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A narrative review of patients' lived experience of having a pressure injury

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ABSTRACT

Aims: To explore patients' experiences of living with pressure injuries.

Design: A qualitative narrative review and thematic synthesis of qualitative research studies.

Data sources: Six electronic databases were searched: Medline, CINAHL, Scopus, Web of Science, Embase, and Google Scholar (for grey literature). The search was conducted between October 2022 and April 2023.

Setting: Acute, community and care home settings across the United Kingdom, Northern Ireland, France, Belgium and the United States.

Review methods: The PRISMA checklist for reporting systematic reviews was used. The included studies were evaluated for quality using the CASP tool. The JBI data extraction tool was used to extract data from the included studies. Thematic synthesis was utilised to identify themes to present a coherent and nuanced understanding of patients' experiences living with pressure injuries.

Results: Nine studies involving 244 participants, aged 21 to 101, with pressure injuries, met the inclusion criteria. Three key themes emerged using the thematic analysis: physiological, emotional and psychological, and social effects. Within these themes, subthemes such as endless life and discomfort, loss of mobility and independence, and social isolation were dominant in all aspects of the lives of patients living with pressure injuries.

Conclusions: This narrative review gives clear and multifaceted insight into the impact of pressure injuries on individuals' lives, emphasising the necessity for, patient-centered care and the integration of evidence-based tools for effective pain management and risk assessment. The impact of pain on emotional and psychological well-being was significant, and the financial implications are scarcely known.

Impacts: Future research is needed to explore the experiences of younger adults and the financial consequences of living with pressure injuries.

Keywords: Pressure injuries, pressure ulcers, pressure sore, emotional and psychological impact, quality of life, social effects, systematic review, experience, physical, qualitative, living.

Introduction

Pressure Injuries are skin or underlying tissue injuries over a bony prominence caused by intrinsic (e.g., ageing, immobility) and extrinsic factors (e.g., pressure and shear) (National Pressure Injury Advisory Panel, 2016). Globally, pressure injuries are a leading cause of preventable patient harm, resulting in a significant increase in morbidity and mortality rates (Sardo *et al.,* 2023). Existing evidence suggests that pressure injuries predominantly affect the ageing population due to frailty and increased risk of immobility (Awad and Hewi, 2020).

Additionally, it is a significant health issue due to the economic impact (e.g., treatment and litigation costs) and health burden (e.g., sepsis) on the healthcare sector and the individual (Hajhosseini *et al.,* 2020). Despite various prevention strategies implemented worldwide to reduce the incidence and prevalence of pressure injuries, recent evidence indicates a substantial rise in pressure injury cases (Triantafyllou *et al.,* 2021). In the United Kingdom (UK), it is estimated that 700,000 people develop pressure injuries yearly at the cost of £1.4 to £2.1 billion to the National Health Service (NHS), which accounts for 4% of the total expenditure (NHS, 2018). Similarly, in the United States, about 2.5 million people are affected by pressure injuries, costing $11.6 billion annually (Geng *et al.,* 2023).

Yet, these estimates do not reflect the individual burden characterised by negative psychological, emotional, physiological, and social impacts (Roussou *et al.,* 2023). A systematic review by Heywood-Everett *et al*. (2023) on the psychological impact of pressure injuries affirmed that pressure injuries affect the physical, emotional, psychological, and social domains of life. However, it focused solely on the Additionally, supporting evidence by Dube *et al*. (2022) indicates that hospital and community-based patients face challenges related to pain, mobility, and social participation. However, these challenges could negatively affect their autonomy, resulting in low self-esteem, anxiety, or depression (Afridi and Rathore, 2020). Therefore, the National Institute for Health and Care Excellence (NICE, 2014) guidelines recommend a holistic care approach in treating and managing pressure injuries. Hence, a narrative review of patients' lived experiences with pressure injuries would improve interventional approaches and care strategies for inpatient and community-based patients when applied in line with NICE guidelines.

