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Nursing people with intellectual disability and dementia experiencing pain: An integrative review

Running head: ID dementia and pain

Author

Imelda Dillane

MSc, RNID

Daughters of Charity,

Limerick,

Ireland

Corresponding Author

Dr Owen Doody

PhD, MSc, BSc, Cert Man, RNID

Senior Lecturer,

Department of Nursing and Midwifery.

University of Limerick,

Ireland

owen.doody@ul.ie

+353 21 31667

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Aim: To explore the current evidence of nurses caring for people with Intellectual Disability and dementia who experience pain.

Background: People with intellectual disability are ageing and are experiencing age related health conditions including dementia and conditions associated with pain, but at an earlier age. Addressing the needs of people with intellectual disability who develop dementia is a new challenge for nurses.

Design: An integrative literature review.

Methods: A systematic search of databases; CINAHL, Medline, PsycINFO, Cochrane, Embase, Academic Search Complete, Scopus and Web of Science from 27 Oct 2017 to November 7th, 2017. Hand searching and review of secondary references were also undertaken. Quality appraisal (Crowe Critical Appraisal Tool), thematic data analysis (Braun and Clarke 2006) and reporting using the PRISMA guidelines.

Results: 7 papers met the inclusion criteria and three themes emerged from this review: nurses knowledge of ageing, dementia and pain, recognising pain in people with intellectual disability and dementia, and the role of nurse education. People with intellectual disability and dementia have difficulty communicating their pain experience compounded by pre-existing communication difficulties.

Conclusions: A pain experience can present similar to behavioural and psychological symptoms of dementia, and diagnostic overshadowing often occurs whereby a pain need is misinterpreted as behavioural and psychological symptoms resulting in inappropriate treatment. Nurses need greater knowledge about the presence of pain and potential causes in people with intellectual disability and dementia and education can be effective in addressing this knowledge deficit.

Relevance to clinical practice: Pain assessment tools for people with intellectual disability and dementia need to include behavioural elements, and baseline assessments are required to identify changes in presentation. Nurses need to recognise and respond to pain based on the evidence in order to deliver quality care.

Key words: pain, intellectual disability, dementia, education, integrative review.

What does this paper contribute to the wider global clinical community?

- Nurses caring for people with intellectual disability often lack knowledge about ageing, dementia and pain.
- Recognising pain in people with intellectual disability and dementia is complex.
- When a person cannot self-report their pain it must be systematically looked for.
- Core training in dementia and responsive behaviours for nurses caring for people with intellectual disability must include pain recognition and management.
- Palliative care specialists need training in caring for people with intellectual disability and dementia.

Introduction

Life expectancy for people with intellectual disability is improving and they are experiencing health conditions associated with ageing at an earlier age than the general population. A consequence to this demographic shift towards a growing older population is an increased incidence of dementia (McCarron *et al.* 2014). The incidence of dementia is up to five times higher for older people with intellectual disability compared to older adults in the general

population (Strydom *et al.* 2013). Pain in people with intellectual disability and dementia is a growing concern given the lack of recognition and understanding regarding pain and intellectual disability which is further compounded by the presence of dementia. People with intellectual disability and dementia have a right to have their needs met (HIQA 2013; 2016; McCallion *et al.* 2017) including their pain needs (McCallion *et al.* 2017). Historically people with intellectual disability were perceived as less sensitive to pain (Beacroft and Dodd 2010) though research has challenged this assumption and generalisation (McGuire and Kennedy 2013). Nurses must be knowledgeable regarding the possible causes of pain that people with intellectual disability and dementia may experience, how to assess for and recognise pain particularly when a person is unable to self-report and they must facilitate pain relieving interventions. Where nurses and carers lack this knowledge, they cannot meet a person's pain needs effectively.

People with intellectual disability and dementia experience the same age-related health conditions as the general population such as arthritis (McGuire and Kennedy 2013, Doody and Bailey 2017). While many people with intellectual disability live healthier lives than previous generations, they are more likely to experience health conditions than the general population which increase the likelihood of experiencing pain, for example due to musculoskeletal problems (De Knecht and Scherder 2011), gastro oesophageal reflux, dental/oral disease (Kerr *et al.* 2006). Gastrointestinal disorders including gastro-oesophageal reflux and constipation are common in people with intellectual disability and can cause changes in presentation due to pain (British Pain Society - BPS 2015). Infections including urinary tract infections are common in people as dementia advances due to reduced immune responses, urinary retention and incontinence (BPS 2015), which can cause significant discomfort. Given the complexity of pain recognition and treatment for people with intellectual disability and dementia experiencing pain there is a need to synthesise the evidence and unitise this evidence to deliver a quality service.

