

## Pressure ulcers and their treatment and effects on quality of life: hospital inpatient perspectives

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### Abstract

**Title.** Pressure ulcers and their treatment and effects on quality of life: hospital inpatient perspectives

**Aim.** This paper reports a study exploring patients' perceptions and experiences of the impact of a pressure ulcer and its treatment on their health and quality of life.  
**Background.** Pressure ulcers are a significant health problem, and their prevention and management in primary and secondary care is high on the clinical and policy agenda. However, patients' perspectives and experiences of the impact of pressure ulcers on health and quality of life is not understood.

**Method.** Qualitative semi-structured interviews were carried out from 2002 to 2004 with a purposive sample of 23 hospital inpatients (five men, 18 women: aged 33–92 years) with a pressure ulcer (graded 2–5) at various anatomical sites and with varied reasons for hospital admission. Data were analysed thematically.

**Findings.** The majority of participants (91%;  $n = 21$ ) indicated that the pressure ulcer and its treatment affected their lives emotionally, mentally, physically and socially. They presented their perspectives on the causes of their pressure ulcer and descriptions of pain (experienced by 91%), appearance, smell and fluid leakage. Patients described amounts and quality of care they received, including levels of comfort of dressings and pressure relieving equipment and the timing of interventions. They were largely dependent on others to treat, manage and care for their ulcer, but indicated that the pain, discomfort and distress of pressure ulcers was not acknowledged by nursing staff. The pressure ulcers could be pivotal in preventing full recovery, were perceived to increase hospital stays and resulted in ongoing treatments.

**Conclusion.** Healthcare professionals can learn from these patients' experiences about the management of dressings, providing information (in particular about realistic time expectations for healing), providing preventative interventions and understanding the importance of comfort and positioning for patients. The study highlights the complexities of evaluating the impact of pressure ulceration.

**Keywords:** management, nursing, patient experience, pressure ulcers, prevention, qualitative interviews, quality of life

## Introduction

Pressure ulcers (also known as pressure sores, bed sores and decubitus ulcers) represent a significant healthcare problem. Pressure ulcer prevalence in the United Kingdom (UK), United States of America (USA) and Canada ranges from 5% to 32%, depending on case-mix (Kaltenthaler *et al.* 2001). Pressure ulcers are most likely to occur in those who are older, seriously ill, neurologically compromised (e.g. with spinal cord injuries), have mobility problems or suffer impaired nutrition (Allman 1997; Banks 1998; Berlowitz *et al.* 1997; Bianchetti *et al.* 1993; Ek *et al.* 1990).

Bennett *et al.* (2004) estimate that the cost of pressure ulcers to the UK health and social care system is between £1.4 and £2.1 billion per year (using UK National Health Service (NHS) unit costs at 2000 prices). This resource cost is dominated by Registered Nurses' and nursing assistants' time spent dressing wounds, repositioning patients, monitoring and risk assessment. The clinical importance of the prevention and management of pressure ulcers in primary and secondary care is highlighted by guidelines published by the National Institute for Health and Clinical Excellence (NICE 2003, 2005), and pressure ulcer treatment, management and care are key responsibilities for nursing staff worldwide. However, there is limited research on the impact of pressure ulcers on patients' health and quality of life.

## Background

Quality of life issues have attracted increasing interest from healthcare professionals and researchers; however, there is little agreement as to what the term actually describes (Hendry & McVittie 2004). The term is often used as a proxy for physical health, functional ability, psychological well-being and social relationships (Power *et al.* 1999; Bowling 2001). Despite the lack of consensus, quality of life research is increasing alongside development of measures (generic, disease or population specific, dimension specific and utility) to evaluate health outcomes from the perspective of patients (Garratt *et al.* 2002). Our study aimed at exploring individual patients' perceptions and subjective experiences of the impact of pressure ulcers and treatment on their health and quality of life. Two important points must be acknowledged when researching people's understanding of quality of life. First, those with an illness or chronic condition do not always report poorer quality of life than healthy individuals – the 'disability paradox' (Albrecht & Devlieger 1999). Secondly, quality of life is related to individual expectations, making it a dynamic construct; people's

expectations may therefore alter when they encounter changed circumstances (Carr *et al.* 2001). Thus, the impact of pressure ulceration (and its treatment) has to be considered within the context of existing conditions and separated from perceived quality of life related to other conditions.

