge and efficacy evaluation, and ten completed the post- and retro-pre evaluations. Ten nurses completed the pre-, post- and retro-pre evaluations. One HCA completed the HCA version of the pre-teleECHO knowledge and efficacy evaluation, and no HCAs completed post-ECHO or retro-pre-ECHO evaluations.

Physician pre-ECHO questionnaire responses suggested that there were some areas in which some respondents lacked confidence. These included prescribing analgesia

for administration via syringe driver, intravenous route or transdermal routes, clinical knowledge of pain assessment and management, clinical self-efficacy, and use of best practice approaches in pain assessment and management. The retro-pre ECHO evaluation demonstrated a shift in responses suggesting participants had gained in confidence in these areas. The overall knowledge and efficacy score was significantly higher retro-pre ECHO than pre-ECHO (p=0.014; Mann Whitney U test), suggesting increased confidence in relation to knowledge and self-efficacy in pain assessment and management in advanced dementia nearing the end of life. Post-ECHO evaluations demonstrated the perceived utility of the teleECHO clinics in development of knowledge and skills in pain assessment and management, application of knowledge gained through the clinics, benefit to clinical practice, the value of case-based learning and didactic teaching, and the value of continued clinics.

Nurse pre-ECHO evaluation responses indicated that the majority of nurses felt confident reporting pain, assessing treatment response to analgesia, suggesting an alternative formulation if the oral route was not available, and in discussing cases of unresolved pain. There was greater uncertainty in relation to feeling confident in the following areas: recognising and assessing pain in patients with advanced dementia nearing the end of life, differentiating behavioural indicators of pain from behavioural and psychological symptoms of dementia, recognising and managing breakthrough pain, clinical knowledge and self-efficacy, and using best practice approaches to pain assessment and pain management. Similar to the physician data, the retro-pre ECHO evaluation demonstrated a shift in responses to suggest participants had greater confidence in these areas. The overall knowledge and efficacy score was significantly higher retro-pre ECHO than pre-ECHO (p=0.035; Mann Whitney U test), suggesting increased confidence in relation to knowledge and self-efficacy in pain assessment and management in advanced dementia nearing the end of life. Post-ECHO evaluations demonstrated the perceived utility of the teleECHO clinics in development of clinical knowledge and skills in pain assessment and pain management, and application of the knowledge learnt and teaching other staff what they had learned. Participants also indicated that access to expertise had benefitted their clinical practice, and that case-based discussion and didactic sessions were effective ways to develop clinical knowledge and skills. They indicated that they would support continued clinics for this and other clinical issues. The only area in which opinions differed was whether clinics specifically aimed at nurses would be beneficial, with similar proportions of respondents agreeing or disagreeing with this statement.

The one HCA who completed the pre-ECHO evaluation of knowledge and self-efficacy reported that they were confident in recognising and reporting pain, differentiating between pain and non-pain related challenging behaviour, and discussing pain assessment and management with doctors and nurses.

Seven individuals participated in two focus groups (three in Focus Group 1 and four in Focus Group 2). Participants in Focus Group 1 were specialist nurses (dementia n=1, hospice n=2). Participants in Focus Group 2 included a GP, a consultant physician (geriatrics) and two specialist hospice nurses. Four core themes emerged: knowledge and skills development and dissemination; protected time; areas for improvement; and the future of ECHO[©]. Participants reporting gaining new knowledge and skills, or where new skills and knowledge were not developed, reassurance that they were using approaches in line with best practice and with what the experts were practising themselves. A further benefit was the ability to join clinics without having to leave the

workplace, eliminating the need for travel, expense and significant periods of time away from clinical practice. However, protected time was deemed crucial to facilitate participation in the clinics. Areas in which improvements were required were identified; these included submission of case studies in a timely manner for dissemination to all participants well in advance of the clinic, and improved sound and video quality. Although technical issues were a source of annoyance, they were not sufficient to discourage participants from participating in future clinics. The potential of ECHO© to inform and improve delivery of clinical education and continuing professional development was recognised, with the most significant strength of the model reported to be its multidisciplinary, inclusive approach which created and fostered a sense of community.

