

PAIN ASSESSMENT AND MANAGEMENT FOR PATIENTS WITH ADVANCED DEMENTIA NEARING THE END OF LIFE

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INTRODUCTION

PREVALENCE OF DEMENTIA WORLDWIDE AND IN THE UNITED KINGDOM

The World Health Organisation (WHO) highlighted dementia as an increasing challenge for global health (World Health Organisation, 2012) as demographic trends shift towards an increased proportion of older persons in the population. The World Alzheimer Report published in 2015 estimated that 46.8 million people worldwide are living with dementia, and this number is expected to almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050 (Prince et al., 2015). In the United Kingdom (UK), the Alzheimer's Society estimate that there are 850,000 people are living with dementia, with numbers set to rise to over 1 million by 2025 and 2 million by 2051 (Alzheimer's Society, 2017). In 2011, it was estimated that there were 19,000 people in Northern Ireland (NI) living with dementia, the vast majority of whom were aged 65 years or over (Department of Health, Social Services and Public Safety, 2011). However, this is expected to rise to 23,000 by 2017 and around 60,000 by 2051, due to population ageing (Department of Health, Social Services and Public Safety, 2011). The Office for National Statistics reported in 2017 that dementia and Alzheimer disease replaced ischaemic heart diseases as the leading cause of death in England and Wales, accounting for 11.6% of all deaths registered in 2015 (Office for National Statistics, 2017). The Registrar General Report for causes of death in NI indicates that Alzheimer's and other dementias were responsible for 11% of the 15,548 deaths in 2015, placing it as the fourth leading cause of death in the province behind cancer, circulatory and respiratory conditions (Northern Ireland Statistics and Research Agency, 2016). As with the global burden of disease, both the prevalence and cost of care of dementia in the UK are expected to continue to rise incrementally with the growth of an ageing population (Alzheimer's Society, 2013).

HEALTHCARE POLICY PRIORITIES FOR END OF LIFE AND PALLIATIVE CARE IN DEMENTIA

Palliative care has been defined by the World Health Organisation (WHO) as: "...An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual...". End of life, in the context of palliative and end of life care, has been described as the period of time during which an individual's condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months, but it is recognised that a specific timescale cannot always be applied (Department of Health, Social Services and Public Safety, 2010). End of life care places a strong emphasis on: symptom management to enable patient comfort, helping patients to adapt to the changes in lifestyle and to cope with the emotional impact of their illness, to allow the person to live as comfortably as possible until death, and to enable a death with dignity (Marie Curie Cancer Care, 2013). The Department of Health identified the importance of improving end of life care as a key objective in the Dementia Strategy for England published in 2009 (Department of Health, 2009), defining it as care that "helps all those with advanced, progressive, incurable illness to live as well as possible until they die". In the NI context, a similar emphasis has been placed on end of life care; "Living Matters, Dying Matters", the palliative and end of life care strategy for Northern Ireland published in March 2010 stated that: 'Any person with an advanced, non-curative condition lives well and dies well irrespective of their condition or care setting' and the Dementia Strategy published in November 2011 made recommendations aimed at improving the services and support arrangements available for people with dementia, their families and their carers, from diagnosis to the end of life (Department of Health, Social Services and Public Safety, 2011; Department of Health, Social Services and Public Safety, 2011). Furthermore, a position paper of the European Association for Palliative Care (EAPC) defining optimal palliative care in older people with dementia identified "optimal treatment of symptoms and providing comfort" as a key research priority

(van der Steen et al., 2014). A Cochrane systematic review of palliative care interventions in advanced dementia was published in 2016 in recognition of the increased focus worldwide on extending palliative care beyond patients with cancer to all those who need it; this reflects the immense clinical and public health importance of provision of appropriate care to the growing number of older people living and dying with dementia (Murphy et al., 2016).

THE ASSESSMENT AND MANAGEMENT OF PAIN IN DEMENTIA

The 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). Studies suggest that, depending on the setting 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 (Pinzon et al., 2013; van der Steen, 2010; Mitchell et al., 2009). One study reported that people with dementia are more likely to experience pain in the last six months of life, compared to cancer patients (McCarthy et al., 1997). A recent study by Etkind et al. (2017) calculated projections for palliative care need by disease group, and incorporated pain prevalence into their calculations. They estimated that pain prevalence in dementia was 60% (Moens et al., 2014), and that by 2040, 393,101 (70.1%) of people in England and Wales within the palliative care need estimate will have pain; of these, 131,645 deaths will be from dementia. Although these projections do not include Scotland or NI, the authors' conclusion that, along with cancer, dementia is a dominant illness accounting for the growth in palliative care need, is applicable across all regions of the UK, and indeed any country with similar demographic and disease changes will experience comparable rises in palliative care need (Etkind et al., 2017). 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. Untreated pain in people with dementia has serious implications for quality of life and 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).

The gold standard for diagnosing pain is patient self-report; the guiding principle being that since pain is a highly subjective, individualised experience pain is 'what the patient says it is' (McCaffery, 1968). Health professionals therefore rely on patients to communicate critical information regarding the pain experience including its presence, intensity, temporal pattern, location and the impact on the patient's life to arrive at a correct diagnosis of type (e.g. neuropathic etc.) and select appropriate management. However, disease progression in dementia brings with it increasingly profound deficits of memory, language, executive function and other cognitive abilities which serve to erode and in many cases, remove patient self-report). The loss of the ability to effectively communicate their discomfort (Jordan & Lloyd-Williams, 2010) leaves this patient population at risk of under-assessment, under-diagnosis and under-treatment for pain (Hadjistavropoulos et al., 2007; Husebo et al., 2008; Park et al., 2010; Lints-Martindale et al., 2012). In the absence of this information, health professionals must arrive at this information through other means, commonly via observation and interpretation of both the behavioural and nonverbal indicators of pain (e.g. crying, shaking, frowning, agitation, vocalisations, sweating, resistive behaviour, increased immobility or mobility, changes in personality or demeanour, guarding etc.) (Herr et al., 2006a; Zwakhalen et al., 2006; Van Herk et al., 2007; Lichtner et al., 2014; van der Steen et al., 2014).

It is unsurprising therefore, that given the challenges of assessing pain in this patient population, there has been increasing focus in research on addressing these. Much of this previous work has consisted of identifying the behavioural and nonverbal indicators of pain and on the development of pain assessment tools to facilitate health professionals with the observation and interpretation of these indicators (Abbey et al., 2004; Warden et al., 2003; Fuchs-Lacelle & Hadjistavropoulos, 2004; Holen et al., 2007). 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 nonverbal indicators of pain, attribute a numerical score representing estimated severity for each behavioural/nonverbal cue observed and aggregate scores to produce an overall score of estimated severity (Abbey et al., 2004; Warden et al., 2003; Fuchs-Lacelle and Hadjistavropoulos 2004; Herr et al., 2006b; Hølen et al., 2007; Lichtner et al., 2014).

However, the reliability and validity of observational pain assessment tools and their clinical utility in practice has been the subject of ongoing debate in the research literature primarily due to the large variation in the methods, participants, disease severity and settings in which these tools were developed and the limited evidence of 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, as many of the behavioural and nonverbal cues that indicate pain may also be expressions of non-pain related distress, there is no clear indication or consensus as to whether OPTs are able to distinguish between pain and distress or whether they may be detecting both (Regnard et al., 2007; Brörson et al., 2014; van der Steen et al., 2015). Calls for further evaluation and development of available tools to achieve clarity on these issues have been made several times (Herr et al., 2006b; Corbett et al., 2012; Lichtner et al., 2014; Husebo et al., 2016).

Several studies have reported several challenges experienced by health professionals when using OPTs in practice (Ballard et al., 2011; Zwakhalen et al., 2007; Brörson et al., 2014; Barry et al., 2012; Ghandehari et al., 2013). These include: difficulties differentiating between behavioural indicators of pain from behavioural expressions of non-pain related distress, insufficient training and support on conducting pain assessments with severely cognitively impaired patients, inconsistency in attributing pain scores, overestimation or underestimation of pain and workload and other organisational and institutional pressures which constrict the time required to conduct and interpret pain assessments (Ballard et al., 2011; Zwakhalen et al., 2007; Brörson et al., 2014; Barry et al., 2012; Ghandehari et al., 2013). Furthermore, health professionals' attitudes towards, knowledge of and approaches to pain in older adults with and without dementia, have critical implications for assessment and treatment, with misguided beliefs regarding pain in cognitively impaired adults had negative attitudinal beliefs associated with delayed

assessment of pain, suboptimal treatment and underuse of pro re nata (PRN) analgesia (Kovach et al. 2000, Nygaard & Jarland 2005, Kaasalainen et al. 2007, Zwakhalen et al. 2007, Barry et al. 2012).

Despite these challenges and debates, health policies, clinical recommendations and guidelines widely recommend the use of pain assessment tools when assessing pain in people with dementia and many private health 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 practices and what the impact of their use has on clinical outcomes for patients remains a critical gap in current evidence.

Pain assessment outcomes have serious consequences for pain management since 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 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).

The under-representation of older adults in clinical trials of analgesics may mean that key outcome measures including toxicity and drug action do not accurately reflect their use in patients with multiple comorbidities and significant physical frailty and can lead to variability in treatment outcomes (Borgsteede et al., 2009; Lövheim et al., 2008; Husebo et al., 2011; McLachlan et al., 2009; McLachlan et al., 2011; Mallet et al., 2007; Brenes-Salazar et al., 2015; Crome et al., 2011; Crome et al., 2015).

The inclusion of older, comorbid adults in clinical drug trials is attracting increasing research interest (Crome et al., 2011; Watt, 2012; Crome et al., 2015). A substantial body of compelling evidence has identified deficits in nurses' knowledge of pain assessment, pharmacology, side-effects and dosing schedules and the presence of 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). This has been observed in a study undertaken in NI by members of the research team in which nursing home managers' knowledge of and attitudes towards pain management in patients with dementia were explored (Barry et al., 2012). The barriers to optimal pain management in people with dementia were well-recognised by nursing home managers. Respondents in this study 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. In addition, 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. This study concluded that further research is required to explore the formulations of analgesics regularly prescribed for dementia patients, their success in achieving symptom control, and GPs' reasoning and attitudes behind their reluctance to prescribe these formulations for people with dementia.

The findings of this study are supported by other published work. A study examining perceptions of 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 General Practitioners (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 primary care, secondary care and hospice care settings acknowledged that further training in assessing pain, in pain management and in 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 also suggested that antipsychotics and opiates are often prescribed to manage challenging behaviours which they felt originated from and were attributable to pain. In particular, residents with dementia who did not otherwise display challenging behaviours of an aggressive or verbally abusive nature but who demonstrated these during physical contact as part of a personal care/hygiene routine was highlighted as an example. In these cases, nursing staff reported that they felt physical handling of residents provided a stimulus for pain and explained why residents displayed uncharacteristic challenging behaviours during these times. However; these residents were frequently prescribed antipsychotics without a pain assessment being undertaken.

Pain was also identified by carers as an issue (De Witt Jansen, 2014). One carer reported that a patient who had undergone surgery for a hip replacement was assumed not to be in pain because the patient could not verbalise their experience of it. Upon discharge to the nursing home, the patient had become very challenging to manage thus prompting the family to request an assessment with a behavioural

nurse. The assessment revealed that the patient had not completed the course of analgesia for the surgery, was being walked daily to avoid skin breakdown and had a history predating the dementia of polymyalgia rheumatica which resulted in consistent chronic pain.

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 (Spilsbury & Meyer, 2004; Kessler et al., 2010; Department of Health, 2013). Healthcare assistants (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 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. "My life until the end: Dying well with dementia", published by the Alzheimer's Society in October 2012, highlighted pain as one of the key issues faced in end of life care for patients with dementia. It recommended that all people with dementia should be free from pain at the end of life, with training and systems in place to detect and manage pain even when patients' ability to communicate pain is diminished. It also advocated that further research be undertaken to understand the detection of pain in people with advanced dementia and for further training for all staff on detecting and treating the symptoms of pain in people with dementia. 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.

RESEARCH 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.

FRAMEWORK FOR RESEARCH METHODOLOGY

This study was set within the Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Craig et al., 2008). Complex interventions are usually described as those which contain several interacting components, or which have other factors such as: number or difficulty of behaviours required by those delivering or receiving the intervention; number of groups or organisation levels targeted by the intervention; number and variability of outcomes; or where a degree of tailoring or flexibility of the intervention is permitted (Craig et al., 2008). The MRC guidance suggests that the process of development and evaluation of such interventions consists of several phases, which may not necessarily have a linear sequence. Key elements of this process are presented in Figure 1.

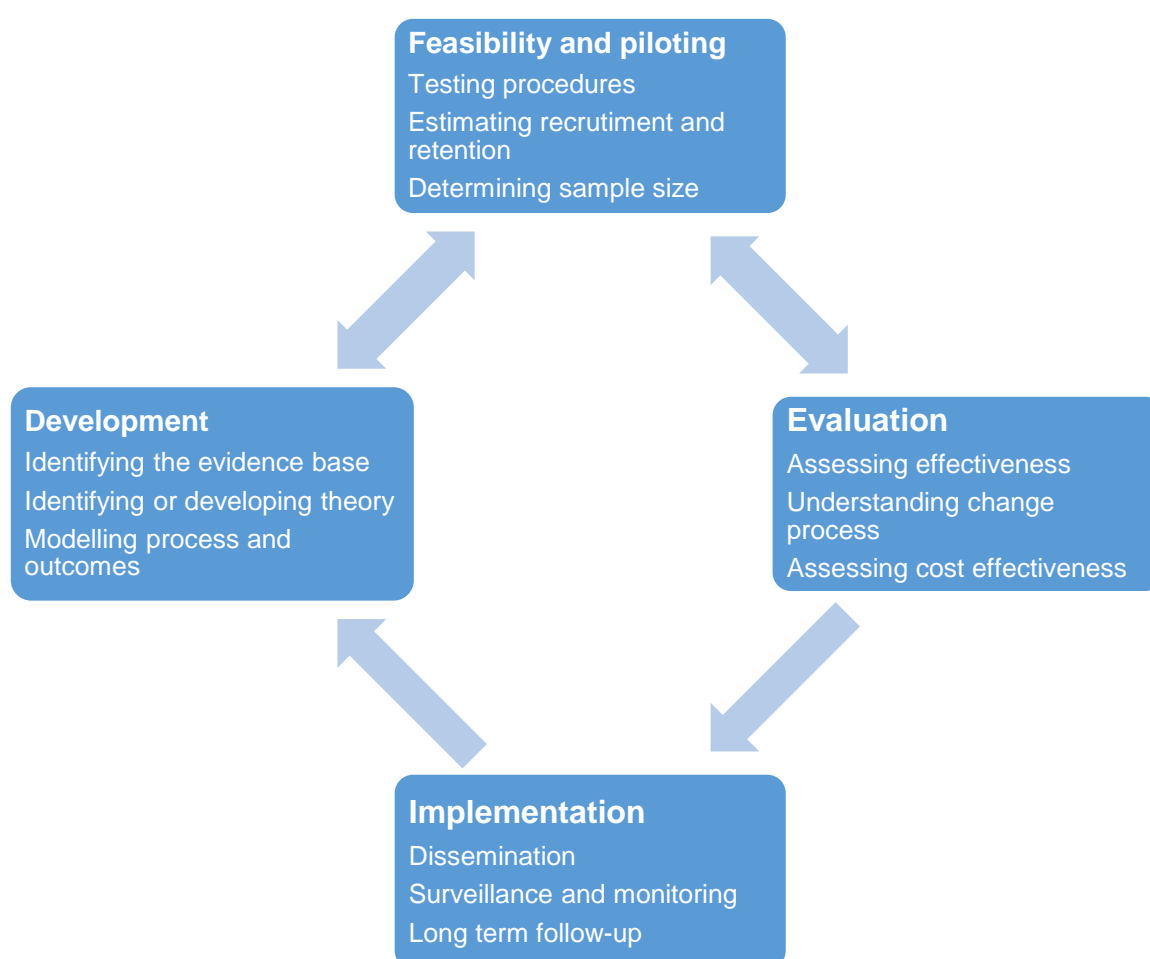


Figure 1. Key elements of the development and evaluation phase (reproduced from Craig et al. (2008))

DEVELOPING A COMPLEX INTERVENTION

The process of developing and evaluating a complex intervention begins with the development phase, and may involve the following steps (Craig et al., 2008):

IDENTIFYING EXISTING EVIDENCE

The intervention must be developed to the point where it can be reasonably expected to have a worthwhile effect before it can be evaluated. The first step is therefore to identify from relevant literature what is already known about similar interventions and the methods used for evaluating these interventions.

IDENTIFYING AND DEVELOPING THEORY

Developing a theoretical understanding of the likely process of change by drawing on existing evidence and theory is a key early task in developing and evaluating a complex intervention, and this should be supplemented if necessary by new primary research.

MODELLING PROCESS AND OUTCOMES

Modelling a complex intervention before a full-scale evaluation can provide important information about intervention and evaluation designs.

ASSESSING FEASIBILITY

Evaluations may be undermined by problems with acceptability, compliance, intervention delivery, recruitment and retention, and smaller than expected effect sizes that could have been predicted through piloting (Eldridge et al., 2004). A pilot study need not be a scale model of the proposed intervention, but should consider the key uncertainties identified during development.

EVALUATING A COMPLEX INTERVENTION

Researchers should consider a number of aspects when undertaking evaluation of a complex intervention, including assessing effectiveness, measuring outcomes, and understanding change process.

IMPLEMENTATION

Process evaluations, which explore the way in which the intervention under study is implemented, can provide valuable insight into why an intervention fails, or has unexpected consequences, or why a successful intervention works and how it can be optimised. The term implementation is used within complex intervention literature to describe both post-evaluation scale-up (i.e. the ‘development-evaluation-implementation’ process) and intervention delivery during the evaluation period.

We used the MRC framework, as described above, to meet the research aims and objectives. 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).

THE PROJECT MANAGEMENT GROUP (PMG)

The Project Management Group was responsible for the overall conduct and direction of the research study and comprised the following:

Dr Carole Parsons, School of Pharmacy, Queen's University Belfast (Principal Investigator)

Dr Bannin De Witt Jansen, School of Pharmacy, Queen's University Belfast (Post-doctoral Research Fellow)

Professor Kevin Brazil, School of Nursing and Midwifery, Queen's University Belfast

Professor Peter Passmore, Centre for Public Health, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast

Professor Max Watson, Northern Ireland Hospice (now Hospice UK and Western Health and Social Care Trust)

Professor Sonja McIlpatrick, School of Nursing, Institute of Nursing and Health Research, University of Ulster

Dr Sharon Morgan, Marie Curie Hospice, Belfast

Dr Doreen Maxwell, Kerrsland Surgery, Belfast

Dr Hilary Buchanan, PPI representative and a carer for a person living with dementia

This group comprised two practising academic-physicians in geriatrics/dementia and palliative care, four academics specialising in palliative care, nursing and pharmacy, three General Practitioners (GPs) with a special interest in older adults, dementia and palliative care, and one patient and public involvement representative (also a retired GP). The PMG met for bi-monthly meetings at the School of Pharmacy, Queen's University Belfast. The minutes for all PMG meetings have been stored alongside other project data at the School of Pharmacy.

PHASE I: QUALITATIVE INTERVIEWS

METHODOLOGY

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 healthcare assistants).

Bereaved participants are often involved in end of life studies to provide proxy reports on pain and symptom management and to provide retrospective assessment

of quality of care, quality of life and satisfaction with care (Arons et al., 2013; Lawson et al., 2013; van Uden et al., 2013). Retrospective research provides participant protection that prospective research cannot including: avoiding intruding on time spent with dying family members and avoiding burdening families at a particularly challenging and emotional time (Teno, 2005). Retrospective research also eliminates the need for healthcare professionals to identify patients who are close to dying (which in dementia is extremely challenging and may be distressing to the patient and their family) and reduces the risk of poor quality and/or missing data as a result of increasing cognitive burden in participants who are emotionally distressed (Teno, 2005). Bereaved participants' reports of palliative and end of life care provide valuable insight into care provision particularly when this information is unavailable from patients themselves and their retrospective reports and evaluations of care provision have been found to remain consistent over time (Cartwright et al., 1973; Casarett et al., 2003; Arlt et al., 2008; Huang et al., 2009).

A semi-structured qualitative 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.

STUDY SETTING AND LOCATION

Physicians, nurses and healthcare assistants (HCAs) were recruited from primary, secondary, hospice and nursing home settings across NI. Bereaved carers were recruited through carer support groups co-ordinated and hosted by the Alzheimer's Society NI. The geographical distribution of the Alzheimer's Society NI support network groups are as follows.

North and East Regions

- Antrim & Ballymena
- North Down & Ards
- Coleraine
- Mid-Ulster
- East Antrim
- Down & Lisburn

South and West Regions

- Armagh & Dungannon
- Newry & Mourne
- Craigavon & Banbridge
- Omagh
- Fermanagh
- Foyle

STUDY POPULATION

The two key informant groups included in this phase of the study were healthcare professionals (physicians, nurses and HCAs) and bereaved carers.

CARERS

Bereaved carers were defined in this study as people who have formerly provided long-term care in an unpaid capacity for a person with dementia who have since died. Bereaved carers may be any relation or close friend of the decedent. This definition of bereaved carer has been used and approved in a previous study conducted by members of the research team and was originally adapted from the definition of 'carer' as published in the DHSSPS document 'Valuing Carers': "Carers who are people who, without payment, provide help and support to a family member or friends who may not be able to manage at home without this help because of frailty, illness or disability (Department of Health, Social Services and Public Safety, 2002).

The two key considerations in retrospective studies involving the bereaved are firstly, whether and how accurately participants will be able to recall the event of interest and the relevant circumstances that surround it and secondly, whether and how participants' perceptions of the event are impacted by their experience of grief (Teno, 2005). These considerations have been addressed in the design of this study as described below.

Bereaved carers were recruited through the carer support services co-ordinated and hosted by the Alzheimer's Society NI. This recruitment strategy was selected according to the ethical principles governing the involvement of bereaved participants in research studies (McPherson & Addington-Hall, 2004) and has been applied in previous work undertaken by members of the research team. The use of a trusted third party to identify and make an initial approach is thought to provide a gatekeeping element in which the party to whom the participant's circumstances are known can identify those who are likely to be harmed by being approached or whose circumstances are such that an approach would be inappropriate (McPherson & Addington-Hall, 2004). 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.

These criteria were selected in consideration of recommendations from published literature on the collection and use of retrospective data provided by proxy respondents on outcomes in end of life care (McPherson & Addington-Hall, 2004; Teno, 2005; Lawson et al., 2013). Exclusion criteria are proposed for the protection of carers in the acute and/or immediate periods of grief and who may likely be negatively impacted by being approached for participation in such a study (Parkes, 1995; Sque, 2000; Fried & O'Leary, 2008). A two-year cut off is considered to minimise the potential for recall bias among carers who have been bereaved for a longer duration (Teno, 2005). These eligibility criteria were previously applied in study by members of the research team.

HEALTHCARE PROFESSIONALS

Healthcare professionals in this study comprised: physicians, nurses and HCAs recruited from four settings of care including: primary and secondary care, hospice and nursing homes across NI. 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.

These criteria were selected to ensure the recruitment of key informants with relevant expertise in the assessment and management of patients with advanced dementia who have died (or who are approaching death) and were previously applied in a study undertaken by members of the research team (11/NI/0052, De Witt Jansen, 2014).

SAMPLING AND RECRUITMENT

BEREAVED CARERS

A purposive approach to sampling was applied to recruit a maximum variation sample of 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 Northern Ireland. The Alzheimer's Society NI facilitated the identification and recruitment of carers to this study. Published literature has recommended that the initial screening and approach of bereaved

persons be conducted through a third party with whom the bereaved person has an existing or prior relationship. In this present study, the screening and initial approach of bereaved carers was conducted by Alzheimer's Society Dementia Service Managers (DSMs). These staff provided support and guidance to carers and the decedents during the life of the latter. Thus DSMs had a prior, trusted relationship with bereaved carers and were well-positioned to identify carers who met the eligibility criteria. Critically, DSMs could also identify carers whose personal circumstances made their participation in such a study unsuitable or would present a risk to carers' psychological health (i.e. those undergoing professional bereavement counselling); in this way, DSMs prevented such carers from being approached.

HEALTHCARE PROFESSIONALS

Recruitment procedures varied slightly between settings of care, as discussed below. As with carers, the study 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.

PRIMARY CARE

A nominated sampling approach (also referred to as 'snowballing') was applied to identify primary care healthcare professionals for inclusion in this study. This method of approach is commonly used in such studies to ensure that key informants have the relevant expertise to discuss the research topic (Grbich, 1999).

SECONDARY CARE

This study aimed to recruit physicians and nurses from secondary care settings governed by the five Health and Social Care Trusts across NI: Northern, Southern,

South-Eastern, Western and Belfast. In accordance with Trust Governance regulations, 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.

HOSPICE CARE

Within the hospice setting, the Medical and Nursing Directors of the 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.

NURSING HOMES

Nursing 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. At the time of this study, all nursing homes which participated in the study were caring for people living and dying in the advanced stages of dementia.

INTERVIEW SETTING, DESIGN AND PROCEDURE

INTERVIEW LOCATIONS

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.

INTERVIEW DESIGN

Participants' experiences and perspectives of pain assessment and management in advanced dementia were explored through semi-structured, face-to-face, key informant interviews. This approach facilitated the identification and investigation of key clinical issues in the assessment and management of pain in people with advanced dementia approaching the end of life within a respectful, safe and private environment (Berntsen & Rubin, 2002). The semi-structured approach (the use of guiding questions) provides a coherent framework within which respondent experiences may be compared and contrasted and from which commonalities and key themes may emerge (Greenhalgh & Taylor, 1997; Rabins & Black, 2007).

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). Hilary Buchanan, the PPI representative for this study and a carer for a person living with dementia, reviewed and commented on both sets of interview guides. In particular, she informed the wording of questions used in the carer's version to ensure they would elicit the relevant information whilst remaining respectful both to carer participants and their deceased family member or relative. Initial questions focused on demographic data and progressed to the general question "Can you tell me about your experiences of the assessment of pain for your husband/wife/sibling in the final few weeks, days and hours of life?" (Carer version); "What is your experience of managing pain in patients with dementia in the final weeks, days and hours of life?" (Healthcare professional version).

General questions are commonly used in research to open discussion of emotive/sensitive topics as they allow the participant to speak first, at their own pace and to decide which aspects of experience they feel comfortable revealing at early stages of the interview (Sque, 2000; Rabins & Black, 2007). Additionally, respondents' replies may elucidate issues not previously considered by the research team and which may be of importance to the research topic; a semi-structured approach allowed these issues to be explored further in later questions (Riessman,

1993). Other questions in the discussion schedule were more specific and were designed to elicit information to address the research aims of this project.