Background

Pain in people with dementia, with and without intellectual disability, is often under detected and undertreated (Cohen-Mansfield 2014; Burns and McIlpatrick 2015). A self-report of pain is the gold standard in pain management (McCaffery and Beebe 1989; Pasero and McCaffery 2010; Twycross *et al.* 2015). However, people with intellectual disability and dementia may

lose the ability to recognise and report their pain experience due to their disability or as the dementia progresses, which makes pain recognition and treatment more challenging. Thereby, they are less likely to have their pain needs met adequately (Kerr *et al.* 2006; 2011; Plooij *et al.* 2012; Cleary and Doody 2017a; Doody and Bailey 2017). The inadequate recognition of a person's pain experience can result in diagnostic overshadowing whereby behavioural changes displayed are attributed to the intellectual disability or dementia rather than considering other causes such as pain (Kerr *et al.* 2006; 2011). If pain is not recognised as a possible cause of this behaviour, it can result in inappropriate use of antipsychotic medication. While nurses may be aware of the correlation between people with dementia experiencing pain and exhibiting responsive behaviours, pain is often underestimated and undertreated (Chen and Lin 2016; Dowding *et al.* 2016). Research exploring pain in people with dementia has increased over recent years. However, research exploring pain in people with intellectual disability and dementia is limited (de Knegt and Scherder 2011) and generally the evidence identifies that carers (formal and informal) do not adequately recognise or consider pain as a possible cause for changes in presentation (Plooij *et al.* 2012, Cleary and Doody 2017a). While pain assessment tools are available and recommended their use appears limited (BPS 2015). As far back as 1996 the World Health Organisation (WHO) guidelines identified that "as required" (PRN) pain relief is not an appropriate approach to managing pain in people with dementia (WHO 1996). WHO developed the analgesia pain ladder, recommending regular administration of pain relief where pain is suspected, with regular reassessment and review, recommending a recognised pain assessment tool and a three-step approach to analgesic medication based on effectiveness and response (WHO 1996). Misconceptions by nurses and healthcare professionals regarding people with intellectual disability are that they are seen as a homogenous group, who are insensitive to pain and considered to have a higher pain threshold (Symons *et al.* 2008; Beacroft and Dodd 2010). However, this is not substantiated within research (McGuire and Kennedy 2013) and current opinion is that the low-level reports of pain are due to communication challenges rather than an absence of pain (Kerr *et al.* 2006; Cleary and Doody 2017a).

Methods

Aim

To explore the current evidence of nurses caring for people with intellectual disability and dementia who experience pain.

Design

An integrative review was chosen to determine the current level of knowledge on a topic as it identifies, analyses and synthesises the results of previous research so that new frameworks or perspectives can be generated (Torraco 2005). Whittemore and Knafl (2005) five-stage frameworks was utilised to conduct this review; problem identification, literature search, data evaluation and extraction, data analysis and presentation of results. The PRISMA checklist (supplementary file 1) and PRISMA flow diagram (Moher *et al.* 2009) were utilised to report this review, and Kahn *et al.* (2003) PEO format (Population, Exposure, Outcome) were utilised to frame the research question Table 1 (Aslam & Emmanuel 2010).

Supplementary file 1

Table 1. PEO framework formulating the research question

Search method

An initial scoping search of the literature was conducted to generate an understanding of research in the topic area and develop the search strategy (Table 2). Within the scoping search a broad range of terms were identified in the literature including; intellectual disability, cognitive disorder, cognitive impairment, learning disability, Alzheimer's disease, pain assessment, pain management, pain treatment, nurses and carers. A systematic search of eight academic databases relevant to nursing and healthcare was performed; CINAHL, PsychInfo, Medline, Embase, Scopus, Academic Search Complete, Cochrane, Web of Science during the period 27 October 2017 to 7 November 2017. Additional hand searching of the reference lists of papers that met the inclusion criteria was performed as databases may only yield 50% approximately of eligible studies due to indexing problems and inconsistent search terminology (Whitmore and Knafl 2005).

Table 2. Search Strategy

Search outcomes

Search results were exported to Endnote© and recorded in PRISMA format (Figure 1). 350 papers were identified in database searches and hand searching yielded an additional 5 papers. 21 duplicates were identified and removed and 224 papers were excluded during title review. Abstract review resulted in 51 papers been excluded leaving 59 for a full text review of which 7 papers met the inclusion criteria (Table 3) and the screen process was conducted by both authors.

Table 3. Inclusion/Exclusion search criteria

Figure 1. PRISMA flow diagram

Quality appraisal

Each paper was appraised using the CCAT critical appraisal tool (Crowe and Sheppard Crowe 2011) and all papers scored highly 36-39 out of 40 across the eight sections of the appraisal tool. Appraisal was conducted by both authors to form a consensus.

Data abstraction

Each paper was read and reread highlighting relevant details for extraction and a data extraction table provided a framework to focus and structure the examination of the papers. Data extracted included details on; author, year, title, country, care setting, aim of study, methodology, sampling, data collection, data analysis, summary of findings, limitations and quality score (Table 4). The process enabled data to be extracted or summarised easily and presented a clear synopsis of each study so comparisons or evaluation of the total evidence could be made.

Table 4. Data Extraction Table

Synthesis

As both qualitative and mixed methods research was included in this review, thematic analysis was undertaken (Braun and Clarke 2006). Analysis was an iterative process whereby the findings of included papers were read and reread line by line (Braun and Clarke 2006).

Notes made from statements extracted from each paper and grouped according to similarities generating initial codes. These codes were reviewed and organised into subthemes according to similarities, differences, patterns and relationships and connected to become themes (Vaismoradi *et al.* 2016). Three themes emerged (Table 5); nurses knowledge of ageing, dementia and pain; recognising pain in people with intellectual disability and dementia; and the role of nurse education.

