

ORIGINAL ARTICLE

Exploring ways to enhance pain management for older people with dementia in acute care settings using a Participatory Action Research approach

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Abstract

Background: Dementia is a progressive condition that leads to reduced cognition, deteriorating communication and is a risk factor for other acute and chronic health problems. The rise in the prevalence of dementia means untreated pain is becoming increasingly common with healthcare staff being challenged to provide optimal pain management. This negatively impacts the person living with dementia and their carers. There is minimal evidence that explores the pain management experience of patients as they move through acute care settings.

Objective: To understand the complexities of managing the pain of older people with dementia as they progress through acute care settings, with the view of assisting staff to improve practice.

Method: A Participatory Action Research approach, guided by the Promoting Action Research in Health Services framework, was used. Three Action Cycles were completed comprising of an exploratory audit and two case studies (Action Cycle One), three focus groups with a total of 14 participants (Action Cycle Two) and the development and implementation of immediate and long-term actions (Action Cycle Three).

Results: Thematic analysis identified four themes that affected pain management practices. These were not knowing the patient; balancing competing priorities; knowledge and understanding of pain and dementia and not assimilating available information.

Conclusion: Pain management practices for patient living with dementia, across acute care settings, was influenced by shared ways of thinking and working. Not knowing the patient, fragmentation of information and having insufficient knowledge of the subtleties of dementia led participants to deliver task-focused, target and policy-driven care that was not person-centred in its approach. Facilitated reflection enabled acute care teams to actively participate in identifying problems and finding solutions to enhance practice.

KEYWORDS

acute care, context, dementia, older people, pain management, Participatory Action Research

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1 | BACKGROUND

The lack of dementia-friendly care in hospitals is an important area to address. Dementia is a global health concern, with current estimates suggesting that 50 million people are living with some degree of this disease (Alzheimer's Disease International, 2019). There are many different types of disorders that result in dementia, with symptoms depending on each individual's form of the disease and which parts of the brain are affected (Alzheimer's Society, 2017). As the disease progresses, it results in the person becoming more forgetful and some may develop difficulties in communicating (Alzheimer's Society, 2017). Dementia is unique to each person, resulting in every person's experience of the condition being different. Although dementia has no age boundaries, it is much more common in older people (≥ 65 years), (Gagliese et al., 2018). Therefore, it is likely the person will have other co-morbidities (Dewing & Dijk, 2016), and as a result may already be experiencing chronic pain (Browne et al., 2017; Husebo et al., 2016). Research suggests that hospital settings are not dementia-friendly areas; resulting in longer stays and poorer outcomes (Dewing & Dijk, 2016; Shepherd et al., 2019). Nevertheless, people living with dementia have a 1.42 times greater risk of hospitalisation compared to people without dementia (Shepherd et al., 2019). Figures from England show a significant rise of 35% in hospital admissions for people living with dementia from 2013 to 2018 (Torjesen, 2020).

Access to adequate pain management is considered a fundamental human right (Cousins & Lynch, 2011). However, for older people living with dementia and who are admitted to acute care, pain management remains inadequate (Lichtner et al., 2015; Timmons et al., 2016; Allione et al., 2017; Shepherd et al., 2019). Multiple co-morbidities and the likelihood of polypharmacy make pain management with older people challenging. The issues become more complex when people also experience dementia, particularly as it is accepted internationally that self-report is the best way to understand an individual's pain experience. Patients living with dementia may find it challenging to self-report their pain, thus healthcare teams must find other ways to assess it, such as involving the family and utilising behavioural pain assessments (Harmon et al., 2019). Untreated pain not only impacts the person with dementia and their families and carers but adds burdens, including cost, to the health services (Afonso-Argilés et al., 2020).

It is essential that staff have knowledge of the patient's pain history (Closs et al., 2016; Gregory, 2015), as people with dementia often have underlying painful conditions (Wright, 2014). The patients' inability to communicate effectively may result in the under-assessment and treatment of their pain (Manias, 2012; Tsai et al., 2018). In these instances, families can provide valuable information to assist with the patient's pain management (Fry et al., 2015; Scotland, 2016). As these approaches are not without their limitations (Gregory, 2015), national guidelines have been developed to assist practitioners with ways to optimise pain assessment and management with older people, including those with dementia (Schofield, 2018; Schofield et al., 2022).

