

Pain associated with pressure injury: a qualitative study of community based, home-dwelling individuals.

Debra Jackson RN PhD FACN^{1,2,3}, Lisa Durrant PhD⁴, Emily Bishop RN⁵, Helen Walthall RN PhD⁶, Ria Betteridge RN, MSc⁷, Sarah Gardner RN, MSc⁸, Wendy Coulton⁹, Marie Hutchinson RN, PhD¹⁰, Stephen Neville RN PhD FCNA (NZ)¹¹, Patricia M Davidson RN, PhD FAAN¹², Kim Usher RN PhD FACN FACMHN¹³

¹Professor, Oxford Institute for Nursing, Midwifery & Allied Health Research (OxINMAHR), The Colonnade, Oxford Brookes University, Oxford, UK. djackson@brookes.ac.uk (corresponding author).

²Professor, Oxford University Hospitals NHS Foundation Trust, Oxford, UK.

³Professor of Nursing, University of Technology, Sydney, Australia.

⁴Project Manager, OxINMAHR, Oxford Brookes University, Oxford, UK. l.durrant@brookes.ac.uk

⁵Quality & Clinical Standards Manager, Oxford Health NHS Foundation Trust, Oxford, UK.
Emily.Bishop@oxfordhealth.nhs.uk

⁶Programme Lead, Department of Nursing, Oxford Brookes University, Oxford, UK. hewalthall@brookes.ac.uk

⁷Consultant Tissue Viability Nurse, Oxford University NHS Foundation Trust, Oxford, UK.
ria.betteridge@ouh.nhs.uk

⁸Clinical Lead Tissue Viability, Oxford Health NHS Foundation Trust, Oxford, UK.
sarah.gardner@oxfordhealth.nhs.uk

⁹Patient Representative, OxINMAHR, Oxford Brookes University, Oxford, UK.

¹⁰Associate Professor, Southern Cross University, Lismore, New South Wales, Australia.
Marie.Hutchinson@scu.edu.au

¹¹Associate Professor, Auckland University of Technology, Auckland, New Zealand. stephen.neville@aut.ac.nz

¹²Professor, Dean of Nursing, Johns Hopkins University, Baltimore, USA. pdavids3@jhu.edu

¹³Professor, University of New England, Australia. kusher@une.edu.au

ABSTRACT

Aims: To provide deep insights into the pain associated with pressure injuries in home-dwelling individuals using narrative accounts.

Background: Pressure injuries or pressure ulcers are burdensome and costly. Prevalence data, surveys and systematic reviews demonstrate that pain associated with pressure injury is widespread, but voices of home-dwelling patients have remained largely unheard.

Design: Concurrent mixed methods case study of a UK community of approximately 50,000 adults.

Methods: Qualitative interviews, conducted in 2016, of twelve home-dwelling adult participants with a current pressure injury (n=10), or a recently healed pressure injury (n=2).

Findings: Pain impacted adversely on activities of daily living, mobility and sleep. Participants described days that were clouded in pain; a pain they felt was poorly understood and often out of control. Thematic content analysis revealed two major themes; these are: Poorly controlled pain: *'I just want the pain to go away'*; and, Uncertainty for the future: *'it almost seems insurmountable'*.

Conclusion: Findings of our study support the need to develop an appropriate assessment tool for pressure injury patients in the community to enable health care professionals and patients to recognise and manage pressure injury related pain effectively.

Keywords: care at home, community case study, community nursing, home-dwelling, narrative, pain, patient voice, pressure injury, pressure ulcer.

SUMMARY STATEMENT

Why is this research needed?

- Prevention, diagnosis and management of pressure injury are core dimensions of nursing practice in both acute care and the community.
- Pressure injury incidence is predicted to increase as healthcare moves from the hospital to home, but there is a paucity of pressure injury research in all community settings.
- All categories of pressure injuries are painful and are associated with poor outcomes for patients.

What are the key findings?

- Pressure injury related pain is poorly managed for some home-dwelling patients in the community setting.
- Pressure injury pain has a pervasive impact on the lives of patients in the community setting.
- Patients experience frustration and find they are unable to adequately communicate their pain to their health care teams.

How should the findings be used to influence policy/practice/research/education?

- Pain should be assessed for individuals with pressure injury to explore how the timing and nature of analgesia can be improved.
- Advances in practice are required for health care professionals and patients to recognise and manage pressure injury related pain effectively.
- Clear processes for patients to report pressure injury related pain, to elicit a timely and appropriate response, should be incorporated into community healthcare policy.

INTRODUCTION

Pressure injuries (PI), also referred to as pressure ulcers or bed sores, are a leading cause of preventable patient harm (Gorecki *et al.* 2009; Dealey *et al.* 2012). The International Pressure Ulcer Advisory Panel (NPUAP 2014: 14) defines a pressure ulcer as ‘a localised injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear’.