Example questions from the carer's interview guide included the following:

- Can you tell me about your experiences of the assessment of pain for your husband/wife/sibling in the final few weeks, days and hours of life?
- Can you tell me about your experiences of the management of pain for your husband/wife/sibling in the final few weeks, days and hours of life?
- Do you think that the assessment of pain in patients with advanced dementia who are nearing the end of life could be improved? If so, how?
- Do you think that pain management for people with advanced dementia who are approaching the end of life could be improved? If so, how?
- What makes it difficult to tell/how can you tell if someone with advanced dementia is in pain?

Examples of questions from healthcare professionals' interview guide included the following:

- What is your experience of assessing pain in patients with advanced dementia in the final weeks, days and hours of life?
- Tell me about your experience of managing pain in patients with advanced dementia who are nearing the end of life
- Are there any barriers that limit the use of pain assessment tools?
- Are there facilitators that improve the use of pain assessment tools?

- How do the results from pain assessment tools influence pain management strategies used?
- Do you think that the assessment of pain in patients with advanced dementia who are nearing the end of life could be improved? If so, how?
- Can the management of pain in people with advanced dementia who are nearing the end of life be improved? If so, how?
- Do you think any additional training/education is required for assessing pain in patients with advanced dementia who are nearing the end of life and who do you see delivering this?
- Do you think additional training/education is required by healthcare professionals for the effective management of pain in people with advanced dementia who are nearing the end of life? If so, what training would be beneficial and who do you believe should deliver this?

Full interview guides for both carers and health professionals are detailed in Appendix 1.

In addition, the following demographic data were collected from participants:

Bereaved carers

- age, gender, ethnic origin
- relationship to decedent
- length of time care provided
- length of time bereaved
- county of residence (rural/urban)
- number of years of decedent's illness
- decedent's place of death
- decedent's medical history (any other chronic co-morbidities)

Healthcare professionals

- age
- gender
- ethnic origin
- number of years' clinical experience
- county of practice

- type of HCP (nurse, doctor etc.)
- care setting

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.

DATA ANALYSIS, RELIABILITY AND VALIDITY

DATA ANALYSIS

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. Thematic analysis is commonly applied in healthcare research to explore the experiences of specific groups within this setting (e.g. healthcare professionals, patients etc.) The advantage of using this method of data analysis lies in the potential to identify commonalities of experience across particular groups and to report these in a meaningful way to others outside this setting (i.e. academic researchers, policy-makers etc.) (Boyatzis, 1998; Braun & Clarke, 2006). The exploratory nature of thematic analysis makes it particularly suitable for use in studies which focus on research topics on which there is little previous published literature. The versatility of this analytical method may be used to investigate complex phenomenon and social constructs that do not easily lend themselves to quantitative measurement.

This study used the approach to thematic analysis proposed by Braun and Clarke (2006) developed response to considerable criticism regarding the application of thematic analysis in qualitative research. It has been evaluated for epistemological and scientific rigour and for its application in healthcare research and has been widely applied in published studies in medicine, psychology, social sciences and other healthcare-related fields (King and Horrocks, 2010). The method of analysis applied to the qualitative data in this study is illustrated in Figure 2:

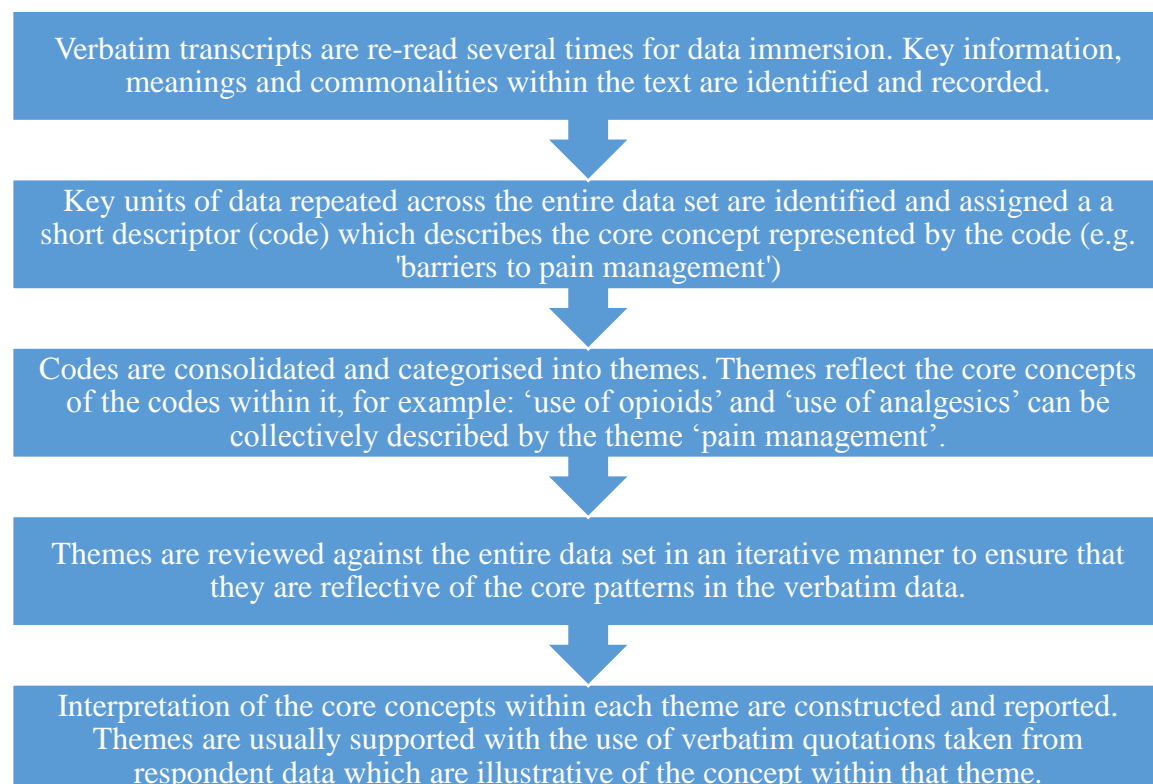


Figure 2. Method of analysis for qualitative interviews

RELIABILITY AND VALIDITY

In qualitative research, validity is embodied in the concepts of rigour or trustworthiness which are considered to indicate the accuracy with which the reported findings reflect the situation, experience or group that forms the focus of the investigation. Reliability refers to the way in which the chosen method was applied with rigour and dependability during data collection, analysis and the reporting of the

findings (Lincoln & Guba, 1985). Reliability in qualitative research refers to the way in which the chosen method was applied with rigour and dependability during data collection, analysis and the reporting of findings (Lincoln and Guba, 1985; Golafshani, 2003). Reliability may be tested using a process of audit in which a selection of data are independently analysed (using the same protocol for analysis as per the original author) by a researcher/researchers with relevant expertise in both the method and topic area. On completion of the audit, the independent researcher and original author should engage in discussion related to the themes on which they agree and disagree; both must reach consensus on themes that are to be included or omitted from the final report (Hoepfl, 1997).

This study employed processes for maintaining validity and rigour throughout the transcribing and analytical processes. Firstly, a cross-section of transcripts from each health professional group were reviewed against the original digital recordings by two members of the PMG, HB and KB. This ensured the accuracy and precision of the transcriptions as compared to the original audio recording and provided an opportunity for two other members of the research team to familiarise themselves with the raw data. The research fellow undertook primary analysis of the dataset and, in accordance with recommendations for ensuring reliability and validity described above, a selection of transcripts was also independently analysed by KB and CP. The outcomes of these analyses were discussed and agreed among these three authors.

As data collection progressed, differences in the nature of the data for pain assessment and management began to emerge. Core themes in pain management differed between physicians and nurses and in the case of nurses, were also linked to setting-specific differences. Key themes in pain assessment; however, were expressed in global terms; that is, the challenges appeared to be inherent in the patient population and the difficulties of interpreting behavioural and nonverbal indicators of pain from the biological and psychological symptoms of dementia and distress. It was important therefore, that independent analyses were conducted in accordance with a set protocol to ensure that this difference between the datasets accurately reflected the content of the raw data. A decision to extend recruitment of health professionals was made to ensure that data saturation occurred in both pain management and assessment. The difference between the datasets and its impact

on the analytical approach taken was discussed among PMG members; many of whom are experienced in both the analysis and interpretation of qualitative research and in the topic of the study. The final core themes were discussed among the PMG in relation to other published works and the current literature. Changes made to the key themes were in relation to their wording rather than to their substantive content. An audit trail of data analysis was kept and includes the codebook for analysis, the protocol for checking transcripts and for data analysis and records of PMG discussions documented in meeting Minutes. In addition, when reporting the results of the study in papers submitted for consideration for publication, guidelines provided by the Consolidated Criteria for Reporting Qualitative Studies (COREQ) were utilised (Tong et al., 2007). These guidelines consist of a 32-item checklist which aims to improve the quality and rigour of qualitative research reporting.

DATA PROTECTION AND STORAGE

Digital recordings were copied from the digital recorder, stored on a password-protected, encrypted computer and erased from the digital recorder. Digital recordings were transcribed verbatim (using Microsoft Word 2010) and anonymised accordingly. Each transcript was assigned a code comprised of a number and a participant type e.g. P04_Nurse; P06_GP. Numerical codes reflected the sequence in which the participants were interviewed (e.g. P06 will be the sixth respondent to have been interviewed). Transcript codes were assigned to differentiate between participants and are reported in the results for the reader's clarity. Consent forms and transcripts are currently being stored in separate drawers in locked filing cabinets in the School of Pharmacy, Queen's University Belfast for a period of five years after which they will be securely destroyed.

ETHICAL CONSIDERATIONS

INFORMED CONSENT

We adhered to the principles of informed consent by providing all participants (carers and healthcare professionals) with relevant, clear and sufficiently detailed explanations, at an appropriate level, of the background of the study, its aims and objectives, and the reasons for collection of data via the interview method. Information relating to indemnity provisions, the protocols for managing distress, the reason for storage of data during and beyond the duration of this study and the potential risks and benefits of participation were available to all participants in the information sheets and briefly summarised verbally by the research fellow (BDWJ) prior to the interview. Prior to the start of the interview, carers and healthcare professionals were asked to sign an interview consent form to confirm that they consent to undertake the interview and that the interview may be digitally recorded.

RESULTS

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 healthcare assistants) recruited to the study. The demographic characteristics of these participants are detailed in Table 1 below.

Table 1. Demographic characteristics of healthcare professional participants

Healthcare professional	Gender	Mean Age (years)	Clinical experience (Mean no. years)	Care setting
Doctors	Male 7 (30%) Female 16 (70%)	42.6	17.5	Primary 9 (39%) Secondary 7 (30%) Hospice 7 (30%)
Nurses	Male 1 (4%)	36.8	13.8	Primary 12 (50%)

	Female 23 (96%)			Secondary 6 (25%) Hospice 6 (25%)
Healthcare assistants	Male 1 (7%) Female 13 (93%)	44.9	15.4	Primary 9 (64%) Secondary 2 (14%) Hospice 3 (21%)

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.

Three bereaved carers were also recruited to the study; the characteristics of these study participants are outlined in Table 2.

Table 2. Demographic characteristics of bereaved carers

	n (%)
Gender	
Male	1 (33%)
Female	2 (67%)
Average age (in years)	60.7
No. years of care provided to care-recipient	7
Relationship to care-recipient	
Spouse: Husband	1 (33%)
Adult Child: Daughter	2 (67%)
Average length of time bereaved (in months)	14.3
Care-recipient place of death	
Own home	2 (67%)
Nursing home	1 (33%)

It was anticipated that approximately 10 bereaved carers could be recruited via the Alzheimer's Society; an estimation based on recruitment used in a similar, previous study (11/NI/0052). Bereaved carer recruitment commenced on 26 May 2014 and proceeded slower than anticipated. In total, thirteen carers were approached for

participation; eight declined at first approach, two declined participation after being booked for interview and three carer interviews were conducted. Reasons for declining interviews were offered (but not asked for) by both carers who withdrew from the study; in one case, discussion with other members of their family who did not approve of the subject matter being explored had caused a change of mind; in the other case, the carer experienced a sudden loss of an adult child through traumatic means and felt unable to participate.

The PMG agreed that the high rate of decline at initial approach (n=8), coupled with a limited population from which to recruit resulted in exhaustion of the population available through the Alzheimer's Society alone. Several meetings were held with the Director of the Alzheimer's Society and the two regional operational managers in post at that time, to problem-solve the ongoing issues with recruitment. In addition, the research fellow attended regional meetings held with local branch managers assisting with recruitment to identify and address these challenges. A key obstacle to recruitment of bereaved carers was due to the fact that the Society's carers meetings are designed for and predominantly attended by carers whose family members/relatives were still living, placing them outside the eligibility criteria for this study. Local meetings were often assisted by volunteer staff; it was anticipated that these staff would be approached for participation; however, all volunteer staff identified by local branch managers were beyond the 24-month bereavement cut-off set in the exclusion criteria. Local DSMs and regional managers informed us that most carers usually stopped attending carers meetings upon the death of their family member or relative and those who returned as volunteers typically did so after significant time had passed. DSMs who had recently joined the Society and those who had not been in post for long expressed significant discomfort with contacting bereaved families that they had not known previously and in some cases declined to make these approaches. As a result of these ongoing issues, and in consideration of advice provided by the Alzheimer's Society, alternative sources were considered and a Substantial Amendment to ORECNI ethical approval was submitted in March 2015 and subsequently approved, thereby allowing recruitment through five additional sites (GP practices and nursing/EMI homes). Sixteen nursing homes were approached; 15 declined at the outset citing workload pressure and unwillingness to approach families of deceased former residents. The one nursing home that agreed

to facilitate recruitment has significant links with community and hospice palliative care teams and is widely recognised for its excellent standards of care. It was therefore considered by the PMG that recruiting from this home would yield potentially biased data. Four GP surgeries were approached for participation; three declined for reasons of intense pressure on primary care services and one practice (comprising two GPs) agreed to facilitate recruitment but was subsequently obliged to withdraw due to the unexpected long-term sickness of one GP partner. Other routes for recruitment were considered: recruitment of bereaved carers directly from care settings was discussed with each local index contact assisting with health professional recruitment. These contacts reported that this placed a large burden on both themselves and their staff and would require additional administrative support to identify deceased patients, screen notes for eligibility and contact families. As these contacts were already assisting with recruitment of health professionals, they felt that an additional set of index contacts plus additional administrative support for each Trust would be required to facilitate bereaved carer recruitment. The research fellow also discussed recruitment with Cruse Bereavement and the Bereavement Co-ordinators of each Trust. The Director of Cruse Bereavement reported that as cause of death/reason for bereavement was not routinely recorded in that level of detail, they would not be easily able to screen for eligible participants and that reviewing case notes would be a significant burden of time which they could not accommodate at that time. A very similar case was put forward by local HSC Trust Bereavement Co-ordinators who ultimately also felt unable to facilitate. Advertising via local radio was also discussed by the PMG; however, the resulting quotes received from key stations (i.e. those with an appropriate audience demographic) were prohibitive and required several stages of review and approval from Queen's University Belfast's Press Office prior to dissemination. Therefore, in the interests of remaining within project timelines and budget, the PMG took the decision that carer recruitment should cease.

That we did not recruit the number of carers anticipated at the outset of the study despite significant efforts to problem-solve, encourage research participation and increase research visibility among this community, even with the collaboration and advice of local charities and organisations, was disappointing to the research team.

CARER 1

The first carer reported mixed experiences of pain assessment and management for his wife towards the end of life. This participant reported finding recognising pain in his wife relatively easy; this was attributed to his extensive knowledge of her characteristic responses to pain developed over the course of a long marriage. Prior to end stages but when self-report had become unavailable, this carer had developed a strategy for enabling his wife to express pain.

When [my wife] was in pain she, she would have rattled the, uh, I had her—at that stage I had her in a hospital bed at home and she would have rattled the side of the bed with her ring until I bought her a wee bell and then at that stage she would have actually known she would have to just ring.

This participant also reported that facial expressions and shaking hands were clear indicators of pain in his wife.

But I would have known to look at her face she would have grimaced when she was in pain and I'd have just known most of the time as I'd have been there all day with her, holding her hand and it would have been the reactions and her body that would have told me that she was in pain...her body...when her body starts shuddering...but I had lived with her for so long that I was you know nearly almost knowing what she was thinking.

However, whilst this participant could recognise signs of pain, he expressed uncertainty regarding other information regarding the pain experience including its cause and location.

I honestly was never sure whether that was her back pain or what actual pain was bothering her at that time.

Carer 1 reported having a good relationship with his wife's GP; as carer 1 felt supported by her physician, he did not communicate about pain management preferring to leave treatment decisions to the GP.

Interviewer: Was [your wife's] pain medication discussed with you or members of your family?

Carer 1: No, no, I left it all up to the doctor.

Carer 1 felt that pain management for his wife had been adequate and effective in the time leading up to the end of life when she had been cared for at home and attended by the GP; however, he reported that problems started to appear in the last few weeks when his wife's condition deteriorated and she was moved into a residential home. Initial difficulties appeared when carer 1 observed that nursing staff did not appear to recognise when his wife was experiencing pain; a difficulty coupled with the fact that during her life, his wife had always managed to cope well with pain and had not been accustomed to reporting pain to others. Problems with pain management in the care home continued as ongoing deterioration and loss of swallow resulted in a change of pain medication requiring the use of a syringe driver. Carer 1 reported that nursing staff had significant difficulty setting up the driver which resulted in a highly distressing experience for both himself and his wife.

...the nurses never gave her any extra tablets because the unfortunate thing was that in all the time that [my wife] was in that home she never rang for a nurse once, you know, she seemed to just put up with what was going on.

Towards the end [my wife] wasn't able to swallow the tablets and then they started giving her liquid tablets well then later on when she wasn't even able to swallow they decided to put on a syringe driver and that syringe driver thing

was the...was the worst experience I had altogether. They brought in a nurse to put on the syringe driver and I actually would have known as much about it as the nurse. She didn't know what to do, she kept running in and out of the office reading the instructions before she got this syringe driver settled on to [my wife] and when she got it on and went away, the syringe driver wouldn't work and they had to bring in a nurse from [another town] in the middle of the night to set up the syringe driver. When that particular nurse was setting it up they brought the first nurse to come and watch cos she never—not only could she not do it she never ever saw it done before. I think that was awful distressing for me and the family but I think it was terribly distressing for [my wife] as well.

Carer 1 reported that his wife experienced ongoing difficulties with achieving effective management for her pain. This carer felt that many of the nursing and care staff involved in his wife's care were unable to recognise signs of pain and lacked understanding of the unique needs of people with dementia. Carer 1 reported uncertainty with regards to whether his wife received adequate pain management at the end of life and described the approach to treating her pain as 'chaotic'.

The medication that [my wife] was getting up until about that couple of weeks before she died seemed to be quite adequate but when she went on to the later you know just the late stage before she did die I think the pain management was just chaotic. They didn't know, they couldn't...the staff just didn't seem to know what to do you know. I thought the syringe driver would have sorted everything out and I suppose it would have if it would have been fitted right but I know that the night they put the syringe driver in she was in agony.

Carer 1 strongly believed that better training and education with regards to recognising pain, its management and caring for people with dementia generally was required. He believed that pain assessment was largely 'guesswork' once patients were unable to report pain. Additionally, he believed that all staff required training in understanding and coping with the needs of older adults with dementia.

I think the nursing staff before they go in to a nursing home at all should be taught a lot of these things. The unfortunate thing that I see about the nursing home is they work with minimum staff and most of the nurses down there were young girls just qualified. They hadn't got the experience really of nursing dementia patients. I think that more than anything else they need they need to be trained to work with people with dementia and I feel that they're not and it's most of it guesswork even with the senior nurses. I think nurses who want to work with Alzheimer's patients should definitely be trained to work in that end of the profession.

CARER 2

Carer 2 reported overall positive experiences of pain assessment and management for her mother at the end of life. As with Carer 1, this participant found it relatively easy to recognise the signs of pain in her mother as the same facial expressions, vocalisations and other behavioural cues were used to express pain. However, similarly to Carer 1, this participant also reported that she was unable to tell what the cause of pain was or where it was located.

Well initially she could communicate pain it was only, it was only in the last month that Mum couldn't communicate just so well as in speech wise but she would have been able to express that she was in pain um, her facial expressions would tell us that or she would make some form of noise that something was hurting her. It was usually her facial expressions would have told us she was in pain, she would grimace or sometimes she would have grabbed on to the bedclothes for instance if they were moving her, she would have grabbed on and it was a very quick jerk reaction so you would have known something had hurt her at that moment.

We couldn't pinpoint it, we would have to go through her whole body maybe it was her hip or sometimes it was just whatever way she'd been lying at night.

Carer 2 reported some initial difficulties with pain assessment and management four to six months prior to the end of life. This participant reported being that her mother's diagnosis of Parkinson's Disease and previous experiences of limb rigidity made her acutely aware that pain required ongoing assessment and management where required. However, care staff at this stage did not appear to consider this and continued to ask her mother if she required pain relief even though she was unable to indicate this. This prompted Carer 2 to request that her mother be moved to transdermal pain patches to ensure adequate, ongoing management.

When the carers came in they asked her do you need pain relief [mum name]? I don't think she really knew whether she did or not. We asked then that she be put on patches and I very much preferred it when she was on the patches because we knew then it would be constant rather than relying on her to know she needed it. To me, asking her whether she needed pain relief at that stage was never going to work.

Carer 2 reported an excellent relationship with her mother's GP and the district nursing team. She reported that both had known her mother very well as she had previously been in the care profession for 25 years. Carer 2 felt that this knowledge allowed the GP and district nurses to recognise changes in her mother's behaviour or demeanour that would prompt a pain assessment. Carer 2 reported that the GP would regularly discuss pain assessment and management with her and other members of the family and took time to explain any new symptoms. In this way, Carer 2 was made aware that her mother was experiencing the terminal stages of her illness; something that the participant had not previously been aware of but felt allowed her and her family to prepare. This personal connection was important to Carer 2 and contributed to a largely positive experience of end of life care.

Our family doctor was fantastic, he knows the family, he knows the history, he was just fantastic so we have no complaints there. Whatever we felt we needed, he was quite willing to provide. He knew Mum before the diagnosis, he knew the type of lady that she was so he was able to recognise new symptoms in Mum and was able to explain to us that the problems with rigidity were really escalating problems coming to the end of life. I mean we didn't even realise that Mum was end of life at that stage, we thought she could probably go on for a long time. We just had a great relationship with our doctor as I say he could just recognise things and he would explain them to us. When we told him that giving Mum medication orally wasn't working and suggested pain patches it was no problem he was willing to help us in any way he could. I think it made a difference that he knew her and could recognise changes in her as opposed to a locum doctor coming in and just treating symptoms.

Carer 2 believed that her mother had received a very good standard of end of life care and had been pain free towards the end of life. She believed that a close, positive relationship with the care staff, GP and district nurses had been key to allowing her mother to remain at home at the end of life.

We were pretty confident that she wasn't in any pain towards the end because it was always very quickly dealt with by our GP. In the last two weeks she was pretty relaxed, her facial expressions were...I would say that she was pretty relaxed, she was on a syringe driver at that point and it was pretty easy to tell that she wasn't in any pain. I was in with her day and night, me, my sister and my father and we knew she wasn't in any pain. And our community nurses were excellent, really excellent again, a lot of them would have known Mum previously, Mum was a carer in the community for 25 years, so they knew her and I think that helped a great deal. I think we had a great support network and only for that were we able to keep her at home. So I think it worked out very well for us yeah.

Carer 2 did however, report some initial challenges with care in the community carers who she felt did not have the relevant understanding or training required to work with people with dementia.

We had care in the community carers coming in full time for the last probably 4 to 6 months and at the start it really did not work, really did not work. We had a lot of problems with the care in the community. Initially it was young girls and they just didn't know how to communicate with mum and in fact when the girls came in we would have done the majority of the work because the girls would have looked to us to help them. I feel it was just total lack of training. These were young girls coming in to a home with no experience of working with a person of dementia and they would have just kept repeating things to mum and she would have just got agitated. We had a meeting with our social worker and just put it that this just wasn't working and these girls were unsuitable and they got in more mature, experienced carers and that just solved it. They were better able to cope with mum, they were able to notice wee behavioural changes or if they turned her a particular way they noticed her reactions.

Similarly to Carer 1, this participant 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.

If Mum was in pain she could become a little bit aggressive and I mean a little bit and the carers maybe wouldn't have recognised that she was in pain they would have just have said "your mother's very aggressive today". We would have said "but do you not think she would have been sore she has a lot of rigidity?" But a lot of young girls you see I just don't think they understand that. They definitely need a lot more training coming into homes of people with dementia, a lot of those young girls didn't understand.

It must be very difficult for somebody to not be able to express that they're in pain. It must be looked at as to how you can train professionals to recognise the symptoms or recognise something different, that what that person's doing is not normal or wouldn't be normal behaviour for them. I don't know how that would be done but there has to be signs that people can be trained to look out for, be it facial awareness or things like I had said earlier about mum grabbing on to the sheets. Those are the things they have to be aware of definitely.

CARER 3

This participant's experience of pain assessment and management was in stark contrast to Carer 1 and Carer 2. This participant reported finding it extremely difficult to recognise the signs of pain in her mother. She attributed this to the fact that her mother had never been accustomed to report pain prior to her diagnosis and had often coped with pain without resorting to painkillers.

When Mum got to the end of life it was very difficult to understand when she was in pain. You could only tell if Mum was in pain if something had happened to her that you could physically see like a fall or something but otherwise she couldn't really tell you.

Mum would never rely on painkillers, she was always all go, she always kept herself well. Maybe that characteristic was still there at the end in amongst all the Alzheimer's. She'd always been a copper and maybe she just didn't tell us about the pain because she wasn't that kind of person that had done that in her life. We just don't know.

Carer 3 reported that over time, she became aware that aggressive and/or resistive behaviour in her mother may have indicated pain; she often used this indicator to identify urinary tract infections but reported often finding it difficult to identify other

occurrences of pain and to distinguish aggressive behaviour as a sign of pain from that of distress or the neuropsychiatric symptoms of dementia.

She really was quite difficult to deal with at times, she would have lashed out to hit us and you didn't really know what was going on at times whether it was all mixed up with pain from her hip replacement or arthritis or diabetic foot or what. The aggressiveness would have told us so if there was a kidney infection and pain on passing water she would have got more aggressive and that's when I would have rang (sic) the doctor.

Carer 3 reported largely negative experiences with the care her mother received in secondary care following hip replacement surgery. She reported that the staff appeared overwhelmed and unable to cope with her mother's challenging behaviours and left her restrained in a wheelchair for long periods of time. Although her mother was being seen for hip replacement surgery, Carer 3 reported that she was unclear whether her mother was provided with pain relief but noted that was given large amounts of diazepam which had resulted in an adverse event on two occasions.