How could the findings be used to influence policy or practice or research or education?

- Understanding the complexities of delivering a good patient experience to older people with pain and dementia, nursed in acute care settings, requires nuanced exploration. Supporting healthcare teams to critically examine their practice, through Participatory Action Research, helps them to actively participate in identifying problems and find solutions to improve pain management practices.
- Persons with dementia admitted through Emergency Departments need to be identified clearly and early in acute hospital systems.
- To obtain a holistic picture of the person, healthcare staff need to gather and assimilate evidence from patients, families/carers and nursing home staff.
- Identifying pain, using the appropriate pain assessment tool, is crucial to optimal pain management practices.

What does this research add to existing knowledge in gerontology?

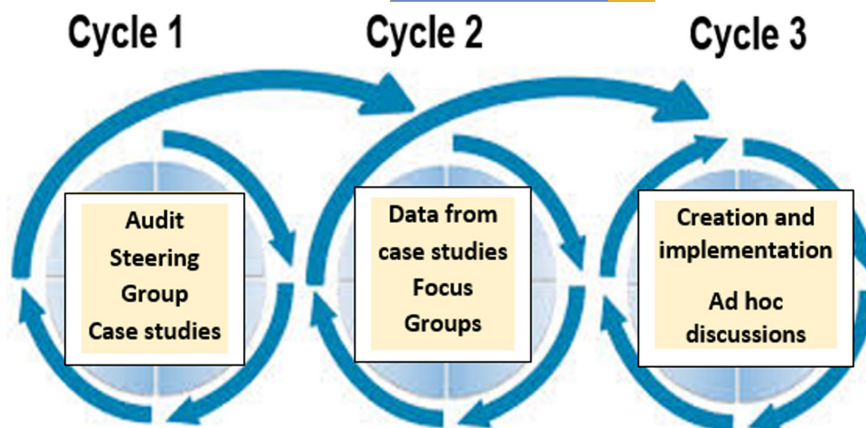
- Multidisciplinary teams working in acute care settings require on-going training and education in relation to how pain and dementia affects patients to increase their awareness and close the knowledge gap.

What are the implications of this new knowledge for nursing care with older people?

- A change in culture is required, to one where the person with dementia is placed high, or of at least of equal importance, on staffs' list of priorities in acute care.
- Facilitated reflection helps healthcare staff to recognise and address issues in practice. However, they need organisational support to implement changes into practice.

While guidelines offer some direction, the importance of the environment in which care takes place (context) and the prevailing ward culture are known to have an impact on pain management practices (Brown & McCormack, 2011; Harmon et al., 2019). Evidence from a variety of sources, such as guidelines, research, practitioner-acquired knowledge and patient feedback, are all perceived as forms of knowledge that healthcare staff can use to deliver better care (Parahoo, 2006). Nevertheless, the challenges of implementing evidence into practice have been extensively discussed within the literature (e.g. Boaz et al., 2011; Harvey & Kitson, 2015). Kitson and Harvey (2016) suggest that facilitation is key to helping people explore how they practice, make sense of the available evidence and understand what is occurring in the context in which they work. Authors of the Promoting Action Research in Health Services

FIGURE 1 Overview of the three action cycles



framework (PARIHS) (Kitson et al., 1998) suggest the three key elements of evidence, context and facilitation provide a structure to explore issues in practice to try and ensure sustainable practices. While there is an abundance of pain management research examining the complexities of caring for older people with dementia in long-term settings (Koppitz et al., 2017; Labonté et al., 2019; Achterberg et al., 2019; Pringle et al., 2021), less is known about the pain management challenges experienced by people with dementia as they move from the emergency department (ED) to in-patient wards, in acute care. Therefore, this study aimed to understand the complexities of managing the pain of older people with dementia as they progress through acute care settings, with the view of helping healthcare staff to improve practice.

2 | METHOD

A Participatory Action Research (PAR) approach, underpinned by the PARIHS framework as a conceptual guide was used. The PAR approach involved the researcher (DH) acting as a lead facilitator to work with patient and staff participants to unearth issues in the practice setting and explore potential actions with the view to implementing change. The PARIHS framework explores the interplay between the elements of context, culture and facilitation and the impact that this may have on practice. As a theoretical framework, it offered the flexibility to allow for the complexity of a PAR approach while being sufficiently structured to guide the research's direction and aid the co-researcher's understanding (Brown & McCormack, 2011).