We located our study within existing knowledge by reviewing studies that had assessed the impact of pressure ulcers on quality of life. We searched CINAHL, MEDLINE and Embase databases (May, 2006) using the terms 'pressure ulcers' and 'quality of life', both as free text and subject headings, and exploded both terms to include all subheadings. Four relevant studies were identified focusing on two narrowly defined populations: spinal cord injured patients or community-dwelling patients.

Two studies (Franks *et al.* 2002; Krause 1998) used generic quality of life measures to assess the impact of pressure ulcers. However, neither of these studies provides meaningful insights. In the study by Franks *et al.* (2002), it is difficult to separate the impact of a pressure ulcer from the impact of other conditions on quality of life; the impact of a pressure ulcer on quality of life may be similar to that of other conditions experienced by people receiving community nursing. The study by Krause (1998) also raises the problem of distinguishing the impact of a pressure ulcer from other conditions because it is not clear whether the pressure ulcer is the direct cause of reduced quality of life or a consequence of worsening health status (such as poor nutrition or mobility). These studies highlight the difficulties of using generic quality of life measures to assess the impact of a specific condition (pressure ulceration) when it is known that patients who have pressure ulcers often have co-morbidities, which will affect their quality of life.

Two qualitative studies provide insights into the possible impact of pressure ulcers. Langemo *et al.* (2000) explored the 'lived experience' of an existing or healed pressure ulcer for eight US individuals living in the community: half the participants were spinal cord injured, the others had surgical flap reconstruction. The findings of this phenomenological study reveal the impact of pressure ulcers on people's lives including their physical, social and financial status, changes in body image and loss of independence and control. Fox (2002) explored the perceptions and feelings of five UK community-dwelling patients with pressure ulcers, which extended into subcutaneous tissue and deep fascia. Participants reported pain specifically related to their pressure ulcers and effects on their quality of life caused by problems with wound exudation, loss of independence, emotional factors, and worries about healing, relationships, body image and social isolation. Although these studies provide useful insights into the impact of pressure ulcers, they are limited by the fact

that they relate to patients with narrowly defined conditions living in the community.

## The study

### Aim

The aim of the study was to explore the following questions in hospital inpatient settings:

- How people with pressure ulcers rate their health and quality of life?
- What are patients' experiences of developing a pressure ulcer?
- What are patients' experiences of pressure area care and treatment?

### Participants

The study reported here was undertaken alongside a large multicentre, randomized controlled trial (funded by the NHS Health Technology Assessment Programme) comparing the clinical and cost-effectiveness of alternating pressure mattress overlays and replacements (Nixon *et al.* 2006). Participants in this study were not participants in the larger trial but were from centres participating in the trial.

We recruited a purposive sample of 23 participants (five men, 18 women: age range 33–92) from medical, elderly care, orthopaedic and vascular surgery wards in four NHS hospitals, which we considered reflected the core characteristics of the study population (Patton 1990). We asked clinical research nurses (CRNs) working in sites participating in the larger trial to identify potential participants for the interview study. The CRNs provided patients with information about the study and contacted us with details of those who expressed interest in taking part. The refusal rate was not recorded. Sampling variables included sex, age, reason

**Table 1** Pressure ulcer and skin classification scale (Nixon *et al.* 2005)

Grade	Description
0	No skin changes
1a	Redness to skin (blanching)
1b	Redness to skin (nonblanching)
2	Partial thickness wound involving epidermis/dermis only (i.e. skin break or blister)
3	Full thickness wound involving subcutaneous tissue
4	Full thickness wound through subcutaneous tissue to muscle or bone
5	Black eschar

**Table 2** Characteristics of the participants

	Male ( <i>n</i> = 5)	Female ( <i>n</i> = 18)
Age (years)		
Range	33–86	40–92
Median	78	78
Centre		
1	3	10
2	0	1
3	0	4
4	2	3
Location of ulcer		
Heel	1	6
Sacrum	2	9
Buttock	0	1
Heel and buttock	0	1
Heel and sacrum	1	1
Sacrum and buttock	1	0
Grade of ulcer		
2	3	3
3	1	6
4	1	3
5	0	2
Not recorded in medical notes	0	4
Mobility prior to admission		
Fully mobile	1	8
Wheelchair	2	5
Walking sticks	0	2
Frame/wheelchair	2	3

for admission – acute event, chronic condition or pressure ulceration (four patients were admitted specifically because of a pressure ulcer), grade (2–5) and anatomical location of pressure ulcer. The pressure ulcer grading classification system we used was adapted from international classification scales [Agency for Health Care policy and Research (AHCPR) 1992; European Pressure Ulcer Advisory Panel (EPUAP) 1999] to meet the practical data collection requirements for the PRESSURE trial (Table 1; Nixon *et al.* 2005, 2006). Details of study participants appear in Tables 2 and 3.