I don't think the hospital were able to cope with her and they had her so long and she deteriorated into crisis. They would ring us and say your mum's going mad get in here, just get in here and I mean I live 20 miles away from [the hospital] and my sister got the calls too. We felt were constantly running to help and we felt that we had to be there for mum's sake. I don't know what pain relief they give her but I do know that she was given lots of Valium and that's when she had to be resuscitated. My sister was in at the time the crash team was called and they found out that people just kept giving them to her. I don't think anybody did anything to really look at or understand what was going on with her they just kept giving her more and more stuff to knock her out and keep her sedated.

During this stay, Carer 3 had attempted to speak with the medical team regarding her mother's treatment but found that she was often left waiting for appointments and reported that when seen, health professionals appeared rushed and under pressure.

At hospital the doctors and nurses never had time. We had asked to see the doctor but it was fraught because we really were so annoyed about the whole thing that we sent a letter to them afterwards how bad it was. We just felt the care that was given to Mum wasn't good. They probably just didn't have the time to deal with her. It was very difficult to see a doctor and when you did get an appointment to see one you had to wait and they were so rushed.

Carer 3 reported that her mother was discharged with a prescription for quetiapine but had not been provided with any pain relief. Carer 3 believed that hospital staff had focused on her mother's diagnosis of dementia and had not prescribed pain relief due to her mother's inability to report pain.

We really just tried our best but all we could get was more sedative, uh, quetiapine or Seroquel I think you call it which was really just a sedative, Mummy wasn't given any painkillers because she couldn't tell us.

Carer 3 also reported negative experiences with a local nursing home. Similarly as with the hospital setting, Carer 3 believed that nursing staff were unable to manage her mother's behaviour and relied on increasing amounts of sedative to cope with her resistive behaviours. Carer 3 reported feeling shocked at the amount of sedatives being administered given her mother's recent history. This left Carer 3 feeling that she could not trust health professionals with her mother's care and had worked alone without the advice of a health professional to reduce her mother's daily dose of quetiapine.

We had to put her into a nursing home for three weeks when I went away to [country] and she was quite difficult, she just wanted home. In there, I might as well have been in with her because the nursing home kept ringing me 'your mum's this, your mum's that' it was constant. They just kept increasing her Seroquel, just kept saying she needed sedated and she ended up on 8 Seroquel a day! After that I never bothered to put her in care ever again, I just couldn't trust anyone to help or look after her. It took a long time but got her down to 2 tablets after she came out.

Carer 3 reported that whilst she had a positive relationship with her mother's GP; no health professionals in hospital, primary or nursing home care had talked about or mentioned pain relief. This participant felt that she had let her mother down with regards to her care and management at the end of life.

At home we never gave her painkillers because we didn't know to do that. It was hard to distinguish pain and you were very much left on your own and you would have relied on the carers that came in to look after her to tell you anything. Sometimes I think they just told us "oh it's her Alzheimer's" and I think a lot of the time she got ignored that way. The doctors, the nurses, I mean we had the doctor out a few times but no one ever talked about pain they were more concerned about the diabetes. But no, painkillers never came into the equation. I believe that we let her down too because you're inclined to believe that something else is the problem like the blood sugars or the confusion so pain can be overlooked very easily. No one ever actually asked her if she was in pain, you could see the arthritis in her hands you know she had quite arthritic hands. But sitting all the time, her wee bottom was red, we tried to keep her moving as much as we could.

Carer 3 reported that even though her mother was admitted to hospital days prior to her death, pain had not been raised as an issue or a concern. In retrospect, Carer 3 believed that pain should have been investigated given her mother's comorbid conditions.

She was in hospital again at the end of life as she had another complication, she was diabetic and insulin dependent. No one ever said anything about pain and it was only after mum died that I wondered about her arthritis in her legs and hands and when she had the kidney infections, all that was given was antibiotics but we never thought to give her painkillers as well. We wouldn't have known to do that and the doctor never said to us about it, she gave me the antibiotics so I could give them to mum anytime I felt she had an infection but nothing was ever mentioned about painkillers.

Carer 3 expressed significant regret at the care which her mother had received at the end of life both care provided by health professionals and by herself and her family. She strongly believed that health professionals required further training in recognising pain in people with dementia who also experience the behavioural and psychological symptoms of dementia. This participant strongly believed that her mother's pain was overlooked because of her diagnosis of dementia and felt that health professionals needed further education in looking beyond resistive behaviours as part of the diagnosis and to recognise it as a sign of pain; however, she expressed nihilistic view that improvements in care provision for older adults both with and without dementia would be feasible in light of ever-increasing pressures on the health service and its professionals.

I think they [health professionals] need to know how to cope with people with dementia, perhaps they haven't got time I don't know. But nobody seemed to know how to cope with Mum and they just relied on us. And we didn't know either, we just had to muddle through and try our best. Even when she went into hospital at the very end, even then people just kept putting it down to her Alzheimer's or diabetes, no-one ever considered that it might have been pain,

even ourselves. But with all the cutbacks in the health service I don't have much hope that anything is going to be improved for the care of older people with dementia and even those without dementia. It seems to be all cutbacks now so I don't think anything can improved or will be.

PHYSICIAN AND NURSE PERSPECTIVES ON PAIN ASSESSMENT

Twenty-three physicians and 24 nurses were interviewed. Three core themes were identified:

- (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.

These are discussed in full overleaf.

(1) USE OF PAIN ASSESSMENT TOOLS IN ADVANCED DEMENTIA TOWARDS THE END OF LIFE

All participants reported that their care setting mandated or incorporated the use of a standardised assessment tool as part of pain assessment protocols for patients and residents in any stage of dementia. However, only 13 (27.6%) of participants (nurses n=11; physicians n=2) in this study reported using a standardised assessment for pain with patients in advanced stages of dementia approaching the end of life. Most participants who routinely used a tool were using the Abbey Pain Scale (n=12; 92%); one participant used an in-house purpose-designed pain assessment protocol. Within this group, participants' attitudes towards the use of and efficacy of these assessment tools were evident; furthermore, these attitudinal variations impacted on the way in which standardised assessments were used in practice. Five participants (2 hospice nurses and one secondary care physician; 2 nursing home nurses)

reported that standardised pain assessment tools resulted in in prompter recognition of pain, identification of patients' patterns of presenting pain, facilitated estimation of pain severity, assisted with treatment response monitoring and improved continuity of pain assessment and management across changing staff shifts when used appropriately in accordance with tool's instructions and as part of wider pain protocols.

[Standardised pain assessments] can be really useful because if somebody's coming in in the last few weeks it's for symptom control which is pain, so obviously you want to get that sorted out straightaway. We'd be starting them on the pain chart and from that there we can see where's this pain coming from? Is it from this area, this area, this area? 'Cause you need to know is it the same area all the time? Is it different areas? (NURS06, RGN, Hospice)

Some participants believed that reporting pain and communicating about pain within and across teams and specialties was also improved with the use of a standardised pain assessment tool as clinical measures were more easily and universally understood across specialties than qualitative descriptions.

It allows us to work interchangeably with the palliative care team because that's what they're used to so it means that we're working off the same page. (PHYS03, Consultant Psychiatrist, Hospital)

Nursing home nurses believed that standardised assessments improved pain reporting to GPs.

[The Abbey Pain Scale] is the one that is in use in most of the nursing homes [here]. It's not going to give you all the answers but it can certainly give you an indication, and it's also a recognised tool so when you're speaking on behalf

of the patient to the GP, if you're able to say that you used this recognised tool, rather than going on and just saying "I feel that my resident is in pain", if you have a recognised tool and an assessment and a score to give them, then you'll very often find that you'll be listened to more. (NURS010, RGN, Nursing Home)

Some nursing home participants believed that pain assessment tools facilitated less experienced staff to learn and recognise the behavioural and nonverbal signs of pain in residents unable to self-report.

It is a useful tool for, for example neuro nurses who aren't aware of if somebody [who] has dementia is sore, you know? We just take it as a given and we know what to look for in terms of facial expression or changes in behaviours but if you were new to caring for people with dementia, it is useful to say oh these are the things that I should be looking at. (NURS015, RGN, Nursing Home)

However; most participants in this group (n=8) reported using pain assessment tools simply to comply with company care provider or local trust protocols but questioned their efficacy and reliability when used with patients dying with advanced dementia. Many believed that the pain assessment tool mandated or recommended for use (in these cases, the Abbey Pain Scale (Abbey et al., 2004) did not seem appropriate for use with patients in the advanced stages of dementia and who were dying. Most reported difficulty observing behavioural and nonverbal cues in patients with flat affect, those who fluctuated in consciousness and patients with conservative responses to pain. Uncertainty as to whether the behavioural and nonverbal cues observed for were definitively pain-related or whether they were also detecting non-pain related distress or the behavioural and psychological symptoms of dementia was widely reported.

It's easy probably if you can see those tell-tale signs that the Abbey Pain Chart is asking you but whenever the resident is just completely unconscious you would question it. If there is another tool that we could use and compare it with, yeah why not, but I think we have been using Abbey Pain Chart for quite a while and you would question does it really work? You know? Is there something better out there that we could use? (NURS02, RGN, Nursing Home)

They weren't designed for use with terminally ill patients with dementia. (NURS013, RGN, Nursing Home)

Traditionally I haven't been using standard pain tools to look at pain in the dementia population of the practice largely because it's a lot more difficult to use those tools with such patients. (PHYS08, GP, Primary Care)

Most expressed a belief that pain scores lacked clinical meaning without consideration of other critical contextual and collateral patient knowledge; all eight participants reported that pain scores were not routinely recorded nor were they used to inform treatment.

Well I would sometimes use the PAINAD, you know, the PAINAD advanced dementia tool, not as formally as counting it up but just using the facial expression and behaviour and vocalisation measurements to assess. But I wouldn't formally put a score on it. (PHYS04, GP, Primary Care)

Sorry I have to say I'm not convinced having one of those tools is going to make that patient any more comfortable. Because generally, if our patients are towards the end of their days our focus is going to be their comfort so the Abbey may not be formally documented as such, but we would be observing

for signs of distress or pain and acting on that, you know, definitely for end of life care. (NURS021, RGN, Care of the Elderly, Hospital)

(2) BARRIERS TO THE USE OF PAIN ASSESSMENT TOOLS AND THE IMPORTANCE OF 'ADDED VALUE'

Most participants (n=34; 72%), of which physicians formed the majority (n=21; 61.76%), did not use pain assessment tools with patients dying with advanced dementia. Participants' beliefs and perceptions regarding the limitations of standardised tools, in addition to difficulties experienced with their implementation and with regards to consistent and appropriate application motivated decisions to abandon their use. A recurring strong belief expressed by participants was that pain assessment tools did not add anything of value to existing approaches.

We wouldn't routinely use a tool like that in our in-patient setting unless we were struggling because it's kind of what we do, and we're very tuned in to it so a tool doesn't add anything on top of what we already know and what we're already assessing. (PHYS01, Consultant Palliative Medicine, Hospice)

When you're examining somebody you tend to have a gut feeling yourself and you tend to know if they're in pain. So it is very much your general feel of how that patient is clinically and what they're responding to and using a pain tool I think a lot of the time wouldn't change necessarily what you feel you're finding. (PHYS013, GP, Primary Care)

These participants preferred to continue with existing practices which involved drawing from a holistic evidence base that included patients' medical histories, pain histories, recent and current symptomology, collateral psychosocial history from key care staff, allied professionals, patients' families and clinical and physical examinations. Participants perceived existing practices to form a more thorough and

informed approach to pain assessment and for many, a relatively simplistic tool was not considered a suitable substitute for or addition to clinical training and experience.

I'm not using any standardised pain assessments for people with dementia. It's not the way I've been trained or taught in our medical school and in clinical practice. I take a history find out what they've been like before and then find out what they're like now and then do a medical assessment: do they have a temperature, any evidence of infection, chest infection, kidney infections, what are they like when they're being moved by the nursing staff, whenever they're moved do they appear to be in pain? I do a medical assessment and then do a physical examination, you know, chest, heart, abdomen make sure they haven't got retention of urine, and also move their arms and their legs see if there is anything obvious there. (PHYS021, GP, Primary Care)

You know to me, it's paper exercise and I think with years of nursing experience, I don't need a piece of paper with scores on it to tell me that somebody's in pain and I need to do something about it. (NURS01, RGN, Nursing Home)

In many cases, pain assessment tools had dropped out of use due to inconsistent use and documentation of tools, large variation in pain scores for the same patient which was attributed to changes in staff rather than changes occurring in the patient and increasing tensions among staff regarding pain scoring and interpretation. In some cases, experienced professionals had withdrawn their use due to staff completing assessment paperwork in the absence of patient observation and review.

I would have noticed that staff were perhaps guessing that the score was going to be the same and they weren't going back and actually looking at the resident and assessing them. (NURS010, RGN, Nursing Home)

[Pain assessment tools] they weren't always taken into account but whether it was that, as medics, we were bad at reviewing those scales on a daily basis or even on a weekly basis, um, whether that was the issue or whether it was because it quite often would be that the nursing staff didn't necessarily bring things to your attention based on that sheet, um, it was uncommon that someone would ask you about or mention a patient having a problem with pain based just on that sheet and the way they had rated their symptoms.
(PHYS017, Palliative Medicine Physician, Hospice)

Experienced participants attributed these difficulties to ineffective implementation strategies in healthcare policy. A strong focus on application simplicity in a clinical area widely recognised as complex was perceived to disregard health professionals' years of extensive training and experience and was an approach that was widely criticised among these participants.

I think that when one gets into such a routine that you use the skills which you've acquired, you don't necessarily move to just start using a new tool.
(PHYS05, Consultant Psychiatrist, Hospital)

I wouldn't associate it with any of the medical staff actually going to perform it themselves and documenting it as one of their interventions or assessments.
(PHYS014, Psychiatrist, Hospital)

These participants also commented on the (perceived) failure of policy and recommendations to provide sufficient rationale regarding the selection of a special tool, lack of information regarding the positive outcomes arising from its use and lack of guidance regarding how the new tool might be integrated with existing clinical practice and protocols.

They're coming in with the Abbey Pain Scale, they're teaching how to administer it in a very quick manner but they're not actually showing why it needs to be done and showing the uniqueness of end stage dementia and the unique challenges that that presents. (NURS010, RGN, Nursing Home)

A need for considered translation of interventions from academic research to clinical practice which clearly describe a process of integration and demonstrate how such interventions improve current practice and/or patient outcomes was emphasised.

The issue with policies is that there are so many different problems and there are so many assessment tools now I think that the wards are kind of bombarded with that. I suppose it's just making sure that we're not adding to the paperwork burden too significantly and that the staff are aware of how to use those tools to work out if they patients seem sore and emphasising the best practice approach to symptom assessment and management. (PHYS015, Consultant Palliative Medicine, Hospice)

(3) IMPROVING CURRENT PRACTICE

Most participants reported that pain recognition and diagnosis of pain type, location and intensity remained challenging in this patient population making appropriate pain management difficult to achieve in some patients. A critical need for investment in upskilling HCPs across setting and specialities to appropriately and confidently manage end of life care including pain and symptom management was emphasised.

I think there should be a rolling programme within the Trust, I think it should be part of our mandatory training, and I think it should be for all levels of staff. I think it is a major, major gap within the Trust. I think it's a major gap within the NHS as a whole. It is trying to get that balance of ensuring the fact that

they have dementia doesn't take away from the fact that they still need clinically treated in exactly the same way as a person who is compos mentis and doesn't have any cognitive issues. I think it [pain assessment] should be part of the induction, I think it should be mandatory training. (NURS022, RGN, Hospital)

Ongoing training and professional development in symptom (including pain) assessment and management and end of life care was reported as essential. Most participants strongly emphasised that such training required a needs-drive approach to course content, needed to offer a balance of didactic training and patient case discussion, be focused on transferable knowledge and skills rather than theory and be clinician-led and delivered.

You could have a case report like Mr X has such and such and then group work to try and figure out what could be the possible causes, what to look out for, how to use the tool in that case and things like that. (PHYS06, Psychiatrist, Hospital)

Experienced physicians emphasised the need for robust evaluation of all training and educational interventions to determine their feasibility, utility, their ability to deliver educational objectives and their impact on staff and patient outcomes.

I think a key thing would be to assess does it actually change their practice or influence their practice because sometimes training is done but the benefits can be lost if they're not implemented by the person and if there's not a culture of change. There has to be a culture, staff have to be working in an environment where there's a culture of improvement and where there is attention given to that particular area. (PHY015, Consultant Palliative Medicine, Hospice)

PHYSICIANS' PERSPECTIVES ON PAIN MANAGEMENT

Six key themes emerged from interviews with 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.

These are discussed in turn below and overleaf.

(1) DIAGNOSING PAIN

Difficulty diagnosing pain was the most commonly reported barrier to managing pain appropriately in people with advanced dementia approaching the end of life. Loss of the critical patient-physician pain dialogue and the absence of any obvious physical cause of pain (e.g. fracture, wounds) or painful comorbid condition (e.g. cancer) made it difficult to identify and characterise pain.

In a patient with dementia, if you have no history or communication from the patient, it's impossible to get an accurate history to be able to identify the character of pain in the way you would be with a patient who could communicate and had understanding. (PHYS011, GP, Primary Care)

In the absence of the gold standard for pain assessment; patient report, respondents observed for, and interpreted, behavioural and nonverbal signs of pain. All

respondents were acutely aware of the limitations of this approach, recognising that many of these indicators could also be expressions of fear, anxiety and other non-pain related distress. Most expressed concern regarding potential misinterpretation of these cues and advocated caution in relying on this information.

The signs of pain in this particular patient group could be signs of something else as well, and that's where you have to be very careful to recognise what is their normal behaviour and what has changed or what can we link to pain.
(PHYS012, Consultant Palliative Medicine, Hospice)

The presence of neuropsychiatric symptoms in these patients further complicated pain diagnosis. Some participants highlighted the potential for misinterpretation of these cues to result in inappropriate treatment, for example, pain relief for emotional distress, whilst others reported uncertainty in decisions to treat the patient for (presumed) pain or for the manifested psychiatric symptoms.

Saw a patient yesterday or two days ago who appeared to be in pain, she had advanced dementia, I felt she was in the last days of her life and she was lying on the bed occasionally agitated, throwing her arm up around her head. Hard to know if that's pain or not. So do I treat her for pain in that scenario? **(PHYS019, GP, Primary Care)**

(2) COMPLEX PRESCRIBING AND TREATMENT APPROACHES

The impact of complex comorbidity profiles, neurodegenerative disease, low body mass index and ageing physiology on the pharmacodynamics and pharmacokinetics of many analgesics were key considerations for physicians.

In the very severe stages we get people who can be very, very, physically failed and frail, very low body mass, really no musculature, usually sort of dehydrated, usually with sort of poor cardiac output. Often we're not actually sure how much pain relief is getting in to somebody. Often the difference between what you think the analgesic's going to be and what it actually does to a patient in that kind of stage—the difference is quite substantial. (PHYS03, Consultant Psychiatrist, Hospital)

Participants described past experiences in which analgesic effects had been highly unpredictable, resulting in over-treatment for some patients, poor pain control in others, and adverse events for a minority.

I've had it where I've given one big fellow a very strong painkiller and it floored him; I've seen a wee lady half the size and very frail and actually it wasn't working on her at all. So although I assumed little old ladies need less, it actually went the opposite way. It's really very individual, like with everything, everybody's different (PHYS011, GP, Primary Care)

Most respondents therefore exercised caution in prescribing, particularly when treating new patients, and many followed the principle 'start low and go slow' using paracetamol as the preferred first-line treatment, particularly in cases where pain diagnosis was ambiguous.

I would start off with maybe a trial of analgesia but I would start off with the mildest form like paracetamol or something just to see if it made a difference. If they seemed to be responding, I suppose I would use the WHO analgesia ladder and just come up very, very cautiously. (PHYS04, GP, Primary Care)

Pain management was often described as a ‘trial and error’ process in which pain relief was titrated in response to changes in behaviour, non-verbal cues, vocalisation and levels of consciousness. Psychiatrists and GPs found the World Health Organisation (WHO) Analgesic Ladder (World Health Organisation, 2017) helpful in guiding upwards titration; hospice physicians relied on their own previous clinical experience and consultation with colleagues and preferred the national Palliative Adult Network Guidelines (PANG) (Watson et al., 2017). All physicians regularly prescribed a wide range of analgesics including opioid and compound opioid preparations in a variety of formulations including transdermal patches, intramuscular injections and syringe drivers. GPs and psychiatrists often sought advice or confirmation from specialists such as community hospice, palliative medicine and psychogeriatric practitioners when titrating to higher doses.

If these patients are already on medication for pain it's like where do you go to augment and increase it? So having input from people who are specialists is always appreciated. (PHSY014, Psychiatrist, Hospital)

(3) SIDE-EFFECTS AND ADVERSE EVENTS

Participants described the challenge of prescribing for patients with advanced dementia nearing the end of life as a ‘catch-22’ situation in which multiple symptom control (including pain), was required, while minimising polypharmacy and avoiding drug interactions and adverse and/or side-effects.

There's a catch twenty-two, there's potential for a lot of interactions with the other medication that they are on, then you face the difficulty with the side effects of medications. So it's really about hitting the balance of making sure that you're doing the patient no harm and treating their pain. It's finding that fine line (PHYS07, Psychiatrist, Hospital)

Many patients required a greater degree of pain control than could be provided by paracetamol and other simple analgesics, however; codeine and other opioid-based preparations were deemed to carry a high risk of respiratory depression, sedation, constipation and falls, whilst non-steroidal anti-inflammatory drugs (NSAIDs) were associated with risk of gastric bleeding, cardiovascular and stroke events. Side-effects such as constipation (a trigger for onset of acute delirium) and nausea (difficult to detect in the absence of patient self-report), respiratory depression and sedation were considered highly detrimental to patients and contravened participants' goals of care.

The likes of the more codeine-based [preparations], it's the risk of them becoming constipated and making things worse and then I suppose the more heavy morphines and so on, it can just floor them, really wipe them off their feet, more prone to more falls, makes them more drowsy. (PHYS06, Psychiatrist, Hospital)

Most participants reported that these factors restricted choice of suitable analgesics and often resulted in off-label prescribing. Many GPs and psychiatrists found this challenging due to unfamiliarity with off-label uses for palliative purposes, requiring guidance from palliative care specialists.

[Palliative care] has taught me things about using certain agents, midazolam, for example ... something that isn't used widely in my world but it's used widely in [the] palliative world. (PHYS09, Consultant Psychiatrist, Hospital)

(4) ROUTE OF ADMINISTRATION

All participants reported challenges with routes of administration for patients with dementia approaching the end of life. Oral administration was compromised in

patients with significant swallowing difficulties, poor gut absorption, nausea and/or vomiting, impaired consciousness (sedation, coma, sleep or drowsiness), or in those who refused to take medication.

... so perhaps liquids might be refused, tablets may not be taken, they may not be able to take anything orally and they may need medication by a different route. (PHYS015, Consultant Palliative Medicine, Hospice)

Many respondents described difficulty encouraging compliance in patients who lacked capacity to engage in discussion regarding the need for symptom control. Syringe drivers, normally considered when oral administration is not viable, presented a number of complications including: forceful removal by agitated patients, lack of available staff experienced in their set-up and use; and in some cases, lack of access to necessary equipment or resources.

Intravenous [administration] I would have to say we actually rarely use. The problems being that maintaining venous access in somebody who's failing is a problem, it's often painful and distressing for patient and we open up then risks of infection and so on as well. So we often try and go for, for subcuts if we can, or patches. (PHYS03, Consultant Psychiatrist, Hospital)

Transdermal patches were a preferred route for overcoming the challenges posed by oral and syringe driver routes.

We're maybe more likely to use medications administered by patch through the skin rather than tablets because it's felt to override the challenges of patients being able to take their oral medication reliably. (PHYS017, Consultant Palliative Medicine, Hospice)

Transdermal patches were considered particularly suitable for agitated patients due to their unobtrusive and non-invasive nature and for avoiding difficulties associated with *pro-re-nata* (PRN) prescribing in non-verbal patients.

We would try and use patches sometimes because they're less noticeable to the patient, and if the pain is more stable that can be a way around it.
(PHYS015 Consultant Palliative Medicine, Hospice)

Physicians, particularly GPs, highlighted the importance of selecting a route of administration appropriate to a patient's health status and needs, and the need to ensure the availability of healthcare staff appropriately trained to administer and monitor medication via that route.

You've an issue with trying to select the type of medication you're going to use and you've an issue then with what way you're going to administer it to them and then who's going to manage that and monitor it as well. **(PHYS022, GP, Primary Care)**

(5) SHARING KNOWLEDGE

All respondents strongly believed that the care of people with dementia approaching the end of life, including pain management, required input from families and healthcare professionals across disciplines. Physicians believed their key responsibility was to provide optimal care for their patients, which included recognising and addressing their own limitations. Narratives revealed an interactive interface across primary, secondary and hospice care settings and medical specialties through which knowledge and expertise were exchanged.

When it comes to end of life then, we're sharing knowledge, we're the experts in antipsychotic medications and they [palliative medicine physicians] are finding that with people with challenging behaviour, they may need to go that route so we're sharing in terms of cross-populating our knowledge base.
(PHYS09, Consultant Psychiatrist, Hospital)

GPs and psychiatrists sought advice from palliative and hospice care physicians and psychogeriatricians regarding: off-label use of analgesics; titration for patients already receiving pain relief; use of opioid preparations; combining pain-relieving agents; combining analgesics with mild sedation; managing background or breakthrough pain; and routes of administration. Hospice physicians sought guidance for particularly complex patients from neurology, psychogeriatrics, palliative pharmacy and psychiatry. In many cases, participants wanted confirmation of their proposed treatment; receiving support from other specialties and knowing they were 'on the right track' with prescribing and treatment increased confidence and job satisfaction. Many enjoyed learning from and sharing their expertise with other doctors outside their care setting and medical specialty.

I would ring, for example, [the hospice] and speak to one of the consultants and I would ask "This is what I'm thinking of doing, do you think this sounds okay?" And then I would get that advice. It just gives me that bit more confidence that the patient's getting maybe the best they could get; because I don't think I'm the best, I think I'm a GP and I think a palliative care consultant would be the best. **(PHYS08, GP, Primary Care)**

Families were perceived to hold key collateral information such as patients' former beliefs about medications, previous pain thresholds, whether they were likely to report pain or 'suffer in silence', drug tolerance and allergies, behavioural and non-verbal indicators of pain, and preferred methods of medication delivery.

We very much work with the families because the families usually know this person to the point that they know what they maybe would have wanted or how they are going to respond so we try and get everybody in on the decision-making. (PHYS012, Consultant Palliative Care, Hospice)

Physicians used this knowledge to inform prescribing decisions and to assess treatment response.