PIs impose a huge burden on both individuals and the healthcare sector through increased hospital stays, disability and long-term dependence on treatment (Theisen *et al.* 2012, Guest *et al.* 2015). In terms of patient safety, PIs are the most widely reported preventable patient harm in both hospital and community settings (NHS Safety Thermometer, 2016). Figures suggest that 700,000 people in the United Kingdom (UK), are affected by pressure ulcers each year (NHS Safety Thermometer 2016) at an estimated annual cost to the NHS of £1.4 to 2.1 billion (Bennett *et al.* 2004). The scale of the problem is similar in the United States, with 2.5 million PI patients costing \$11.6 billion per year (Lyder *et al.* 2012; Russo *et al.* 2008). These figures likely underestimate the true financial burden of PI as only hospital or long term care patients were considered, and not those living at home in the community or those at risk of PI and receiving costly preventative measures. Globally, Sen *et al.* (2009) calculated at least 7.4 million people are affected by PI, again an underestimate as many developing countries were not included in the evaluation. It is difficult to quantify worldwide PI costs and of little worth to patients as the figures alone do not reflect the huge individual burden of PI in terms of morbidity, reduced quality of life or potential mortality (Gorecki *et al.* 2009, 2012; Latimer *et al.* 2014).

To date, PI treatment and prevention has predominantly focussed on acute, hospital-based models (Guihan *et al.* 2014). However, PIs are most commonly a chronic condition (Jaul & Menzel 2014) with the majority affecting people living in the community. Chronic wounds account for 78% of the NHS spending on wound treatments (Guest *et al.* 2016). In the UK, measurements and metrics have been implemented to record occurrences of PI (NHS Safety Thermometer 2016). In the community these measurements, taken on a specific day of the month, probably do not capture all of the home-

dwelling patients and significant under-reporting in the community is likely as patients move between a multitude of care providers. Under-reporting is a phenomenon already reported in the hospital setting (Smith *et al.* 2016), the scale in the community is unknown but likely significant as only 1% of patient safety incidents reported occurred in primary care although this is where 90% of all NHS patient contacts take place (Illingworth 2015).

Background

Pain is associated with PI as a result of tissue damage and aggravated by medical treatments, inappropriate dressings, repositioning and medical devices (Gorecki *et al.* 2011, Bell & McCarthy 2010, McGinnis *et al.* 2014). Systematic reviews of both hospital and community research studies have found that pain is common in PI patients, is present in all categories of PI, and the intensity of pain is not related to the severity of the PI (McGinnis *et al.* 2014, Briggs *et al.* 2013, Ahn *et al.* 2015). Researchers have provided varied estimates quantifying the presence of PI related pain; 75.6% to 100% in community based patients (McGinnis *et al.* 2014, Quirino *et al.* 2003). However, methods for evaluating pain make interpretation of values difficult. The lack of a validated pain measure for PI, coupled with the subjective nature of pain further clouds quantification (Rutherford *et al.* 2016).

Prevalence data, surveys and systematic reviews reveal that PI pain is widespread and poorly managed (Pieper *et al.* 2009; Günes 2008; Kim *et al.* 2016; Briggs *et al.* 2013; Gorecki *et al.* 2009, 2011; Girouard *et al.* 2008; McGinnis *et al.* 2014); but crucially, voices of patients have remained largely unheard. Hopkins *et al.* (2006) reported patient descriptors of PI-associated pain that included ‘excruciating, ‘constant’ and ‘burning’; this pain was described as ‘endless’ and made patients ‘fearful to move’. Gorecki *et al.* (2012), found patients were able to provide rich accounts of their pain; but processes were not in place for service providers and health care professionals to respond and act on these accounts; meaning that ultimately the patients felt ignored. Importantly, PI pain was also emphasised as an indicator of early pressure damage rather than just a symptom (Gorecki *et al.* 2009;

Briggs *et al.* 2013; Smith *et al.* 2017). However these vital, early warning cues preceding PI development were dismissed by nurses (Gorecki *et al.* 2009, 2011) and the Francis report (2013) and Pinkney *et al.* (2014) demonstrated that if the patient voice is ignored then patient harm, including serious PI, can occur.

During the period 2000-2012 only eight published papers were identified that contained detailed storied accounts of PI related pain from PI patients, rather than questionnaire or survey based data. These papers comprised interviews from a total of 84 individuals (Rastinehad 2006; Hopkins *et al.* 2006; Bale *et al.* 2006; Fox 2002; Langemo *et al.* 2000; Spilsbury 2007; Gorecki *et al.* 2012; Gorecki *et al.* 2010). Two of these eight papers used the transcripts from existing studies without adding to the patient numbers (Bale *et al.* 2006; Gorecki *et al.* 2012), and only twenty-five of the eighty-four patient voices captured in these papers were living with PI at home. Given that more and more care is delivered in the community, there is clearly a need for more focus on community-based patient experience.

THE STUDY

Aim: The aim of the study was to provide rich, narrative accounts of pain associated with PI, derived from in-depth qualitative interviews from people with experience of living with PI in their own homes.

Design: This paper is drawn from a larger and on-going mixed methods case study regarding PI in a defined diverse community. In accordance with a case study definition, this research focused on the specific phenomenon of PI in the community examined in a real life context through both qualitative and quantitative methodologies (Cresswell 2003, Yin 1984). Unlike previous UK studies of large populations (approximately 250,000 to 500,000 people; Stevenson *et al.* 2013, Vowden & Vowden 2009), this case study, drawn from a population of approximately 50,000 people, ensured the experiences and voices of individuals were heard.

Recruitment in community studies can be challenging and limited by funding (Stevenson *et al.* 2013, Cullum *et al.* 2016). To maximise participation, close links were established with key healthcare providers who would have contact with potential participants; district nurses and podiatrists working in a community bounded by a single postcode area (target community), and the tissue viability team working with patients at an acute hospital, the primary referral site for the target community. Inpatients were eligible, if they had experience of living with a PI at home.