Background

The lived experience of pressure injuries is a complex phenomenon that refers to an individual's personal and subjective experience of living with one (Prosek and Gibson, 2021). According to NHS (2023), the lived experience' encompasses personal knowledge of individuals living with chronic conditions and their impact on them or their carers. Roussou *et al.* (2023) state that an individual's lived experience provides valuable insight into the severity of their pain, discomfort, and profound impact on their quality of life. Despite a lack of clear consensus on the term “lived experience” (Rittenbach *et al.,* 2019), exploring the perceptions of individuals living with pressure injuries is imperative to gain a deeper understanding of their experience.

Prevalence data, surveys, and reviews have primarily focused on the incidence, risk factors, treatments, and risk assessment of pressure injuries (Anthony *et al.,* 2019; Kandi *et al.,* 2022; Geng *et al.,* 2023). In recent years, qualitative research methodologies have aided a more comprehensive understanding of nurses' and carers' experiences caring for patients with pressure injuries (Rafiei *et al.,* 2021; Heerschap and Woo, 2022). However, there is a paucity of 'patient-led’ research on patient experiences living with pressure injuries (Burston *et al*., 2023). Embracing patient experiences will nonetheless assist healthcare professionals and policymakers in adopting new approaches to pressure injury management (Ledger *et al.,* 2020). Thus, this narrative review will provide a unique insight into patients' lived experiences with pressure injuries. This will aid healthcare professionals in providing comprehensive wound care, psychological support, social interventions, and financial guidance to mitigate the adverse effects on patients' well-being.

THE REVIEW

Aims

This narrative review aims to synthesise and analyse qualitative studies on patients' experiences living with pressure injuries.

Design

A qualitative narrative review with thematic analysis was conducted using an inductive approach to gain unbiased and deep insights into patients' lived experiences. This approach is seen as effective in eliciting patients' holistic views (Braun and Clarke, 2023).

Search Methods

The research question was structured using the SPIDER (sample, phenomenon of interest, design, evaluation, and research type) tool (Cooke *et al*., 2012). The search terms, Boolean operators, and truncation symbols used are detailed in Table 1.

Table 1

Six electronic databases were searched. CINAHL, Web of Science, MEDLINE, Embase, and Scopus Google Scholar were explored between October 2022 and

April 2023. No restrictions on the country were imposed. The inclusion and exclusion criteria are shown in Table 2

Table 2

Search Outcomes

An initial advanced search from 2003 to 2022 was undertaken across all six databases in October 2022, yielding 3570 studies. Duplicate removal and screening based on title, abstract, inclusion, and exclusion criteria led to the removal of 3501 papers, yielding 69 articles. A full-text search led to the further removal of five articles that could not be accessed. After the full-text review, a total of six articles were retrieved. Notably, an additional paper was later identified following reference list screening. A further updated search was undertaken in April 2023 to ensure the inclusion of all the peer-reviewed articles published between 2000 to 2003. Consequently, two subsequent articles were identified, bringing the total number to nine. The PRISMA (2020) flow diagram shows the search steps (see Figure 1).

Figure 1

Quality appraisal

A Critical Appraisal Skills Programme (CASP, 2018) tool was adopted to systematically assess and ensure the included studies' trustworthiness, value, and relevance. The CASP tool is recommended by Cochrane and the World Health Organisation as an evidence-based health-related research checklist (Noyes *et al.,* 2019). The overall study quality for the nine studies was rated high, indicating high rigour in the research process.

Data abstraction

Each study was screened and read thoroughly multiple times, both electronically and manually, to familiarise with the content and ensure relevance and accuracy before extraction. Following the screening, the Joanna Briggs Institute QARI data extraction tool for extracting qualitative studies was adapted to suit the review's aim and identify key concepts from the included studies (Aromataris and Munn, 2020).

Synthesis

This narrative review utilised a thematic synthesis and an inductive approach (Thomas and Harden, 2008) to analyse and synthesise data. This review aimed to minimise bias and aid reflexivity by following Braun and Clarke's (2023) six-phase thematic analysis alongside an inductive approach.