One thing is us giving the families information but the other thing is asking them their perception of whether they perceive that something has helped or not and whether they have noticed any signs of side-effects. They're just better placed—if they're with the person a lot, to identify whether or not the medication has made them confused or that kind of thing. (PHYS017, Consultant Palliative Care, Hospice)

(6) TRAINING NEEDS

Physicians were dedicated to providing optimal care for patients often within multiple organisational constraints. All respondents believed that the knowledge, skills and expertise required to optimally manage pain in this complex patient population existed within the health professions but were highly dispersed across medical and other disciplines and care-settings. Physicians considered pharmacology, pharmacotherapeutics, managing pain in patients with challenging behaviours, and distinguishing between pain-related and non-pain related behavioural and psychological symptoms of dementia (BSPD), to be key areas for further training. The majority described physician-to-physician mentoring, in the form of regular meetings of an established network of practitioners from across care settings and disciplines to discuss anonymised real patient cases, as an ideal approach to ongoing professional development.

The best would be experiential learning where you can go on a ward round, discuss a case, ask questions, that's the gold standard. (PHYS012, Consultant Palliative Care, Hospice)

Physicians widely believed that this approach would have greater clinical utility and impact than workshops, training days or didactic lectures.

I think that case-based learning is useful because I think it gets people to think about what they do themselves and how they would manage a particular problem. I think that has more relevance and power in terms of changing what people do for the better. (PHYS015, Consultant Palliative Care, Hospice)

NURSES

Nurse participants' experiences were characterised into three core themes:

- (1) challenges administering analgesia
- (2) the nurse-physician relationship
- (3) interactive learning and practice development.

A number of sub-themes were identified; a full list of core themes with sub-themes are presented in Table 3. The theme "challenges administering analgesia" reflects challenges arising from the inherent complexity of the patient population (people dying with advanced dementia) and as such, nurses' experiences were universal and not differentially impacted by setting. The second and third core themes comprised commonalities of experience across settings, with sub-themes reflecting setting-specific challenges. In these cases, experiences were common to nurses within a specific care setting (e.g. acute care) but differed from experiences of nurses in other settings (e.g. hospice).

Table 3. Core themes and sub-themes identified in within-group and cross-group analysis

Core theme	Sub-theme
Challenges administering analgesia	(a) Medication refusal (b) Route of administration
The nurse-physician relationship	(a) Positive relationships (b) Difficult relationships
Interactive learning and practice development	(a) Hospice nurses (b) Acute care and nursing home nurses (c) Whole-group perspectives on interactive learning and development

(1) CHALLENGES ADMINISTERING ANALGESIA

Commonly experienced challenges with the administration of analgesia comprised patient refusal of pain relief and difficulties with routes through which analgesics could be administered.

MEDICATION REFUSAL

Patient refusal of analgesia (and other medications) was commonly experienced by participants with most perceiving refusal as the result of patient anxiety and/or fear regarding medication use. It was believed that profound deficits in cognition prevented patients from recognising medications as such, and impairments in communication removed the possibility of engaging in nurse-patient dialogue to

explain the need for, and benefits of, analgesia, through which patients' fears and anxieties might be allayed.

It can be difficult then to explain that this is what is working for you and we think that this will help you". (NURS022, Hospice)

In some cases, patients' inability to understand the purpose of pain relief provided, combined with the pain they were experiencing, culminated in aggressive resistance to treatment.

Some of them would be aggressive, they will just full stop not take any pain relief from you and yet you know they need the pain relief. (NURS02, Nursing home)

Many nurses expressed deep empathy for patients, reflecting that fear and/or anxiety were natural responses in dying patients who are entirely dependent on others for care and who cannot understand or adequately express their needs.

Put yourself in the shoes of the resident, you're lying there, you can't talk, you can't understand. You're really at the mercy of the people looking after you. (NURS016, Nursing home)

ROUTE OF ADMINISTRATION

Participants reported barriers to pain management in patients dying with advanced dementia resulting from constraints on available and appropriate routes of administration. Oral administration of analgesia was challenging in dying patients

with frequent and/or excessive drowsiness or who were asleep for extended periods of time. Tablet and liquid formulations of analgesics carried a high risk of aspiration pneumonia for patients with dysphagia, a common feature in end-stage dementia, often necessitating a review of patients' analgesic regimens.

The challenge is they can't take it orally a lot of the time because their swallow deteriorates and they frequently get aspiration pneumonia so whatever oral pain relief they would have been on previously, they can't take anymore.
(NURS09, Hospital)

Participants reported that syringe drivers, injections and intravenous administration could be challenging when used for end-stage patients with dementia with low body fat, little musculature and cachexia.

People with advanced dementia tend to have skin and bones as they haven't been eating great so even like giving subcut [subcutaneous] injections or intramuscular sometimes there's nowhere to put it that's not going to cause more pain whenever you're administering it. **(NURS020, Hospital)**

Many expressed concern regarding the use of needles in dying patients due to beliefs that these routes were painful and distressing for patients, especially for those who were already anxious and/or agitated.

...they can become more anxious coming near the end...if they see a needle they're freaked out so you have to assess the situation, is it really worthwhile me putting such and such through this here? **(NURS06, Hospice)**

Respondents preferred less invasive methods such as suppositories and transdermal patches over subcutaneous and intravenous delivery in the final weeks of life and for the imminently dying; these were considered to be minimally invasive with low risk of injury to patients during administration.

We start with a patch of some description for pain relief, so that keeps them pain free. I find that for people who have dementia, you don't tend to need syringe pumps, you'd use paracetamol suppositories, maybe diazepam suppositories. (NURS09, Hospital)

(2) THE NURSE-PHYSICIAN RELATIONSHIP

POSITIVE RELATIONSHIPS

All hospice nurses reported positive nurse-physician relationships which were characterised by mutual professional respect, trust and collaboration. They perceived themselves to be working in successful partnership with medical staff towards a common goal of pain management.

I think we're doing quite well [in managing pain], but I think it is because we have such a good, you know, we have a good team and we have specialists, you know, as well, I think that all ties in together. (NURS017, Hospice)

Just over half of nursing home nurses and acute care nurses also reported positive nurse-physician relationships. These nurses perceived that physicians responded promptly to reports of pain and to prescription requests, demonstrated shared goals of care, and valued nurses' contribution to patient care. Open and articulate communication facilitated a collaborative relationship between nurses and physicians

in which disciplinary knowledge was shared to meet the challenges of managing pain as well as other aspects of patient care.

The GPs are there all the time to help, they always go with us because they know that we are the ones seeing [the patients] everyday, we know each and every difference in them from yesterday, today, tomorrow. So when we explain, they have trust in us. (NURS013, Nursing home)

DIFFICULT RELATIONSHIPS

Difficult nurse-physician relationships were reported by both nursing home and acute care nurses. Some nurses felt that physicians were reluctant to conduct patient assessments and ignored requests for help with complex cases.

Some will say: well, what's wrong with them? And try and diagnose over the phone, rather than actually coming out and doing a home visit. Probably one of the biggest issues that we have, is that the GPs wouldn't always come out and help us assess. (NURS015, Nursing home)

Negative relationships were also reported where participants experienced difficulties or delays in obtaining scripts, where prescribing decisions were perceived (and/or transpired) to be sub-therapeutic, and where treatment appeared to be unreflective of patient needs.

Sometimes I think there's reluctance on the part of the medical [staff], especially if it's a junior medic, you know, to even prescribe something. (NURS021, Hospital)

Senior acute care and nursing home nurses felt confident in advocating for patients in cases where nurses' and physicians' goals of care were perceived to be discordant but acknowledged that confidence to query prescribing decisions varied among nurses.

Some [GPs] have their own thoughts and trends in their head and what they believe is right. I think they open a book and it says A, B, C and D to them and therefore they want to follow A, B, C and D to do their best, but sometimes they forget to listen to the nurses who do know. I think it depends on how empowered a nurse is to actually say to a GP: hold on a minute, and to be an advocate for our residents. (NURS03, Nursing home nurse manager)

Nurses with 20 or more years' nursing experience believed that poor communication skills and inadequate reporting among nursing staff contributed to the difficulties experienced in nurse-physician relationships. Failure to provide salient, contextual information about patients (such as changes in swallow) clouded the clinical picture for physicians, especially for those not present in the care setting daily, in some cases resulting in clinical errors and/or inappropriate treatment.

If it's a GP writing up, their initial thing would be to write up the ordinary capsules but it's the nurses being proactive to say, whenever they're getting it prescribed: "Oh this patient's swallow is quite impaired, is there any other form that can be given in?" So it's not the GP's fault, it's the nurses not informing them of the actual situation. (NURS010, Nursing home)

(3) INTERACTIVE LEARNING AND PRACTICE DEVELOPMENT

HOSPICE NURSES

Hospice nurses perceived themselves to be fortunate in being able to readily access ongoing professional development across many aspects of dementia care including pain management.

I think we are quite lucky here because we get quite a lot of training [...]. You're getting your practical training, you have your mentor, and you learn so much from your mentor. And then we have online training and we have certain study days dedicated to it [dementia] and if we want we can get external training as well. (NURS05, Hospice).

They expressed preference for interactive, group discussion of patient cases alongside structured didactic teaching, reporting that these approaches facilitated and encouraged knowledge exchange between nursing staff.

Usually here we would have small groups [...] and it's very interactive and it's not very formal but it's very, very, informative, very good. And then you can bounce ideas off each other, it's very good I think. (NURS011, Hospice)

ACUTE CARE AND NURSING HOME NURSES

These nurses' experiences of training and development differed substantially to those of hospice nurses. Opportunities for professional and practice development were often limited due to constraints on staff time, heavy workload and the need to travel to training events.

I think the problem with the training is the training days aren't local for the staff and there might only be one training day and not all the nurses can go on that one day. (NURS08, Hospital)

Opportunities for learning and development were also often negatively impacted by the financial resources available in their respective organisations.

...the problem is that a lot of the training is quite expensive so the nursing homes are not subscribing to it. I mean some of these training days can cost £1200 for the day. (NURS10, Nursing home)

Barriers to training and practice development resulted in some staff having received no training in dementia care including in pain management.

I haven't had any training with regards to dementia so it's just something that I'm maybe learning from colleagues. (NURS20, Hospital).

WHOLE-GROUP PERSPECTIVES ON INTERACTIVE LEARNING AND PRACTICE DEVELOPMENT

All respondents believed that access to ongoing professional development was critical in empowering staff to effectively and safely manage pain and provide a good standard of holistic care to people dying with advanced dementia. When asked to describe their preferences for training approach, the vast majority believed that mentoring and/or shadowing experienced nurses constituted an ideal approach to training. Both senior and less experienced nurses believed that 'leading by example'

and 'learning by example' were methods most likely to encourage and promote professional and practice development.

I'm saying to them think about it yourself: if co-codamol isn't strong enough, what would be your next pain relief that you would use? If someone's on this [analgesic] now, how much morphine is this? And if I had to change it, what would I do next? And the staff find that approach is very helpful. (NURS05, Hospice)

Participants emphasised that training and practice development should be an ongoing process and required a needs-based approach with input from nursing staff.

You would have to do a needs assessment around the staff and it should be a continual thing not a one-off. But I think staff need to sit down together and start off deciding what their needs are and then they can grow from there. (NURS24, Nursing Home)

All nurses reported training in pharmacology was required; some reflected on the dichotomy of holding a position with legal and professional responsibility for administering a large number of medications to vulnerable patients daily without full understanding of what they were providing.

I think nurses are very guilty of sometimes handing out all these medicines and, you know, we hand them out because they're prescribed by the GP but do we really know, you know, do we know the action of these drugs? Do we, you know, are we sure that they're not going to interact with any of the other drugs that they have? (NURS01, Nursing home)

All participants in this study expressed that having the appropriate skills and knowledge to competently and confidently manage patients dying with dementia to a 'good death' was of paramount importance.

I want to feel totally equipped to be able to deal with all aspects of their care and never to feel that there was something extra that I could have done...Something that I should have done. (NURS03, Nursing home)

HEALTHCARE ASSISTANTS

Fourteen HCAs participated in interviews. Three key themes emerged from analysis of their interview transcripts, as detailed below:

- (1) recognising pain
- (2) reporting pain
- (3) training and upskilling.

(1) RECOGNISING PAIN

Most participants recognised pain to be a key care concern for people with dementia and emphasised a need for vigilance in identifying its presence, particularly for residents unable to self-report. Although not required to conduct formal pain assessments, HCAs' narratives revealed that they regularly performed informal relationship-centred pain assessments using knowledge of residents acquired during the course of daily care provision. In so doing, HCAs identified behaviours, non-verbal cues and other activities which departed from residents' daily norms, and interpreted these as potential indicators of pain, distress or health decline. A minority of participants, however, reported challenges recognising pain in this patient population. These sub-themes are discussed in detail overleaf.

KNOWING THE RESIDENT

Close daily contact with patients during the course of providing care resulted in participants accruing detailed comprehensive knowledge of their patients including their preferences, normative patterns of behaviours, moods, demeanour, cognitive and physical functioning and routines. Unusual or unexpected changes in these domains were interpreted as warnings of acute illness, pain, or other health decline, whilst changes in appetite and toileting routines prompted consideration of constipation and urinary tract infections. Care tasks which required moving, lifting, turning and providing personal care meant participants were often the first to notice obvious causes of pain such as contractures, bruises, cuts, lacerations and abrasions, pressure sores, rashes and other injuries.

It could be just that, you know, they're maybe not using a hand the way they usually do, or as I say the way they behave, you know, it could be aggressive behaviour or it could be, as I say, going into their shell. Maybe they've stopped eating or they're refusing to eat or they won't go to the toilet or they're going to the toilet more. It's these things you just have to go into: is it because of infection? Or is it because of something else? Knowing the resident is the most important thing from A to Z as far as I'm concerned. (HCA01, Nursing Home)

When we were getting [the resident] up, she was really, really, really contracted [in] her arms. It was so bad you couldn't get the hoist straps in...and I know from getting her up before on other days, it would have been easy. And it was something to do with her hands as well; she had wee sores [between] her fingers so we found them as well. So she was going through the pain of us holding her hand and lifting her up. (HCA012, Nursing Home)

OBSERVING AND INTERPRETING BEHAVIOURAL AND NONVERBAL INDICATORS OF PAIN

HCAAs in this study were not required to conduct formal pain assessments and did not use standardised pain assessment tools; eleven participants reported being unfamiliar with their contents and application. However, participants' narratives revealed that when pain was suspected in non-verbal patients and no obvious physical cause could be determined, most HCAAs observed patients for many of the behavioural and non-verbal expressions of pain usually considered in such assessments. These observations were interpreted within the context of HCAAs' holistic knowledge of residents, which facilitated distinction between expressions of pain and other, non-pain related states (e.g. boredom, hunger). Participants also reported that pain recognition was facilitated in residents who exhibited characteristic expressions of pain which only manifested at intermittent intervals and disappeared following administration of pain relief. Most participants believed that learning to recognise and interpret the ways in which residents expressed pain was critical but reported difficulty in doing so for newly admitted residents with whom they were unfamiliar. In these cases, HCAAs sought additional information regarding patients' normative behaviours and/or behaviours, activities or non-verbal cues known to be expressions of pain from residents' referral letters, nursing notes and anecdotal information provided by nurses and patients' families, friends and social workers. Three HCAAs regularly accompanied nurses during administration of the Abbey Pain Scale; these narratives revealed disparities between HCAAs' and nurses' knowledge of residents and participants emphasised the importance of interpreting scores within the context of patient norms. A minority (n=4) of participants expressed task-oriented attitudes to care and reported feeling under-educated in recognising behavioural and nonverbal indicators of pain. These HCAAs used nurses' reports of pain to adapt care routines to accommodate pre-existing pain rather than proactively monitoring for new occurrences of pain, and did not regularly liaise with residents' families.

Most of the time they're [residents] unable to tell us so therefore we're looking for non-verbal facial expressions, movement of the hands, grimacing of the face

and also times where they're nearly putting their body into the foetal position. That would alert us to pain. Um, agitation, if they're agitated then we try to work out if it could be pain causing that. We also would look to families because they've been looking after them and they may recognise that it's when the [resident's] left hand comes up to their head that we will know that they're in pain. (HCA04, Hospice)

A lot of the time some of them can be between scores - do you know what I mean? And it does depend on the person who's doing it, if the nurse is doing it and they don't really know [the resident] as well, the nurse could say: well she does usually move this much and I would say: no, she doesn't usually move that much. So that's why when they're doing the Abbey Pain Scale, one of us would be with [the nurse] as well. (HCA08, Nursing Home)

Interviewer: How would you recognise pain in someone with advanced dementia approaching the end of life?

HCA011: You know, just facial, noise, sometimes movement. I would say there's [sic] probably other ways but I don't know. (HCA011, Nursing Home)

(2) REPORTING PAIN

All HCAs reported pain to nursing staff within their setting. However, the quality of pain reporting varied according to HCAs' approaches and attitudes to care, their relationships with other health professionals and the extent to which they felt recognised and valued within the team. HCAs' narratives revealed positive and negative relationships with other healthcare professionals and their perspectives on inclusion in, and exclusion from, multidisciplinary team meetings (MDTs).

POSITIVE WORK-RELATED IDENTITIES AND RELATIONSHIPS

Positive work-related identities and relationships with other healthcare staff were formed when HCAs felt encouraged and supported in raising and discussing their concerns about patients (including but not limited to pain), and where they felt qualified professionals recognised and valued their role. These staff provided detailed reports which described their observations and offered a rationale for suspecting pain. They believed that quality in pain reporting resulted in their concerns being taken seriously and allowed patients to be assessed quickly. These participants were consequently motivated to monitor for and report on patients' responses to analgesia which they believed was necessary to alert nursing staff to cases of potentially unresolved pain. They adapted care routines, postponing tasks that involved touching, lifting, moving or turning residents until after analgesia had taken effect.

We had this gentleman who was coming to the end of life. I said to the nurse, he's got to be sore; he's making all these noises, facial expressions as well, the frowning and the hand up (gestures stop signal with her hand), trying to stop you touching [him]. Straight away the doctor was called, the prescription was written and that was it. Life was comfortable for him after that. (HCA02, Nursing Home)

If a pain relief hasn't been effective, we will then go and say to the nurse we don't think that has worked and then they will follow that up with the GP. (HCA010 Nursing Home)

I would leave whatever we're doing, if we're getting her [the resident] up in the morning, I would leave her for fifteen minutes or until the painkillers actually kick in before I go back and start getting her up and everything like that. (HCA012, Hospice)

NEGATIVE WORK-RELATED IDENTITIES AND RELATIONSHIPS

Five participants employed in nursing homes reported problematic relationships with nursing staff and/or physicians. This occurred when HCAs perceived other health professionals to emphasise and maintain professional hierarchies which created distance between these professionals and HCAs, leaving the latter feeling ignored and under- or even de-valued and resulting in communication breakdown among staff. Negative relationships with other health professionals resulted in pain reporting that was perfunctory, ambiguous or uninformative. HCAs who reported these relationships did not engage in monitoring or reporting treatment response or adapting care routines to take account of onset of analgesic effect. No participants were invited to attend or participate in multidisciplinary team meetings; this was a cause of disappointment and frustration even among those who reported positive work relationships. Experienced HCAs believed that in the absence of HCA input, multidisciplinary teams missed out on critical information exchange that could inform patient care, and that their omission, as frontline staff, weakened the entire healthcare team. Others expressed frustration at being unable to contribute to care discussions despite their significant knowledge and understanding of residents. These participants expressed a belief that the lack of professionalism attached to their role (i.e. being unqualified, unregistered) was a key factor in being omitted from multidisciplinary team meetings.

Sometimes doctors don't like you telling them what you think, you know, because I'm only a care assistant, you know? (HCA01, Nursing Home)

I'd go and tell them 'uns [ones] and just say I don't think he's well and then they [nursing staff] come down and assess him and whatnot. (HCA09, Nursing Home)

Sometimes it can be a wee bit frustrating for us as healthcare assistants because we have so much contact with the patients, we would have a lot more really than the qualified nurses would have. I mean their focus is mainly on administering medications and there's other duties that they have that we're not carrying out, but we're there with the patients a lot more and we know them quite well and we get to know when their pain is inclined to be particularly bad or worsen or be better. (HCA04, Hospice)

(3) TRAINING AND UPSKILLING

Thirteen participants believed that HCAs required ongoing, formal, needs-driven training in order to manage the demands of their role and provide high standards of care. One participant believed that most necessary knowledge and skills were developed through performance of the role, negating the need for additional training. The majority felt strongly that provision of excellent standards of care was dependent on the knowledge, skills and ability of all healthcare staff, including those providing care at the frontline. Many felt they could make a greater contribution to pain assessment and management in advanced dementia and much interest was expressed in learning to use and report basic assessments such as the Abbey Pain Scale, and in receiving formal instruction on how to monitor for and report treatment response, side and adverse effects. HCAs believed that the use of standardised tools would improve consistency in HCA pain reporting to health professionals. None of the participants anticipated that their use of assessment tools would replace or take precedence over assessments conducted by qualified staff. E-learning, the most common platform for delivery of training to HCAs in this study, was widely and heavily criticised for delivering generic, unengaging content of limited utility which failed to address their learning needs.

Any extra training is beneficial for our patients as well ourselves, you know, even if we were to do the Abbey Scale, you know, or something like that. (HCA012, Hospice)

If we had a trained nurse to teach us what to look for, like treatment response, and if they could show us the signs and explain to us how to interpret [them], that would be beneficial. (HCA06, Nursing Home)

I just find that the e-learning especially, it's just very boring and really time-consuming and then I do get bored of it and I'm like [sighs loudly] I don't want wanna ever read through that, so I skip that, whereas face-to-face training is more interesting, they can make it fun and it's not just reading off the computer screen. (HCA07, Nursing Home)

DISCUSSION

PHYSICIANS' AND NURSES' PERSPECTIVES ON PAIN ASSESSMENT

Although all participants in the present study appeared to be aware of health policy and clinical recommendations regarding the use of pain assessment tools with patients with dementia, only a low proportion were routinely adopting this practice with patients dying with advanced dementia. Among these participants, there was variation in attitudinal beliefs towards pain assessment tools and in their application. A small minority had effectively integrated the use of a standardised pain assessment tool with existing practice resulting in positive outcomes including quicker recognition and understanding of pain experiences for newly admitted patients, improved continuity of pain assessment and management across staff and changing shifts and improved pain reporting within and across care teams, professions, care settings and specialties. Other studies have reported similar positive outcomes associated with appropriate and consistent use of pain assessment tools including improvements in symptom assessment and management and overall care provision (Pieper et al., 2017). However, most participants who reported using pain assessment tools did so solely to comply with local

recommendations or healthcare policies but did not use these to inform treatment decisions and in many cases, did not document pain scores. Doubts regarding the clinical utility of subjective observation scores as measures of pain rather than distress or both and difficulties using tools with patients not able to or not accustomed to expressing behavioural and nonverbal signs of pain resulted in uncertainty regarding the clinical meaningfulness of pain scores. In these cases, participants abandoned pain scores relying instead on existing practices and protocols to inform treatment decisions. Other studies have reported similar findings regarding challenges experienced by HCPs when using pain assessment tools with people with dementia (Ballard et al., 2007; Zwakhalen et al., 2007, Brörson et al., 2014; Barry et al., 2012; Ghandehari et al., 2013).

Most participants in this study did not use pain assessment tools when assessing for pain in people with advanced dementia in the final month of life. Participants' beliefs about the limitations of pain assessment tools, difficulties experienced with their application with dying patients, inconsistencies with their use and documentation, staff disagreement regarding observational scores and beliefs that the outcomes of such assessment did not offer anything of 'added value' to existing approaches to pain assessment were key reasons for their discontinuation. Participants' narratives revealed largely consistent approaches to pain assessment in which contextual knowledge of the patient was drawn from multiple sources including medical and pain histories (including pain threshold, response to pain, pain coping strategies), current and recent symptomology, clinical and physical examinations, medication regimens, direct patient contact and knowledge of psychosocial history provided by care staff, patients' families and significant others (e.g. clergy). This approach largely follows published practice guidelines for assessing pain in older adults with dementia (Hadjistavropoulos et al., 2010). However, evidence has suggested that overreliance on personal knowledge and collateral information alone may also prove an inadequate approach to pain assessment if attitudinal beliefs towards the patient population are negative, where the patient is unknown or unfamiliar to the care team and in cases where staff are inexperienced in recognising the behavioural indicators of pain in people dying with dementia (Kovach, 2000; Kappesser et al., 2006; Regnard, 2011). Other studies have identified a need for nursing home staff to

receive ongoing, regular training and support in developing and conducting pain assessment protocols within their setting and in responding appropriately to their outcomes (McAuliffe et al., 2012; Cohen-Mansfield et al., 2014; Burns and McIlfatrick, 2015).

Participants with extensive clinical experience commented on the failure of research interventions to translate into clinical practice. These participants believed that health policy and other clinical directives placed emphasis in the wrong direction, focusing on the simplicity of the recommended tool/s in a clinical area widely recognised as challenging and critical to get right. Failure to highlight the benefits of using the new tools and lack of guidance on how the tools might be integrated with existing practice were other criticisms raised. This finding, although arising from small proportion of participants, echoes larger key themes reported in an increasing body of work examining effective translation of research interventions into clinical practice (McGlynn et al., 2003; Green and Seifert, 2005; Pronovost et al., 2008; Lynn et al., 2007; Westfall et al., 2007; Grimshaw et al., 2012). This work has noted significant disparity between funding revenue for healthcare research and the number of interventions subsequently successfully integrated and implemented in practice (McGlynn et al., 2003; Green and Seifert, 2005; Pronovost et al., 2008; Lynn et al., 2007; Westfall et al., 2007; Grimshaw et al., 2012). Criticisms have been raised regarding the manner in which health policies, directives, guidelines and recommendations attempt to manifest change without understanding or consideration for the processes which underlie and impact on health professionals' adoption of changes in practice (Grimshaw et al, 2012). Others have suggested that successful integration and implementation requires policies, directives, recommendations and other literature to reflect the values, culture, training and expertise of the professionals expected to adopt a novel intervention/approach (Cabana et al.,1999; Larisch and Oertel, 2009). A focus on simplicity and the lack of knowledge and skills required to use the intervention may prove counterintuitive resulting in rejection by health professionals, particularly physicians, who pride themselves on their professional knowledge, training and skills (Cabana et al.,1999; Larisch and Oertel, 2009; Grimshaw et al, 2012).