### Data collection

Data collection took place between April 2002 and April 2004. Following CRNs' identification of potential participants for the study, a researcher (EAN, KS) made an appointment to meet with the patient. At this meeting we ensured that patients had read the information sheet (or spent time reading it with them) and answered any questions or concerns.

We used semi-structured interviews to gather data on patients' general health, their pressure ulcer (such as when it developed, duration and treatments), and the impact of the

Table 3 Reason for hospital admission

Patient number and sex	Patient age (years)	Reason for admission	Other conditions (reported by patients)
M1 (male)	56	Pressure ulceration	Degenerative spinal condition
F2 (female)	90	Fall and fractured hip	Arthritis
F3 (female)	48	Fall	Multiple sclerosis/ovarian cyst
M4 (male)	78	Road traffic accident	Prostate cancer
F5 (female)	76	Amputation (leg)	Osteoporosis
F6 (female)	68	Infected amputation stump	Amputation (leg)/diabetes
F7 (female)	68	Broken leg	Stroke
F8 (female)	75	Angioplasty (three cardiac arrests during procedure)	<i>None reported</i>
F9 (female)	79	Fall and fractured hip	Diabetes/arthritis
F10 (female)	85	Pressure ulceration	Venous leg ulcers/myeloma
F11 (female)	40	Pressure ulceration	Multiple sclerosis
F12 (female)	78	Ischaemic leg	Diabetes
F13 (female)	92	Fall and fractured pelvis	Angina/hiatus hernia/arthritis
F14 (female)	82	Fall	Previous stroke
F15 (female)	88	Hip replacement	<i>None reported</i>
F16 (female)	63	Hip replacement following fall	Diabetes/amputation (above knee)
M17 (male)	33	Pressure ulceration	Spina bifida
F18 (female)	73	Fall and fractured hip	Parkinson's Disease
F19 (female)	77	Fall and fractured hip	Osteoporosis/pneumonia
F20 (female)	79	Leg ulceration	Arthritis
F21 (female)	88	Road traffic accident	Bladder cancer
M22 (male)	78	Chronic lung infection	Osteoporosis
M23 (male)	86	Fall and fractured hip	Parkinson's disease/ Cancer of bowel/ Leg ulceration

ulcer and its treatment on physical health, functional ability, psychological well-being and social relationships. To minimise our influence as researchers, throughout the interviews we responded to issues raised by patients by checking meaning and understanding (Holstein & Gubrium 1995). All interviews were recorded (with participants' consent), transcribed verbatim and imported into a qualitative data analysis management software package (QSR Nvivo v.2).

### Ethical considerations

The study was approved by a Multi-centre Research Ethics Committee, the Local Research Ethics Committees and the research governance and management departments of the participating centres. Participants were informed of the study aims (to understand their experiences of developing a pressure ulcer and their experiences of pressure ulcer care and treatments), what would be involved if they agreed to take part and how their narratives would be used and disseminated. They were informed that they could choose to stop the interview at any point, without giving a reason, and reassured that their decision to take part (or not) would not affect any aspect of their care. Written consent was gained

from all participants and they were reassured of confidentiality and anonymity.

### Data analysis and rigour

We undertook a thematic analysis of the data (Miles & Huberman 1994). Details of the themes and sub-themes identified appear in Table 4. To enhance rigour, we used two researchers (KS, EAN) to code the data, thereby ensuring the trustworthiness of our findings and encouraging reflexivity (Hammersley & Atkinson 1995). By providing a clear account of data collection and analysis, and patients' quotes to support data interpretation, we have enabled readers to judge the authenticity of our conclusions (Mays & Pope 2000). In addition, our description of the research process and patient characteristics suggests that our findings, while not generalizable, are transferable to other groups of patients and settings (Lincoln & Guba 1985).