Table 5 Theme development

Finding

Seven papers met the criteria for inclusion in this review of which six were qualitative and one mixed methods. Three were conducted in Ireland and four in the UK. Two studies each produced two papers (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011) and one was a literature review (Cleary and Doody 2017b). This highlighted that only four original research studies which included aspects of pain management in people with intellectual disability and dementia were conducted up to 2017. Research has primarily focussed on exploring the views and experiences of nurses or carers with pain emerging as a theme or subtheme.

Nurses knowledge of ageing, dementia and pain in people with intellectual disability

Increased life expectancy has resulted in a demographic shift towards an older population in intellectual disability services. Challenges for service providers and gaps in services have been identified in meeting the needs of the older person including knowledge of issues related to ageing, dementia and painful conditions associated with ageing (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011; Fahey-McCarthy *et al.* 2009). Pain has historically been under recognised and undertreated in older people in the general population so it was unsurprising to find it similarly under treated in people with intellectual disability (Wilkinson *et al.* 2004;

2005; Kerr *et al.* 2006; 2011). People with intellectual disability and dementia experience the same age related painful conditions as the general ageing population (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011; Cleary and Doody 2017a), though at a younger age. Common conditions include arthritis, dental decay and gum disease, impacted earwax, eye infections, urinary tract infections and constipation (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011; Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a; 2017b). People with intellectual disability also tend to experience more chronic health conditions which cause pain and discomfort than the general population including gastric reflux, osteoporosis and chronic constipation (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; Cleary and Doody 2017a).

Nurses who have worked in intellectual disability services for many years may not have had significant education in the care of the older person (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011; Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a; 2017b). Where nurses lack an awareness of painful conditions, they are less likely to assess for and treat pain appropriately. A knowledge deficit historically existed among carers in intellectual disability services regarding pain detection and management, and pain and dementia (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; 2011). Where carers did not consider pain as an issue for people with intellectual disability and dementia (Wilkinson *et al.* 2004; Kerr *et al.* 2006; 2011; Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a). As knowledge regarding dementia and ageing in people with intellectual disability has improved, knowledge and practice regarding pain management appears to have improved also. Where carers in intellectual disability services have gained knowledge regarding dementia, they demonstrate an awareness of the possibility of the person experiencing pain, were more likely to actively observe for pain and consider pain as a cause of distress (Wilkinson *et al.* 2004; Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a). More experienced nurses recognised that the person may not be able to articulate or communicate the type and location of the pain that they are experiencing. They recognise mental pain and distress (Kerr *et al.* 2006; Cleary and Doody 2017a), with pain relief provided by both administration of analgesia and through reassurance, comfort and time spent with the person. Experienced nurses recognise the role of non-pharmacological interventions such as massage and touch that reduce stress and thereby alleviate pain and distress (Kerr *et al.* 2006; 2011).

Fahey-McCarthy *et al.* (2009) found that pain recognition and management skills were lacking in nurses in intellectual disability services, though they recognised the need for these skills. Nurses and carers appear to rely on personal knowledge of the person rather than

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recognised pain assessment tools (Kerr *et al.* 2006; 2011; Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a) when pain is considered. Even where nurses show an awareness of the possibility of pain, they do not routinely use recognised pain scales to assess pain and depend on their own knowledge of the person to decide if behaviour indicates pain (Kerr *et al.* 2006; Cleary and Doody 2017a). The association of behavioural and psychological symptoms with dementia saw many inexperienced nurses interpret behaviours as challenging and due to the persons intellectual disability and/or dementia rather than considering the possibility of pain as a cause, particularly where nurses were not knowledgeable about dementia (Wilkinson *et al.* 2004; 2005; Cleary and Doody 2017b). Wilkinson *et al.* (2004; 2005) and Kerr *et al.* (2006; 2011) identify where carers familiar with the presentation and behaviours of people with intellectual disability and dementia identified pain as a cause for distress they were met with resistance from GP's when prescriptions for analgesia were requested.

Recognising pain in people with intellectual disability and dementia

Pain is a subjective experience (Kerr *et al.* 2006; Cleary and Doody 2017a) only the person experiencing pain will know how uncomfortable they are. Recognising pain in people with intellectual disability and dementia is complex (Wilkinson *et al.* 2005; Cleary and Doody 2017a; 2017b). Pre-existing cognitive and communication impairments impact on a person's ability to express their pain, its location, type and severity (Kerr *et al.* 2006; 2011; Cleary and Doody 2017a; 2017b) and the effects of dementia compounds this (Kerr *et al.* 2006; 2011; Cleary and Doody 2017b). People who could communicate well previously can lose the language and words to describe their pain. They can lose the geography of their body and become unable to identify the ability to identify the location of their pain or describing it (Kerr *et al.* 2006; 2011). Several factors affect the ability, likelihood and willingness of a person with intellectual disability reporting pain. Kerr *et al.* (2006; 2011) notes that many older people with intellectual disability spent their younger years living in institutional type settings and it is likely that they had limited access to generic healthcare and interventions. In addition, they may not have been sympathetically responded to when they reported pain as staff may not have been sensitive to their anxieties (Kerr *et al.* 2006; 2011) due to misconceptions regarding people with intellectual disability been a homogenous group who are less sensitive to pain and have a higher pain threshold. Therefore, they may associate

pain, reporting and medical interventions as being unpleasant experiences and have learned not to report their pain. In addition, many older people have a stoical attitude to pain, reducing their likelihood of reporting pain voluntarily and as dementia progresses and recent memories are lost, the person with intellectual disability and dementia may return to their earlier memories where they did not report pain (Kerr *et al.* 2006). Or revert to using terms to describe discomfort when they were younger as an expression of pain/discomfort and these may not be correctly interpreted by nurses or carers (Kerr *et al.* 2006; 2011). Where people with intellectual disability and dementia reported pain that did not match their clinical presentation it lead nurses to determine that people with intellectual disability and dementia have a high pain threshold (Kerr *et al.* 2006; 2011; Cleary and Doody 2017a). However, we need to challenge this view held by some professional carers as a communication difficulty does not remove the potential for and the experience of pain (Kerr *et al.* 2006; 2011).