Most participants emphasised a need for ongoing professional development and training in symptom management and end of life care provision in dementia. When asked specifically what an educational intervention should aim to achieve and what components it might consist of, participants' preferences indicated a needs-driven, clinician-led and delivered package which balanced didactic training with group discussion, skills transfer and patient case discussion. Such a system, known as Project ECHO[®] (Extension for Community Healthcare Outcomes) was launched in 2003 and has since been extensively trialled and evaluated across a range of health conditions internationally (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014; Burdette Mendonca, 2012; Masi et al., 2012; Scott et al., 2012; Khatri et al., 2013; Cahana et al., 2013; Katzman et al., 2014; White et al., 2016; Ní Cheallaigh et al., 2017). This system, which connects a multidisciplinary expert panel within specific health conditions (e.g. dementia, diabetes etc.) with health professionals from multiple specialties and professions across primary, secondary, hospice and community care in real time clinics using teleconferencing technology, provides a forum for mentoring and skills and knowledge transfer. Previous studies have demonstrated positive outcomes of Project ECHO[®] in increasing health professionals' substantive knowledge, self-confidence and efficacy in managing complex patients, improvements in patient outcomes and better integration of primary and secondary care services (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014; Burdette Mendonca, 2012; Masi et al., 2012; Scott et al., 2012; Khatri et al., 2013; Cahana et al., 2013; Katzman et al., 2014; White et al., 2016; Ní Cheallaigh et al., 2017).

These findings revealed several key issues regarding the integration and implementation of pain assessment tools as part of pain assessment protocols in primary, secondary, hospice and nursing home settings. Difficulties with applying the tools in practice, lack of guidance regarding the rationale for changing practice and how to integrate tools with existing protocols along with uncertainty regarding the clinical validity and reliability of the use of standardised assessments with dying patients with advanced dementia were significant barriers to their use. Policy makers may require caution in placing emphasis on ease and simplicity alone, particularly in clinically challenging and complex areas as this could prove counterintuitive leading

to abandonment of the new intervention and strengthening commitment to traditional practice. Health professionals continue to report pain assessment as challenging and emphasise a need for ongoing investment in training and education; however, these need to take into consideration health professionals' educational needs, must balance theory with practical application of knowledge and skills and content should be driven by their educational needs.

THE PHYSICIAN PERSPECTIVE OF PAIN MANAGEMENT

To our knowledge this is the first comprehensive exploration of the challenges in pain management for people with advanced dementia approaching the end of life, from physicians' perspectives. People with advanced dementia require the same vigilance in pain management as patients dying with terminal cancer; however, available guidelines offer little advice on how this may be achieved (Scott et al., 2012; National Institute for Health and Care Excellence, 2006). Pain control in this patient population can be difficult to achieve and the findings presented here offer greater insight into these challenges from the perspectives of those primarily responsible for this aspect of patient management (Achterberg et al., 2013).

The gold standard in diagnosing pain is self-report. In advanced dementia, this is rarely available; much of the critical information required to accurately assess, diagnose and target treatment is lost (McAuliffe et al., 2012). The findings of this study indicate that in the absence of patient report, collateral history from patients' families and other health professionals, along with clinical investigation and interpretation of changes in mood, behaviour, and other non-verbal cues, become important (McAuliffe et al., 2012; American Geriatrics Society, 2002). However, participants widely acknowledged that many well-recognised behavioural indicators of pain, such as distress, agitation, wailing, screaming, frowning and apathy, are identical to those expressed through anxiety, boredom, frustration and emotional distress (Ballard et al., 2011). Behavioural interpretation leaves room for misinterpretation and potentially inappropriate treatment (Ballard et al., 2011). Physicians' prescribing decisions were also shaped by patients' comorbidities, ageing physiology, existing medication regimens, physical and cognitive impairments and health status, which were perceived to restrict the range and strengths of

analgesics that may be safely tolerated (McLachlan et al, 2011). Changes in drug pharmacokinetics and pharmacodynamics, and variation in gut absorption and body fat index may result in over-treatment, delayed effects of pain relief and increased risk of side-effects and adverse events, making management complex and uncertain (McLachlan et al., 2011). Most physicians adopted a cautious approach to management. Route of administration was reported as problematic in severely cognitively impaired, dying patients. Loss of swallow, patient refusal and altered consciousness often precluded oral administration, whilst syringe driver use was problematic due to forceful removal by agitated or distressed patients and issues regarding availability of appropriately experienced nursing staff to set up and monitor the equipment. Medication delivery via the transdermal route was considered a better alternative.

Physicians across specialties and care settings often sought and shared advice and approaches to pain management. Most respondents strongly believed ongoing CPD via mentoring and knowledge exchange using real-patient cases would empower non-palliative specialists to effectively manage patients approaching the end of life. Previous studies have identified a need for further training for healthcare professionals in pharmacology and the use of nonpharmacological treatments, and in discriminating between behavioural and psychological symptoms caused by pain and those which are not pain-related in origin (Achterberg et al., 2013; Tousignant-Laflamme et al., 2012). The present findings corroborate these suggestions, and provide additional insight into physicians' training preferences.

Sharing knowledge extended beyond health professionals; most participants found collateral history provided by families to be helpful in assessing pain and interpreting nonverbal cues. This echoes other studies which report that good communication, shared knowledge and a mutually respectful relationship between the healthcare team and family carers are critical if treatment is to reflect the interests of the dying patient and achieve clinical goals of care (Denning et al., 2013; Lopez et al., 2013). Some of the above findings echo those reported in the nursing literature, indicating that medical, nursing and other healthcare staff experience similar challenges in assessment and management of pain for patients with dementia and emphasising the need for effective multidisciplinary working and open communication between

healthcare professionals (Burns et al., 2015a; Burns et al., 2015b; Fry et al., 2016; Birch & Draper, 2008).

THE NURSE PERSPECTIVE OF PAIN MANAGEMENT

This study reported on the experiences of nurses from hospice, acute care and nursing home settings in managing pain for people dying with advanced dementia. Although healthcare policy and clinical guidelines identify symptom management, including pain, as a cornerstone of care at end of life, participant experiences reported in this study illustrated that nurses can find this highly challenging to achieve in practice, a finding also reported by others (van der Steen et al. 2014). This study found that pain management in the final weeks of life was impacted by a number of patient-related, nurse-related and organisational factors. Whilst patient-related factors appeared to be universal across care settings, nurse-related and organisational factors varied between settings, differentially impacting on nurses' experiences of pain management.

Administration of analgesia was a challenge for all nurses in this study due to patient refusal and/or limited routes of administration. Most believed that patients' severe cognitive impairment and loss of communication inhibited their recognition of analgesia as such and their understanding of its need, prompting refusal. Many nurses were empathetic towards patients' perspectives but felt restricted in their approaches to encouraging compliance in the absence of the nurse-patient dialogue. Difficulties in nurse-patient communication in dementia are well recognised and methods to improve this have been well-researched; however, our findings suggest that many of these strategies may remain in the literature and fail to translate into clinical practice (Finke et al. 2008, Weitzel et al. 2011). Patients' physical decline (dysphagia, low body musculature etc.) and/or altered states of consciousness (drowsiness, excessive sleep etc.) limited routes by which analgesia could be administered. Oral, intravenous and subcutaneous administration were considered problematic and perceived to present a high risk of injury, pain and distress to dying patients. Most participants preferred the use of suppositories and transdermal

patches, considering them to be low risk and less invasive. Our findings did not elucidate whether difficulties with administration resulted in non-compliance. There has been surprisingly little investigation into the challenges of medication administration in dementia, despite the serious implications of non-compliance for patient outcomes; this area warrants further investigation (Passmore et al. 2010).

In this study, nurse-physician relationships appeared to be differentially impacted by care setting. Whilst hospice nurses unanimously reported good working relationships with physicians, acute care and nursing home nurses reported mixed experiences. Positive relationships were characterised by nurses' perceptions that their contribution towards patient care was valued, that they were working in collaborative partnership with physicians and where there was mutual professional respect. Difficult nurse-physician relationships were reported where nurses described themselves as working in parallel with physicians, where participants perceived physicians to be reluctant to assist with complex cases, and/or where pain was inadequately managed. Highly experienced nurses described instances where nurse-physician relationships were negatively impacted by poor communication skills and inadequate reporting among nursing staff, sometimes resulting in inappropriate patient treatment.

The setting-specific differences in nurse-physician relationships reported here may, in part, reflect the palliative focus of the hospice setting, its ethos, the relative stability and continuity of staff and availability of additional organisational resources. Staff turnover in acute care and nursing home settings may inhibit the establishment and development of close working relationships between nursing and medical staff, particularly in the nursing home context where physicians are based in external surgeries (Tjia et al. 2009). Nurse-physician communication and relationships have been studied extensively and positive relationships have been reported to result in higher job satisfaction for nurses and physicians, sharing of disciplinary knowledge and improved patient outcomes (Prescott & Bowen 1985, Keenan et al. 1998, Manojlovich 2010). Difficult relationships have resulted in poor job satisfaction, feelings of professional isolation, and errors in patient assessment and management (Donchin et al. 1995, Manojlovich 2010). Clarity in inter-professional working is essential in healthcare and is critical in patient populations unable to effectively communicate their needs; however, these relationships are complex and often

impacted by professional boundaries, personal perceptions and organisational cultures.

Hospice nurses were satisfied with the quantity and quality of opportunities for professional development. Acute care and nursing home nurses, however, experienced significant barriers to accessing training and practice development due to financial, travel and time constraints. Some nurses received no training in dementia; this is a significant concern given the complexities of these patients, their need for tailored care, the prevalence of dementia in these settings and the substantial evidence reporting poor outcomes for pain assessment and management in dementia as a result of inadequately trained staff (Brunier et al. 1995, Closs 1996, Kovach et al. 2000, Weiner & Rudy 2002, Auret & Schug 2005, Plaisance & Logan 2006, Barry et al. 2012, Ghandehari et al. 2013).

Most respondents believed that learning through case-based discussion and/or mentoring by senior nurses were most likely to stimulate practice development and change. These opportunities needed to be ongoing and developed in consideration of nurses' needs. Participants emphasised that pharmacological training was required, with some expressing concern regarding their lack of understanding of the regimens they administered. This is a key area of practice development given the available evidence regarding inadequate pharmacology knowledge among nursing staff and medication administration errors, omissions and adverse events (McBride-Henry & Foureur 2006, Dilles et al. 2011).

These findings provide new insight into the experiences of nurses across care settings in which patients dying with advanced dementia commonly end their lives and the gap between healthcare policy and clinical recommendations for pain management at end of life. Nurses' experiences revealed a number of barriers to pain management at end of life some of which corroborate those reported in Brörson et al. (2014). In addition, our findings highlight areas across and between settings in which nurses are under-supported and may be inadequately equipped to meet standards expected by policy makers.

The complexity and challenges of pain assessment and management for people with advanced dementia are well-recognised and documented with much of this previous work focused on the experiences of nurses and physicians on whom the responsibility of these assessments usually falls (Passero & McCaffery, 2005; Jordan et al., 2007; Achterberg et al., 2013). To our knowledge, this is the first study which explores HCAs' perspectives and experiences of, and their role in, pain assessment and management for people with advanced dementia approaching the end of life.

HCAs in this study were not required to conduct formal pain assessments for their residents and most reported being unfamiliar with the contents and application of standardised pain assessment tools. However, participants' narratives revealed that most regularly performed informal relationship-centred pain assessments as an inherent part of care provision. Such assessments occur when knowledge and understanding of patients' normative patterns of behaviour, physical and cognitive functioning and past reactions to pain are used to inform recognition and interpretation of behavioural and nonverbal pain cues (Clark et al., 2004). Daily care provision brought HCAs in this study into close physical and social contact with residents, allowing them to develop a comprehensive knowledge and understanding of their care-recipients over time (Stacey 2005; Wilson et al., 2009; Lloyd et al., 2011; Morgan et al., 2016). In most cases, changes in residents' norms prompted HCAs to observe for behavioural and non-verbal indicators of pain and interpret them within contextual knowledge of the resident. Closer analysis revealed that most were performing many of the observations required by standardised assessment tools recommended by healthcare policies for use in this patient population (Abbey et al., 2004; Warden et al., 2003; Department of Health 2009; Department of Health, Social Services & Public Safety, 2011; World Health Organisation, 2012; van der Steen et al., 2014). Participants' knowledge of residents also allowed idiosyncratic expressions of pain to be recognised as such and facilitated distinction of behavioural indicators of pain from non-pain related cues, overcoming a commonly reported difficulty associated with pain assessment in nonverbal patient populations

(Passero & McCaffery, 2005; Jordan et al., 2007). Understanding the residents for whom they cared was perceived to be critical to recognising and reporting pain, illness or distress in these patients, particularly for those unable to self-report. Many participants in this study reported difficulties and limitations in recognising pain in residents with whom they were unfamiliar. Previous research reported similar findings for nurses and certified nursing assistants (CNAs) (Clark et al., 2004). Interestingly, in the present study, most HCAs sought to gain insight into residents' past pain experiences and behaviours through liaison with patients' families, friends and other key health and social care staff. The involvement of families and other key social contacts in pain assessment for patients with severe cognitive impairment and/or dementia for whom self-report is unavailable, has been widely recommended (Fisher et al. 2002; Menten et al., 2004; Herr et al., 2006b; Buffum et al., 2007; Burns et al., 2015b).

Findings in this study illustrated three cases of disparities between HCAs' and nurses' knowledge of residents which may have critical implications for the interpretation of pain scores. The finding reported here suggests that both staff should be present during assessment to allow outcomes to be considered alongside other collateral patient information (Ersek et al., 2010; Ruder, 2010; Regnard et al., 2007). Participants with task-oriented approaches to care were a minority in this study. These staff reported being under-skilled in recognising pain and relied largely on nurses' reports of existing pain to approach care routines with additional caution, rather than attempting to observe for signs of new pain. Previous studies have reported poor patient and staff outcomes which result when healthcare staff lack understanding of the pain experience in people with dementia and are inadequately trained and supported to recognise, assess and manage pain for these patients (Kovach et al., 2000; Nygaard & Jarland, 2005; Kaasalainen et al., 2007; Zwakhelen et al., 2007).

Pain reporting was heavily impacted by the nature of relationships with other healthcare staff. Participants who were openly encouraged and supported to raise and discuss all concerns, including pain, and who felt valued for their contribution to patient care provided detailed reports which expounded their interpretations of observed behaviours (Borrill et al., 2000). These HCAs monitored for and reported back on patient response to analgesia and, without nurse direction, planned care

tasks to allow the benefits of pain relief to manifest before attempting to move, lift or turn patients. Positive work-related identities and relationships with other staff have resulted in improved staff morale, increased confidence and improvements to care quality and patient outcomes [Stacey, 2005; Wilson et al. 2009; Lloyd et al., 2011; Borrill et al. 2000). Negative relationships were reported in cases where professional hierarchies dominated and participants felt ignored or undervalued. Strong in-group identities among HCAs can propagate 'us and them' attitudes leading to negative perceptions of and noticeable professional distance from nursing and medical staff; a finding reported in another study of HCAs in working in dementia care (Lloyd et al., 2011). Pain reporting was severely impacted by negative work-related identities and relationships; in such cases it was at best perfunctory and detail-poor, and at worst uninformative, with participants referring to general ill-health rather than pain. Work-related identity construction is recognised to impact significantly on patient care and outcomes and has been studied extensively using social identity theory (Tajfel, 1978; Tajfel & Turner, 1979; Hogg et al., 2004; Abrams & Hogg, 1988; Hogg & Terry, 2000; Ouwerkerk et al. 1999; Brown, 2000). Negative work-related identities, strong in-group membership and dysfunctional team dynamics are associated with deterioration of collaborative approaches to care and withholding or poor exchange of information, exacerbating the challenges of complex care and resulting in negative outcomes for patients and staff (Lloyd et al., 2011; Royal College of Psychiatrists, 1996; Simpson 2007; Aranda, 2008; Manojlovich, 2010). The impact of the quality of communication between healthcare professionals on patient outcomes has been studied extensively across multiple health conditions including dementia; much of this previous work has focused on nurse-physician interactions (Manojlovich, 2010; Shortell et al., 1991; Donchin et al., 1995). Although this study provides insight into HCA reporting of pain, the findings are limited to their perspectives alone. Future studies may wish to examine nurses' and physicians' experiences of and perspectives on communicating with HCAs, or explore communication dyads and triads among these staff in order to elucidate how information provided by HCAs is received, understood and processed by qualified health professionals. This is particularly important given that tensions in relationships between CNAs and registered nurses have been previously reported (Clark et al., 2004).

Participants expressed frustration and disappointment at being excluded from multidisciplinary meetings with many believing this resulted from stigma regarding their status as unqualified workers. Most believed the benefits of HCA participation in the multidisciplinary team would be reciprocal with all members of the team benefitting from having access to patient information that could inform care practice. Lloyd and colleagues (2011) warn that exclusion may result in HCAs feeling isolated from the wider care team, strengthening in-group identities and lead to difficulties as described above (Lloyd et al., 2011). The importance of inclusivity and teamwork among health professionals is emphasised in a number of health policies and is a required competency of the HCA role (Baker et al., 2006; American Psychiatric Association 1997; National Collaborating Centre for Mental Health, 2006; Department of Health, 2007; Department of Health, 2008; Wolfs et al., 2008). Future research could evaluate the impact of the inclusion of these staff in the multidisciplinary team on patient care and team dynamics, and should include the perspectives and experiences of HCAs as well as other members of the multidisciplinary team.

The large majority of participants believed that ongoing, needs-driven training which actively enhances knowledge and practical skills is required for all professionals and frontline staff involved in the care of people with dementia. Interestingly, the minority of participants who provided sparse answers for other interview questions responded comprehensively when asked whether further training was required. Appropriately educating staff to understand the complexities of dementia care results in better management of the emotional and physical demands of the work, increased engagement with the role and adoption of person-centred approaches to care (Zimmerman et al., 2005). Healthcare policy emphasises a need for all staff (including HCAs) working in dementia to be appropriately educated, trained and equipped to competently provide high quality care but does not suggest appropriate platforms for delivery of this training (Department of Health, 2009; Royal College of Nursing, 2012). Most participants reported that e-learning was unengaging, generic and resulted in little, or no, skills and knowledge development. These findings are reiterations of those in many other studies indicating little progress in this area and suggesting the need for a continued effort towards developing and trialling engaging and appropriate educational programmes for these staff (Morgan et al., 2016;

Ingleton et al., 2011; Devlin & McIlfatrick 2009). Few studies have been completed in this regard; however, positive outcomes for HCAs' confidence, motivation to engage in care and reporting to professionals have been reported following practical skills training in palliative care (Holme & Hart, 2007). Many participants believed that the HCA role could be expanded in dementia care; a sentiment echoed in recent work (Goodwin, 2015). In the current study, most participants (including task-oriented HCAs) expressed significant interest in learning how to monitor for and report on treatment response, side and adverse effects, and how to use and report basic assessments such as the Abbey Pain Scale to standardise and improve the quality of reporting among HCAs. Tools such as the Abbey Pain Scale are simple to use and do not require extensive training; previous work reports no significant difference in the ability of qualified health professionals and unqualified staff working outside the healthcare setting to detect pain in facial expressions (Lautenbacher et al., 2013). However, given the challenges experienced by nursing and other health professionals in the use of these tools, and that assessment scores are often interpreted in conjunction with clinical judgement and collateral information from multiple sources, a number of factors must be considered when exploring an expanded role for HCAs in pain assessment. Firstly there is the question of how training should be delivered, and by whom. Secondly, given the variation in knowledge, skills and competence of HCAs, the process of selecting staff for this expanded role, the selection criteria used and how competence is determined must be considered. The manner in which this might be implemented in clinical practice without duplicating or complicating current use of pain tools and approaches to pain assessment, and without creating and/or exacerbating interdisciplinary tensions, requires careful consideration. Finally, there must be formal, robust evaluation of the use of pain tools by HCAs and the impact on patient care and outcomes, the culture of multidisciplinary working and approaches to end of life care across healthcare settings.

SUMMARY OF FINDINGS AND CONCLUSIONS

The key themes emerging from the healthcare professional interviews are presented in Table 5.

Table 5. 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. General Practitioners [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 require 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 (HCPs) 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 HCP 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.

LIMITATIONS

There are some limitations with this study. The sampling approach may have resulted in a skewed sample of physicians with an interest in, or past experience of, research participation, who felt comfortable talking about professional challenges. We aimed to recruit physicians across acute specialties; the low participation by physicians outside psychiatry (possibly due to staffing pressures and workloads) is an acknowledged limitation. Future studies might consider exploring physicians' approaches to pain management for people with advanced dementia with a broader sample of acute physicians. As with physician participants, the nature of the self-selecting sample may have encouraged participation from nurses with an interest in research and those who felt comfortable describing experiences that included accounts of low confidence or competence, or which provided critical accounts of nursing staff and/or care organisations. Nursing home staff comprised 50% of the total sample. However, within whole-group analyses, nursing home nurses' experiences did not differ substantially from those of acute care and hospice nurses, and in other cases, their experiences reflected those of acute care nurses suggesting that the core themes emerging are not substantially biased to the nursing home context. It is acknowledged that acute care nurses were recruited from care of the elderly units linked to teaching hospitals and are likely to display greater awareness of pain in dementia than acute care nurses working in other wards. The findings reported here represent the commonalities of experience and perspectives of this participant sample, drawn from three different care settings and are likely to be reflective of nurses working with the same patient population in the same contexts of care (Mays & Pope, 1995).

Although we aimed to recruit for maximum variation among participants, recruitment relied on contacting participants through networks established by members of the PMG. Acute and hospice care settings in this study are linked to teaching hospitals and a university; therefore it is likely that staff are better aware of pain in people with dementia than those in settings without connections to academic teaching and research. The majority of HCAs were recruited from nursing home settings; the shortfall of HCAs from acute care reflects the difficulties in interviewing staff working

in this setting, whilst limited numbers recruited from hospice resulted from low take up of participation among these staff despite attempts to publicise the study in these organisations. Although data analysis did not identify significant difference between perspectives and experiences across care settings for most findings, negative relationships were only reported in the nursing home setting. Future studies may wish to expand on this study using a broader selection of HCAs across settings. 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. However, whilst findings related to specific elements of pain assessment and management may reflect more instances of best practice than general practice among HCAs, many of the general principles regarding the way these elements are impacted by social and group identities, dynamics and relationships are supported by other studies of staff working in palliative and dementia care and other patient populations.

PHASES II AND III: INTERVENTION DEVELOPMENT AND PILOTING

The findings from Phase I indicated that training and ongoing continuing professional development was an important and recurring theme in both pain assessment and management. Given the challenges with using existing pain assessment tools, HCPs did not believe that development of another tool would help with meet the barriers to pain assessment and management. Healthcare professionals' interviews elicited specific information regarding health professionals' ideas for optimal training and educational approaches in this area. This covered training needs, substantive knowledge requirements, training regularity, accessibility, preferred methods and formats of delivery and ideal trainer attributes. All respondents expressed a strong preference for case-based learning led by a health professional with clinical experience of the patient population. Physicians preferred this to be delivered by physicians; nurses however, indicated willingness to be trained by physicians provided such training was relevant to nursing practice and did not focus exclusively on physician-specific domains. Healthcare assistants wished to participate in face-to-

face training with other health professionals rather than completing online training packages. Physicians and nurses collectively identified a need for further training in the following areas: recognition and interpretation of behavioural and non-verbal indicators of pain and differentiation of these from BPSD, available routes of administration in patients dying with dementia, assessing treatment response, side-effects/adverse effects of analgesia, opioid use, moving beyond the analgesic ladder, pharmacology (physicians) and pharmacotherapeutics (nurses/HCAs) in palliative care, and non-pharmacological approaches to pain management.

Health professionals in this study routinely shared and exchanged knowledge and skills across specialities and care-setting to meet the challenges in assessment and management of pain for patients with dementia. However, in this study, knowledge networks were often informal and knowledge exchange accessed on an ad-hoc basis as and when the need arose. Participants expressed a preference for an established forum through which knowledge and skills may be formally exchanged between primary, secondary, hospice and community care.

This practice of sharing knowledge and expertise, often known as knowledge networks, communities of practice or communities of care, has long-been an integral feature of medical and nursing education and practice and is essential for the exchange and trade of information, knowledge and skills across care settings, specialities and the professions which work within healthcare (Wenger et al., 2011). Communities of practice are becoming ever-important in a time in which rapid and significant developments in medical innovation, surgery, pharmacology, medical technology and clinical practice are occurring and in which pressures on organisational resources and patient care are significantly increasing. In such times, health professionals must keep abreast of policy changes, clinical recommendations and a growing evidence-base for practice change whilst attending to the detail of daily work (Wenger et al., 2011; Kahnum et al., 2016).

Interest in teleconferencing and digital technologies in healthcare has bloomed since the late nineties with increasing focus directed towards the use of digital innovations to assist health professionals to meet the challenges of modern medical and nursing practice (Kearney et al., 1998; Affara et al., 2001; American Nurses Association, 2001; Jenkins and White 2001; Washer et al., 2002; Van de Castle et al., 2004; Li &

Wilson, 2006; Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Ferguson, 2013; Arora et al., 2014). Teleconferencing technologies such as Skype, FaceTime, Zoom Conferencing as well as some forms of social media have been of considerable interest given that they are ubiquitous in modern life and remove difficulties associated with geographical distances and the economic burdens of travel, time and financial resources (Kearney et al., 1998; Affara et al., 2001; American Nurses Association, 2001; Jenkins & White, 2001; Washer et al., 2002; Van de Castle et al., 2004; Li & Wilson, 2006; Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Ferguson, 2013; Arora et al., 2014).

Several studies have reported positive outcomes for nursing practice including improvements in care provision, upskilling and knowledge development (Kearney et al., 1998; Jenkins and White, 2001; Crawford et al., 2010). In the UK, the Information Systems for European Nursing Care (WISECARE), evaluated and reported positive outcomes with the use of then state-of-the-art technology in standardising nursing practice in cancer across Europe (Kearney et al., 1998; Sermeus et al., 2000). The use of teleconferencing and digital technologies has also resulted in the spread of clinical expertise, often concentrated in urban areas with links to teaching and research facilities and in specialist care, to primary care providers and to health professionals working in rural areas (Jenkins and White, 2001; Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014).

One such digital innovation, Project ECHO® (Extension for Community Healthcare Outcomes) has achieved increasing interest since its launch in 2003 and the publication of the first results in 2010 (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014). This distance health education model uses teleconferencing technology to connect HCPs across multiple settings and disciplines in real time clinics. Its “hub and spoke” model, in which the ‘hub’ comprises the central physical location from which a specialist team hosts the clinic and the ‘spokes’ are HCPs who dial in remotely from their workplace facilitates information exchange and transfer of specialist knowledge from secondary care specialists to primary care providers (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014). Based on the principles of ‘trading zones’ and interactional expertise, the model offers health professionals access to specialist

knowledge, skills and tools, breaks down disciplinary and care setting silos and boundaries and moves professionals towards personal and professional development rather than reliance on doctrine (Galison 2010, Goreman 2010).

In consideration of the outcomes of this 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 clinical knowledge and self-efficacy needs identified by health professionals in Phase I.