Limitations

A number of limitations must be considered when interpreting the findings of this study. In Phase I, the sampling approach may have resulted in a skewed sample of physicians, nurses and HCAs with an interest in, or past experience of, research participation, who felt comfortable talking about professional challenges. Although we aimed to recruit for maximum variation among participants, recruitment relied on contacting participants through networks established by members of the PMG. The self-selecting nature of the sample means that the views of engaged, motivated participants with an aptitude for providing person-centred care may be overrepresented. In Phases II and III, there was a reticence on the part of participants to put forward patient cases for discussion. This meant that often cases were circulated to clinic participants on the day before or the day of the clinic, and did not allow sufficient time for participants to familiarise themselves with the case before the start of the clinic. There were some technical issues due to poor sound quality and unstable internet connections, and it was not possible for the equipment and software to be approved on Trust computers for one Health and Social Care Trust, meaning that the firewall prevented participation of healthcare professionals from that Trust. Despite continued attempts by the research team to gain approval for Trust computers to access the teleconferencing and camera software, this issue remained unresolved even after the final ECHO clinic had taken place. It was not possible for us to complete the full set of pre-, post- and retro-pre questionnaires for all participants due to respondent fatigue. Respondents who completed the post-ECHO evaluation of their experiences and the utility of the ECHO model also completed the knowledge and self-efficacy evaluation. However, whether this retro-pre evaluation was completed by respondents on the basis of evaluating their knowledge and self-efficacy prior to participation but with the benefit of knowing what they did not know before participating in the ECHO clinics, or whether they completed it as a post-ECHO evaluation, is unclear. Irrespective of their perspective in completing this evaluation, however, it was evident that there was greater confidence regarding knowledge and self-efficacy for both physicians and nurses. A further limitation was that only one HCA completed the pre-ECHO evaluation and no HCAs completed the post or retro-pre evaluations, despite assurances from the research team regarding anonymity and confidentiality.

Reasons for this may include a lack of engagement with the process of evaluation or a feeling that it was not applicable to them, a reflection of the feeling held by HCAs that they are not truly part of the multidisciplinary healthcare team, or a fear that if they are deemed not to be delivering best practice, this may be used against them. Furthermore, HCAs do not routinely have regular access to computers, with the exception of undertaking mandatory online training, and this may have acted as a barrier to completion of online evaluation of the TEAM Pain AD teleECHO clinics.

Conclusion

The interview data from Phase I highlighted the importance of knowledge exchange across specialties and care settings, between physicians, nurses and HCAs. The evaluation of the TEAM Pain AD teleECHO clinics reinforced the value of knowledge and skills exchange between participants at the spokes and specialist experts at the hub, and reiterated the value of developing cross-specialty networks bridging primary, secondary, nursing home, community and hospice care. The need for training and ongoing professional development in the area of pain assessment and management in advanced dementia emerged as a strong, recurrent theme across physician, nurse and HCA interviews. Participants expressed a strong desire for case-based learning led by a health professional with clinical experience. Learning by experience, sharing disciplinary knowledge and opportunities to co-manage complex cases were considered to be key elements of education and training capable of facilitating sustained practice change. These findings provided the evidence for using the Project ECHO© model as the basis of our intervention in Phases II and III. The evaluations of the TEAM Pain AD teleECHO clinics confirmed the suitability of the ECHO model in addressing the learning needs of participants. The interview data from Phase I also revealed the importance of good communication between healthcare professionals and adoption of a team approach to patient care. The frustration and disappointment felt by HCA participants at being excluded from multidisciplinary team meetings represents a highly significant finding. Many believed that HCA participation in the multidisciplinary healthcare team would benefit patient care, as HCAs bring access to patient information not necessarily available to other healthcare professionals. The Phase III evaluations demonstrate the value of the Project ECHO© model in enhancing healthcare professional confidence in knowledge and self-efficacy in assessing and managing pain for people with advanced dementia, and the potential for this type of educational intervention in other clinical areas. We advocate the adoption of the Project ECHO© model for healthcare professional education and patient care management, not only for pain assessment and management in advanced dementia but for other patient populations and other clinical areas.