Sample/Participants: Patients were recruited through the local National Health Services in the UK. A convenience sample of eligible patients were provided with information about the study from clinical staff during routine, scheduled appointments. Potential participants were encouraged to discuss the study information with their family and carers, they then had the choice whether or not to directly contact the research team. No additional prompts or contacts were made. Patients who contacted the research team to participate in the study selected a time and place for the interview. All participants provided informed consent, and this included being given further information, an opportunity to ask questions, and the option of having a carer or family member present during the interview. Data collection continued until saturation was reached (Fusch & Ness 2015). The research team did not have access to the personal details of the convenience sample and due to the voluntary nature of recruitment reasons for non-participation were not recorded.

Inclusion and exclusion criteria: Inclusion criteria for the study required participants were aged 18 years and over and currently receiving care, or had received care for a PI within the last 3 months. Community based patients were included if they were resident within their own home within the target community but not receiving 24 hour nursing care. Hospital inpatients were included if the patient had not acquired the PI during their current inpatient admission and had experience of living with a PI at home. Participants were required to have the ability to engage in a conversational-style interview in any language. Provision was made available for interpreters for patients who required this support to participate; however, this service was not requested. Those patients receiving end-of-life

care, or deemed by their direct care teams to lack capacity to provide informed consent were excluded.

Data collection: Data for this qualitative phase of the study were collected during May to October 2016. Participants were interviewed by a female postdoctoral researcher (XX) trained as an allied health professional with 10 years experience of patient care. Participants were asked a broad range of questions to elicit storied narrative accounts of their lives with a PI during a single semi-structured interview session. Open questions, used to prompt but not lead discussion of pain and pain management, included “what are the ways that having a pressure injury affects you on a day to day basis?”, and “what things could be done to make having a pressure injury easier for you?” Interviews lasted on average 37 minutes (range 16-69 minutes). Field notes were not taken by the interviewer, but all accounts were audio-taped and transcribed. All participants requested to receive a summary of the study results on completion of the study but not their full transcripts.

Ethical considerations: Ethical approvals were sought and obtained from the sponsoring university, two NHS Foundation Trusts (one providing in-hospital care, and one providing community-based care), and the National Research Ethics Committee.

Data analysis: The data were analysed manually, using thematic content analysis, by three experienced qualitative researchers (XX, XX & XX) who then agreed on common themes derived from the data (Borbasi & Jackson 2015). Following this, all team members were provided with the opportunity to comment on the themes. Participants did not provide feedback on the themes, but the patient expert provided valuable comments. A random alphabetical letter drawn from the first 12 letters of the alphabet is used in the paper to report individual participant’s responses.

Validity and reliability: The interviewer, defined as a ‘researcher’ on the patient information sheet, was not involved in the patient’s medical treatment or care, and was unknown to the participants prior to the study. Semi-structured interviews were conducted using an interview guide to ensure the same

topics were explored with each participant (Di Cicco-Bloom & Crabtree 2006). The guide was reviewed prior to study commencement by tissue viability nurses and a patient expert with personal experience of living with a PI within the home setting. Verbatim transcripts encouraged the researchers to revisit and immerse in narratives to remain true to participants' accounts (Noble & Smith 2015).

FINDINGS

A total of 36 patients met the inclusion criteria for the larger case study, 4 were ineligible with hospital acquired PI and a lack of PI experience at home. Of the 32 remaining patients, 12 offered to participate in the study and were consented (38% response rate). All 12 patients normally resided in the community but on the interview day, one patient was currently hospitalised for issues unrelated to their PI. Interviews were conducted in various locations according to patient preference: these included a private hospital room (n=3, for two participants who chose to be interviewed on a day they had a planned out-patient appointment at the hospital, and for one patient currently hospitalised for issues unrelated to their PI) and participants own homes (n=9). Private hospital rooms indicate the participant was not interviewed on a public ward or in public out-patient setting, to offer similar privacy afforded to patients in their own homes and the opportunity to disclose personal health related information confidentially. Participants ranged in age from 31-92 years, nine were female. All patients had a number of co-morbidities including rheumatoid arthritis, diabetes, obesity, osteoarthritis, chronic obstructive pulmonary disease, asthma and heart failure. All had a PI that ranged in severity from category 2-4 (NPUAP 2014), and had been affected by their PI for various periods of time, ranging from 2 months to more than 20 years. PI's were located on the sacrum, coccyx, buttocks, heels, toes and feet. PI related pain was reported in 11/12 patients, one paraplegic patient lacked sensation to feel pain at the site of the PI.

Qualitative findings revealed that for most participants, living with a PI meant living a life of pain. Participants described days that were clouded in pain; a pain they felt was poorly understood and

often out of control. The following themes provide more insight into the nature of the pain participants experienced as a result of their PI. The themes are: Poorly controlled pain: *'I just want the pain to go away'*; and, Uncertainty for the future: *'it almost seems insurmountable'*. These themes are presented in detail below.

Poorly controlled pain: 'I just want the pain to go away'

Participants generally experienced their PI as extremely painful and through their narratives, they revealed how dominant and unrelenting the pain was. This excerpt from participant L reveals her sense that she should be able to deal with the pain better than she does, but felt powerless, and that she had no choice but to take medication to try to control it.