### Findings

Although the age range of our sample was quite broad (33–92 years), 70% ( $n = 16$ ) of the patients were aged over 70

**Table 4** Summary of the study findings

Research objective	Theme	Sub theme (first interview)
To explore how patients with pressure ulcers rate their health and quality of life	Contextual detail	Age; chronic condition; levels of dependence; living arrangements
To explore patients' experiences of developing a pressure ulcer	Perceived cause of ulcer	Level of mobility; dependence to move; bed/chair-bound; skin condition; shearing pressure in bed; delay noticing ulcer; delay treating first signs; poor health; poor diet/appetite; lack of knowledge; actions of 'another'; 'susceptible'
	Descriptions of ulcer	Pain; skin condition; dimensions of ulcer; origins of ulcer; first signs of ulcer; physical appearance; physical sensations; 'poison' in the body; leakage from ulcer; smell from ulcer; unable to see ulcer
	Impact of ulcer	Lack of impact (acute); further impact for acute patient; emotional; mental; physical; social
To explore patients' experiences of pressure ulcer care	Dressings/treatments	Variety; painful; staff approach to care; allergies; poorly applied dressings; disruptive; time consuming
	Pressure equipment	Mattresses; cushions; variable comfort; safety; delay in provision
	Professional attention	Variety involved; reliance on professional; attitude of staff to care; poor information; conflicting information; lack of advice

(median age: 78 years). The majority (83%,  $n = 19$ ) had been admitted to hospital for reasons other than a pressure ulcer (Table 3) and 21 (91%) reported that they had a chronic condition (e.g. multiple sclerosis, Parkinson's disease, stroke, other neurological conditions, arthritis, osteoporosis, leg ulcers, diabetes and cancer). We therefore considered it important to obtain descriptions of patients' health and quality of life, which could provide insights into their condition before they developed a pressure ulcer. In the quotations below, male patients are identified by the letter M and their interview number, and females by 'F' and their interview number.

### Patients' descriptions of their health and quality of life

Chronic conditions experienced by our participants had a number of effects on their health and quality of life. Twenty participants described their dependence on others. The level of dependence varied greatly; some ( $n = 7$ ) required a 'care package' from social services (involving home carers and day centres) for assistance with activities of daily living, whilst others ( $n = 13$ ) reported requiring less help (usually from a family member) for activities such as shopping. Participants varied widely in how they felt about requiring assistance from a family member; younger participants were more likely to express resentment at needing help because they felt like a burden to others:

But when I'm at home as well I'm having to rely on other people to do things for me. Well, it's not right nice for them. Because, I mean, I'm having to rely on my sister to do that and she's got a job to go to, she's got a son to look after, she's got her own life to lead. (M17)

People's living situation already exerted a big influence on their quality of life and it is likely that this would be compounded following development of a pressure ulcer. Prior to admission to hospital, 20 participants (87%) were living alone, two with their spouse and one with her teenage children. Living with a chronic condition, particularly where mobility was affected, had required some patients to adapt their living arrangements ( $n = 5$ ), for example, installing chairlifts or widening doors for a wheelchair. For others it had required a move to more suitable accommodation ( $n = 2$ ):

I thought, 'One of these days I'm going to fall backwards.' You can't always guarantee that you're going to go forwards! So I thought, 'Well, that's it, I'll stay downstairs and put the house in for an exchange.' (F3)

### Perceptions of impact of pressure ulcer

Twenty-two patients described the emotional and mental, physical and social impacts associated with pressure ulcer development. A lack of immediate impact was noted for two patients with multiple injuries following a road traffic

accident, the ulcer being relatively unimportant when compared to traumatic injuries:

The sore has had no impact whatever since the beginning. If the nurse hadn't told me I'd got one, I shouldn't know I'd got one. (M4)

However, this patient went on to develop a further sacral ulcer, which proved more painful and problematic:

I was spending a lot of time in bed and I did develop soreness and quite bad soreness in my bottom – from lying in bed presumably? (M4)

Patients described varying levels of preoccupation with their ulcer. Three patients felt it was the least of their health concerns and seven felt it was an added health complication and a setback to their recovery:

If this pressure ulcer hadn't have developed I would have been all right. (F16)

Thirteen patients reported high levels of preoccupation. They anticipated pain whenever they considered moving position and worried that the ulcer would not heal or would deteriorate:

Well, I suppose you do have some concerns whether they're going to heal up or whether they're going to break down in the future. (F13)

Patients described '*hating*' their ulcer and trying to distract their attention away from it by '*not dwelling*' and '*keeping busy*'. The pressure ulcers were referred to as '*troublesome*', '*annoying*', '*disruptive*' or '*inconvenient*'. The pressure ulcer caused some patients ( $n = 8$ ) to feel depressed or miserable, and for others decreased their confidence because of the emotional and mental impact, or because of the physical and social impact of the ulcer.