The Project ECHO® (Extension for Community Healthcare Outcomes) Model

Project ECHO® 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). Project ECHO®, originally developed at the University of New Mexico (UNM) in Albuquerque, was designed to provide primary care physicians access to secondary care specialist knowledge and expertise in real-time to facilitate the co-management of complex cases of hepatitis C virus in rural, primary care settings, overcoming financial and time restrictions and avoiding lengthy waiting times for referral to secondary care (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2014). It uses a 'hub and spoke' model' (Figure 3), 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. These healthcare professionals typically include physicians, nurses and other health and allied health professionals working in areas relevant to the topic of the clinic.

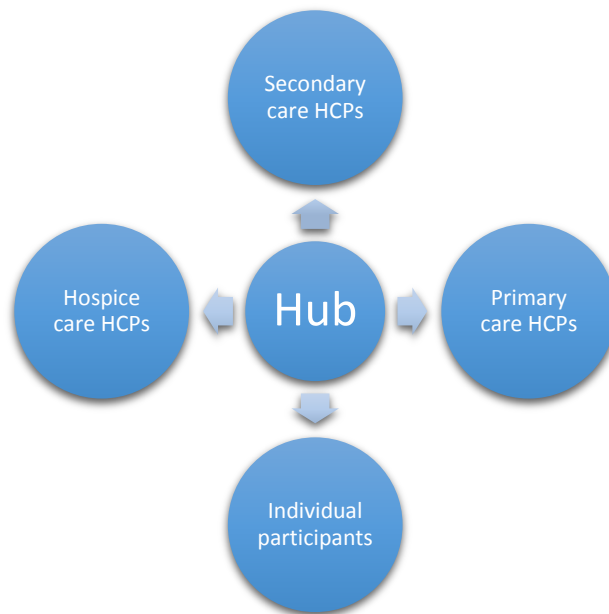


Figure 3. ECHO 'hub and spoke' model.

A typical ECHO clinic is illustrated in Figure 4. In this case, the 'hub' comprised the secondary care hepatology team; the left screen typically displays thumbnails of all clinic participants, the right screen displays the current speaker or learning materials (i.e. PowerPoint presentations, graphs etc.).



Figure 4. Project ECHO Hepatitis C Virus clinic (<http://echo.unm.edu/>)

ECHO clinics are held weekly or monthly as needed and are typically two hours in duration. Clinic membership is determined by the health condition and/or patient population on which clinics are focused (e.g. dementia, cancer etc.), and clinic participants drive curriculum development. 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).

The underlying philosophy of ECHO is the promotion and facilitation of cross-population of knowledge between professionals across specialties and care settings through a sustainable, effective and cost and time-effective system. ECHO has been trialled and evaluated across a range of health conditions and has demonstrated continued success in increasing substantive knowledge and professional self-efficacy, improving patient outcomes and promotion of primary and secondary care integration (Arora et al., 2010; Arora et al., 2011a; Arora et al., 2011b; Arora et al., 2014; Harkins et al., 2011; Burdette Mendonca, 2012; Masi et al., 2012; Scott et al., 2012; Katri et al., 2013; Cahana et al., 2013; Katzman et al., 2014; White et al., 2015; White et al., 2016).

PROJECT ECHO NORTHERN IRELAND

The Project ECHO Northern Ireland (Project ECHO NI) superhub is commissioned by the Health and Social Care Trust Business Services Organisation (HSC BSO)

and is located at and hosted by, Northern Ireland Hospice (NI Hospice). At the time of the study, HSC BSO had commissioned a number of ECHO trials in ophthalmology, diabetes, dermatology, nursing home care, General Practitioner (GP) training and with informal and family carers of people receiving palliative care (the evaluation of this programme has subsequently been published by White et al., [2016]). NI Hospice also provides training and support to other organisations across the United Kingdom (UK) and Europe who wish to become ECHO partners.

Members of the PMG had previously hosted (MW), facilitated (MW) and evaluated (MW, SMc) existing ECHO trials; others (CP, KB, BDWJ) had attended one or more ECHO clinics. The PMG, in consideration of the outcomes of current trials and the findings of Phase I, discussed and agreed to utilise the Project ECHO model as the basis of the proposed intervention aimed at addressing the clinical knowledge and self-efficacy needs identified by health professionals in Phase I.

ECHO[®] CLINIC COSTS

The Project ECHO[®] Model has been described as a low-cost, high impact model which can be adapted to meet the needs and resources of different communities and populations. At a time when health care providers are under mounting pressure to do more and spend less, it has been suggested that this model provides an affordable solution to addressing growing need in the UK in training and supporting healthcare professionals (White et al., 2016). Costs associated with establishing the hub include the purchase of a dedicated PC with appropriate video card for two screens, two large televisions and a videoconferencing camera such as the Logitech Conference Cam CC3000e videoconferencing camera (approximately £600). The Zoom Pro teleconferencing software package, which would be sufficient for a hub to facilitate up to 100 participants, costs approximately £12 per month. A further key requirement is a broadband connection capable of streaming a video from the internet without too much stuttering. Depending on numbers at the spoke, most modern handheld device with speakers and microphones are able to connect to the hub via Zoom software. Alternatively, a laptop or PC with a plug and play camera, microphone and speakers

is required. If it is likely that a group of more than three will be using the spoke consistently then a bigger screen and a camera with a wider field of vision would be required. Costs for participants at the spokes is therefore minimal.

PHASE II INTERVENTION DEVELOPMENT

The Project ECHO[®] model requires participants to attend and engage in a pre-ECHO workshop; this serves to familiarise participants with the model, enables trust relationships between the spokes and the hub to form and provides an opportunity for participants to design the curriculum. The pre-ECHO workshop is not seen as formality but rather as a critical and important part of developing the ‘community of care’ on which the model relies.

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 **P**ain in **A**dvanced **D**ementia (TEAM Pain AD) teleECHO workshop. An introductory email, workshop flyer and the TEAM Pain AD teleECHO clinic information sheet were disseminated via the following routes:

- PMG members, who disseminated the information to relevant colleagues and other contacts as appropriate
- the Health and Social Care Dementia Strategy Implementation Group (DSIG)
- HSC Research and Development Division (HSC R&D)
- Medical and Nursing Directors in hospices
- local collaborators (consultant physicians) in each of the five HSC trusts
- care home managers in nursing and residential care homes

AIMS AND OBJECTIVES OF TELEECHO WORKSHOP

The aims and objectives of the teleECHO workshop were as follows:

- To disseminate findings of Phase I (qualitative interview study)
- To present the proposed intervention: Telementoring to Enhance Assessment and Management of Pain in Advanced Dementia (TEAM Pain AD)
- To elicit input into and feedback on the proposed intervention (to identify the finer details of intervention; specifically to consider curriculum development, clinic frequency (i.e. weekly, monthly), clinic duration and evaluation measures, and gauge interest among health professionals regarding facilitating and/or leading didactic teaching in clinics

Delegates were also advised that they could register their interest in participating in the TEAM Pain AD teleECHO clinics.

WORKSHOP

Forty-two people registered to attend the workshop held on 28th April 2016 in the NI Hospice Training and Education Centre, then based at Jennymount Business Park, Belfast. Twenty-one healthcare professionals (excluding PMG members) attended in person or via teleconferencing. Attendees were health professionals (doctors [n=11], nurses [n=9] and pharmacists [n=1]) from psychiatry, general practice, geriatric medicine, care of the elderly, pharmacy, palliative medicine and pain specialists representing primary, secondary, nursing home, community and hospice care settings. Table 6 provides further details of the healthcare professionals who participated in this workshop.

Table 6. Characteristics of pre-ECHO workshop participants

Healthcare professional	Area of clinical practice	Setting	Number participating in pre-ECHO workshop
Nurse	Palliative care	Hospice	5
Nurse	Dementia	Hospital	3
Nurse	Pain	Hospital	1
Physician	Palliative care	Hospice	3
Physician	Palliative care	Hospital	1
Physician	General Practice	Primary care/community	2
Physician	Psychiatry	Hospital/secondary care	3
Physician	Geriatrics	Hospital/secondary care	1
Physician	Pain	Hospital/secondary care	1
Pharmacist	Pharmacy and Medicines Management	Health and Social Care Board	1

The workshop commenced with presentations by CP and MW that covered the following:

- the findings of Phase 1
- 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 1

- 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 as follows:

Table 7: Curriculum for TEAM Pain AD teleECHO clinics

Date	Topic, facilitator and didactic teaching details
01 June 2016	<p>Managing challenges of routes of administration in pain management for people with advanced dementia (inc. managing non-compliance) + patient case discussion</p> <p>Didactic specialist: Dr Pamela Bell (Pain Alliance Northern Ireland)</p> <p>Facilitators: Dr Carole Parsons and Prof. Max Watson</p>
8 June 2016 (subsequently rescheduled to 6 July 2016)	<p>Non-pharmacological aspects of pain management in advanced dementia (inc. working with families, managing BSPD and distress) + patient case discussion</p> <p>Didactic specialist: Ann Scott , Specialist Registered Mental Health Nurse, South Eastern Health and Social Care Trust (retired)</p> <p>Facilitator: Dr Carole Parsons</p>
15 June 2016	<p>Pain assessment in advanced dementia (inc. diagnosing pain, integrating pain assessment tools into clinical practice, clinical utility, limitations and practicality of assessment tools) + patient case discussion</p> <p>Didactic specialist: Professor Brian McGuire, Professor of Clinical Psychology and Co-Director of Centre for Pain Research – National University of Galway, Ireland</p> <p>Facilitator: Dr Carole Parsons</p>
22 June 2016	<p>Pharmacology in advanced dementia (inc. polypharmacy, drugs to avoid, identifying and managing side and adverse effects) + patient case discussion</p> <p>Didactic specialist: Professor Peter Passmore, Consultant Geriatrician, Centre for Public Health, Queen’s University Belfast</p> <p>Facilitator: Dr Carole Parsons</p>
29 June 2016	<p>Differentiating the behavioural indicators of pain from anxiety, agitation and other non-pain related behaviours in dementia + patient case discussion</p> <p>Didactic specialist: Dr Conor Barton, Consultant Old Age Psychiatrist, Mater Hospital, Belfast Health and Social Care Trust</p> <p>Facilitator: Dr Carole Parsons</p>

A number of participants committed to providing didactic training, patient cases and facilitation for clinics at the workshop; however, others were approached after the curriculum was decided at the workshop.

PHASE III PILOT OF TEAM PAIN AD TELEECHO CLINICS

Project ECHO® clinics follow a standardised structure and protocol; these have been approved for use by HSC BSO for the purpose of delivering professional mentoring and education to health professionals. TEAM Pain AD teleECHO clinics were developed as detailed above and in accordance with protocols and guidance provided by the NI Hospice Training and Education team who manage Project ECHO NI.

AIM AND OBJECTIVES OF TELEECHO CLINIC EVALUATION

AIM

To evaluate the impact of a needs-driven curriculum and novel model of professional-to-professional telementoring on health professionals' self-reported clinical knowledge and self-efficacy in pain assessment and management in advanced and end-stages of dementia.

OBJECTIVES

The specific objectives of the evaluation were as follows:

- to analyse physicians', nurses' and HCAs' scores from self-reported pre-, post- and retrospective-pre-teleECHO evaluations of clinical knowledge and self-efficacy in pain assessment and management in advanced and end-stages of dementia

- to explore participants' experiences of teleECHO professional mentoring and its perceived impact on practice change
- to evaluate the feasibility and utility of establishing a teleECHO Pain Clinic to cover pain management across health conditions and patient populations.

STUDY OUTCOMES

Primary outcome: to evaluate and report on 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.

Secondary outcome: to examine the utility of the teleECHO Pain Clinic to cover pain management across health conditions and patient populations.

CLINIC MEMBERSHIP

TEAM Pain AD teleECHO clinic membership included: physicians, nurses, HCAs and other health and allied health professionals (such as 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 exact composition of each clinic was determined by the curriculum and topic being discussed.

PRE-TELEECHO CLINIC ADMINISTRATION

The research fellow (BDWJ) arranged for the download and installation of ECHO software for participants (Zoom Web Conferencing software, Zoom Video Communications, Inc, USA). Information technology (IT) support was provided by the

NI Hospice Project ECHO NI technician. Logitech Video Conferencing Cameras (for 2 or more members at spoke venues) and Plug n' Play detachable cameras (approved for this use by HSC BSO) were provided to participants.

Curriculum topics were circulated by email to all health professionals who registered for participation in the TEAM Pain AD teleECHO clinics; participants were asked to identify clinics at which they wish to present a patient case.

TELEECHO CLINIC STRUCTURE

Clinics were led by the principal investigator (CP) who undertook facilitator training with NI Hospice. 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. Participants signed out and the clinic link closed.

Clinics were digitally recorded using video with audio. Informed consent was deemed to have been given on participation in the clinic. HSC BSO has approved this use of audio-visual data for training purposes.

PARTICIPANTS OF TEAM PAIN AD TELEECHO CLINICS

Numbers and types of healthcare professionals participating in each of the five teleECHO clinics are detailed in Table 8.

Table 8. Characteristics of healthcare professionals participating in each of the TEAM Pain AD teleECHO clinics.

Healthcare professional	Area of clinical practice	Setting of clinical practice	ECHO 1 (N)	ECHO 2 (N)	ECHO 3 (N)	ECHO 4 (N)	ECHO 5 (N)
Healthcare assistant	Nursing home	Nursing home	3	0	1	0	
Nurse	Dementia	Secondary care	1	2	3	2	2
Nurse	Nursing home	Nursing home	1	1	4	3	1
Nurse	Nurse Education	Secondary care	0	1	0	0	0
Nurse	Mental Health	Secondary care	0	1	0	6	3
Nurse	Palliative care	Hospice	6	3	4	5	7
Nurse	Palliative care	Secondary care	0	0	1	0	0
Nurse	Pain	Secondary care	1	0	1	0	0
Occupational Therapist	Dementia	Secondary care	0	1	0	1	0
Pharmacist	Pharmacy and Medicines Management	Health and Social Care Board	1	2	0	0	
Physician	General Practice	Hospice	0	0	1	0	1
Physician	General Practice	Primary care	0	3	3	0	0
Physician	Pain	Secondary care	1	0	1	0	0
Physician	Palliative care	Hospice	2	0	1	1	0
Physician	Palliative care	Secondary care	1	0	0	0	0
Physician	Geriatrics	Secondary care	0	1	0	2	1
Physician	Psychiatry	Secondary care	0	3	1	3	3
Social worker	Mental Health	Secondary care	0	0	0	1	0
Total			17	18	21	24	18

PARTICIPANTS OF TEAM PAIN AD TELEECHO EVALUATION

Participants were physicians, nurses and HCAs who participated in the TEAM Pain AD teleECHO clinics. Other health and allied health professionals such as speech and language therapists, occupational therapists, pharmacists who attended clinics provided feedback on the clinics. However, they were not asked to complete the clinical knowledge and self-efficacy evaluations nor were they invited to participate in the focus group.

SAMPLING

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.

RECRUITMENT

Physicians, nurses and HCAs were informed of the evaluation component and of the focus group at the TEAM Pain AD teleECHO workshop. Information regarding the self-reported evaluation of clinical knowledge and self-efficacy and the focus group was included in the TEAM Pain AD teleECHO Evaluation and Focus Group Information Sheet included in the workshop delegate information pack.

Participants were advised in the information sheet, and were reminded verbally during the TEAM Pain AD teleECHO clinics, that the purpose of the self-reported evaluations and the focus group was to evaluate the efficacy and utility of the teleECHO model and curriculum, and not to evaluate participants' competence or ability in their job role.

The facilitator reminded participants that participation in the evaluations and focus group was voluntary and that participants could withdraw at any time. A reminder was given that all data and completed evaluation forms submitted until the point of withdrawal would remain in the study as evaluations are anonymous and it would not be possible to link any specific form with any individual participant. This information was stated in the participant information sheet.

DATA COLLECTION AND ANALYSIS

The following data were collected from the TEAM Pain AD teleECHO clinics:

- participant characteristics
- curriculum topics
- total number of participants per clinic
- attendee type per clinic

EVALUATIONS

PRE-, POST- AND RETROSPECTIVE-PRE-TELEECHO EVALUATIONS

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). The retro-pre-ECHO is a standard approach to evaluation in the ECHO model recommended by the original content developers and NI Hospice. Post-teleECHO and retrospective-pre-teleECHO online evaluations (Appendix 2) were disseminated at the end of the final teleECHO clinic and two focus groups held after the final TEAM Pain AD teleECHO clinic (July 2016 and September 2016). Submission of completed evaluation forms was deemed to constitute consent to participate in the questionnaire evaluation, and written consent was obtained for participants of the focus groups.

THE TELEECHO EVALUATION FORM: PHYSICIAN VERSION

The teleECHO evaluation form was divided into three sections; the first, comprised 14 items rated on a 5-point Likert type scale (range: 1=Strongly Disagree to 5=Strongly Agree) measuring self-reported evaluation of clinical knowledge and self-efficacy in pain assessment and management in advanced dementia nearing end of life. Participants were asked to complete this section in the pre- and retro-pre teleECHO evaluations.

Section two comprised 17 items rated on a 5-point Likert type scale (range: 1=Strongly Disagree to 5=Strongly Agree) evaluating participants' experiences of the teleECHO curriculum and model of telementoring, its perceived impact on clinical knowledge and self-efficacy and perceptions of the utility and future continuation of teleECHO clinics. Participants were asked to complete this section in the post-teleECHO evaluation.

Section three comprised an open-response/free text response which asked participants for their views and suggestions on the teleECHO model. Participants were asked to complete this section in the post- teleECHO evaluation.

TELEECHO EVALUATION FORM: NURSE VERSION

This form was divided into three sections as per the physician version; however, items in the first section (clinical knowledge and self-efficacy) differed to reflect the role of nurses in pain assessment and management. Section two (evaluation of TEAM Pain AD teleECHO and curriculum) contained 18-items. As with the physician version of the evaluation, participants were asked to complete section one to assess self-reported clinical knowledge and self-efficacy in the pre- and retro-pre teleECHO evaluations, but sections two and three were completed for the post-teleECHO evaluation only.

TELEECHO EVALUATION FORM: HEALTHCARE ASSISTANT VERSION

This version comprised three sections as per physician and nurse versions; however, section one (clinical knowledge and self-efficacy) comprised 7 items and section two 18 items. The shorter questionnaire length reflected the remit of the HCA role. Again, participants were asked to complete section one to assess self-reported clinical knowledge and self-efficacy in the pre- and retro-pre teleECHO evaluations, but sections two and three were completed for the post-teleECHO evaluation only.

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 $p=0.05$.

FOCUS GROUP DATA COLLECTION AND ANALYSIS

Physicians, nurses and HCAs were invited to participate in a focus group held using the same teleconferencing format as the TEAM Pain AD teleECHO clinics. The focus group explored physicians', nurses' and HCAs' experiences of the TEAM Pain AD teleECHO pain clinics. A topic guide (Appendix 3) 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 health conditions and patient populations).

Focus group discussions were video-recorded and audio data was 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).

METHODOLOGICAL VALIDATION

Data analysis was conducted by the research fellow (BDWJ). As with previous phases of the study, independent analysis was conducted by CP and the final findings presented to and discussed with all members of the PMG.

DATA STORAGE

Data from evaluation forms were downloaded from Survey Monkey and stored on a password-protected computer. Focus group consent forms are stored separately to evaluation forms in locked filing cabinets in the School of Pharmacy, Queen's University Belfast for a period of 5 years after the end date of the research, after which they will be securely destroyed.

EDUCATIONAL GOVERNANCE

We sought educational governance 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 for this phase of the research and confirmed that Trust permissions for the inclusion of secondary care health professionals in this study were not required.

RESULTS

PRE-ECHO EVALUATIONS

Seven physicians completed the pre-teleECHO knowledge and efficacy evaluation, representing old age psychiatry (n=4), palliative medicine (n=2), and geriatrics/care of the elderly (n=1). Four respondents were specialty doctors, and the remaining three held consultant posts. Years in medical practice ranged from 6 to 39 (mean=18 years). All but one respondent practised in secondary care (n=6), with the remaining participant practising in the hospice setting (n=1).

Ten nurses completed the Nurse version of the pre-teleECHO knowledge and efficacy evaluation, representing the following specialties: dementia (n=4); palliative care (n=3); care of the elderly (n=1); mental health services for older people (n=1); and pain management (n=1). Respondents defined their staff grade as follows: Band 6 (n=2); nurse (n=1); registered nurse (n=1); ward sister (n=1); staff nurse (n=2); nurse manager (n=1); clinical manager (n=1); or specialist palliative care sister (n=1). Years in practice ranged from 5 to 38 (mean=24.1years). Two respondents worked in primary care, three in secondary care, three in hospice and the remaining participants worked in a residential care home (n=1) and a memory clinic in secondary care (n=1).

One HCA completed the HCA version of the pre-teleECHO knowledge and efficacy evaluation. This nurse worked in care of the elderly, and had practised for 24 years. Further details of the setting in which this respondent worked have not been included to preserve anonymity.

Responses to each of the statements in each version of the pre-ECHO questionnaire are detailed in Tables 9-11 overleaf.

PHYSICIANS

Table 9. Pre-ECHO questionnaire responses for physician respondents (n=7)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	1 (14.3)	1 (14.3)	5 (71.4)	0 (0)
2. I feel confident establishing a pain diagnosis for patients with advanced dementia nearing the end of life	0 (0)	1 (14.3)	2 (28.6)	4 (57.1)	0 (0)
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	1 (14.3)	4 (57.1)	2 (28.6)	0 (0)
4. I feel confident prescribing for pain in patients with advanced dementia nearing the end of life	0 (0)	2 (28.6)	2 (28.6)	3 (42.9)	0 (0)
5. I feel confident prescribing for and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	2 (28.6)	3 (42.9)	2 (28.6)	0 (0)
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	1 (14.3)	4 (57.1)	2 (28.6)	0 (0)
7. I feel confident prescribing analgesia for administration by syringe driver in advanced dementia at end of life	1 (14.3)	3 (42.9)	1 (14.3)	2 (28.6)	0 (0)
8. I feel confident prescribing analgesia for intravenous (IV) administration in advanced dementia at end of life	2 (28.6)	2 (28.6)	2 (28.6)	1 (14.3)	0 (0)
9. I feel confident prescribing transdermal analgesics in advanced dementia at end of life	0 (0)	4 (57.1)	0 (0)	3 (42.9)	0 (0)
10. I feel confident prescribing analgesia for subcutaneous administration in advanced dementia at end of life	1 (14.3)	3 (42.9)	0 (0)	3 (42.9)	0 (0)
11. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	1 (14.3)	0 (0)	3 (42.9)	3 (42.9)	0 (0)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
12. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	3 (42.9)	2 (28.6)	2 (28.6)	0 (0)
13. I feel confident I am using best-practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	3 (42.9)	3 (42.9)	1 (14.3)	0 (0)
14. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	3 (42.9)	2 (28.6)	2 (28.6)	0 (0)

NURSES

Table 10. Pre-ECHO questionnaire responses for nurse respondents (n=10)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	4 (40)	4 (40)	1 (10)
2. I feel confident reporting pain in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	2 (20)	6 (60)	1 (10)
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	3 (30)	2 (20)	4 (40)	1 (10)
4. I feel confident administering analgesia by syringe driver to patients with advanced dementia nearing the end of life	0 (0)	0 (0)	0 (0)	0 (0)	2 (100)*
5. I feel confident administering analgesia by intravenous routes to patients with advanced dementia nearing the end of life	0 (0)	0 (0)	0 (0)	2 (100)*	0 (0)
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	0 (0)	2 (20)	8 (80)	0 (0)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
7. I feel confident suggesting alternative formulations of analgesia when oral route is unavailable	0 (0)	2 (20)	0 (0)	7 (70)	1 (10)
8. I feel confident recognising and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	3 (30)	2 (20)	5 (50)	0 (0)
9. I feel confident discussing cases of unresolved pain following administration of analgesia with doctors for patients with advanced dementia nearing the end of life	0 (0)	2 (20)	2 (20)	5 (50)	1 (10)
10. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	0 (0)	2 (20)	3 (30)	5 (50)	0 (0)
11. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	3 (30)	2 (20)	5 (50)	0 (0)
12. I feel confident I am using best practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	5 (50)	4 (40)	0 (0)
13. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	6 (60)	4 (40)	0 (0)

* 2 respondents administered analgesia to patients with advanced dementia nearing the end of life via syringe driver or intravenous routes and could therefore respond to statements 4 and 5 respectively.

HEALTHCARE ASSISTANTS

Table 11. Pre-ECHO questionnaire responses for HCA respondents (n=1)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel confident recognising pain in patients with advanced dementia nearing the end of life	0	0	0	1 (100)	0
2. I feel confident reporting pain in patients with advanced dementia nearing the end of life	0	0	0	1 (100)	0

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
3. I feel confident identifying pain from challenging behaviour in patients with advanced dementia nearing the end of life	0	0	0	1 (100)	0
4. I feel confident discussing pain assessment with doctors	0	0	0	1 (100)	0
5. I feel confident discussing pain management with doctors	0	0	0	1 (100)	0
6. I feel confident discussing pain assessment with nurses	0	0	0	1 (100)	0
7. I feel confident discussing pain management with nurses	0	0	0	1 (100)	0

POST-ECHO AND RETRO-PRE ECHO EVALUATIONS

Thirteen physicians completed the post and retro-pre teleECHO evaluations, of whom six were male and seven female. Respondents represented the following medical areas or specialties: geriatrics/care of the elderly (n=3); general practice (n=6); palliative medicine (n=3) and psychiatry (n=1). Two respondents were specialty grade physicians, five held consultant posts, and the remainder were general practitioners. Years in medical practice ranged from 4 to 35 (mean=24.2 years). Four respondents practised in secondary care, six practised in GP surgeries, two in the hospice setting and one in both hospital and community settings.

PHYSICIANS

Although 13 physicians completed the demographic questions for the post- and retro-pre teleECHO evaluations, three did not indicate their level of agreement with any of the statements in the post- and retro-pre evaluation sections. These non-responders were all general practitioners. In the tables below, the total number of respondents has been amended to 10, to take account of these non-responses.