You tend to think that pain is a question of mind over matter, but it isn't. There's nothing, apart from taking the pain killers. You are at its mercy. And pressure sores are relentless. ... the pressure ulcer is there 24 hours. And it doesn't matter where you sit, where you lie, where you turn, it's there, there's no getting away from it (participant L).

No matter what they did, the pain was constantly on their minds and through their narratives participants referred to their pain again and again. Before participant D fully realised what was wrong with her, she was aware of persistent pain, *'it was very painful, I knew it hurt and I knew I was nearly screaming with it'* (participant D). Their pain was worsened by the fact that normal movement was affected. Participant F had a PI on his heel, and he experienced pain with every step he took, *'You try to walk on it, it's like something stick in you. It's bloody nasty man. God Almighty.'* (participant F).

Participant H also had a PI on his heel. He was determined to stay as mobile as possible, but he also experienced considerable pain in mobilising. Like participant F, he likened his pain to a sense that he had a foreign body in his foot, and this was very painful for him.

Like there's glass in it, that's what that feels like. All the time, like I've got glass in my foot. It just rubs all the time. It's horrible. Stings as well as rubs and they just cover it up (participant H).

Participants also experienced pain with sitting or lying down. Resting in their previously preferred positions was no longer restful – these positions had now become painful.

It's uncomfortable. I have to be careful how I sit ...I tend to wriggle a bit to try and ease it off... It's constant really, doesn't matter where I sit, you just sort of wriggle about to get as comfortable as possible. They've given me pain killers... I get pills and I just take them now (participant G).

Participants did try to manage their pain, but were not able to achieve adequate pain management – they reported that even opioid pain relief did not adequately mitigate the pain. Participant K reported taking ‘*high doses of morphine and that, for the pain, the pain*’. Inadequate pain relief was a severe problem for participant I – she reported that her PI was ‘*sore all the time*’ (participant I). She had tried to initiate a new pain regime, but was also considering having a below knee amputation in the hope that her pain would be relieved once and for all.

If not [pain control doesn't work] I shall ask them to chop it off from the knee downwards. To get rid of the pain. If not I'll do it myself (participant I).

Unfortunately, wound dressings exacerbated the pain for many participants, who described the intense pain associated with having their wounds attended. When participants were in the community setting, optimal pain control for dressings was difficult to achieve because they were not able to appropriately time their pain relief to coincide with the nurse visits, thereby optimally reducing the pain of the dressing. This was because they were not exactly sure when the nurse would arrive to do the dressing.

Over the past few weeks if they had done it [dressing] every day I don't think I would have coped because it's so painful when they dress it.... I can have codeine phos. if I want it but you never know what time they [nurses] are coming... It's timing with painkillers (participant L).

The pain was such that some participants had difficulty finding the words to express their level of pain, other than describing it as ‘*overwhelming*’, and ‘*terribly painful*’ (participant D). Participant L couldn't find the right words to describe the pain her dressings caused her, but her narrative provides insights into how traumatic and distressing she found this procedure.

When it comes to my dressing, I'm a gibbering idiot because it is, well I can't describe the pain. The other day I nearly squeezed the nurse's hand off. I hang onto this bar with this hand and the nurse's hand with this hand and just grit my teeth... (participant L).

The pain permeated every aspect of the lives of participants. Sleep and rest were affected, with participants reporting their sleep was often interrupted, sometimes for prolonged periods. Participant D commented that despite taking 'painkillers all through the day', the pain caused her considerable sleep disruption, and she stated 'sometimes I'm up all night with it' (participant D). She had reported this problem to her care team, who had reviewed her analgesia, with a view to improving her sleep. This had some positive effect but she still experienced considerable disruption to her sleep.

The last few weeks I've got to take a codeine at night, I don't like codeine and I refuse codeine all the time. But [doctor] wanted me to take a codeine tablet every night ... and to take that every night to help with the pain, which I had to do, of course I couldn't keep refusing... and I have to say it has been better since then. I'm having a bit more sleep with it, having this one codeine (participant D).

Uncertainty for the future: 'it almost seems insurmountable'

Participants had been affected by PI for various time periods ranging from two months to more than 20 years, and had suffered pain associated with this for considerable periods of time. But despite the differences in duration, all had come to understand how difficult it was to overcome a PI.

Participants experienced doubt and uncertainty in relation to the healing and current condition of their PI. Participant D was unable to visualise the injury and was reliant on information provided by health care staff, which was generally not adequately informative 'I ask and I'm told sometimes it looks a bit better and then another time it looks a bit worse'. Participant F was uncertain about whether or not it was realistic to expect improvements, 'Nobody can say if it will get better or if it will get worse, you never can tell, it just works like that'. There was a general sense of helplessness in being able to achieve any meaningful improvement, 'I don't know. I really don't know... I just thought well it's there there's nothing I can do about it. I just, you know, I just hope it gets better (participant G).

Their narratives highlight the dominant place that the PI had assumed in their lives. Participant L, who also had heart problems, described feeling ‘consumed’ by her PI, both because of the pain, and the fear it would not heal.

The one thing that’s consuming me at the moment is the pressure sore. Everything else fades into insignificance, the fact that your heart might stop at any moment doesn’t worry me as much as the pressure sore. It’s consumed me in the last two to three weeks... (participant L).