Practice and Policy Implications/Recommendations

- To enhance engagement and increase the likelihood of delivering sustained practice change, future education and training programmes in pain assessment and management for people with advanced dementia must be needs-driven, available on a regular basis, and should involve service users (i.e. those

individuals who require the training) in the co-design of the curriculum and the scheduling of the training sessions/clinics. This should include all health and allied health professionals (doctors, nurses, HCAs, speech and language therapists, occupational therapists, pharmacists) who have responsibility for the treatment, management and/or care of patients in advanced and end-stages of dementia.

- The Project ECHO© model, which crosses specialisms and care settings, and involves all members of the multidisciplinary healthcare team, patients' families and other key health and social care staff, should be utilised for education and training. It also has significant potential for patient care management. This applies to pain assessment and management in advanced and end stage dementia, but will also translate to other patient populations and clinical areas, and could be integrated into the Northern Ireland End of Life Care Operational System (ELCOS), the aim of which is to prompt practitioners in the development of an individualised care plan.

- The Project ECHO© model should continue to be developed and evaluated in terms of its impact, not only on healthcare professional knowledge and self-efficacy, but also on service delivery and patient outcomes

- The role of HCAs should be expanded to include monitoring for and reporting on treatment response, side and adverse effects, and use of basic pain assessment tools such as the Abbey Pain Scale. However, it must be recognised that a number of factors require significant consideration when exploring the possibility of an expanded role for HCAs in pain assessment and management. These include the way in which training is delivered, and by whom, and the process of selecting staff for this enhanced role, given the variation in knowledge, skills and competence of HCAs.

- Observational pain tools may have a role in pain assessment, however, further evaluation of the reliability and validity of these tools and their ability to discriminate between pain and non-pain related distress is required.

Pathway to Impact

In this study, the Project ECHO© model demonstrated benefits in enhancing healthcare professional confidence in knowledge and self-efficacy in pain assessment and management for people with advanced dementia. It has potential for use in other clinical areas. This is confirmed by the interview data in which participants expressed a desire for confirmation of their proposed treatment plan; and reported that receiving support from other specialties and knowing they were 'on the right track' with prescribing and treatment increased their confidence and job satisfaction. Further, the post-ECHO physician and nurse evaluations demonstrated the perceived utility of the clinics in development of clinical knowledge and skills in pain assessment and management, application of knowledge gained, benefit to clinical practice, the value of case-based learning and didactic teaching, and indicated continued support for pain clinics and for other clinical issues. We therefore recommend the adoption of this

model of healthcare professional training and education in the clinical area of pain in dementia, and suggest that it also translates across clinical areas. We suggest that the ECHO model should continue to be developed and evaluated in terms of its impact, not only on healthcare professional knowledge and self-efficacy, but also on service delivery and patient outcomes, recognising that work is required to enhance response rates in future evaluations and to ensure that future ECHO networks meet the needs of the population for whom they are intended. This work should address minor technological issues to enhance sound and video quality and connectivity, and to facilitate access from some sites currently unable to connect due to security policies.

Acknowledgements

References

Abbey J, Piller N, De Bellis A, Esterman A, Parker D, Giles L, et al. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. Int J Palliat Nurs. 2004:10(1):6-13.

Afzal N, Buhagiar K, Flood J, Cosgrave M. Quality of end-of-life care for dementia patients during acute hospital admission: A retrospective study in Ireland. Gen Hosp Psychiatry 2010, 32(2), pp. 141-146.

Ahn H, Garvan C, Lyon D. Pain and aggression in nursing home residents with dementia: Minimum data set 3.0 analysis. Nurs Res. 2015; 64:256-263.

Anthierens S, Tansens A, Petrovic M, Christiaens T. Qualitative insights into general practitioners views on polypharmacy. BMC Fam Pract 2010; 11: 65

Arora S, Kalishman S, Dion D et al. Partnering urban academic medical centers and rural primary care clinicians to provide complex chronic disease care. Health Aff 2011b;30:1176-84.

Arora S, Kalishman S, Thornton K, et al. Expanding access to Hepatitis C Virus treatment – Extension for Community Healthcare Outcomes (ECHO) Project: disruptive innovation in specialty care. Hepatology 2010;52:1124-1133

Arora S, Thornton K, Murata G et al. Outcomes of treatment for Hepatitis C Virus Infection by primary care providers. N Engl J Med 2011a;364:2199-2207.