The physical impact of pressure ulcers manifested in three ways. First, they affected patients' positioning and comfort. Patients with a sacral ulcer reported difficulties associated with sitting in a chair and keeping pressure off their ulcer. Many of these patients were positioned in bed on their side but found this uncomfortable. They reported difficulties staying off their ulcer, pain when moving position and pain in their limbs because of adopting positions to protect their ulcer:

I have to lie on my side for as long as I can bear [because of the ulcer], but actually my arms begin to ache after a while because, laying on your side, you can't do anything. (F20)

Secondly, the presence of a pressure ulcer had an impact on a range of everyday activities (such as moving from bed to chair or showering). A number of patients highlighted that on discharge the pressure ulcer and its treatment would affect

activities such as housework or shopping, and also viewed it as having a social impact. A younger patient highlighted an additional social impact associated with a heel ulcer:

I can't wear any shoes... I prefer to wear shoes... and, apart from that, you don't go shopping in slippers! (F3)

The third physical impact of pressure ulcers related to infections, which led to delayed healing and additional health problems:

November last year, I didn't feel too well because the pressure sore had got infected and I just felt really ill with it. (F17)

### Perceptions of cause of pressure ulcer

Over half of the participants ( $n = 12$ ) attributed the development of their pressure ulcer to decreased mobility:

Well, my own understanding of a pressure sore is that it's something that occurs in some people when they're confined to a bed, with all the accompanying nonmovement and so forth. (M4)

The pressure caused by being confined to bed or chair was also referred to as '*scuffing*' or '*rubbing*' and patients indicated a belief that pressure damage was more likely to occur because of the condition of their skin being '*tender*' or '*like paper*' ( $n = 5$ ). Being confined to a bed or chair ( $n = 12$ ) made it difficult to move independently. Patients described relying on clinical staff to help them reposition but felt repositioning was often not carried out as frequently as they would have liked. As a result they attempted to move themselves, causing further pressure damage:

Pushing on my heels to push myself up, you see, that started the heels. And then being immobile too, as well. Gradually the pressure sores started on the buttocks as well, you see. (F13)

All participants attributed blame for pressure ulcer development. Some participants ( $n = 8$ ) directed blame at their chronic condition, poor health, or loss of weight and appetite. Patients who suffered with diabetes indicated that this slowed ulcer healing. Other participants blamed themselves for developing an ulcer ( $n = 3$ ): poor hygiene practices, lack of knowledge, ignorance or naivety such that they did not seek advice or treatment:

I don't know what went through my mind really. I must have been totally naïve. I just thought [the pressure ulcer] would go away like. But it didn't. (M1)

Others specifically blamed healthcare professionals ( $n = 7$ ) for failing to attach priority to their reports of an ulcer or delays in skin inspection:

I kept saying, 'My bottom hurts'. 'Does it love? Oh, we'll have a look in a bit.' [patient mimics nursing staff comments]... and it was about two or three days when I had this that they came and looked and said, 'Oh gosh, have you seen this?' (F19)

A small number ( $n = 3$ ) reported it was the actions of healthcare professionals that caused the ulcer. For example, one patient (M3) reported that the ulcer had developed because of an ill-fitting splint; another described the '*persist-ence*' of staff using a hoist to move her from bed to chair which resulted in her skin splitting:

I've got a certain amount of cellulite on my legs, after having been in bed so long, and when they put on the hoist they bring up two strong bits between your legs and hook them on. And as they did that they pulled my bottom apart... in the end [my bottom] sort of split and I can hear them saying, 'Oh, it's split again!' And I had to make quite a lot of fuss. (F20)