2.1 | Ethical approval

Ethical approval was obtained from the Governance Filter Committee of the Institute of Nursing and Health Research, University of Ulster; the Office for Research Ethics Committees Northern Ireland (ORECNI; Project Ref: 235521); and the Research Governance office of the participating organisation.

2.2 | Setting

This study was undertaken in an acute city-based general hospital in the United Kingdom which offers a range of services to an estimated population of 303,207 people. It has a 24-h a day ED, 472 inpatient beds and a cancer centre (Northern Ireland Statistics and Research Agency, 2019). It is estimated that 49,709 people in the catchment area are over the age of 65 years. Many people with an underlying diagnosis of dementia and pain are admitted and discharged daily, though the exact number is unknown. For this reason, an exploratory audit was undertaken to identify how many patients with a diagnosis of dementia accessed ED and to which wards patients were subsequently admitted.

2.3 | Sample and data collection

Action research requires working with participants in action cycles to identify issues and consider potential actions to enable changes in practice. Three action cycles were undertaken. The data generated from each action cycle informed the subsequent action cycle (see Figure 1).

2.3.1 | Action Cycle One

This cycle encompassed undertaking an exploratory audit, establishing a steering group and completing two case studies. Audit data were obtained retrospectively from the admission notes of all patients ($n = 2532$) presenting to ED, for two separate weeks (week beginning 06/02/17 and 24/04/17) and were reviewed by the researcher (DH) and ED Practice Educator. This review revealed that 44 people (2%) who attended ED had an underlying diagnosis of dementia. Of these 43% were transferred to either the acute medical unit (AMU) or a general surgical ward (SW). The data also highlighted that people with dementia presenting to the ED peaked between 7 pm and 8 pm. These results suggested that a number of people with dementia had not been identified in admission to ED. Nevertheless,

the information helped inform the planning of the project, enabling contact to be made with the three areas who participated in this study (i.e. ED, AMU and SW).

A steering group was established to provide a mechanism for reporting on the PAR study data and seeking their feedback on planned actions arising from this work. It comprised of the patient and public representatives from dementia/Alzheimer's voluntary sectors ($n = 3$), including a person living with dementia, a geriatrician, pharmacists ($n = 2$) senior nurse managers ($n = 5$) and a pain nurse specialist. Formal meetings were convened at the end of each action cycle and at the end of the study. Each lasted for approximately 90 min.

The case study inclusion criteria were: two patients who presented to the ED who had a diagnosis of dementia and were accompanied by a family member. The degree and type of dementia and the presence of pain were not recruitment criteria, as this study sought to explore potential as well as the actual presence of pain. The ED staff identified potential participants to the researcher (DH), on a first come first selected bases (i.e. convenience sample). Case studies incorporated non-participant observation of pain management practices for the two people living with dementia as they progressed from ED through to a ward. Observation periods lasted for 1 h, for a maximum of 20 h, within 72 h of the patient's admission to the ED (Hammersley & Atkinson, 2007). All members of the multidisciplinary team were included (nurse $n = 20$; AHP $n = 8$; pharmacists $n = 2$; medical $n = 5$). Semi-structured interviews with staff ($n = 6$) and family members ($n = 2$), and a review of nursing and medical notes in relation to pain assessment and management were also undertaken to provide a more complete picture of the care of both patients received.

2.3.2 | Action Cycle Two

This cycle comprised of data analysis and three focus groups with healthcare staff, facilitated by DH. Individual unit focus groups were conducted in ED, SW and the AMU. Participants from ED ($n = 5$), AMU ($n = 5$) and SW ($n = 4$) involved healthcare staff who had cared for the case study participants as they moved through the hospital settings (see Table 1). Each focus group lasted between 60 and 70 min and provided participants, as co-researchers, with an opportunity to critically reflect on what they thought was occurring in the case study data, share their views on the enablers and barriers to pain management practice across the acute care settings, and from

these discussions identify actions to develop further in Action Cycle Three.

2.3.3 | Action Cycle Three

In Action Cycle Three, DH and the co-researchers, individually and in small groups, worked on developing and implementing the agreed short- and long-term actions identified from Action Cycle Two. PAR requires researchers to be reflexive to bring about action and consider their impact on the research project. Throughout all action cycles the researcher maintained a reflexive diary.