Arora S, Thornton K, Komaromy M et al. Demonopolizing medical knowledge. Acad Med 2014;89:30-32.

Auret K, Schug S. Underutilisation of opioids in elderly patients with chronic pain. Drugs Aging 2005;22(8):641-654.

Ballard C, Creese B, Corbett A, Aarsland D. Atypical antipsychotics for the treatment of behavioral and psychological symptoms in dementia, with a particular focus on longer term outcomes and mortality. Expert Opin Drug Saf 2011; 10: 35-43.

Barry HE, Parsons C, Passmore, AP, Hughes CM. An exploration of nursing home managers' knowledge of and attitudes towards the management of pain in residents with dementia. Int J Geriatr Psychiatry 2012; 27(12): 1258-1266.

Bell ML. Postoperative pain management for the cognitively impaired older adult. Semin Perioper Nurs 1997;6: 37-41.

Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3:77-101.

Brörson H, Plymoth H, Örmon K, Bolmsjö I. Pain relief at the end of life: nurses' experiences regarding end-of-life pain relief in patients with dementia. Pain Manag Nurs 2014;15(1):315-23

Bruneau B. Barriers to the management of pain in dementia care. Nurs Times 2014; 110: 12-15.

Cervo FA, Raggi RP, Bright-Long LE, Wright WK, Rows G, Torres AE, et al. Use of the certified nursing assistant pain assessment tool (CPAT) in nursing home residents with dementia. Am J Alzheimer's Dis Other Dem. 2007; 22:112-119.

Chang E, Hancock K, Harrison K, Daly J, Johnson A, Easterbrook S et al. Palliative care for end-stage dementia: A discussion of the implications for education of health care professionals. Nurse Educ Today 2005; 25: 326-332

Closs SJ. Pain and elderly patients: A survey of nurses' knowledge and experiences. J Adv Nurs 1996; 23(2), pp. 237-242.

Coker E, Papaioannou A, Kaasalainen S, Dolovich L, Turpie I, Taniguchi A. Nurses' perceived barriers to optimal pain management in older adults on acute medical units. Appl Nurs Res 2010; 23(3): 139-146.

Cook AKR, Niven CA, Downs MG. Assessing the pain of people with cognitive impairment. Int J Geriatr Psychiatry 1999; 14(6): 421-425.

Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, Ballard C. Assessment and treatment of pain in people with dementia. Nat Rev Neurol. 2012: 10;8(5):264-74. doi: 10.1038/nrneurol.2012.53.

Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008;337:a1655.

Department Of Health, 2009. Living well with dementia: a National Dementia Strategy. Department of Health.

Department Of Health, Social Services And Public Safety, 2011. Improving dementia services in Northern Ireland: a regional strategy. DHSSPS.

Department of Health. The Cavendish Review: an independent review of healthcare assistants and support workers in NHS and social care settings. 2013. https://www.gov.uk/government/publications/review-of-healthcare-assistants-and-support-workers-in-nhs-and-social-care. Accessed 15 Nov 2015.

De Souto Barreto P, Lapeyre-Mestre M, Vellas B, Rolland Y. Potential underuse of analgesics for recognized pain in nursing home residents with dementia: A cross-sectional study. Pain 2013; 154: 2427-2431. doi:10.1016/j.pain.2013.07.017.

De Witt Jansen B. Medication-related challenges in the management and care of people with dementia. PhD thesis, Queen's University Belfast, Belfast, 2014.

Eagar K, Senior K, Fildes D et al. The Palliative Care Evaluation Tool Kit: A compendium of tools to aid in the evaluation of palliative care projects. 2004; Centre for Health Service Development, University of Wollongong. Available at: http://ro.uow.edu.au/cgi/viewcontent.cgi?article=1004&context=chsd. Accessed 15 February 2016.

Fuchs-Lacelle S, Hadjistavropoulos T. Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). Pain Manag Nurs. 2004; 5(1):37-49.

Ghandehari OO, Hadjistavropoulos T, Williams J, Thorpe L, Alfano DP, Dal Bello-Haas V et al.A controlled investigation of continuing pain education for long-term care staff. Pain Res Manage 2013; 18(1):11-18.