Others ( $n = 2$ ) questioned the delayed timing of preventative interventions, such as fitting pressure-relieving cushions in wheelchairs:

The point is, these people at the wheelchair centre know I'm in this [wheelchair] all the time. They know I'm sitting down all the time. They know there's a possibility of getting sores. So they should have been thinking about it. (M17)

### Descriptions of the pressure ulcer

Almost all patients ( $n = 21$ ) experienced pressure ulcer pain. Of the two who denied experiencing pain, one reported having a neurological condition and reduced sensation, and the other was not aware that the pressure ulcer had developed. Reports of pain ranged from extreme pain '*worse than toothache*' to at least '*little shooting pains*'. Other words used to describe pain included '*stabbing*', '*jumping*', '*nig-gling*', '*red hot poker*', '*carpet burn*', '*tender*' and '*raw*'. There were variations in timing of pain – it could be constant or worse at night, and could vary from day to day, hour to hour or intensify with contact (e.g. with bed clothes). Some patients ( $n = 6$ ) suggested that healthcare professionals did not fully appreciate the pain of pressure ulcers and that their complaints of pain were ignored:

I've got more pain now than I had before I came in...I can't stand it no more. That's if they bloody take notice of me. (F12)

Patients offered other descriptions of their ulcer including skin texture ('*loose*', '*dead*' or '*hard*'), ulcer dimensions ('*cavity*' or '*hole*', '*shallow*' or '*deep*'), origin of ulcer ('*underneath*' or '*surface*'), first sensations ('*scratch*', '*sting-ing*', '*irritation*' or '*blister*'), physical appearance ('*angry*',

*'raw*', '*black and nasty*'), leakage ('*fluid*', '*blood*' or '*poison*') and smell:

I noticed the nurses were changing the dressings: they could hardly stand the smell of it. The smell is terrible. It comes through the whole bandage, you see, and to me it's an embarrassment. (F10)

A majority of patients ( $n = 14$ ) said they could not see their pressure ulcer (because of anatomical position – sacrum or heel) but stated they did not want to, even when offered the opportunity (e.g. using a mirror, photograph or video). Participants commented on descriptions used by nurses to help them visualise their ulcer, which focused predominantly on size, but detailed information about healing progress was often lacking:

They don't tell you a lot. Each time I've said, 'What's it like?' – 'Oh better, getting better.' So I take their word for it. (F2)

However, three participants questioned the appropriateness of the language used by nurses to describe pressure ulcers because it could depict a horrific image:

The way people described it to me, it just made it sound horrific. I mean, you're talking about a three inch hole and you can put your fingers down to the bone. And to me that's horrific. (F11)

### Experiences of pressure ulcer treatment, management and care

Patients described pressure ulcer dressings and their experiences of having these applied, but there were no patterns in data related to experiences of pressure ulcer treatment, management and care when data were interrogated by age, sex, and chronic or acute condition. Some ( $n = 8$ ) reported pain associated with dressing changes caused by tenderness of the pressure ulcer, the technique of professionals, an allergy to the dressing, the adhesiveness of the dressing or problems with application:

I don't know whether it's my pressure sore or if it's the dressings that they're putting on, but they actually leak quite a lot. And because they get wet, they come unstuck and they actually come off regularly. Which means I'm having to get my dressings done about two or three times [a day]. (M17)

Others ( $n = 4$ ) reported increased comfort, a sense that infection was '*sucked out*' by dressings and easing of pain:

The nurses haven't changed [the dressing] yet. That's what I'm waiting for, love. It eases [the pressure ulcer] when they do my dressing and all, but I don't know when they're going to come. (F12)

Several patients ( $n = 8$ ) saw the time devoted to dressing changes as an inconvenience (due to time taken). However, the majority resigned themselves to 'putting up' with treatments. For others ( $n = 4$ ), the inconvenience (and disruption) was being admitted to hospital with an ulcer that could not be treated in the community:

[The pressure ulcer] didn't heal completely but it did close down a little bit, which is why I was discharged from ward [name]. But as soon as I was discharged and went home it opened up again. So reluctantly I went back in [to hospital]. (M17)

Patients' experiences and perceptions of pressure-relieving mattresses and cushions were related to issues of comfort, safety and availability. There were variations in patients' reports of mattress comfort, one patient commenting the mattress was like 'somebody cares', others ( $n = 6$ ) suggesting the alternating pressure mattresses were uncomfortable (because of noise or restricted movement). Over half ( $n = 12$ ) indicated a lack of availability of pressure-relieving cushions which they believed were important for prevention of pressure ulcers. However, a limited number of participants ( $n = 4$ ) suggested that the air-filled cushions made them feel unsafe and they feared falling from their chair.