Participants reported feeling despair and despondency at having a painful and limiting injury that was longstanding, with no imminent hope of recovery.

At this moment in time, as of today, it almost seems insurmountable. I can’t see a future without a pressure sore and that depresses me more than anything. It gets you down. It gnaws away at you... I suppose it’s in the back of my mind, once a pressure sore starts, you’re never free of them. (participant L).

They expressed frustration with the slowness of healing. Reflecting on a six year history of PI, participant E commented that despite the years of active treatment, the injury had ‘never healed completely’. Participant B had multiple pressure injuries, and attended to them as best she could, with the help of her carer who resided with her. Despite the close attention, she did not feel confident they would ever heal, stating, ‘the heel never will clear up ... it will never clear up’. Similarly, participant G was also of the view that a sacral PI would not heal, ‘I can’t see it getting much better to be honest because let’s face it I have to sit on it, and it doesn’t help’.

Through their narratives, participants revealed their understanding that it was a slow journey and featured set-backs and exacerbations. They were also quite incredulous and somewhat disbelieving that there was so little that health professionals could do to enhance healing and speed recovery.

There’s nothing that goes on it, why is there nothing they can put on? All I get is a bit of gauze. ... there’s nothing that they put on them you know I sort of feel there might be some sort of ointment cream or something they could put on, but it’s just a bit of plain gauze or something that goes on it...

when all you get is someone who comes in and slaps a bit of gauze on and goes out again, it doesn't really make it very helpful (participant D).

The preventable nature of PI provided another source of anxiety and tension to participants. They reflected on how they had come to develop their PI in the first place, and this caused them considerable distress.

Why does this have to happen to me? ... why me? That makes me angry. That makes me get quite angry with myself. How did I let this happen to me? ... There's no answer to that why is there? If you've got it, you've got it and you've got to make the best of it. But sometimes that's very, very hard because of all this pain. But I can't let a pressure sore defeat me. I can't let that be the end of the battle (participant L).

DISCUSSION

Our findings highlight that pain remains a significant problem for patients and health care professionals in the management of PI. Since Fox (2002) questioned if the patients' voice has been assimilated into practice or changed outcomes for patients with PIs, our study shows there is still a lack of improvement or supporting evidence. The experience of patients suffering PIs within their own homes is still under-researched.

In our study, participants regardless of age, classification of PI or length of time they had been living with a PI expressed pain as an issue within their daily life. This finding mirrors those found by Günes (2008), where 94.6% of patients reported PI pain. In our study patients spoke vividly of the pain related to their PI describing it as always being there, that it was an unrelenting constant in their lives. They were able to describe the pain by means of descriptive words such as *stinging*, but also through similes such as *'I've got glass in my foot'* or *'it's like something stick in you'*. Our findings are consistent with those found by Gorecki *et al.* (2011) in their systematic review of patient-reported PI pain. These authors found that, although patients were able to describe the pain they were experiencing, as we have shown, they also highlighted patients were frustrated in how best to

effectively communicate their pain to the health care team. This was also shown in our patient narratives, with patients recognising they were unable to adequately communicate their pain.

Our findings further highlight the importance of effective pain assessment to facilitate meaningful communication of pain between patients and health care professionals. A relevant, validated tool could offer an efficacious strategy to achieve this; however, there would need to be an agreed discourse for the tool to work effectively and ensure it provides both consistency of assessment and a shared understanding of the meaning of the assessment from both patients and health care professionals' perspectives. Many studies have explored pain assessment in PI (Pieper *et al.* 2009; Gorecki *et al.* 2011; Rutherford *et al.* 2016) but have not been able to determine the most effective tool for assessment. The McGill Pain Questionnaire (MPQ) which is used extensively to assess pain has not been validated for use with this patient group, and indeed many of the descriptors of pain used in the MPQ were not used by participants within our study. Furthermore, there is uncertainty as to the dominant type of pain experienced by patients with PI. Wound pain has been classified by Krasner (1995) into three main categories; cyclic acute pain, noncyclic acute pain and chronic pain. In our study the predominate form of pain experienced by the participants was cyclic acute pain, whereby the patients expressed sensing more pain during a cycle of care, mainly during the dressing of the PI, and chronic pain, which is characterised as a pain that is constant and persistent in nature. Moreover, patients in our study also discussed how they experienced cyclic acute pain during activities, such as walking, changing position or even lying down in bed. These findings are in line with other studies who have explored the prevalence of pain associated with PI (Quirino *et al.* 2003; Briggs *et al.* 2013). In a broader view, the chronic nature of both PI duration and pain resonates with the description of refractory long term pain from leg ulcers, where Taverner *et al.* (2014) propose that care should shift to embrace symptom management, rather than just treatment with a healing intent, to improve the patient's quality of life. The findings of our study support the need to find an appropriate assessment tool for patients with a PI to enable the health care professional and the patient to manage their pain more effectively.

A further point identified by many of our participants, was the ineffective use of analgesia. Achieving effective pain relief was revealed as a problem, not only during the wound dressing stage, but also within their daily lives. Regular analgesia was not always readily available to the community-dwelling participants, but even when it was taken it did not always relieve the pain for the patient. A number of participants attempted to self-manage their pain, others sought help from their general practitioner, yet all forms of attempt to mitigate pain by the participants were ultimately unsuccessful, with patients not being pain free on a daily basis, and in fact subject to cyclic acute pain associated with treatments and when undertaking normal activities such as walking. None of the participants discussed a partnership of pain management with the nursing team responsible for their care. McGinnis *et al.* (2014) has previously suggested nurses need to be more proactive in the management of pain in patients with PI, although active collaborations between healthcare professionals and patients with chronic illnesses are acknowledged to be challenging (Coates *et al.* 2015).