2.4 | Data analysis

Data from the focus groups were thematically analysed using Braun and Clarke's (2006) six-step approach. Within the case studies, having multiple sources of evidence helped to provide an in-depth picture of both patients. The qualitative data from both case studies were thematically analysed inductively using Yin's (2018) analytic technique. This analytic technique required all audio-recorded interviews to be listened to before being transcribed verbatim. Any initial ideas from the recordings were noted down. The transcripts were then read and re-read enhancing familiarity with the data. Data were coded and gathered into themes. Themes were identified from close familiarisation and analysis of the data. The defining and naming of themes were then discussed with the research team and finalised. Data analysis was carried out by the researcher (DH).

3 | RESULTS

Data analysis from the case studies, facilitated reflective focus groups, and ad hoc follow-up meetings revealed that pain management for the older patient living with dementia was hindered by the constant competing pressures of the busy care environment, reducing pain management to a matter of low priority. Furthermore, not amalgamating the relevant information obtained from different departments, between healthcare staff and from family/carers, was apparent. The findings are presented under four main themes arising from the data: not knowing the patient; balancing competing priorities; knowledge and understanding of pain and dementia and not amalgamating the available information (i.e. not joining the dots).

Emergency department	Acute medical unit	Surgical ward
Sister ($n = 1$)	Ward manager ($n = 1$)	Ward manager ($n = 1$)
Staff nurses ($n = 2$)	Staff nurses ($n = 1$)	Staff nurses ($n = 1$)
Nursing assistant ($n = 1$)	Nursing assistant ($n = 2$)	Nursing assistant ($n = 2$)
Occupational therapist ($n = 1$)	Pharmacist ($n = 1$)	

TABLE 1 Participants from each ward within the current study

3.1 | Not knowing the patient

The first theme arose from healthcare participants, across all departments, only focusing care on the patient's primary reason for admission to the hospital. Both case study participants had family members present in ED, offering a valuable opportunity to gain additional information. However, upon examination of their patient notes, it was revealed that their dementia diagnosis went unnoticed from admission to ED until sometime after the patients were admitted to the ward. Additionally, neither patient had their pain assessed throughout their time in ED, despite spending up to 8 hours in the department. Unpicking this in facilitated focus groups, participants agreed that not knowing the patient as a person outside of their primary reason for admission to the hospital was a considerable barrier to optimal pain management practices. They identified that they had a limited desire to know about other underlying conditions:

... because we are in the acute, we want to fix what can be fixed within that acute phase...we don't do well looking at other things around that.

(Nurse)

Overall, ED participants considered that patients were not in their care for sufficient time for staff to get to know them.

...They move on so quickly that you don't get to know them as well as you'd like to.

(Nurse)

Specifically exploring pain management and the complex needs of older people with dementia, participants described the difficulties faced when assessing pain. Participants noted difficulties arose due to a breakdown in communication:

...because he's not communicative and if he can't talk to you, then other people aren't going to [use] other ways of assessing how pain can be assessed.

(Nurse)

They also found pain tools limiting:

I don't think it fits everyone, its good but I just think because people react differently, sometimes you might get a dementia patient who's very fidgety anyway.

(Nursing Assistant)

The patient being unable to vocalise or communicate their needs in busy working environments, and not really knowing the person, meant that non-verbal patients were sometimes overlooked. For example:

...they are not able to vocalise and I don't want to say this, but they get forgot about...

(Nurse)

Examining potential ways to enhance care led the participants to acknowledge the benefits of working with the patient's family to assist with communication:

...ask the family what the signs are if they are normally in pain, what they are, how they would know?

(Allied Health Professional [AHP])

Discussions led participants to recognise that family members were helpful in advocating for and reassuring these patients in busy and confusing settings, at times providing a hidden workforce within acute care. This was in keeping with the case study findings. Facilitated reflection raised participants' awareness of the need for a high level of communication between healthcare staff and these patients or family members, acute care departments and the nursing home/hospital. Immediate actions included introducing a family/carer communication tool (ED), highlighting the need for enhanced communication at the ward managers' meetings and ward pharmacists reconsidering their communication with patients, families and carers.