Assessment and management of pressure ulcers was perceived to involve a variety of healthcare professionals and carers. Overwhelmingly, patients referred to their dependence on others to assess and treat their ulcers, provide help during treatments and assist with gaining a position of comfort:

As I am now, I can't turn over and I'd been on my back quite a lot and I did try to turn over once or twice. But it's very, very difficult and I can't really do it on my own, you know. (F13)

Some older patients ( $n = 6$ ) commented on the negative attitude of some staff when asked for help with positioning, perceiving this was carried out at the convenience of staff rather than in relation to patients' need. At the other extreme, two patients reported staff religiously turning them in bed during the night shift so that they felt exhausted because of a disturbed night's sleep.

Patients identified healthcare professionals as crucial to treatment and management of pressure ulcers but reported that there was a lack of clear, and sometimes conflicting, advice given to them. In addition, there were also some frustrations about lack of initial advice about length of time required for ulcer healing:

Nobody actually come out and said, 'Oh, it'll take this long to heal'...But it's sort of, I don't know, you just drift on, like, from week to week with them. (M1)

## Discussion

In this paper, we describe the experiences and perceptions of the impact of a pressure ulcer and its treatment on a purposive sample of hospital inpatients with a range of conditions. We recruited a sample which represented different sexes, ages, grades and anatomical positions of pressure ulcers, and reasons for admission (including pressure ulceration, chronic and acute conditions).

Clinicians generally accept that a pressure ulcer will have some impact on patients' quality of life and may even make assumptions about what it must be like to experience a pressure ulcer. Ours is the first study to explore the impact of a pressure ulcer, and its treatment, with a varied hospital inpatient population. The findings add to existing knowledge and have international relevance to nurses who are caring for patients with a pressure ulcer. This study describes the effects of a pressure ulcer in patients' own words and highlights the wide-ranging impact of both the ulcer and associated treatments (Table 4).

Contextual detail provided by the participants is crucial for understanding the real impact of an ulcer. Many of the participants (21/23) were living with chronic conditions which influenced their experiences. This is an important consideration when attempting to understand the impact of pressure ulceration, which is often a consequence of poor health, from the impact of the chronic condition (Spink 1999). Despite most patients having severe co-morbidities, our study shows that pressure ulcers had a profound impact on their lives, physically, socially, emotionally and mentally. These findings are supported by other studies (Langemo *et al.* 2000; Fox 2002) but add to them by exploring the impact of pressure ulcers on a more diverse group of hospital inpatients. In addition, we have considered the impact of the pressure ulcer within the context of existing conditions and perceived quality of life related to these other conditions.

Our participants highlighted that pressure ulcers are associated with pain, fluid leakage and smell, discomfort, and difficulties with mobility. The only patients who did not describe such an impact were the two patients admitted with multiple injuries following road traffic accidents; the pressure ulcer was perceived as relatively unimportant in these circumstances (although later development of a sacral ulcer for one of these patients was painful and problematic). However, all other patients admitted with acute or chronic conditions or a pressure ulcer described a marked impact.

Guidelines clearly indicate the instrumental responsibilities of healthcare professionals to prevent and manage pressure ulcers (NICE 2003, 2005). Patients in this study felt that they



### What is already known about this topic

- Pressure ulcers are a significant health problem.
- Nursing staff have a major role in the prevention, treatment, management and care of pressure ulcers.
- There is limited research on the impact of pressures ulcers and their treatment on quality of life.