POST-ECHO EVALUATION

Table 12. Post-ECHO questionnaire responses for physician respondents (n=10)

	Number (%) of respondents selecting				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Participation in the TEAM Pain AD teleECHO clinics has developed my clinical knowledge in pain assessment in advanced dementia	0 (0)	0 (0)	2 (20)	5 (50)	3 (30)
2. Participation in the TEAM Pain AD teleECHO clinics has developed my clinical skills in pain assessment in advanced dementia	0 (0)	0 (0)	2 (20)	6 (60)	2 (20)
3. Participation in the TEAM Pain AD teleECHO clinics has developed my clinical knowledge in pain management in advanced dementia	0 (0)	0 (0)	0 (0)	6 (60)	2 (20)
4. Participation in the TEAM Pain AD teleECHO clinics has developed my clinical skills in pain management in advanced dementia	0 (0)	0 (0)	2 (20)	7 (70)	1 (10)
5. Did you present a patient case at a TEAM Pain AD teleECHO clinic? IF YES: I am confident/comfortable presenting patient cases during TEAM Pain AD teleECHO clinics	0 (0)	0 (0)	0 (0)	4 (100)	0 (0)
Presenting a patient case in the TEAM Pain AD teleECHO clinics benefitted the patient in my care	0 (0)	0 (0)	0 (0)	2(50)	2(50)
IF NO: I would be confident/ comfortable presenting patient cases during TEAM Pain AD teleECHO clinics	0 (0)	0 (0)	1 (16.7)	3 (50)	2 (33.3)
I learned from providers who present their patient cases during TEAM Pain AD teleECHO clinics	0 (0)	0 (0)	0 (0)	5(83.3)	1(16.7)
6. I apply knowledge learned in TEAM Pain AD teleECHO clinics to other patients who have similar symptoms in my care	0 (0)	0 (0)	3 (30)	6 (60)	1 (10)
7. I teach other clinical staff what I have learned in TEAM Pain AD teleECHO clinics	0 (0)	0 (0)	3 (30)	6 (60)	1 (10)
8. Access to specialist expertise and consultation is an important area of need for me and my care staff team	0 (0)	0 (0)	0 (0)	7 (70)	3 (30)
9. Collaboration with specialists and physicians from other specialties has been a benefit to my clinical practice	0 (0)	0 (0)	0 (0)	7 (70)	3 (30)
10. Access to expertise in pharmacology has benefitted my clinical knowledge and practice	0 (0)	0 (0)	0 (0)	6 (60)	4 (40)

	Number (%) of respondents selecting				
	Strongly Disagree		Neither Agree nor Disagree	Agree	Strongly Agree
11. Access to expertise in behaviour and mental health has benefitted my clinical knowledge and practice	0 (0)	0 (0)	0 (0)	5 (50)	5 (50)
12. TEAM Pain AD teleECHO clinics have improved the way that health professionals communicate with each other about pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (20)	4 (40)	4 (40)
13. Learning about complex chronic disease through participation in TEAM Pain AD teleECHO clinics is an effective way to enhance clinical knowledge and skills	0 (0)	0 (0)	0 (0)	6 (60)	4 (40)
14. Case-based learning as the focus for discussion is an impactful way of learning	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)
15. Didactic sessions during TEAM Pain AD teleECHO clinics were an effective way for me to develop my clinical knowledge and skills	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)
16. I would continue to attend TEAM Pain AD teleECHO clinics for pain assessment and management in dementia	0 (0)	0 (0)	0 (0)	6 (60)	4 (40)
17. I believe that TEAM Pain AD teleECHO clinics should be continued for pain assessment and management in other conditions	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)

RETRO-PRE ECHO EVALUATION

Table 13. Retro-Pre-ECHO questionnaire responses for physician respondents (n=10)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)
2. I feel confident establishing a pain diagnosis for patients with advanced dementia nearing the end of life	0 (0)	0 (0)	0 (0)	8 (80)	2 (20)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	4 (40)	4 (40)	2 (20)
4. I feel confident prescribing for pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)
5. I feel confident prescribing for and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	0 (0)	1 (10)	7 (70)	2 (20)
7. I feel confident prescribing analgesia for administration by syringe driver in advanced dementia at end of life	0 (0)	0 (0)	1 (10)	6 (60)	3 (30)
8. I feel confident prescribing analgesia for intravenous (IV) administration in advanced dementia at end of life	2 (20)	1 (10)	3 (30)	2 (20)	2 (20)
9. I feel confident prescribing transdermal analgesics in advanced dementia at end of life	0 (0)	0 (0)	0 (0)	6 (60)	4 (40)
10. I feel confident prescribing analgesia for subcutaneous administration in advanced dementia at end of life	0 (0)	0 (0)	0 (0)	7 (70)	3 (30)
11. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	7 (70)	2 (20)
12. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	7 (70)	2 (20)
13. I feel confident I am using best-practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	0 (0)	7 (70)	2 (20)
14. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	0 (0)	7 (70)	2 (20)

Table 14. Pre- and retro-pre teleECHO evaluations for physician respondents (n=7 pre-ECHO evaluation, n=10 retro-pre ECHO evaluation)

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (14.3)	0 (0)	1 (14.3)	1 (10)	5 (71.4)	6 (60)	0 (0)	3 (30)
2. I feel confident establishing a pain diagnosis for patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (14.3)	0 (0)	2 (28.6)	0 (0)	4 (57.1)	8 (80)	0 (0)	2 (20)
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (14.3)	0 (0)	4 (57.1)	4 (40)	2 (28.6)	4 (40)	0 (0)	2 (20)
4. I feel confident prescribing for pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (28.6)	0 (0)	2 (28.6)	1 (10)	3 (42.9)	6 (60)	0 (0)	3 (30)
5. I feel confident prescribing for and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (28.6)	0 (0)	3 (42.9)	1 (10)	2 (28.6)	6 (60)	0 (0)	3 (30)

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-Pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	0 (0)	1 (14.3)	0 (0)	4 (57.1)	1 (10)	2 (28.6)	7 (70)	0 (0)	2 (20)
7. I feel confident prescribing analgesia for administration by syringe driver in advanced dementia at end of life	1 (14.3)	0 (0)	3 (42.9)	0 (0)	1 (14.3)	1 (10)	2 (28.6)	6 (60)	0 (0)	3 (30)
8. I feel confident prescribing analgesia for intravenous (IV) administration in advanced dementia at end of life	2 (28.6)	2 (20)	2 (28.6)	1 (10)	2 (28.6)	3 (30)	1 (14.3)	2 (20)	0 (0)	2 (20)
9. I feel confident prescribing transdermal analgesics in advanced dementia at end of life	0 (0)	0 (0)	4 (57.1)	0 (0)	0 (0)	0 (0)	3 (42.9)	6 (60)	0 (0)	4 (40)
10. I feel confident prescribing analgesia for subcutaneous administration in advanced dementia at end of life	1 (14.3)	0 (0)	3 (42.9)	0 (0)	0 (0)	0 (0)	3 (42.9)	7 (70)	0 (0)	3 (30)

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-Pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
11. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	1 (14.3)	0 (0)	0 (0)	0 (0)	3 (42.9)	1 (10)	3 (42.9)	7 (70)	0 (0)	2 (20)
12. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (42.9)	0 (0)	2 (28.6)	1 (10)	2 (28.6)	7 (70)	0 (0)	2 (20)
13. I feel confident I am using best-practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (42.9)	1 (10)	3 (42.9)	0 (0)	1 (14.3)	7 (70)	0 (0)	2 (20)
14. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (42.9)	1 (10)	2 (28.6)	0 (0)	2 (28.6)	7 (70)	0 (0)	2 (20)

Pre- and retro-pre teleECHO knowledge and self-efficacy scores were also calculated for each physician respondent; it was not possible to compare changes in individuals' responses between the pre- and retro-pre evaluations as respondents completed evaluation questionnaires anonymously and as such it was not possible to link responses. Furthermore, seven physicians completed the pre-ECHO evaluation, and 10 completed the retro-pre evaluation; some physicians completed the pre-evaluation, some the retro-pre evaluation and some may have completed both. Scores were obtained for each respondent by summing scores for each of the 14 statements, using 1=Strongly Disagree; 2=Disagree; 3=Neither Agree nor Disagree; 4=Agree; and 5=Strongly Agree. Possible scores for this measure therefore ranged from 14 to 70.

The mean pre-ECHO Knowledge and Efficacy Score for physicians was 41.4 (± 10.6), while the mean retro-pre score was 55.8 (± 10.2). The overall knowledge and efficacy score was significantly higher retro-pre ECHO than pre-ECHO ($p=0.014$; Mann Whitney U test). Examination of responses to individual statements demonstrated an increase in the responses in the Agree and Strongly Agree categories in the retro-pre evaluation compared to the pre-ECHO evaluation. This suggests an increase in confidence across the domains considered in the evaluation; as the retro-pre evaluation required respondents to consider their knowledge and self-efficacy prior to participation in the teleECHO clinics but with the benefit of knowing what has been learned during the course, this may suggest that while respondents possessed the knowledge and self-efficacy to assess and manage pain in people with advanced dementia approaching the end of life, they may not have recognised this until they had participated in the teleECHO clinics. Participation in the teleECHO clinics may therefore impact upon physicians' confidence to provide care to these vulnerable patients.

NURSES

Twelve nurses completed the post and retro-pre teleECHO evaluations (9 female, 3 male). Respondents represented the following areas or specialties: psychiatry/old

age psychiatry (n=5); palliative care (n=3); learning disability (n=1); dementia/memory (n=2); and pain (n=1). Six respondents were managers (ward manager, nurse manager, residential home manager, ward sister), four were staff nurses/registered nurses, and two were nurse specialists. Years in nursing practice ranged from 13 to 32 (mean=26.1 years). Five respondents practised in secondary care, four in community, two in residential care homes and one in education.

POST-ECHO EVALUATION

Although 12 nurses completed the demographic questions for the post- and retro-pre teleECHO evaluations, two did not complete the post-ECHO questionnaire, one did not complete the retro-pre questionnaire and one partially completed the retro-pre questionnaire. These non-responders were a registered nurse and a lead nurse specialist, from community and hospital settings respectively. In the tables below, the total number of respondents have been amended to take account of these non-responses.

Table 15. Post-ECHO questionnaire responses for nurse respondents (n=10)

Knowledge and self-efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. Participation in the teleECHO clinics has developed my clinical knowledge in pain assessment in advanced dementia	0 (0)	0 (0)	1 (10)	4 (40)	5 (50)
2. Participation in the teleECHO clinics has developed my clinical skills in pain assessment in advanced dementia	0 (0)	0 (0)	2 (20)	5 (50)	3 (30)
3. Participation in the teleECHO clinics has developed my clinical knowledge in pain management in advanced dementia	0 (0)	0 (0)	2 (20)	3 (30)	5 (50)
4. Participation in the teleECHO clinics has developed my clinical skills in pain management in advanced dementia	0 (0)	0 (0)	2 (20)	4 (40)	4 (40)

Knowledge and self-efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
5. Did you present a patient case at a teleECHO clinic?					
IF YES: I am confident/comfortable presenting patient cases during teleECHO clinics	0 (0)	0 (0)	0 (0)	0 (0)	2 (100)
Presenting a patient case in the teleECHO clinics benefitted the patient in my care	0 (0)	0 (0)	0 (0)	0 (0)	2(100)
IF NO: I would be confident/ comfortable presenting patient cases during teleECHO clinics	0 (0)	1 (12.5)	1 (12.5)	6 (75)	0 (0)
I learned from providers who present their patient cases during teleECHO clinics	0 (0)	0 (0)	0 (0)	5 (62.5)	3 (37.5)
6. I apply knowledge learned in teleECHO clinics to other patients in my care who have similar symptoms and diseases	0 (0)	0 (0)	0 (0)	6 (60)	4 (40)
7. I teach other clinical staff what I have learned in teleECHO clinics	0 (0)	0 (0)	1 (10)	7 (70)	2 (20)
8. Access to specialist expertise and consultation is an important area of need for me and my care staff team	0 (0)	0 (0)	0 (0)	3 (30)	7 (70)
9. Access to specialist expertise and health professionals from other specialties has been a benefit to my clinical practice	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)
10. Access to expertise in pharmacology through the teleECHO clinics has benefitted my clinical knowledge and practice	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)
11. Access to expertise in behaviour and mental health through the teleECHO clinics, has benefitted my clinical knowledge and practice	0 (0)	0 (0)	0 (0)	5 (50)	5 (50)
12. teleECHO clinics have improved the way that health professionals communicate with each other about pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)

Knowledge and self-efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
13. Learning about complex chronic disease through participation in teleECHO clinics is an effective way to enhance clinical knowledge and expertise	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)
14. Case-based learning as the focus for discussion is an impactful way of learning	0 (0)	0 (0)	0 (0)	4 (40)	6 (60)
15. Didactic sessions during teleECHO clinics were an effective way for me to develop my clinical knowledge and skills	0 (0)	0 (0)	0 (0)	5 (50)	5 (50)
16. I would continue to attend teleECHO clinics for pain assessment and management in dementia	0 (0)	0 (0)	0 (0)	5 (50)	5 (50)
17. I believe that teleECHO clinics should be continued for pain assessment and management in other conditions	0 (0)	0 (0)	0 (0)	3 (30)	7 (70)
18. I believe a separate teleECHO for nurses would be beneficial	0 (0)	3 (30)	3 (30)	3 (30)	1 (10)

RETRO-PRE-ECHO EVALUATION

Table 16. Retro-pre-ECHO questionnaire responses for nurse respondents (n=10 or 11 depending on the statement, due to partial response)

Knowledge and efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	5 (41.7)	4 (33.3)	3 (25)
2. I feel confident reporting pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (16.7)	7 (58.3)	3 (25)
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	1 (8.3)	3 (25)	6 (50)	2 (16.7)
4. I feel confident administering analgesia by syringe driver to patients with advanced dementia nearing the end of life*	0 (0)	0 (0)	0 (0)	0 (0)	2(100)
5. I feel confident administering analgesia by intravenous routes to	0 (0)	0 (0)	0 (0)	0 (0)	1(100)

patients with advanced dementia nearing the end of life*					
Knowledge and self-efficacy evaluation statement	Number (%) of respondents who selected				
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	0 (0)	3 (30)	4 (40)	3 (30)
7. I feel confident suggesting alternative formulations of analgesia when oral route is unavailable	0 (0)	0 (0)	1 (10)	7 (70)	2 (20)
8. I feel confident recognising and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (30)	6 (60)	1 (10)
9. I feel confident discussing cases of unresolved pain following administration of analgesia with doctors for patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (20)	4 (40)	4 (40)
10. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	0 (0)	5 (50)	4 (40)
11. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	1 (10)	4 (40)	4 (40)
12. I feel confident I am using best practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	1 (10)	0 (0)	5 (50)	4 (40)
13. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (20)	4 (40)	4 (40)

Table 17. Pre- and retro-pre teleECHO evaluations for nurse respondents (n=10 pre-ECHO, n=10 or 11 retro-pre ECHO)

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-Pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
1. I feel confident recognising and assessing pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	0 (0)	4 (40)	5 (41.7)	4 (40)	4 (33.3)	1 (10)	3 (25)
2. I feel confident reporting pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	0 (0)	2 (20)	2 (16.7)	6 (60)	7 (58.3)	1 (10)	3 (25)
3. I feel confident differentiating the behavioural indicators of pain from behavioural and psychological symptoms of dementia in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (30)	1 (8.3)	2 (20)	3 (25)	4 (40)	6 (50)	1 (10)	2 (16.7)
4. I feel confident administering analgesia by syringe driver to patients with advanced dementia nearing the end of life*	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (100) ^a	2(100) ^b
5. I feel confident administering analgesia by intravenous routes to patients with advanced dementia nearing the end of life*	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (100) ^a	0 (0)	0 (0)	1(100) ^b

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-Pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
6. I feel confident assessing treatment response to analgesics in patients with advanced dementia who are nearing the end of life	0 (0)	0 (0)	0 (0)	0 (0)	2 (20)	3 (30)	8 (80)	4 (40)	0 (0)	3 (30)
7. I feel confident suggesting alternative formulations of analgesia when oral route is unavailable	0 (0)	0 (0)	2 (20)	0 (0)	0 (0)	1 (10)	7 (70)	7 (70)	1 (10)	2 (20)
8. I feel confident recognising and managing breakthrough pain in people with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (30)	0 (0)	2 (20)	3 (30)	5 (50)	6 (60)	0 (0)	1 (10)
9. I feel confident discussing cases of unresolved pain following administration of analgesia with doctors for patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (20)	0 (0)	2 (20)	2 (20)	5 (50)	4 (40)	1 (10)	4 (40)
10. I feel confident in my clinical knowledge of pain assessment and management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	2 (20)	1 (10)	3 (30)	0 (0)	5 (50)	5 (50)	0 (0)	4 (40)

Knowledge and efficacy evaluation statement	Strongly Disagree Pre-ECHO	Strongly Disagree Retro-pre-ECHO	Disagree Pre-ECHO	Disagree Retro-pre-ECHO	Neither Agree nor Disagree Pre-ECHO	Neither Agree nor Disagree Retro-Pre-ECHO	Agree Pre-ECHO	Agree Retro-pre-ECHO	Strongly Agree Pre-ECHO	Strongly Agree Retro-pre-ECHO
11. I feel confident in my clinical self-efficacy in the assessment and management of pain in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	3 (30)	1 (10)	2 (20)	1 (10)	5 (50)	4 (40)	0 (0)	4 (40)
12. I feel confident I am using best practice approaches to pain assessment in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	1 (10)	1 (10)	5 (50)	0 (0)	4 (40)	5 (50)	0 (0)	4 (40)
13. I feel confident I am using best practice approaches to pain management in patients with advanced dementia nearing the end of life	0 (0)	0 (0)	0 (0)	0 (0)	6 (60)	2 (20)	4 (40)	4 (40)	0 (0)	4 (40)

^a 2 respondents administered analgesia to patients with advanced dementia nearing the end of life via syringe driver or intravenous routes and could therefore respond to statements 4 and 5 respectively in the Pre-ECHO evaluation

^b 2 respondents administered analgesia to patients with advanced dementia nearing the end of life via syringe driver, and one administered analgesia via intravenous routes and could therefore respond to statements 4 and 5 respectively in the Retro-Pre-ECHO evaluation

Pre- and retro-pre teleECHO knowledge and self-efficacy scores were also calculated for nurse respondents; it was not possible to compare changes in individuals' responses between the pre- and retro-pre evaluations as respondents completed evaluation questionnaires anonymously and as such it was not possible to link responses. As with the physician evaluations, scores were obtained for each respondent by summing scores for each of the 11 statements answered by all participants (excluding statements 4 and 5), using 1=Strongly Disagree; 2=Disagree; 3=Neither Agree nor Disagree; 4=Agree; and 5=Strongly Agree. Possible scores for this measure therefore ranged from 11 to 55.

The mean Pre-ECHO Knowledge and Efficacy Score for nurses was 37.9 (± 6.5), while the mean Retro-pre score was 44.8 (± 7.0). The overall knowledge and efficacy score was significantly higher retro-pre ECHO than pre-ECHO ($p=0.035$; Mann Whitney U test). Examination of responses to individual statements demonstrated an increase in the responses in the Strongly Agree category in the retro-pre-ECHO evaluation compared to the pre-ECHO evaluation. This suggests a similar increase in confidence across the domains considered in the evaluation to that observed in the physician data; and again suggests that while respondents possessed the knowledge and self-efficacy to assess and manage pain in people with advanced dementia approaching the end of life, they may not have recognised this until they had participated in the teleECHO clinics. This suggests that participation in the teleECHO clinics may have an important impact upon nurses' confidence to provide care to these vulnerable patients.

HEALTHCARE ASSISTANTS AND OTHER HEALTHCARE PROFESSIONALS

No HCAs completed post-ECHO or retro-pre-ECHO evaluations. Other HCPs from pharmacy and occupational therapy participated in the teleECHO clinics but were not invited to complete the evaluations or to participate in the focus group evaluations as per our protocol. However, we did include a brief evaluation for these individuals to

ensure that their views were represented and could be taken into account in future planning where appropriate. The views of these HCPs are detailed below.

All three respondents answered “Yes” to the question “Did you find the TEAM Pain AD series useful in terms of improving your knowledge and self-efficacy in assessing and managing pain for people with dementia?”. When asked if they would change anything about the teleECHO clinics, responses included providing case studies further in advance of the teleECHO and including more practical examples of how to assess pain in dementia, such as demonstrating how to carry out a clinical examination. All three respondents also answered “Yes” to the question “Do you think future teleECHO clinics in pain assessment and management for other chronic conditions would be useful?” Additional comments on participants’ experiences of the clinics included the following:

*I felt the multidisciplinary approach enhanced my learning experience. I also felt that it was very useful to follow up the theory/presentation element of the teleECHO with case study and relevant discussion. **HCP1***

*I found this a valuable and insightful experience.....it was beneficial to learn from the multidisciplinary discussions. **HCP2***

*It was a really worthwhile learning experience. **HCP3***

KEY FINDINGS FROM THE QUESTIONNAIRE EVALUATIONS

Physician pre-ECHO questionnaire responses suggested that there were some areas in which some respondents lacked confidence as indicated by responses in the Strongly Disagree or Disagree and Neither Agree nor Disagree categories. These included confidence in 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; no respondents selected Strongly Disagree for any statement, and there were marked reductions in the numbers who chose Disagree and Neither Agree nor Disagree options, with the majority now selecting Agree or Strongly Agree for each statement. The post-ECHO evaluation also demonstrated the perceived utility of the teleECHO clinics; the majority of respondents (70% or more) agreed or strongly agreed to each of the statements in this evaluation which considered 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 alternative formulation if the oral route was not available, and in discussing cases of unresolved pain, as evidenced by most respondents selecting Agree or Strongly Agree for these statements. There was greater uncertainty, shown by respondents selecting Strongly Disagree or Neither Agree nor Disagree 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; no respondents selected Strongly Disagree for any statement, and there were marked reductions in the numbers who chose Disagree and Neither Agree nor Disagree options, with the majority now selecting Agree or Strongly Agree for each statement. The post-ECHO evaluation demonstrated the perceived utility of the teleECHO clinics; the majority of respondents agreed or strongly agreed that they had developed their clinical knowledge and skills in pain assessment and pain management, that they had applied the knowledge learnt and taught other staff what they had learned, 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 also 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.

Analysis of physician and nurse scores for knowledge and self-efficacy in the pre-ECHO and retro-pre ECHO evaluations demonstrated increased confidence in relation to their knowledge and self-efficacy in their retro-pre evaluations compared to the pre-ECHO survey.

FOCUS GROUPS

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 and are presented below.

THEME 1: KNOWLEDGE AND SKILLS DEVELOPMENT AND DISSEMINATION

Most participants reported that careful consideration and thought had been put into the design of the TEAM Pain AD programme and that it had delivered on its learning objectives. A couple of respondents had attended the pre-ECHO workshop held in April 2016 at which ECHO participants had discussed and identified their key learning needs which subsequently formed the curriculum. These reported that the pre-ECHO workshop was highly beneficial in that it allowed them to meet other

potential participants and to have input into the development of an educational initiative that would address their specific learning needs. The experience also allowed them early experience of the collaborative, multidisciplinary and interactive nature of ECHO and participants felt that this had prepared them for the format of the clinics. Participants strongly believed that the input of clinical health professionals in such programmes was essential given the complex and challenging nature of clinical work. Some participants reported that they had gained new clinical knowledge and skills through participation in the ECHO clinics. In most cases, this was a result of participating in the case discussions in which knowledge and skills were freely exchanged among the experts at the hub and other participants dialling in from the spokes.

I liked having access to people with—with specialist knowledge and experience that was very helpful (GP4, FG2)

In most cases, knowledge and skills development pertained to novel, holistic or alternative approaches to care, the behavioural management of patients with dementia, pharmacological and non-pharmacological interventions for pain management, aspects of pain assessment and ethical and professional practice issues.

We get very focused on our own little worlds you know and I suppose anybody living with a medical condition like dementia their world is so much more complex and so much more multifaceted you know so I think it's really good for us to have to you know to actually to join up and talk to each other um so we have some idea of all the different perspectives (GP4, FG2)

I think it's about, about connecting to the wider networks that are out there really um and also having access to some very, very good teachers was very helpful (GP4, FG2)

The transfer of knowledge, the access to experts that you wouldn't normally that have access to, access to people experiencing similar situations .. certainly the whole ECHO model I thought allowed itself—allowed us to do that
(Dementia nurse 1, FG1)

Most respondents believed they had applied these knowledge and skills to their own patients, particularly in the case of those who had submitted case studies, whilst others reported disseminating these to their clinical teams. One respondent had invited members of their clinical team to attend an ECHO clinic. Those who had submitted a patient for case discussion reported that they had adopted the treatment recommendations to the patient resulting in improvements to the patient's care, strengthening of the relationship between the clinical team and the patient's family, and had allowed them to train other staff following the transfer of the patient to another care setting. Most respondents had actively contributed to the case discussions and expressed that having this opportunity was essential to their learning and development. They felt that the combination of access to an expert panel of experts and being able to participate interactively made ECHO a unique learning experience both professionally and personally.

Access to all the professionals and even when the cases were being discussed and that, even though they were very professional they were sort of informal and it was a very comfortable way of discussing things, I actually enjoyed it.
(Hospice nurse 6, FG2)

Some participants felt that whilst participation may not have resulted in new skills and knowledge development during this round of clinics, they had felt reassured that their approaches to complex and challenging patient care were in line with best practice and with what the expert panel were practising themselves.

Sometimes it's just about reassuring staff they're doing the right thing I think that comes through in some of the cases um you're doing everything you can and that's sometimes good that reassurance and that's good with their own discipline but certainly for knowledge. **(Dementia nurse 1, FG1)**

It's more about being reassured that the way that we work is okay, do you know what I mean, that there isn't anything major that we should be doing that we're not doing, that we are thinking about this holistically, and we are thinking about it from a multiple perspectives, [sic] and we are trying to join the dots for people. It was kind of reassuring to see that that's okay, that that's what other people are trying to do too. (GP4, FG2)

It's good to hear how other people, you know, kind of look after people with dementia and realise that you know our approach, you know, we're not doing too bad and I think to take that back to nursing homes as well and to work colleagues to say, you know, don't get kind of too uptight about things, you're doing a good job and just giving them that wee bit of positive feedback. (Hospice nurse 5, FG2)

I'm not sure whether it was actually new information but it's just about how—it made it meaningful when it was put into the context of how people use it you know. (GP4, FG2)

All participants agreed that hearing the experiences of the other ECHO participants allowed them to reframe how they perceived their own difficulties, that is, challenges were contextualized as a natural by-product of caring for a complex patient population rather than an indicator of personal or professional failure. This realisation was reported to increase both professional and self-confidence, morale, motivation and was experienced as significantly reassuring. For many, this was a significant benefit of participating in ECHO, in addition to skills and knowledge development.

It particularly worked well with dementia I think and with any complex conditions I think it works particularly well and we now face lots of long-time complex conditions you know and lots of evolving challenges as a result of that um so you know for example if we were to look at progressive lung disease, a condition I know I could certainly learn an awful lot from colleagues and respiratory teams if we were to look at other neurodegenerative conditions could learn a lot from colleagues you know there's so much potential really particularly with long-term conditions I think because we get quite good

education around cancer I think but we get much less education around the realities of living with other long-term conditions (GP4, FG2)

THEME 2: PROTECTED TIME

Participants reported that a significant benefit of the ECHO model was the ability to be able to join clinics from their own workplaces eliminating the need for travel, expenses and time out of clinical practice.