3.2 | Balancing competing priorities

Observation of practice revealed that staff worked in complex environments in which they were seen rushing to get things done against the backdrop of a ticking clock. During facilitated focus groups participants reported the challenges they experienced in trying to balance competing priorities. They spoke of "*targets driving practice*," experiencing "*serious staff shortages*," and working in a "*tick box and policy driven culture*". When probed on what causes staff to be target driven in their practice, participants described environmental pressures as a contributing factor to how they prioritise their work.

...because there is systems and protocols in place to guide our practice, you know to make sure that we don't miss the important bits as well so there's a lot of pathways and protocols that do guide, so we are task-oriented and especially in that acute phase of illness.

(Nurse)

The data suggested that staff measured their success by achieving targets, completing tasks and "fixing" situations as they arose. Such cultures "*overshadowed the patients with dementia*" and left participants feeling that people with dementia and pain were not their top priority.

...and that's the sad thing about this type of ward, there is so much happening here on a daily basis that dementia patients are not getting the care that they should be getting really, they're well looked after but you should have that bit more time.

(Nursing Assistant)

Time was a common concern across ED and ward settings. The importance of balancing time and measuring performance through the tasks completed impacted negatively on pain management practices. Participants considered that this meant that the person with dementia's pain management can often go unnoticed by staff in the acute setting:

...any nurse doing a NEWS chart...it prompts you to look at pain...but unless that pain is very visible and the patient is very vocal I would question 'would it be addressed for any patient, let alone a dementia patient?

(Nurse)

Through facilitated reflection participants realised that treating pain does not necessarily take additional time and should be considered of higher importance. As an immediate action they agreed to use a recognised pain assessment tool routinely, consciously aiming to identify people with dementia at triage (ED) and reviewing analgesic prescriptions (AMU), to try to embed this practice (longer-term).

3.3 | Knowledge and understanding of pain and dementia

The third theme highlighted the need for knowledge and understanding of pain specific to older people with dementia, across the multidisciplinary team. One family member stated that *"it's different levels of screaming, that's how we know how strong her pain is."* Focus group data revealed pharmacists and nurses did not understand or have insight into how to assess pain in this patient group:

...they are not actually saying 'I am in pain' so we don't know how to give them a pain score. How do you?

(AHP)

...I assume they wouldn't be able to tell me how much they are in pain, so I would put a question mark, but I'd say that is my lack of communication with them.

(Nurse)

Deficient pain assessment practices and a lack of understanding of how the person with dementia may communicate pain meant that pain often went unmeasured, under-reported and undertreated. This was evidenced in the review of the case study participants' medicine record which revealed minimal analgesia was administered despite one person having an underlying painful condition and the family requesting analgesia for the other.

Nurses stated that at times, doctors sought guidance from nursing staff when prescribing analgesia for people who had both dementia and pain:

There's a huge gap in knowledge for a start, you know for nursing staff...very often the nursing staff are advising the medics...

(Nurse)

Additionally, despite the complexities associated with managing the pain of people living with dementia, analgesic prescriptions were allocated to the junior medical team:

...It's the junior doctors that are left to it, not the senior ones...then the doctors are going - 'but they don't need anything, so I'll change it {prescription} to PRN', but you're going 'but they need it regularly'.

(Nurse)

This led to nursing participants feeling frustrated in their attempts to advocate for the patient. They discussed the advantages of having dementia champions to support them, though they acknowledged the limitations of the role, accepting the person may not always be able to dedicate their time to the person with dementia. They also explored other potential ways to address their knowledge deficits reporting that when they used pain management protocols or guidance tools they felt more supported and motivated to make pain management decisions for people with dementia:

I feel that since the Purple Folder toolkit has been introduced there's been more focus on assessing the pain, knowing the patient and discussing with family, you're not writing question mark and you feel you're doing something about it.

(Nurse)

Visual prompts, such as a small purple dot on the armband of those diagnosed with dementia, presentations at in-house meetings and posters available in the locally designed and implemented Purple Folder Toolkit, appeared to positively influence practice. Participants across all areas commented favourably on having these visual reminders and considered that extending such aids focused their practice on the specific needs of people with dementia. Additionally, participants articulated their desire to have all members of staff provided with a training programme focusing on the complexities of dementia, including pain assessment and management.