Living in pain from a PI also had great emotional consequences for the participants in our study. A number of participants expressed feelings of despair, despondency and having no hope for the future. These feelings were exacerbated by the pain experienced by the participants. Gorecki *et al.* (2011) also highlighted the impact of PI pain on emotional as well as physical well-being. In this work, patients expressed feelings of anxiety and fear all related to the PI and the anticipation of an increase in pain. These feelings were also seen in the narratives of our current participants', where there was an anxiety related to the presence of pain, as pain suggested to our participants that the PI was not healing, and with this, the realisation that it may never get better. There were also responses of 'why me' from some participants, which emerged when the participants openly discussed their PI. However, there was also a viewpoint put forward by some of the participants of resistance; the PI would not win and their attitude to overcoming the PI meant they would not 'give in'.

Pain also had an influence on the physical well-being of participants, including such activities of daily living as walking and sleeping. Many participants described how mobility caused more pain. As a result, where possible, they restricted activities such as, for example, walking, in an attempt to reduce the pain. This however, was not always possible, with participants particularly discussing how

moving in bed or on a chair was challenging and would cause further pain. Sleeping was particularly difficult with many participants trying different pain relieving activities in an attempt to reduce the pain enough to enable them to sleep.

The impact of pain on daily life, especially on the quality of life experienced by people who have chronic wounds is well documented (Quirino *et al.* 2003). This has also been found in relation to people with PI. Gorecki *et al.* (2012) found a number of factors impacted on quality of life in this patient group and formulated a taxonomy of contributory factors to pressure-related health related quality of life. The majority of these specific factors were identified within our participants' narratives and have been illustrated above, namely, symptoms in the form of pain, physical functioning in the form of sleep, mobility, daily activities and psychological well-being.

Limitations

The design of this study limits generalisability but provides a unique voice of patients that will likely be valuable in designing person-centred interventions, particularly in the community. Undertaking the study revealed the complexities of community-based research when care is split across multiple agencies and health care providers. Lengthy negotiations with multiple organisations, and levels within each organisation were required for this study. Stevenson *et al.* (2013) noted that such studies are challenging, time consuming and thus, the true extent of community based PI remains poorly quantified. Bias likely exists within the study due to the sample size, the ageing demographic of community patients and the recruitment method employed. Marginalised, incapacitated or less vocal PI sufferers in the community may not have been recruited and the voices of a hidden population not heard. Pain medication or management strategies were not recorded during this study as access to medical records was limited to district nursing notes or hospital notes, therefore complete medication records were unavailable. Future work, probing the type of pain experienced by an individual, including pain medication and outcomes is clearly warranted.

CONCLUSIONS

The narratives of participants in our study have shown pain is a significant problem for patients who are living with PI, and this negatively affects their physical, social and emotional well-being. Our findings suggest that both the assessment of pain and the subsequent management of the pain were not well managed in this patient group. Indeed this study adds credence to the recent Kings Fund review (Maybin *et al.* 2016) showing community district nurse led care can lack continuity and has become task, rather than patient, focused. Although international guidelines (NPUAP 2014; pp. 38) already advocate a “holistic plan to manage chronic pressure ulcer pain”, there needs to be further exploration of pain assessment for individuals with PI and how the timing and nature of analgesia can be improved, to enhance pain management for people in the community to enable them to have an improved quality of life. There is clearly a need for revised nursing policy and practices with better assessment and recognition of risk to reduce PI developing, strong patient advocacy and involvement to ensure optimal pain management strategies are in place and adhered to.

Funding Statement: This research was supported by

References

- Ahn H., Stechmiller J., Fillingim R., Lyon D. & Garvan C. (2015) Bodily pain intensity in nursing home residents with pressure ulcers: Analysis of national minimum data set 3.0. *Research in nursing & health* **38**(3), 207-212.
- Bale S., Dealey C., Defloor T., Hopkins A. & Worboys, F. (2006) The experience of living with a pressure ulcer. *Nursing times* **103**(15), 42-43.
- Bell C. & McCarthy G. (2010) The assessment and treatment of wound pain at dressing change. *British Journal of Nursing* **19**(11), 4-10.
- Bennett G., Dealey C. & Posnett J. (2004) The cost of pressure ulcers in the UK. *Age and ageing* **33**(3), 230-235.
- Borbasi S. and Jackson D. (2015) *Navigating the maze of research: Enhancing nursing and midwifery practice*. 4th edn. Chatswood, NSW: Elsevier Health Sciences.
- Briggs M., Collinson M., Wilson L., Rivers C., McGinnis E., Dealey C., Brown J., Coleman S., Stubbs N., Stevenson R. & Nelson E.A (2013). The prevalence of pain at pressure areas and pressure ulcers in hospitalised patients. *BMC nursing* **12**(19), doi: 10.1186/1472-6955-12-19.
- Coates V. E., McCann A., Posner N., Gunn K. & Seers K. (2015) ‘Well, who do I phone?’ Preparing for urgent care: a challenge for patients and service providers alike. *Journal of clinical nursing* **24**(15-16), 2152-2163.
- Creswell J.W. (2003) *Research design; qualitative, quantitative, and mixed methods approaches*, 2nd edn. Thousand Oaks, CA: Sage Publications.
- Cullum N., Buckley H., Dumville J., Hall J., Lamb K., Madden M., Morley R., O’Meara S., Goncalves P.S., Soares M. & Stubbs N. (2016) *Wounds research for patient benefit: a 5-year programme of research*. Southampton (UK): NIHR Journals Library. (Programme Grants for Applied Research, **4**(13) Scientific summary. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK379916>

Dealey C., Posnett J. & Walker A. (2012) The cost of pressure ulcers in the United Kingdom. *Journal of wound care* **21**(6), 261-266.