Carers don't always recognise that changes in presentation may possibly be due to pain (Wilkinson *et al.* 2004). Poor recognition of pain can lead to the inappropriate use of antipsychotics and sedatives which can mask painful conditions and further reduce the likelihood of identifying pain (Kerr *et al.* 2006; 2011). Diagnostic overshadowing often occurs whereby changes in a person's behaviour tended to be attributed to the dementia or the persons history of challenging behaviour, without consideration of other possible causes such as pain (Kerr *et al.* 2006; 2011). Painful conditions can result in behaviours which are also labelled as "challenging", these behaviours tend to be considered due to dementia rather than pain (Kerr *et al.* 2006; 2011) such painful conditions can lead a person to exhibit behaviours such as banging, violence, shouting, wandering (Wilkinson *et al.* 2004; 2005), increased irritation, moaning, withdrawal, swearing, aggression, poor eating, anxiety, hitting out, pacing (Kerr *et al.* 2006; 2011). Where a history of responsive behaviour exists, disturbance in behaviour are considered "challenging behaviour" first and pain is not considered a factor (Kerr *et al.* 2006; 2011). These behaviours are easily misinterpreted as "challenging" among people with intellectual disability and dementia (Kerr *et al.* 2006; 2011). However, treating physical causes of pain was found to relieve behavioural symptoms of distress such as shouting or vocalising loudly (Cleary and Doody 2017a).

Sleep disturbance is common in people with dementia, specific changes in circadian rhythms have been found (Kerr *et al.* 2006). Many older people experience sleep difficulties and wake at night. This wakefulness compounded by the confusion and disorientation caused by dementia can result in agitation (Kerr *et al.* 2006). Painful conditions can cause a person to

wake at night, yet sleep disturbance were attributed to dementia as opposed to possible pain (Kerr *et al.* 2006; 2011). Arthritis is common in older people, it causes pain and often results in people waking at night experiencing pain (Kerr *et al.* 2006; 2011). In many cases carers do not appear to consider pain as a potential cause of this behaviour (Kerr *et al.* 2006; 2011; Cleary and Doody 2017b). However, where pain was considered and treated it led to a reduction in some BPSD displayed (Cleary and Doody 2017a).

Role of nurse education

A common issue identified in all literature included in this review is that education and training is effective in improving nurses pain recognition and management for people with intellectual disability and dementia. To appropriately treat pain it must be recognised and even raising awareness can result in improvements to practice and outcomes for people with intellectual disability and dementia, where participation in research alone resulted in greater focus on seeking to identify pain (Kerr *et al.* 2006; Fahey-McCarthy *et al.* 2009). Nurses are open and willing to improve their knowledge and their practice. Nurses with confidence in their ability to provide end-of-life care were experienced in the care of people with intellectual disability and dementia and were supported by organisational policy and palliative care training (Cleary and Doody 2017a). The input and expertise of Clinical Nurse Specialists (CNSs) and Allied Healthcare Professionals (AHCPs) was also valued by nurses providing direct care (Cleary and Doody 2017a). Caring for people with intellectual disability and dementia is stressful (Wilkinson *et al.* 2005; Kerr *et al.* 2006; Cleary and Doody 2017a, 2017b) particularly when staff do not have good knowledge of dementia and its effects (Wilkinson *et al.* 2004; 2005). Where nurses have knowledge and insight regarding caring for people with intellectual disability and dementia, they found it less stressful (Cleary and Doody 2017a). Intellectual disability service providers need to provide training in dementia, pain and ageing needs to address the lack of knowledge and skills regarding pain assessment and management (Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a).

Core training in dementia and responsive behaviours for nurses caring for people with intellectual disability must include pain recognition and management so that carers can interpret behaviours correctly and respond appropriately to expressions of pain (Wilkinson *et al.* 2004; 2005; Fahey- McCarthy *et al.* 2009). Training in dementia for nurses caring for

people with intellectual disability and dementia must focus on the specific needs of people with intellectual disability (Wilkinson *et al.* 2004; 2005; Cleary and Doody 2017b), how dementia presents for people with intellectual disability, the likely progress of the condition, interventions that support the person with dementia. Training in the care of the older person for nurses in intellectual disability services is needed to raise awareness of conditions associated with ageing (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; Cleary and Doody 2017a, 2017b). Ongoing upskilling of staff will be required to meet the changing needs of people (Fahey- McCarthy *et al.* 2009) and training needs to be delivered to all carers providing direct care to the person. Nurses expressed concern regarding non-medically trained staff who provide direct care (Kerr *et al.* 2006; Cleary and Doody 2017a) highlighting that their role in recognising and responding to a person's pain need is vital (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2006; Fahey McCarthy *et al.* 2009; Cleary and Doody 2017a). They are key informants for GP's who will prescribe analgesia, if they lack the skills and knowledge to detect pain or recognise a person's behaviour as an exhibition of pain, they will not be able to adequately meet the persons needs. The extension of palliative care services to include dementia has presented a challenge for specialist palliative care staff when caring for people with dementia and intellectual disability. Specific training for palliative care specialists needs to include dementia and communication strategies in meeting the specific needs of people with intellectual disability (Fahey McCarthy *et al.* 2009; Cleary and Doody 2017a). Palliative care specialist input has been found valuable for carers of people with intellectual disability and dementia (Wilkinson *et al.* 2004; Fahey McCarthy *et al.* 2009; Cleary and Doody 2017a).