Gordon DB, Loeser JD, Tauben D, Rue T, Stogicza A, Doorenbos A. Development of the KnowPain-12 Pain Management Knowledge Survey. Clin J Pain 2014;30(6):521-527.

Hadjistavropoulos T, Herr K, Turk DC, Fine PG, Dworkin RH, Helme R, et al. An inter-disciplinary expert consensus statement on assessment of pain in older persons. Clin J Pain 2007; 23:S1-S43.

Harris JM, Fulginiti JV, Gordon PR, Elliott TE, Davis BE, Chabal C, et al. KnowPain-50: a tool for assessing physician pain management education. Pain Med 2008;9(5):542-554

Herr K, Bjoro K, Decker S. Tools for assessment of pain in nonverbal older adults with dementia: A state-of-the-science review. J Pain Symptom Manage. 2006a; 31:170-192.

Herr K, Coyne PJ, Key T, Manworren R, McCaffery M, Merkel S et al. Pain Assessment in the Nonverbal Patient: Position Statement with Clinical Practice Recommendations. Pain Manag Nurs. 2006b: 7(2):44-52

Hølen JC, Saltvedt I, Fayers PM, Hjermsted MJ, Loge JH, Kaasa S. Doloplus-2, a valid tool for behavioural pain assessment? BMC Geriatr. 2007;7:29. doi: 10.1186/1471-2318-7-29

Husebo BS, Achterberg W, Flo E. Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review. CNS Drugs. 2016;6:481-497

Husebo BS, Strand LI, Moe-Nilssen R, Borgehusebo S, Aarsland D, Ljunggren AE,. Who suffers most? Dementia and pain in nursing home patients: a cross-sectional study. J Am Med Dir Assoc 2008; 9(6):427-433.

Ingleton C, Chatwin J, Seymour J, Payne S. The role of health care assistants in supporting district nurses and family carers to deliver palliative care at home: findings from an evaluation project. J Clin Nurs. 2011:20:2043-2052.

Kaasalainen S, Coker E, Dolovich L, Papaionnou A, Hadjistavropoulous T, Emili A, et al. Pain management decision making among long-term care physicians and nurses. Western J Nurs Res. 2007: 29(5):561-580.

Kessler I, Heron P, Dopson S, Magee H, Swain D, Ashkam J. The nature and consequences of support workers in a hospital setting, Final report. NIHR Service Delivery and Organisation Programme. London: NHS Institute for Health Research; 2010

Khachiyants N, Trinkle D, Son SJ, Kim KY. Sundown syndrome in persons with dementia: An update. Psychiatr Invest. 2011; 8:275-287.

Kovach CR, Griffie J, Muchka S, Noonan PE, Weissman DE. Nurses' perceptions of pain assessment and treatment in the cognitively impaired elderly. It's not a guessing game. Clin Nurse Spec 2000;14(5): 215-220.

Krishnamoorthy A, Anderson D. Managing challenging behaviour in older adults with dementia. Prog Neurol Psychiatry. 2011; 15:20-27.

Krumm N, Larkin P, Connolly M, Rode P, Elsner F. Improving dementia care in nursing homes: Experiences with a palliative care symptom-assessment tool (MIDOS). Int J Palliative Nurs 2014; 20:187-192.

Lichtner V, Dowding D, Esterhuizen P, Closs SJ, Long AF, Corbett A, et al. Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. BMC Geriatr. 2014; 14:1.

Lints-Martindale AC, Hadjistavropoulos T, Lix LM, Thorpe L.. A comparative investigation of observational pain assessment tools for older adults with dementia. Clin J Pain 2012;28(3):226-237.

Lloyd JV, Schneider J, Scales K, Bailey S, Jones R. Ingroup identity as an obstacle to effective multiprofessional and interprofessional teamwork: findings from an ethnographic study of healthcare assistants in dementia care. J Interprof Care. 2011:25:345-351.

Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. NEJM 2009; 361: 1529-38

Morgan DG, Kosteniuk JG, O'Connell ME, Bello-Haas VD, Stewart NJ, Karunanayake C. Dementia-related work activities of home care nurses and aides: frequency, perceived competence, and continuing education priorities. Educ Gerontol. 2016:42(2): 120-135.

Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. J Pain Symptom Manage 2000; 19: 240-593

Nygaard HA, Jarland M. Are nursing home patients with dementia diagnosis at increased risk for inadequate pain treatment? Int J Geriatr Psychiatry. 2005: 20(8):730-737.

Oliver DP, Wittenberg-Lyles E, Washington K, Kruse RL, Alöight DL, Baldwin PK, Boxer A, Demiris G. Hospice caregivers' experiences with pain management: "I'm not a doctor, and I don't know if I helped her go faster or slower". J Pain Symptom Manage 2013; 46(6):846-858.

Park J, Castellanos-Brown K, Belcher J. A review of observational pain scales in nonverbal elderly with cognitive impairments. Res Soc Work Pract 2010; 20(6):651-664.

Pieper MJC, van Dalen-Kok AH, Francke AL, van der Steen JT, Scherder EJA, Husebø BS, et al. Interventions targeting pain or behaviour in dementia: A systematic review. Ageing Res Rev. 2013; 12:1042-1055.

Pinzon LCE, Claus M, Perrar KM, Zepf KI, Letzel S, Weber M. Dying with dementia: symptom burden, quality of care and place of death. Dtsch Arztebl Int. 2013 110(12):195-202.

Plaisance L, Logan C. Nursing students' knowledge and attitudes regarding pain. Pain Manag Nurs 2006;7(4): 167-175.

Rantala M, Kankkunen P, Kvist T. Barriers to postoperative pain management in hip fracture patients with dementia as evaluated by nursing staff. Pain Manag Nurs. 2014;15(1):208-19

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment. J Intellect Disabil Res 2007:51(Pt 4):277-92.

Sampson EL. Palliative care for people with dementia. British Medical Bulletin 2010; 96 (1): 159–174

Smith, F, Francis S, Gray N, Denham M, Graffy J. A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services. Health Soc Care Community 2003; 11: 138-145

Spilsbury K, Meyer J. Use, misuse and non-use of health care assistants: understanding the work of health care assistants in a hospital setting. J Nurs Manag. 2004;12(6):411.

Stacey CL. Finding dignity in dirty work: the constraints and rewards of low-wage home care labour. Sociol Health Illn. 2005:27(6):831-854.

Tan EC, Jokanovic N, Koponen MP, Thomas D, Hilmer SN, Bell JS. Prevalence of analgesic use and pain in people with and without dementia or cognitive impairment in aged care facilities: A systematic review and meta-analysis. Curr Clin Pharmacol 2015; 10: 194-203.

Thune-Boyle CV, Sampson EL, Jones L, King M, Lee DR, Blanchard MR. Challenges to improving end of life care of people with advanced dementia in the UK. Dementia 2010; 2: 259-284

Titler MG, Herr K, Schilling ML, Marsh JL, Xie X, Ardery G, Clarke WR, Everett LQ. Acute pain treatment for older adults hospitalized with hip fracture: Current nursing practices and perceived barriers. Appl Nurs Res 2003; 16(4):211-227.

van der Steen JT. Dying with dementia: what do we know after more than a decade of research. J Alzheimers Dis 2010; 22:37-55

van der Steen JT, Radbruch L, Hertogh CM, De Boer ME, Hughes JC, Larkin P, et al. and on behalf of The European Association For Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med 2014; 28 (3):197-209

van der Steen JT, Regnard C, Volicer L, Van Den Noortgate NJA, Sampson EL, Enfield B. Detecting pain or distress in people with dementia: An appraisal of two strategies. Eur J Palliative Care. 2015; 22:110-113.

Van Herk R, Van Dijk M, Baar FPM, Tibboel D, De Wit R. Observation scales for pain assessment in older adults with cognitive impairments or communication difficulties. Nurs Res. 2007; 56:34-43.

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. J Am Med Assoc 2003:4(1):9-15.

Wilson CB, Davies S, Nolan M. Developing personal relationships in care homes: realising the contributions of staff, residents and family members. Ageing Soc. 2009:29:1041-1063.

World Health Organisation, 2012. Dementia: a public health priority.

Zwakhalen SMG, Hamers JPH, Peijnenburg RHA, Berger MPF. Nursing staff knowledge and belief about pain in elderly nursing home residents with dementia. Pain Res Manag 2007; 12(3):177-184.