### What this paper adds

- Pressure ulcers have a physical, social, emotional and mental impact on patients.
- Pressure ulcers can be pivotal in patients' trajectories from illness to full recovery, are perceived to increase hospital stays, and result in ongoing treatments.
- Pressure ulcers cause much pain, discomfort and distress that is not always recognized or adequately treated by nursing staff.

were not always listened to by healthcare professionals and that the extent of pain caused by pressure ulcers was not fully acknowledged or treated. The presence of a pressure ulcer created a level of dependence on others that many patients felt was difficult to accept, often because they were having to fit in with someone else's time schedule rather than having control over their own activities. Patients required assistance from healthcare professionals both in order to move, and to treat and manage their ulcer. Indeed, they were also dependent on healthcare professionals to provide information about the progress of healing as the location of the ulcer often made it difficult for them to see it. The pressure ulcer could be pivotal in preventing full recovery for patients. Patients reported that infected pressure ulcers led to delayed healing and additional health problems. As such, pressure ulcers were perceived to increase hospital stays, led to unplanned admissions, and could result in ongoing (time-consuming) treatments. As such, pressure ulcers were resented by many of the participants, particularly when the patient blamed healthcare professionals for their development ( $n = 12$ ). It is worth highlighting that *all* participants attributed some sort of 'blame' for the development of their pressure ulcers – directed at the chronic condition, 'self' or healthcare professionals. Attributing blame can be understood as part of the social processes used by individuals to understand, cope and live with a condition that is perceived as being beyond their control (Bury 2005).

Understanding the impact of pressure ulceration raises methodological challenges for researchers. Most people who develop pressure ulcers have greatly reduced mobility because

of a major acute illness or a chronic health problem, and the tissue breakdown that results is a response to this illness and immobility. It is therefore difficult, if not impossible, to measure pressure ulcer specific impact on quality of life using disease specific instruments. This methodological difficulty might lead healthcare professionals and policy makers to assume that pressure ulcers have little impact beyond the financial cost of treatment. Measuring the costs associated with pressure ulcers is not straightforward. A report by Touche Ross (1993) suggests that the treatment of pressure ulcers may be cheaper than prevention where significant hospital resources (such as nurses' time) are used to implement prevention strategies. This is because the 'at risk' group receiving preventative interventions is likely to be larger than the group which would actually go on to develop a pressure ulcer. The authors acknowledge that they did not consider the pain, suffering and nonmonetary costs for patients who develop a pressure ulcer. Our study redresses the balance by highlighting the significant impact that pressure ulcers have on quality of life and supporting the view that studies of cost should include personal and societal, as well as financial, costs.

### Study limitations

Findings from qualitative research cannot be generalized to a larger group. However, the understandings gained from these participants may have transferability to other patients and settings (Lincoln & Guba 1985). The validity of our findings can be judged by the transparency of the research process.

It was not possible to differentiate the impact of the pressure ulcer in relation to length of time participants had suffered with their chronic condition. Information on chronic conditions was provided by patients because we did not have ethics approval to check medical records. Therefore, these data are limited because patients did not always report their co-morbidities (e.g. patient F8 is likely to have had vascular disease), and patients were not always able to recall how long they had been diagnosed with a condition. Researchers may wish to consider how to improve the collection of these data in future research.

### Conclusion

By showing the suffering that pressure ulcers cause for patients, our findings highlight important areas of practice to be addressed by healthcare professionals, including management of dressings, providing information (in particular about realistic time expectations for healing), undertaking preventative interventions and understanding the importance of

comfort and positioning for patients. In addition, healthcare professionals need to respond to patients' criticisms of their lack of involvement, or poor standards in the treatment, management and care of pressure ulcers. Guidelines clearly indicate the instrumental responsibilities of healthcare professionals to prevent and manage pressure ulcers (NICE 2003, 2005).

The findings are also relevant for future studies evaluating the impact on patients' quality of life of conditions that are not stable over time. The long-term trajectory of having a pressure ulcer and its treatment presents challenges for researchers wanting to measure the impact of pressure ulcers on quality of life and the costs associated with treatment and prevention. Researchers will need to find ways of separating the impact of comorbidities on quality of life from the impact of pressure ulceration and its treatment over time. In addition, studies of the costs of pressure ulceration will have to consider 'wider' personal and societal costs (such as pain experienced by patients with a pressure ulcer and the nonmonetary costs of patients' time associated with treatments) and not just the financial costs of treatment and prevention. This presents a challenging future research agenda.

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## Author contributions

EAN, NC, JN and SM were responsible for the study conception and design and KS was responsible for the drafting of the manuscript. KS and EAN performed the data collection and data analysis. EAN, NC, JN, CI and SM

obtained funding. EAN, NC, JN, CI and SM made critical revisions to the paper. EAN and NC supervised the study.

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