Discussion

The absence of pain literature for persons with dementia and intellectual disability is noteworthy by its absence (Wilkinson *et al.* 2004; 2005) and Cleary and Doody (2017b) found pain mentioned in just 4 of 14 papers in their literature review and only mentioned by just half of nurses in their study (Cleary and Doody 2017a). Pain was identified as one of six specific training needs for nurses in intellectual disability and palliative care services (Fahey-McCarthy *et al.* 2009). It is evident that nurses caring for people with intellectual disability often lack knowledge about ageing, dementia and pain (Beacroft and Dodd 2011; McGuire and Kennedy 2013; Doody and Bailey 2017). For nurses to provide true person-centred care,

they require knowledge of age-related health conditions including dementia and pain, and nurses themselves recognise that this is required information, to provide a comprehensive person-centred care. The literature included in this review shows that knowledge and awareness in intellectual disability services of ageing and related conditions including dementia is improving albeit from a very low base.

Detecting pain is challenging in people with dementia who do not have intellectual disability (Cohen-Mansfield 2014; Barry *et al.* 2015) and is a significant quality of life and quality of care issue if poorly treated (Monroe *et al.* 2015). People with dementia with and without intellectual disability experience similar challenges in pain assessment and treatment, as dementia advances they lose the ability to self-report their pain and nurses are uncertain about the pain experiences of the people they care for (Monroe *et al.* 2015). There is a reliance on self-reporting of pain (McAuliffe *et al.* 2009) and the impact of cognitive decline associated with dementia added to any pre-existing communication challenges often results in the person with intellectual disability and dementia not being able to express their pain experience to their carers (Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017b). Diagnosing pain in people with intellectual disability and dementia is difficult (Kerr *et al.* 2006; Cleary and Doody 2017a). Pain must be recognised before palliative care services can be accessed (Wilkinson *et al.* 2004). Specialist palliative care nurses experience difficulties assessing for pain in people with intellectual disability and dementia primarily due to communication challenges (Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017b) though also because of a lack of understanding of intellectual disability (Bailey *et al.* 2016). While a lack of specialist support regarding dementia was noted in the earlier research (Wilkinson *et al.* 2004), the availability of CNSs in Dementia and the input of AHCPs was beneficial and supportive (Cleary and Doody 2017a).

Nurses are committed to providing high quality care to people with intellectual disability, and willing to improve their knowledge of intellectual disability, palliative care and care of the older persons (Cohen-Mansfield 2014; Barry *et al.* 2015). The knowledge, skills and experience of nurses and carers determines the quality of care delivered to people with intellectual disability and dementia (Fahey-McCarthy *et al.* 2009; Cleary and Doody 2017a, 2017b). Nurse in intellectual disability services spends more time than other healthcare professionals with the person, so are ideally placed to meet their needs. However, there is a need for intellectual disability service providers and palliative care service providers to work more closely and collaboratively and share each other's expertise (Bailey *et al.* 2016;

McCarron *et al.* 2018) with a view to improving palliative care for people with intellectual disability and dementia.

The gold standard in pain reporting is a self-report of pain yet Beacroft and Dodd (2011) found that just 35% of people with mild or moderate level of intellectual disability and good verbal skills would tell someone if they were experiencing pain. It is unreasonable therefore to expect that people with significant communication difficulties and a diagnosis of dementia to self-report their pain accurately. On the other hand Barry *et al.* (2015) found that three quarters of nursing home residents were able to self-report their pain despite most having a significant cognitive impairment. For pain to be effectively managed in people who cannot self-report their pain, including people with dementia with and without intellectual disability, it must be systematically looked for. It is not sufficient to wait until a person reports pain for treatment to be initiated. Where a person is unable to self-report their pain they are dependent on the observational skills of carers. When carers know the person, and understand their language and behaviours, they can support the diagnosis of pain and therefore manage it well (McAuliffe *et al.* 2009; McKenzie *et al.* 2013). Key skills that are required by nurses in intellectual disability services in achieving good communication with people with intellectual disability are observation, listening and conveying (Martin *et al.* 2012b). Nurses cannot provide person centred care to people with intellectual disability (Martin *et al.* 2012a) without really knowing the person. This includes knowing their life history, family background, their physical and psychological needs, likes and dislikes etc. The nurse must observe the persons interactions with others, the environment, their facial expressions, gestures, physical expressions, diet, sleep etc. Residential services must be sufficiently resourced in terms of personnel to ensure that care is not rushed and that interactions between residents and nurses and carers is not limited to the provision of personal or health care interventions.