Di Cicco-Bloom B. & Crabtree B.F. (2006) The qualitative research interview. *Medical education* **40**(4), 314-321.

Fox C. (2002) Living with a pressure ulcer: a descriptive study of patients' experiences. *British Journal of Community Nursing* **7**(6), 10-22.

Francis R. (2013) Final report. *Mid Staffordshire NHS Foundation Trust Public Inquiry*. Retrieved from <http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffpublicinquiry.com/report>. Accessed 16th January 2017.

Fusch P.I. & Ness L.R. (2015) Are we there yet? Data saturation in qualitative research. *The Qualitative Report* **20**(9), 1408-1416.

Girouard K., Harrison M.B. & Van Den Kerkof E. (2008) The symptom of pain with pressure ulcers: a review of the literature. *Ostomy wound management* **5**(5), 30-40.

Gorecki C., Brown J.M., Nelson E.A., Briggs M., Schoonhoven L., Dealey C., Defloor T. & Nixon J. (2009) Impact of pressure ulcers on quality of life in older patients: a systematic review. *Journal of the American Geriatrics Society* **57**(7), 1175-1183.

Gorecki C., Closs S.J., Nixon J. & Briggs M. (2011) Patient-reported pressure ulcer pain: a mixed-methods systematic review. *Journal of pain and symptom management* **42**(3), 443-459.

Gorecki C., Lamping D.L., Brown J.M., Madill A., Firth J. & Nixon J. (2010) Development of a conceptual framework of health-related quality of life in pressure ulcers: a patient-focused approach. *International journal of nursing studies* **47**(12), 1525-1534.

Gorecki C., Nixon J., Madill A., Firth J. & Brown J.M. (2012) What influences the impact of pressure ulcers on health-related quality of life? A qualitative patient-focused exploration of contributory factors. *Journal of tissue viability* **21**(1), 3-12.

Guest J.F., Ayoub N., McIlwraith T., Uchegbu I., Gerrish A., Weidlich D., Vowden K. & Vowden P. (2015) Health economic burden that wounds impose on the National Health Service in the UK. *BMJ open* 5:e009283.doi: 10.1136/bmjopen-2015-009283.

Guest J.F., Ayoub N., McIlwraith T., Uchegbu I., Gerrish A., Weidlich D., Vowden K. & Vowden P. (2015) Health economic burden that different wound types impose on the UK's National Health Service. *International wound journal* 14(2), 322-330.

Guihan M., Bombardier C.H., Ehde D.M., Rapacki L.M., Rogers T.J., Bates-Jensen B., Thomas F.P., Parachuri R. & Holmes S.A. (2014) Comparing multicomponent interventions to improve skin care behaviors and prevent recurrence in veterans hospitalized for severe pressure ulcers. *Archives of physical medicine and rehabilitation* 95(7), 1246-1253.

Günes U.Y. (2008) A descriptive study of pressure ulcer pain. *Ostomy Wound Management* 54(2), 56-61.

Hopkins A., Dealey C., Bale S., Defloor T. & Worboys F. (2006) Patient stories of living with a pressure ulcer. *Journal of advanced nursing* 56(4), 345-353.

Illingworth J. (2015 March) Is the NHS getting safer? The Health Foundation. Retrieved from <http://www.health.org.uk/sites/health/files/IsTheNHSGettingSafer.pdf> .

Jaul E. & Menzel J., (2014) Pressure Ulcers in the Elderly, as a Public Health Problem. *J Gen Practice* 2:174. doi: 10.4172/2329-9126.1000174

Kim J., Ahn H., Lyon D. & Stechmiller J. (2016) Building a Biopsychosocial Conceptual Framework to Explore Pressure Ulcer Pain for Hospitalized Patients. *Healthcare* 4(1), <http://dx.doi.org/10.3390/healthcare4010007>

Krasner D. (1995) Managing pain from pressure ulcers. *American Journal for Nursing* 95(6), 22-24.

Landi F., Onder G., Russo A. & Bernabei R. (2007) Pressure ulcer and mortality in frail elderly people living in community. *Archives of gerontology and Geriatrics* 44, 217-223.

Langemo D.K., Melland H., Hanson D., Olson B. & Hunter S. (2000) The lived experience of having a pressure ulcer: a qualitative analysis. *Advances in Skin & Wound Care* **13**(5), 225-235.

Latimer S., Chaboyer W. & Gillespie B. (2014) Patient participation in pressure injury prevention: giving patient's a voice. *Scandinavian journal of caring sciences* **28**(4), 648-656.