3.4 | Not assimilating the information (joining the dots)

This theme became a fine thread that links together all the other themes discussed above. Not joining the dots became apparent through the case study, observation of practice and when health-care participants reflected on notions that not knowing the patient and not understanding the subtleties of dementia, led them

to deliver task focused and sometimes, mediocre care to patients. Families and steering group members also commented on the practice of silo working and the need to develop more holistic approaches to caring for people with dementia. Participants revealed that practitioners in acute care settings did not really consider the person as a whole.

I think sometimes it is just focused on the problem the patient is here for and not anything else.

(Nursing Assistant)

The medical notes and observation of practice demonstrated matters such as their patient's background, cognition status, personal preferences and pre-existing conditions that may cause pain, were not routinely appraised as part of the patient's admission or care documentation. Facilitated reflection assisted participants to recognise that integrating this information into their pain management approach would support them in providing more effective treatment of pain. They also realised that over-reliance on using protocols and meeting targets highlighted as an essential part of acute care environments under the theme balancing competing priorities, caused them to miss focussing on the individual person with dementia.

It just gets so busy out there, you just always focus on one thing without looking at the bigger picture, you have so much to do.

(Nurse)

A consequence of this was that they sometimes missed seeing the person behind the symptoms and the patient with dementia was easy to overlook. This highlighted that not assimilating the information (joining the dots) and viewing patients as a whole person caused a delay in patients receiving the most appropriate care at the right time.

We would notice it quite a bit when we are getting patients up, that they mightn't have had pain relief, we will have to come back and get pain relief and come back in 45 minutes and try them again.

(AHP)

Further facilitated exploration of the issues assisted participants to identify the gaps in care and consider ways to join the dots to improve the experience of care for older people with dementia:

If I was taking a drug history from the family member, I could ask them at that point what would they usually take before they came into hospital and how do you know pain as well.

(AHP)

Feeding back data and using critical reflection assisted health-care participants to realise that they often had, or could access, the

necessary information to treat the patient more holistically. What was required was for them to assimilate the information and focus on the person, not the condition. From this exploration of practice and the data arising from Action Cycle Three, DH and the participants designed a staged teaching programme that needed "to be real and delivered in no more than 30 minutes" (Steering group nurse participant).

4 | DISCUSSION

This study achieved its aim of developing an understanding of the complexities of managing the pain of people with dementia, as they progress through acute care settings. Using PAR, guided by the PARIHS framework (Kitson et al., 1998), participants were facilitated to critically reflect on issues of culture and context and consider approaches to enhance their practice. Findings from this study highlighted that pain management practices for the person living with dementia across acute care settings, were influenced by the context participants worked in, healthcare staffs' shared ways of thinking and working, and how they used sources of evidence. This research found that not knowing the patient, fragmentation of information and having insufficient knowledge of the subtleties of dementia led participants to deliver task focused, target and policy-driven care that was not person-centred in its approach.

The data from this study shows that the need to deliver organisational targets and complete tasks were prioritised over understanding the unique pain management needs of older people with dementia. Participants discussed the importance of meeting the organisation's expectations against a backdrop of staff shortages and limited time. This all impacted their ability to balance competing priorities. Internationally, healthcare research and enquiries have shown that busy practice settings are influenced by contextual factors, such as culture and leadership (Francis, 2013; Dewing & Dijk, 2016; Lichtner et al., 2016; Rogers et al., 2020; Skivington et al., 2021). Culture offers a shared way of thinking and behaving at both an organisational and local level. Being multifaceted in nature, culture requires nuanced approaches to understand its impact on patient experience and service delivery (Mannion & Davies, 2018).

This study, which took place in one organisation, unpicks the micro-cultures that exist in the ED and wards. Within ED a group think of busyness, needing to prioritise emergency care and patients not remaining in ED for long periods of time, led participants to believe it was acceptable to only treat the physiological reason for patients being admitted under their care. This was mirrored somewhat in wards, as participants here too suggested that busyness and staff shortages resulted in missed opportunities to assess and manage pain for people with dementia in a holistic way (Brown & McCormack, 2011). Ward staff also acknowledged that as patients living with dementia were often not able to verbalise their pain, they were at risk of being "forgotten about" or not having their pain assessed. Research in acute care settings has revealed that culture and context are important if pain assessment and management practices are to