Pain assessment tools are not used routinely to assist nurses in recognising pain and monitoring treatment for effectiveness. This appears related to a lack of awareness about the possibility of and presentation of pain and the possible utility of assessment tools. There are a variety of assessment tools used to assess for pain in people with intellectual disability such as STOP-ID (de Knecht *et al.* 2016) and Disability Distress Assessment Tool, DisDAT (Regnard *et al.* 2007) which carers have found useful. Lichtner *et al.* (2014) found limited evidence as to the reliability of pain assessment tools with no gold standard identified across 28 tools identified. No individual tool was found to be more reliable or valid. Behavioural

pain assessment tools where facial expressions, verbal expressions and body movements are observed for are the most appropriate method of pain assessment in people with intellectual disability who have limited communication skills (Doody and Bailey 2017). Baseline observations must be documented for a variation from normal presentation to be identified. Both DisDAT and PAINAD have been found useful in detecting pain and measuring responses to pain relieving treatment in people with advanced dementia (Jordan *et al.* 2012).

The issue of diagnostic overshadowing is a problem in pain management for people with intellectual disability with and without dementia and for people with dementia but not intellectual disability. This occurs when a change in behaviour displayed by a person is considered a symptom of the persons intellectual disability or dementia and is interpreted as challenging, rather than an attempt to communicate their pain (McAuliffe *et al.* 2009; Doody and Bailey 2017). Due to the relatively high incidence of responsive behaviours displayed by people with intellectual disability and by people with dementia, consideration tends not to be given to other possible causes such as pain. Such behaviours tend to be attributed to the intellectual disability or dementia rather than exploring other causes of pain. Night time disturbance can be due to pain caused by arthritis, yet as it is frequently associated with dementia, it tends to be attributed to this rather than considering the possibility of pain. People with intellectual disability experience age related conditions, many of which cause pain, at a younger age than the general population, they will experience care needs that can cause pain. While pain is not the only cause of distress in people with intellectual disability and dementia, it is a cause that can be alleviated. When a person's pain need is not established, ineffective or inappropriate treatment becomes more likely (Kerr *et al.* 2006; Barry *et al.* 2015) and the identification of pain and the need for pain management is not well defined or understood (Peisah *et al.* 2014).

Education has been identified as necessary and effective in raising awareness of pain as an issue for people with intellectual disability and dementia (Wilkinson *et al.* 2004; 2005; Kerr *et al.* 2011; Cleary and Doody 2017a, 2017b). Even participation in research was enough to influence and change practice (McAuliffe *et al.* 2009; Cohen- Mansfield 2014; Dowding *et al.* 2016). Education cannot be a once off activity (Banerjee 2009) and ongoing education and upskilling is needed to ensure that pain assessment and management becomes and remains a priority embedded within practice change principles (Banerjee 2009; Peisah *et al.* 2014). Training in approaches to managing behavioural and psychological symptoms of dementia must include pain management. Education on pain management must include the possible

causes of pain, how to recognise and treat it, and must be provided to all direct care staff including non-nurses and care staff. Nurses must be educated to routinely assess for pain in people with intellectual disability and dementia such as dental pain, constipation, arthritis, post falls, assess for causes of pain and treat them. If pain is not actively considered, it will be overlooked and inadequately treated. Where service providers implement training in the use of pain assessment tools, regular use of them increases (Mackey and Dodd 2011; Cohen-Mansfield 2014). The education gap regarding dementia and pain is largely due to the historically low numbers of older people and people with dementia in intellectual disability services. As the number of people affected by dementia grows, the difficulties experienced by carers will become more widespread and there will be a greater need for a response. Collaborative education including both intellectual disability and palliative care services, providing for the sharing of each disciplines expertise, will help to improve palliative care and end of life care for people with intellectual disability and dementia (Bailey *et al.* 2016).

Conclusion

Ageing and dementia have brought significant changes to intellectual disability services (Fahey-McCarthy *et al.* 2009; McCarron *et al.* 2010) and present different issues for nurses with a change in emphasis of care from one of maximising independence to one where the aim is to maintain existing skills rather than developing new ones (Wilkinson *et al.* 2005). The shift to an older demographic means nurses need to develop new skills in areas such as ageing, dementia and palliative care. It is unreasonable to expect nurses in intellectual disability or any other setting to become experts or specialists of everything. The role of CNSs with knowledge of the needs of the person with intellectual disability in areas of ageing, dementia and palliative care can provide a valuable resource for direct care staff in their role in education and training, advocate for the person with intellectual disability and dementia, developing research to enhance the knowledge base, and developing policies and guidance to promote and support good practice.

The development of local guidelines and policies in dementia, pain management, palliative care and end-of-life care have been found effective in promoting good practice (McCarron *et al.* 2011; Cleary and Doody 2017a). The first line of management when behavioural and psychological symptoms present must be a detailed assessment to identify possible causes and treat appropriately, including pain (Banerjee 2009). Pain assessment tools can be useful

if they include behavioural as well as verbal and facial elements and baseline assessments are required against which changes in presentation can be measured (McAuliffe *et al.* 2009). They should be carried out by direct care staff familiar with the person (McAuliffe *et al.* 2009; Cohen-Mansfield 2014) with training in the use of the observational pain scales (Barry *et al.* 2015). Pain assessment tools can be useful in screening for pain, but screening for pain is one step of the process (Curtiss 2010) and attention needs to be given to treating with pharmacological and/or non-pharmacological interventions and observing for efficacy of the intervention (Curtiss 2010; Cornally *et al.* 2016).