Lyder C. H., Wang Y., Metersky M., Curry M., Kliman R., Verzier N. R. & Hunt D. R. (2012) Hospital-acquired pressure ulcers: results from the national Medicare patient safety monitoring system study. *Journal of the American Geriatrics Society* **60**(9), 1603-1608.

Maybin J., Charles A. & Honeyman M. (2016) *Understanding quality in district nursing services. Learning from patients, carers and staff.* R Mayhew (Ed). London, The King's Fund

McInnes E., Chaboyer W., Murray E., Allen T. & Jones P. (2014) The role of patients in pressure injury prevention: a survey of acute care patients. *BMC nursing* **13**(41). doi: 10.1186/s12912-014-0041-y.

McGinnis E., Briggs M., Collinson M., Wilson L., Dealey C., Brown J., Coleman S., Stubbs N., Stevenson R., Nelson EA. & Nixon J. (2014) Pressure ulcer related pain in community populations: a prevalence survey. *BMC Nursing* **13**(16). doi: 10.1186/1472-6955-13-16.

Noble H. & Smith J. (2015) Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, **18**(2), 34-35.

NHS Safety Thermometer (2016) Patient Harms & Harm Free Care, June 2015-June 2016, official statistics. Retrieved from HSCIC online <http://content.digital.nhs.uk/catalogue/PUB20912/nhs-safe-rep-jun-2015-jun-2016.pdf>.

NPUAP National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance. (2014). *Prevention and Treatment of Pressure Ulcers: Quick Reference Guide.* Emily Haesler (Ed.). Osborne Park, Australia: Cambridge Media

Pieper B., Langemo D & Cuddigan J. (2009) Pressure ulcer pain: a systematic literature review and national pressure ulcer advisory panel white paper. *Ostomy wound management* **55**(2), 16-31.

Pinkney L., Nixon J., Wilson L., Coleman S., McGinnis E., Stubbs N., Dealey C., Nelson A., Patterson M. & Keen J. (2014) Why do patients develop severe pressure ulcers? A retrospective case study. *BMJ open*, **4**(1):e004303 DOI: 10.1136/bmjopen-2013-004303.

Quirino J., Santos V.L.C., Quednau T.J.P., Martins A.P.F., Lima P. & Almeida M.R.M (2003). Pain in Pressure Ulcers. *Wounds* **15** (12), 381-389.

Rastinehad D. (2006) Pressure ulcer pain. *Journal of Wound Ostomy & Continence Nursing* **33**(3), 252-257.

Russo C. A., Steiner C. & Spector W (2008) *Hospitalizations related to pressure ulcers among adults 18 years and older, 2006 Healthcare Cost Utilization Project*. Rockville MD: Agency for Healthcare Research and Quality.

Rutherford C., Nixon J., Brown J.M., Briggs M & Horton M. (2016) The Leeds Assessment of Neuropathic Symptoms and Signs Scale (LANSS) is not an adequate outcome measure of pressure ulcer-related neuropathic pain. *European Journal of Pain* **20**(10):1710-20.

Sen C. K., Gordillo G. M., Roy S., Kirsner R., Lambert L., Hunt T. K., Gottrup F., Gurtner G.C. & Longaker M. T. (2009) Human skin wounds: a major and snowballing threat to public health and the economy. *Wound Repair and Regeneration* **17**(6), 763-771.

Smith I.L., Brown S., McGinnis E., Briggs M., Coleman S., Muir D., Nelson E.A., Stevenson R., Stubbs N., Wilson L., Brown J. & Nixon J. (2017) Exploring the role of pain as an early predictor of category 2 pressure ulcers: a prospective cohort study. *BMJ Open*, **7**:e013623. doi:10.1136/bmjopen-2016-013623

Smith I.L., Nixon J., Brown S., Wilson L. & Coleman S. (2016) Pressure ulcer and wounds reporting in NHS hospitals in England part 1: Audit of monitoring systems. *J Tissue Viability* **25**(1), 3-15.

Spilsbury K., Nelson A., Cullum N., Iglesias C., Nixon J. & Mason S. (2007). Pressure ulcers and their treatment and effects on quality of life: hospital inpatient perspectives. *Journal of Advanced Nursing* **57**(5), 494-504.

Stevenson R., Collinson M., Henderson V., Wilson L., Dealey C., McGinnis E., Briggs M., Nelson E.A., Stubbs N., Coleman S. & Nixon J. (2013). The prevalence of pressure ulcers in community settings: an observational study. *International journal of nursing studies* **50** (11), 1550-1557.

Stop the Pressure (2016, November). NHS Improvement. Retrieved from <https://www.england.nhs.uk/2014/01/stop-the-pressure/>.

Taverner T., Closs S. J., & Briggs M. (2014). The journey to chronic pain: a grounded theory of older adults' experiences of pain associated with leg ulceration. *Pain Management Nursing* **15**(1), 186-198.

Theisen S., Drabik A. & Stock S. (2012). Pressure ulcers in older hospitalised patients and its impact on length of stay: a retrospective observational study. *Journal of clinical nursing* **21**(3-4), 380-387.

Vowden K.R. & Vowden P. (2009). The prevalence, management, equipment provision and outcome for patients with pressure ulceration identified in a wound care survey within one English health care district. *Journal of Tissue Viability* **18** (1), 20-26.

Yin R.K. (1984). *Case Study Research: Design and Methods*. Beverly Hills, CA: Sage Publications.