be sustainably achieved (Brown & McCormack, 2011; Harmon et al., 2019). Manley et al. (2011) contend that workplace culture, the level at which most healthcare is delivered and experienced, encompasses the individual and team values and beliefs that are held by staff. These influence how people behave and impact the social norms that people in that environment come to accept. Seedhouse (2017) argues that while values such as; working together for patients; respect and dignity; commitment to quality of care; compassion; improving lives and that everyone counts are placed high on the National Health Service (NHS) principles, when it comes to real life, these values are diluted by other demands placed on the context in which people work. In this study, it was evident that despite participants' wish to provide optimal pain practices for people living with dementia, they were inclined to opt-out of completing accurate pain assessment, as pain assessment was not prioritised. The need for more careful thought and understanding of pain in older people is confirmed by Harmon et al. (2019). Raising co-researchers' consciousness of the issues that people with dementia experienced in relation to pain management, helped them implement better use of pain assessment tools, though this alone does not address the complexity of providing holistic care for these patients. The first priority is the need for the person living with dementia to be identified in the system within acute care settings.

While documentation is seen as a healthcare imperative (Tower et al., 2012), facilitated reflection on practice assisted participants to realise that they missed opportunities to enhance their records by not communicating well with other departments, families/carers and nursing homes, thus, documentation remained fragmented. Instead, staff relied heavily on using guidelines and protocols. This has advantages as the Purple Folder Toolkit (McCorkell et al., 2017), a local tool with visual prompts, available on all wards, designed specifically to enhance communication, pain assessment and recognition of delirium, in older people with dementia, supported and motivated participants to make pain management decisions. Participants suggested they required such tools to remind them of the need to prioritise the pain management of patients with a diagnosis of dementia.

Exploring their practice helped participants realise the profound effect under-treated pain has on the patients' quality of life (Lichtner et al., 2016). They requested more specific knowledge and training in relation to underlying pain conditions, non-verbal signs of pain and how to observe and report these signs for people living with dementia. Focusing on a rigorous approach to optimise pain management for people with dementia (Closs et al., 2016), participants worked with the researcher to develop a training tool to effectively join the dots. Participants in the study reported here also identified, that often junior doctors were nominated to manage the prescriptions of older people. Feast et al. (2018) recommended the use of regular analgesia for people with dementia, within acute care settings to prevent delirium and prolonged hospital stay. It would therefore seem necessary for on-going training and education on pain management in dementia to be delivered

throughout the healthcare professions, to close the gap in knowledge and deliver effective holistic care.

5 | LIMITATIONS

Using only two case studies, as a basis to start exploring pain management practices with older people living with dementia, potentially offers a narrow view of issues in practice. However, Yin (2018) argues that the importance is not always on how many case studies are undertaken, but instead focusing on the quality of evidence gathered from the various sources of the case. While results are limited to the setting of this research project, the literature suggests they have the potential to be transferrable to other acute settings. It is important to acknowledge that the researcher (DH) had been a nurse in the Trust where this research took place and thus may inadvertently introduce bias to the investigation. To address issues of the insider/outsider researcher, DH maintained a reflexive journal throughout the project. Finally, this study was limited by the absence of medical staff as part of the focus groups, however, they were represented in the steering group and the case studies.

6 | CONCLUSION

Contemporary pressurised acute care environments impact negatively the pain management practices for older people with a diagnosis of dementia. The unique needs of these older patients can be lost when organisational cultures prioritise targets and physically measurable outcomes over treating the person holistically. Supporting healthcare participants to examine their practice and the culture in which they worked helped them to identify the complex and multifaceted environments in which they work (context). Through facilitated critical reflection they articulated a desire to embrace more holistic pain management practices. However, finding workable actions to manage culture and balance competing priorities was challenging. Nevertheless, using an action-orientated research approach raised participants' consciousness of the issues older patients with a dementia diagnosis faced and assisted them to identify some actionable solutions. This enabled them to work towards developing a tool to help them assimilate information (join the dots) and treat their patients more holistically.

AUTHOR CONTRIBUTIONS

DH, VC and DB made substantial contributions to the conception, design, analysis and interpretation of data. DH collected data and undertook the participatory initial analysis of data. DH, VC and DB were involved in drafting the manuscript or revising it critically for important intellectual content; have given final approval of the version to be published. Each author participated sufficiently in the work to take public responsibility for appropriate portions of the content; and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or

integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, [DH], upon reasonable request.

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