While some studies within this review report a good knowledge base and recognition of pain it is also apparent that further education and research would enhance understanding and improve care outcomes for clients. The issues of the lack of knowledge regarding dementia is not limited to intellectual disability services. The increase in prevalence of dementia in society generally has resulted in increased numbers of people with dementia in acute hospitals, requiring home care services and long-stay residential services of older people. As life expectancy increases, the prevalence of all age-related conditions will increase and place changing demands on our health and social care services. Education needs for nurses and healthcare professionals at undergraduate and postgraduate level will be evident across all healthcare settings. Recently published UK guidelines on the assessment of pain in older people Schofield (2018) recommend structured pain education for all health professionals with education and training in the assessment and management of pain given the projected increase on the older population will result in increased prevalence of chronic pain.

Research must include the perspective of the person with intellectual disability (Doody 2018), participants in research included in this review were primarily paid healthcare professionals, with families to a lesser extent. Just one study meeting the criteria for inclusion included people with intellectual disability and dementia as participants (Kerr *et al.* 2006). Those included did not experience communication challenges so caution must be exercised when applying the findings to people with intellectual disability and advancing dementia. The person with intellectual disability and dementia can easily be overlooked but they must be facilitated to ensure their voice is heard (Keenan and Keogh 2011; Watchman 2016; Watchman *et al.* 2017) and to advance understanding of the effects of dementia on them and their experiences (Watchman *et al.* 2018).

Relevance to clinical practice

Pain assessment tools for people with intellectual disability and dementia need to include behavioural as well as verbal and facial elements, and baseline assessments are required against which changes in presentation can be measured (McAuliffe *et al.* 2009). While pain assessment tools are useful in screening for pain, this is only one step in the process which requires a systematic approach of assessment and reassessment of the person including observing for changes in verbal and facial expressions, changes in behaviours, searching for an obvious cause of pain, treating with pharmacological and/or non-pharmacological interventions and observing for efficacy of the intervention (Curtiss 2010; Cornally *et al.* 2016). Nurses have an obligation to recognise and respond to the needs of those they care for in a manner that is evidence based so as to provide the highest quality care.

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Table 1. PEO framework formulating the research question

P-Population	Adults with Intellectual Disability (ID) and dementia
E-Exposure	Pain
O-Outcome	Nursing Care

Table 2. Search Strategy

Search	Keyword and subject headings search terms
1 (P)	Dementia OR Alzheimer's disease OR Alzheimer* OR cognitive disorder OR cognitive impairment
2 (P)	Intellectual disability OR learning disability OR learning disorder OR
3 (E)	Pain OR pain assess* OR pain measure* OR pain manag* OR pain
4 (O)	nurse* OR nurses OR nursing OR carer* OR caregiver
Searches	1 AND 2, 3, 4, 5 (1 AND 2 AND 3 AND 4)

Table 3. Inclusion/Exclusion search criteria

Inclusion criteria	Exclusion criteria
Diagnosis of ID and dementia	Diagnosis of both ID and dementia not confirmed
Over 18 years of age	Under 18 years of age
English language publication	Non- English language
Aspects of pain management referenced	Pain management not referenced

Table 4. Data Extraction Table

Author/Year/Title/ Country	Care setting	Aim	Methodology	Sample strategy & size	Data collection/ analysis	Summary of findings	Limitations	Quality Score CCAT
Cleary and Doody (2017a) “Nurses experience of caring for people with intellectual disability and dementia”, <i>Journal of clinical nursing</i> , 26(5-6), pp.620-631. Ireland	Residential and Day Service provider people with ID	Explore nurses’ experiences of caring for older people with ID who develop dementia	Qualitative descriptive phenomenological	11 nurses, over 2 years nursing experience and 1 year experience working with older people with dementia	Semi structured interviews/ Colazzi’s (1978) data analysis framework	Concern that less experienced colleagues have poor knowledge re dementia Comorbid healthcare needs including pain and palliative care identified. Reliance on personal knowledge of the person rather than pain scales to manage pain. Person centred approach to behaviour management. Impact on peers. Multidisciplinary support valued. Impact of changing needs on provision of activities.	Ethics not referenced Small sample size. Single site. Potential for bias acknowledged.	38/40 95%
Cleary and Doody (2017b) “Professional carers’ experiences of caring for individuals with intellectual disability and dementia: A review of the literature” <i>Journal of Intellectual Disabilities</i> , 21(1), pp.68-86.	Review article	Identify professional carers experiences of caring for people with ID and dementia	Literature review	14 articles	14 articles / thematic analysis not identified	Staff knowledge of dementia, caregiving, challenging behaviour, pain management, mealtime support, coping strategies	Pain a minor theme identified.	38/40 95%
Fahey-McCarthy <i>et al</i> (2009)	Staff in residential ID services	Understand care concerns of staff in	Qualitative Focus group interviews. Pilot educational	Focus group interviews 57 participants: 50	1. Focus group interviews	Training needs identified by both ID and Palliative care re meeting nutrition, hydration and pain	Pain a minor theme.	38/40