It's just the fact it could be accessed during a lunchtime we didn't have to travel miles to get to anywhere but we were able to access lots of people in lots of different settings (GP4, FG2)

The convenience of, you know, being able to dial in from ... my laptop in work is very helpful..... for the two of us contributing here today up in [Trust], having to get down on a weekly basis to something in Belfast you know is not ... feasible (Geriatrician 7, FG2)

This was particularly important considering the geographical spread of participants who took part in this study; two centres (one hospice, one hospital) reported that they would have been unable to participate in the clinics if this had required the need to travel to the hub. These participants were particularly appreciative of the opportunity to link in with the experts in the hub, many of whom are based in the capital city. One participant, however, noted that this convenience was also a 'double-edged sword' in that being physically present in the office or building encouraged staff to call them away to attend to clinical matters on the ward.

That convenience is also sort of a bit of down side as well in that, for my part, being in the building here in the hospital I was, you know, maybe being contacted for things or there was other commitments, you know, that I then was sort of pulled away from some of the meetings or wasn't able to, you know, to

dial in.... I suppose it was sort of maybe two sides of the coin there.
(Geriatrician 7, FG2)

Many participants agreed that protected time was required to allow staff to participate in ECHO clinics uninterrupted. Some recognised that this was easier to achieve in their own settings (e.g. hospice) where ECHO clinics ran over a designated lunch period but would be harder to achieve in primary and secondary care settings. Respondents strongly believed that ECHO clinics needed to be planned well in advance and appropriately advertised to allow staff rotas to be adjusted accordingly to ensure sufficient cover and to minimise the impact of staff absent from the wards/clinics for the duration of ECHO sessions. Participants agreed that individual work plans needed to reflect participation in ECHO clinics as protected time to allow staff to participate uninterrupted and to allow them time to prepare case studies.

I think staff on the ground probably would benefit probably from this interaction, this learning ... obviously it would impact on their time away from the front
(Dementia nurse 1, FG1)

I think when it's a short session for us who manage our own caseloads I think it's okay. I think if there was [sic] staff coming from the [inpatient unit] that would be different, I think there would need to be cover for them ... but I think whenever we manage and plan our day it's okay **(Hospice nurse 2, FG1)**

If there was a dedicated time you would just have to make sure it was part of the day ... the time slots were set and at least you know how long you were going to be away from ... the actual ward so as long as you knew that you could probably factor it in .. yeah. They have to attend to reflection and learning anyway so you just would have that part of it [sic] **(Dementia nurse 1, FG1)**

I suppose ours was round our lunch break time so we were okay **(Hospice nurse 6, FG2)**

It just needs to be planned you know certainly the setting we're in here which is in a day hospice setting it's easier I know than in [hospital setting] or in a GP setting it's so much more difficult to have protected time, and it is I suppose making it explicit at the beginning that protected time is needed in some way so that any individual taking part can have a commitment from their colleagues that they will have protected time...and that's always difficult. (GP4, FG2)

THEME 3: AREAS FOR IMPROVEMENT

Participants noted some difficulties experienced with the submission of case studies. It was tentatively suggested that the novel format of ECHO which involved a diverse audience of clinical professionals across trusts, networks and regions may have contributed to reticence among participants regarding the submission of a case study in which the challenges experienced by the submitting team would be widely exposed. Some noted this resulted in the late submission and dissemination of case materials leaving little time for participant review and preparation ahead of clinics. It was recognised; however, that case submissions got progressively easier once the first few clinics had taken place and the audience were familiar with the format and with each other. It was also reported that case submissions took time to prepare and write; therefore, sufficient time and opportunity were required to allow staff to complete this.

That was just a bit of typical Northern Ireland reticence to put yourselves forward, put your head above the parapet, you know, to put a case out there but once the cases were there I think that led ... to... good back and forth conversation between the group.... I guess it's in terms of how to encourage folk to, you know, to put the cases forward maybe a bit more in advance you know for fuller preparation for the sessions. (Geriatrician 7, FG2)

It's an ongoing conundrum because everybody is so busy and it's partly reticence but partly also because life is so busy, it's just finding time to sit down to you know pull out the essence of a case,,. you know Yeah, it's difficult (GP4, FG2)

Focus group respondents suggested that future ECHOs would need to consider an alternative approach to obtaining case study submissions well in advance of clinics. One participant suggested that the need for case studies to fall within the specific topic of each clinic was often hard to achieve if these cases were not currently being seen by ECHO participants. Allowing participants to submit their most recent or most challenging case was suggested as another approach; however, a couple of respondents who had previously participated in other unrelated ECHO projects had cautioned that allowing 'free' submission of cases had resulted in repetitive discussions of symptom control and reduced learning opportunities. Participants commented that occasional technical glitches resulted in sound and video quality impairment and delays logging in to clinics.

The sound quality every now and again maybe wasn't the best (Hospice nurse 6, FG2)

It was also noted that delays at the start of clinics reduced time for case discussion and on one occasion it was felt that the submitting team had been left without a clear resolution or treatment plan. Despite the technical issues experienced, one participant reported that the technology was more efficient than existing videoconferencing facilities in their trust and that accessing clinics had been easy and quick.

My experience of the technology was that it worked a lot better than other videoconferencing type facilities that we have in the [HSC Trust] that are very prone to breakdown but, you know, the dial-in has been very smooth and straightforward for the most part, you know, and uh the video and sound quality's been pretty good (Geriatrician 7, FG2)

THEME 4: THE FUTURE OF ECHO

Most participants strongly welcomed further ECHO clinics in dementia, pain and other chronic conditions. All agreed that the model was suitable for addressing the learning needs of health professionals primarily through combination of didactic training provided by appropriately qualified and experienced clinical staff and opportunity for case discussion. All participants reported that the most significant strength of the ECHO model lay in its multidisciplinary, inclusive approach which created and fostered a sense of community.

*I mean somebody with dementia, it's not just a diagnosis it's a massive, massive picture that you're looking, you know and that so it's great to get feedback from all angles so yeah definitely multidisciplinary (**Hospice nurse 6, FG2**)*

*I like ... all the different multidisciplinary teams because they bring different information you know because it gives you confidence listening to them and you know you can speak to them (**Hospice nurse 3, FG1**)*

Participants did not see any benefit in holding discipline-specific ECHO clinics (e.g. those to which only nurses or physicians etc. attended) but did believe that ECHO programmes in dementia could be broadened out so that they included other aspects of care rather than a specific focus on one area (e.g. pain). Interconnectivity among frontline and allied health professionals was perceived as the cornerstone of dementia care from which gold standards could be achieved.

*I think absolutely broadened out and encouraged we all work in areas where knowledge is constantly evolving, you know, and ... where the challenges that we face are changing and I suppose in any world of healthcare every person brings a unique story and unique talent so you know we're all learning all the time and it's a great format for learning so I would certainly be very supportive of the approach (**GP4, FG2**)*

Additionally, developing cross-specialty networks which bridged primary, secondary, nursing home, community and hospice care across HSC trusts and geographical regions allowed participants to gain perspective on the nature of dementia care across Northern Ireland. Participants involved in the roll out of the Dementia Strategy in Northern Ireland reported that this allowed them to see variances in the application of that strategy across the region.

Because we use it within our teams and we're across trusts, it allows us to explore even lack of equity across trusts and services and things like that so it's always good to hear what other trusts and services are doing which ECHO will allow you to do. (Hospice nurse 2, FG1)

Most participants reported that the bigger picture perspective allowed them to see themselves as part of a larger community of professionals facing the challenges of managing and caring for a complex patient population; this was important for reducing feelings of professional isolation and maintaining morale and motivation. Participants commented on the 'huge potential' of ECHO to inform and improve the delivery of clinical education and ongoing professional development.

DISCUSSION

The evaluation of the TEAM Pain AD teleECHO clinics, based on the findings from the pre-, post- and retro-pre-teleECHO survey evaluations and the two focus group discussions was largely very positive. Physician pre-ECHO questionnaire responses suggested that some respondents lacked confidence in 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 that respondents felt more confident in prescribing medications for administration via routes other than orally, in their clinical knowledge and self-efficacy and in use of best practice

approaches. Most physician respondents reported development of their knowledge and skills in pain assessment and management, application of knowledge gained through the clinics, benefit to their clinical practice, the value of case-based learning and didactic teaching, and the value of continued clinics.

Similarly, prior to undertaking the TEAM Pain AD teleECHO clinics, some nurses expressed a lack of confidence in recognising and assessing pain, 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. The retro-pre ECHO evaluation demonstrated a shift in responses suggesting that confidence in these areas had improved. Many respondents reported that they had developed their clinical knowledge and skills in pain assessment and pain management, applied the knowledge learnt and taught other staff what they had learned, and that access to expertise had benefitted their clinical practice. They felt that case-based discussion and didactic sessions were effective ways to develop clinical knowledge and skills and indicated support for continued clinics for this and other clinical issues. Analysis of physician and nurse scores for knowledge and self-efficacy in the pre-ECHO and retro-pre ECHO evaluations demonstrated increased confidence in relation to their knowledge and self-efficacy in their retro-pre evaluations compared to the pre-ECHO survey. These findings are similar to results from other studies that have used Project ECHO for palliative care interventions (Reed et al., 2017; White et al., 2015), HIV (Wood et al., 2016), chronic pain (Katzman et al., 2014), complex disease management (Salgia et al., 2014), hypertension (Masi et al., 2012), diabetes (Colleran et al., 2012) and for knowledge networks across a range of clinical areas (diabetes, optometry, palliative care in nursing homes, dermatology, and support for carers of patients with palliative care needs) (White et al., 2016). The focus groups confirmed these findings, with 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. The focus groups also reported that a further benefit of the ECHO model 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. Technical issues, in particular internet connectivity and bandwidth, have been identified as problematic by others (White et al., 2015); however, similar to our study, these issues were not at a level to prevent the vast majority of participants from being willing to recommend ECHO to others. 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. This emphasis on a “community of learners” affirms the Community of Practice Theory, which emphasises the importance of learning through continuous participation in a collaborative community consisting of peer learners and expert individuals, as a foundation of the ECHO model (Socolovsky et al., 2013) and which has been reported in other studies (Wood et al., 2016; Arora et al., 2010).

LIMITATIONS

Our findings must be interpreted in the context of the limitations we experienced a both in the delivery of the teleECHO clinics and in their evaluation. Firstly, despite having approximately five weeks between the pre-ECHO workshop (at which the curriculum, times and dates of the clinics were decided) and the first teleECHO clinic, it was extremely difficult to get patient cases. There was a reticence on the part of participants to put forward cases, as demonstrated by the findings from the focus group evaluations, which resulted in significant work for the research team in contacting individuals and appealing for them to prepare a case 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. The feedback from those who

did put forward cases was, however, positive. Secondly, there were some technical issues due to poor sound quality and unstable internet connections. Thirdly, 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 (one healthcare professional from this Trust participated in the final teleECHO clinic using personal rather than Trust-owned equipment). Despite continued attempts by the research team to gain approval for Trust computers to access the Zoom teleconferencing and camera software, this issue remained unresolved even after the final ECHO clinic had taken place.

It was not possible for us to administer the knowledge and self-efficacy measure to respondents on three occasions, in the pre-, post- and retro-pre teleECHO evaluations, due to respondent fatigue. Other studies have reported difficulties in low evaluation response rates (White et al., 2016). Completing the full set of pre-, post- and retro-pre questionnaires is repetitive and difficult to achieve in practice, resulting in low response and high attrition rates mid-way or early into the evaluation. Respondents who completed the post-ECHO evaluation of their experiences and the utility of the ECHO model did also complete 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 an improvement in 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.

RECOMMENDATIONS FOR POLICY AND PRACTICE

Recommendations emerging from this research can be grouped under a number of broad areas; we suggest that these should be considered as integral to policy and practice development in pain assessment and management for people with advanced dementia who are approaching the end of life. These broad areas are:

1. The value of sharing knowledge across specialties, care settings and disciplines
2. The desire for ongoing, needs-driven education and training, to include case-based discussion and access to specialists with relevant clinical knowledge and expertise
3. The value of inclusion of HCAs in the multidisciplinary patient care team.
4. The value of the Project ECHO model and the need for future research

THE VALUE OF SHARING KNOWLEDGE ACROSS SPECIALTIES, CARE SETTINGS AND DISCIPLINES

The interview data from Phase 1 highlighted the importance of knowledge exchange across specialties and care settings, between physicians, nurses and HCAs. Sharing knowledge extended beyond health professionals to include collateral history provided by patients' families in assessing pain and interpreting non-verbal cues. This reflects the importance of good communication, shared knowledge and a mutually respectful relationship between a multidisciplinary healthcare team and family carers if treatment is to reflect the interests of the patient and achieve clinical goals of care (Dening et al., 2013; Lopez et al., 2013; Burns & McIlfatrick, 2015a; Burns & McIlfatrick, 2015b; Fry et al. 2016; Birch & Draper, 2008). The involvement

of family carers and other key social contacts in pain assessment for people with severe cognitive impairment and/or dementia has been widely recommended in the literature (Fisher et al., 2002; Montes et al., 2004; Herr et al., 2006b; Buffum et al., 2007; Burns et al., 2015b), and is an important component of a knowledge sharing network for pain assessment and management of people with advanced dementia. 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. Policy and practice initiatives in pain assessment and management for people with advanced dementia should cross specialisms and care settings, involving all members of the multidisciplinary healthcare team, patients' families and other key health and social care staff.

THE DESIRE FOR ONGOING, NEEDS-DRIVEN EDUCATION AND TRAINING, TO INCLUDE CASE-BASED DISCUSSION AND ACCESS TO SPECIALISTS WITH RELEVANT CLINICAL KNOWLEDGE AND EXPERTISE

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 datasets in the Phase I interview study. Current available training opportunities were reported to be restricted, with time and financial pressures constituting significant barriers to participation. Further, training opportunities tended to be irregular and tended not to be needs-driven, accessible, or delivered by trainers with sufficient clinical experience and knowledge. 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

Interestingly, while healthcare professionals in Phase I reported pain assessment and management as challenging, at the pre-ECHO workshop participants chose a curriculum for the TEAM Pain AD teleECHO clinics with a focus on assessment. Thematic analysis of the interviews identified a number of topics healthcare professionals believed required further training/input; these were presented at the pre-ECHO workshop and participants asked if these topics were still relevant and if they should be included in the curriculum for the TEAM Pain AD teleECHO clinic programme. Attendees of that workshop chose to remove use of opioids at end of life to focus on routes of administration and behavioural assessment and management. This shift from assessment and pharmacological management to assessment and behavioural management is notable. One possible explanation for this shift could be that if pain assessment is improved, then management of pain consequently becomes more straightforward.

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. Ensuring these key elements are included in design of education and training programmes in the future should enhance healthcare professional uptake of and engagement with training opportunities and increase the likelihood of these programmes delivering sustained practice change.

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 adopted for education and training in pain assessment and management in advanced and end stage dementia. It will also translate to other patient populations and clinical areas, and has significant potential for patient care management. It 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 VALUE OF INCLUSION OF HCAS IN THE MULTIDISCIPLINARY PATIENT CARE TEAM

The interview data from the Phase I study 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. Healthcare policy and practice initiatives for pain assessment and management in dementia should make provision for an expanded HCA role 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.

PATHWAY TO IMPACT: THE VALUE OF THE PROJECT ECHO MODEL AND THE NEED FOR FUTURE RESEARCH

The findings of 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. Our data report changes in physician and nurse scores for knowledge and self-efficacy; due to low response rates from HCAs we were unable to undertake statistical analysis on these data. However, we propose that a similar trend would be observed for this group of healthcare professionals. Whether the retro-pre evaluations can truly be considered as such or were perhaps completed as post-ECHO evaluations despite

our guidance on evaluation completion, the data do indicate that participants experienced increased confidence in their knowledge and self-efficacy after participation in the teleECHO clinics. This is confirmed by the interview data in which participants expressed a desire for confirmation of their proposed treatment; 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 HSC security policies.

It should be acknowledged that implementing the Project ECHO© requires administrative support and sufficient infrastructure to organise and host clinics, call for cases, screen case submissions for HIPAA compliance, disseminate didactic and case presentation materials, open clinic links, provide information technology support (including troubleshooting technical issues), respond to participant queries and concerns and distribute equipment (e.g. webcams). In the present study, this workload was assumed by the research fellow with support from the PI; it is suggested that future trials of ECHO in academic settings have this infrastructure in place at the outset of the study.

Project ECHO© has shown early positive evidence for improving knowledge and skills improvement in primary care providers; however, a need for further evaluation of patient outcomes and exploration of the limitations associated with its evaluation

has been highlighted (Zhou et al, 2016). This will likely be facilitated by the passing of the Expanding Capacity for Health Outcomes (ECHO) Act (also known as The ECHO ACT) in the United States (US), the country in which Project ECHO® was originally developed. Under this Act, the US Department of Health and Human Services (HHS) has been tasked to investigate and evaluate the impact of Project ECHO® across the following domains: care provision in chronic diseases and mental health disorders (including substance misuse); the quality of health professionals' quality of care and on the quality and provision of care in rural and underserved areas (The ECHO Act, 2016). In addition, investigation is also expected to consider the barriers to implementation and evaluation of Project ECHO® in practice. It is anticipated that should the outcomes of these investigations support the efficacy of Project ECHO® in each of these domains, it will be adopted as the national model for provision of telehealth care for rural care provision in the United States (The ECHO Act, 2016).

PERSONAL AND PUBLIC INVOLVEMENT

This study benefited significantly from the involvement of the 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 participated 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.

PUBLICATIONS

De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfatrick SJ et al. Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study. *J Clin Nurs*. 2017;26:1234-1244.

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De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfatrick SJ et al. "There's a Catch-22". The complexities of pain management for people with advanced dementia nearing the end of life: physicians' perspectives. *Palliat. Med*. 2016 Oct 25. Available from, DOI: 10.1177/0269216316673549.

Two further papers reporting findings for nurse and physician perspectives on pain assessment and the TEAM Pain AD pilot have been submitted for consideration for publication in October 2017 to Palliative Medicine and BMC Health Services Research respectively.

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De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfatrick SJ et al. "A tool doesn't add anything". Physicians' perceptions and use of pain assessment tools with people with advanced dementia approaching the end of life. *Palliat Med*. 2016;30:NP45-46. 9th World Research Congress of the European Association for Palliative Care (EAPC), Dublin, 9-11 June 2016. Oral presentation

De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfatrick SJ et al. "I don't need a piece of paper with scores to tell me that somebody's in pain and I need to do something about it". Nurses' and healthcare assistants' perspectives on and use of pain assessment tools with people dying with advanced dementia. *Palliat Med*. 2016;30:NP45-46. 9th World Research Congress of the European Association for Palliative Care (EAPC), Dublin, 9-11 June 2016. Oral Presentation

RESEARCH ACTIVITY AND ENGAGEMENT

Poster presentation: “Research evaluation and outcomes from: Pain assessment and management for patients with advanced dementia nearing the end of life”. All Ireland Institute of Hospice and Palliative Care (AIHPC) Research Network Annual Meeting, 8 December 2016.

Oral presentation: “Pain assessment and management in advanced dementia at end of life: an update and implications for physician and nurse education”. Marie Curie Hospice Belfast, 30 November 2015.

Seminar: “Pain assessment and management in advanced dementia in end of life care.” Queen’s University Belfast School of Pharmacy Lecture Series, 22 April 2015.

Oral presentation: “Assessing and managing pain in end of life care for people with advanced dementia.” Northern Ireland Palliative Care Research Forum (NI PCRF) Research Showcase Event, 23 September 2014.

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Discussion schedule: Carers

1. Thinking back over your experience of caring for your [spouse/parent/sibling] with very advanced dementia who was approaching the end of their illness, how can someone tell or recognise if that person is in pain? ☐
 - Is there anything that makes it difficult to tell if someone with advanced dementia is in pain?
 - Were there any behaviours, expressions or other factors that helped you recognise when your [spouse/parent/sibling] may have been experiencing pain?

2. Can you tell me about your experience of the way in which pain was recognised/assessed for your [spouse/parent/sibling] in the final few weeks, days and hours of life? ☐
 - Did you communicate your feelings/concerns to the healthcare professionals involved? What was the outcome?

3. Which healthcare professionals/carers were involved in recognising pain for your [spouse/parent/sibling]? ☐

4. Was pain assessment discussed with you and your family? How and by whom? ☐

5. Can you tell me about the way in which pain was managed or treated for your [spouse/parent/sibling] in the final few weeks, days and hours? ☐

6. Do you think that the assessment of pain in people with advanced dementia who are approaching the end of life could be improved? Could you suggest how? ☐

7. Thinking about the treatment of pain, do you think this could be improved and how? ☐

8. Do you have any other comments you wish to add? ☐



Discussion schedule: HCPs (Docs/RGNs)

1. Tell me about your experiences of assessing pain in patients with advanced dementia in their last few months, weeks, days and hours of life. ☐

2. What are the likely causes of pain in people with advanced dementia in their last few months, weeks, days and hours of life? ☐

3. Do different types of pain or different combinations of pain (e.g. breakthrough, chronic, acute, acute-on-chronic) impact on assessing whether a dying patient with dementia is in pain? If so, in what way? ☐

4. How do you recognise/identify when a person with advanced dementia who is approaching the end of life is in pain? (Only ask if the participant doesn't cover this in the above questions) ☐

5. Do you use pain tools to help with recognising and assessing pain?

YES

 - Which one(s) do you use and why that/those one(s) in particular?
 - How do you use this/these pain tool(s) in your clinical practice?
 - Are the results of these pain tools recorded/documentated and/or discussed with patients' family and other colleagues?
 - Do the results of the pain assessment tool(s) influence the pain management strategies (i.e. the medications) that you use/prescribe? In what ways?
 - What do you believe are the clinical outcomes of using these tools for managing pain in these patients? ☐

NO

 - Are there any barriers that limit the use of pain assessment tools?
 - What alternative measures do you find useful in helping you assess and manage pain?
 - Are there any factors that would encourage you or make it easier for you to incorporate the use of pain assessment tools in your clinical practice?

6. Do you think that the assessment of pain in people with advanced dementia who are nearing the end of life could be improved? In what ways? ☐

7. Do you think healthcare professionals require additional training/education in assessing pain in patients with advanced dementia? Who do you see delivering this type of training and how do you think it should be delivered? ☐

8. How do you manage pain in patients with advanced dementia in the final months, weeks, days and hours of life? (i.e. in terms of pharmacotherapy) Can you illustrate using a couple of examples from your clinical experience? ☐
(Prescribers only)

Appendix 1

9. Are there any challenges involved in prescribing effective pain relief for patients with advanced dementia who are approaching their last few months, weeks, days and hours of life? (**Prescribers only**) ☐

10. Are there any facilitators that help you meet these prescribing challenges? (**Prescribers only**) ☐

11. Are there any challenges involved in administering effective pain relief for patients with advanced dementia who are in the last few months, weeks, days and hours of life? ☐

12. Are there any facilitators that help you meet these challenges with administration? ☐

13. During clinical decision-making regarding pain treatment in a dying patient with advanced dementia which resources do you make use of? Which do you find most helpful?

- Personal clinical experience
- Consultation with other colleagues and HCPs? Which HCPs? ☐
- Electronic clinical resources
- Other?

14. How do you discuss pain management for patients with their families? Are these decisions documented? If so how? ☐

15. How and with whom do you discuss pain management in cases where there is very little or an absence of family involvement? Are treatment decisions for these patients documented? How? ☐

16. Do you think that the management of pain in people with advanced dementia who are nearing the end of life could be improved? How? ☐

17. Do you think further/additional training in managing pain in patients with advanced dementia is required for healthcare professionals? How do you think this should be delivered (via study days? Case conferencing? Peer-led workshops?) ☐

18. Who do you think is best suited to deliver this training? ☐

19. Do you have anything else you wish to add? ☐



Discussion schedule: Healthcare Assistants (HCAs)

1. How do you recognise/identify when a person with advanced dementia who is approaching their last few months, weeks, days and hours of life is in pain? ☐
 - Are there any behaviours, facial expressions or other factors that help you recognise when a person may be experiencing pain?

2. Are there any factors that make it difficult to tell if someone with advanced dementia is in pain? How do you overcome these challenges? ☐

3. If you believed that a resident with advanced dementia who is approaching the end of life is in pain, would you communicate this to other colleagues/HCPs? Which type of HCP? ☐

4. Can you describe your experiences of discussing pain in residents with advanced dementia with other healthcare professionals? ☐
 - Can you give an example?
 - What was the outcome?
 - How did you feel about this?
 - Did you communicate this to other HCPs involved? What was the outcome?

5. Do you think that the assessment of pain in people with advanced dementia who are in their last few months, week, days and hours of life can be improved? In what ways? ☐

6. Thinking back over your experience of caring for people with advanced dementia who are nearing the end of their lives, can you describe a couple of examples when pain was recognised and managed for a resident? ☐
 - Were there any occasions when you thought pain wasn't being managed?
 - Who did you communicate this to?
 - What was the outcome?

7. Do you think that the assessment of pain in people with advanced dementia who are approaching the last few months, weeks, days and hours of life could be improved? Could you suggest how? ☐

8. Thinking about the treatment of pain, do you think this could be improved? How? ☐

9. Do you think further/additional training in managing pain in patients with advanced dementia is required for healthcare professionals? ☐
 - How do you think this should be delivered? (study days, case-conferences?)

10. Do you have anything else you wish to add? ☐



Discussion schedule: HCPs (Docs/RGNs)

1. Tell us about your experiences of participating in the TEAM Pain AD teleECHO. ☐

2. What were your reasons for participating in the TEAM Pain AD teleECHO clinics? ☐

3. What did you like about the TEAM Pain AD clinics? What did you not like? ☐

4. Did the curriculum (including the cases and didactic materials) address your learning needs? If so, in what way? If not, why not? ☐

5. Do you think the teleECHO model can address the learning needs of healthcare professionals? ☐

6. What are your thoughts on the range of didactic trainers and patient cases provided? ☐

7. What are your thoughts on the varied audience of TEAM Pain AD clinics? Do you see a need or benefit to holding discipline-specific clinics? ☐

8. Did you gain any clinical knowledge or skills through participation in TEAM Pain AD teleECHO clinics? ☐

9. Have you applied any of the learning gained through TEAM Pain AD to your patients? If so, in what way? If not, why? ☐

10. Have you shared any knowledge gained through TEAM Pain AD with other colleagues and care staff? If so, how did you do this? Has it made any difference to pain assessment and management in your care setting? In what ways? ☐

11. What was the impact of your participation in TEAM Pain AD on your clinical teams in terms of staffing, workload and capacity? Is there anything we would need to consider when planning future ECHOs? ☐

12. What are your thoughts on the future of teleECHO clinics: do you see a need for continuing pain clinics in dementia? How about for other chronic conditions? ☐

13. Is there anything that would prevent you from participating in future teleECHO clinics? ☐

14. Do you have any additional comments and/or feedback? ☐

15. Is there anything you would like to ask us about the teleECHO clinics and/or the study? ☐