<p>“Developing an education intervention for staff supporting persons with an intellectual disability and advanced dementia” <i>Journal of Policy and practice in Intellectual Disabilities</i>, 6(4), pp.267-275, Ireland</p>	<p>(6) and specialist Palliative Care service (1)</p>	<p>supporting people with ID and advanced dementia. Develop, deliver and evaluate educational intervention</p>	<p>intervention</p>	<p>from ID services, 7 from specialist care service. Education intervention 16 participants: pre- and post-intervention questionnaires</p>	<p>2. Evaluation of education intervention, pre- and post-questionnaires/ 1. Qualitative content analysis 2. SPSS</p>	<p>concerns. Staff in ID services often lack knowledge and skills in pain and symptom management. Palliative care staff lacked knowledge re ID. Education intervention addressed key training concerns.</p>		<p>95%</p>
<p>Kerr <i>et al</i> (2011) “Responding to the pain experiences of people with a learning difficulty and dementia” <i>International Medical Review on Down’s Syndrome</i>, 15(1): 2-7. UK</p>	<p>Residential and non-residential services for people with learning disabilities</p>	<p>Explore the detection, management and understanding of pain among professionals supporting people with ID and dementia. Record experiences and views of people with ID and dementia</p>	<p>Qualitative, interviews and observation</p>	<p>Six sites across UK 86 people interviewed: Older people with learning difficulty and dementia (12), Support staff, Members of community learning disability team and GP’s.</p>	<p>Interviews, and observation/ Thematic analysis</p>	<p>Diagnostic overshadowing. A focus on “behaviour that challenges” Communication difficulties associated with dementia. Beliefs about pain threshold. Use of PRN medication is problematic. Role for non-pharmacological interventions.</p>	<p>Results extracted from earlier research in 2006. Nurses a small proportion of sample.</p>	<p>38/40 95%</p>
<p>Kerr <i>et al</i> (2006) “Responding to the pain experiences of people with a learning disability and dementia”</p>	<p>Residential and non-residential services for people with learning</p>	<p>Develop understanding of pain experiences of older person with learning</p>	<p>Qualitative, interviews and observation</p>	<p>Six sites across UK 86 people interviewed: Older people with learning difficulty</p>	<p>Interviews, and observation/ Qualitative thematic analysis</p>	<p>Pain experience not always recognised by staff. Diagnostic overshadowing. Communication challenges. Role of staff awareness. Formal assessment tool. Beliefs</p>	<p>Nurses a small proportion of sample.</p>	<p>39/40 98%</p>

York: Joseph Rowntree Foundation. UK	disabilities	difficulty and dementia, explore how they are managed.		and dementia (12), Support staff, Members of community learning disability team and GP's.		about pain threshold		
Wilkinson <i>et al</i> (2005) "Equipping staff to support people with an intellectual disability and dementia in care home settings." <i>Dementia</i> , 4(3), pp.387-400. UK	Service providers for people with ID and dementia	Explore training and support needs of staff when a resident with ID develops dementia	Qualitative Interviews and focus groups	Based on Wilkinson et al (2004) 50 participants: managers (10), Care staff (22), peers (13), family members (5)	Interviews and focus groups/ Qualitative thematic analysis	Staff in ID services require training re dementia. Staff resources required to support ageing in place. Needs of peers and relatives. Need to recognise importance of the built environment. Detection and management of pain lacking. Core training must include pain recognition and management. Access to specialist services such as palliative care, OT, physio.	Pain not explored in detail. Unclear how many nurses in sample. Not recent research. Based on wider study published 2004.	36/40 90%
Wilkinson et al (2004) 'Home for good? Preparing to support people with learning difficulties in residential settings when they develop dementia', <i>Brighton, Joseph Rowntree Foundation, Pavillion Publishing (Brighton) Ltd.</i> UK	Service providers for people with learning disability and dementia	Explore current models of practice for supporting people with LD and dementia. Explore key issues in this group living in care home settings. Describe examples of best practice	Qualitative Interviews and focus groups	50 participants: managers (10), Care staff (22), peers (13), family members (5)	Interviews and focus groups- focussed on case studies of 18 residents with dementia. Qualitative thematic analysis	Timing & management of diagnosis of dementia determines the persons experience. Lack of formalised care pathways. Impact on peers. Needs of relatives. High level of staff commitment. Lack of knowledge among staff, need specific training. Quality of training varied. Waking night staff supports ageing in place. Lack of attention to environmental adaptation and pain management. Three models of service delivery: Ageing in place; In place progression; Referral out.	Pain not explored in detail. Unclear how many nurses in sample. Not recent research	37/40 93%

Table 5. Theme development

Theme	Subtheme	
Nurses knowledge of ageing, dementia and pain	Knowledge of dementia	
	Knowledge of ageing	
	Knowledge of painful conditions	
	Staff issues- knowledge, training	
	Nurses V care staff	
	How nurses assess pain in people with ID and dementia	
Recognising pain in people with ID and dementia	Communicating pain need	
	Pain experience	
	Impact of pain, behaviours, presentation	
	Recognising pain	
	Approach to behaviour management	
	Diagnostic overshadowing	
	Formal assessment tools	
	Recognising pain is complex	
	Beliefs re pain threshold	
	Lack of attention to pain issues	
	The role of nurse education	Training, education needs
		Education addressed concerns
Raised awareness		
Organisational policy supports good practice		
Protocols for non-medically trained staff		



PRISMA 2009 Flow Diagram