The included papers are shown in Table 3.

Table 3

Results

Characteristics of included studies

Nine qualitative studies were selected for inclusion in this review encompassing diverse settings such as communities, hospitals, nursing homes, and rehabilitation centres. The studies were conducted in the UK, Belgium, the United States, and France, with the most significant proportion undertaken in France (Gourlan *et al.,* 2020). The studies utilised semi-structured (n=7) and unstructured (n=2) interviews to gather information from 244 participants. The participants' ages across all studies ranged from 21 to 101 years, with a higher proportion of men (n=155) than women (n=89). Notably, the studies included in this review had varied foci, such as patients with spinal cord injury (Gibson, 2002; Gourlan *et al.,* 2020) and multiple sclerosis (Langemo *et al*., 2000), the impact on quality of life (Spilsbury *et al*., 2007; Gorecki *et al*., 2010), pain (Jackson *et al.,* 2017; Fox, 2002), and the experience of living with multiple losses due to pressure injuries (Jackson *et al.,* 2018).

Synthesis of the identified themes

Data synthesis led to the construction of three analytical themes and three sub-themes. The three major themes identified were physiological, emotional and psychological, and social effects (see Figure 2).

Figure 2

Physiological effects

Results from this systematic review indicate that participants experienced varying degrees of pain and discomfort due to pressure injuries. Most participants reported pressure injury as significantly affecting the physical aspects of their lives, causing endless pain, immobility, dependency, and discomfort (Langemo *et al.,* 2000; Fox, 2002; Gibson, 2002; Hopkins *et al.,* 2006; Spilsbury *et al*., 2007; Gorecki *et al.,* 2010; Jackson *et al.,* 2017; Jackson *et al.,* 2018).

Endless pain and discomfort

Pain was found to be dominating and excruciating. Some participants in the Langemo *et al*. (2000) study described the pain experienced *as "sitting on a bunch of needles"* and another as *"endless."* Similarly, discomfort was prevalent with pain from pressure injury, impeding sleep and other activities of daily living (Jackson *et al*., 2017). Conversely, Gorecki *et al*. (2010) identified participants whose pains were exacerbated during treatment (e.g., debridement) and in the use of pressure-relieving equipment (e.g., hoist). Describing the pain using sensory descriptors such as "*throbbing*" and "*stabbing*." However, due to the severity of pain experienced, handling by healthcare professionals during wound dressing became additionally painful, as expressed by a participant:

> *"When they clean it, it is like a needle scraping my nails. It is very painful"* (Hopkins *et al*., 2006, p. 349).

Participants in the Langemo *et al*. (2000) study reported that their pain intensity was largely unrecognised by the doctors and the analgesics prescribed as ineffective, thus affecting the overall quality of their life (Fox, 2002; Jackson *et al*., 2018).

Loss of mobility and independence

The loss of mobility and independence was found to have a negative impact. In the study by Jackson *et al*. (2018), a participant reported the loss of mobility as "*very handicapping*" because it restricted movement and self-care (Fox, 2002; Gorecki *et al.,* 2010). Similarly, Spilsbury *et al.* (2007) provided further evidence of the effect of losing independence and mobility in older participants. Some participants had to install chairlifts or wider doors for wheelchairs, while others sold their houses in favour of smaller dwellings, therefore reducing their activities:

> *“I thought, one of these days I'm going to fall… I'll stay downstairs and put my house in for an exchange” (Spilsbury et al., 2007).*

Loss of mobility can diminish an individual's independence, resulting in dependency (Hopkins *et al.,* 2006). This dependency led to reliance on carers, as some participants felt their lives had been "*robbed*," making them appear "*useless*" and "*worthless*" (Gibson, 2002). However, the degree of dependence varied considerably among the participants (Gibson, 2002). Some participants required a more extensive care package from social services than others (Spilsbury *et al.* (2007).

Despite the willingness of carers and family members to provide support, younger participants conveyed a sense of resentment stemming from a perception of being a source of burden:

> *“I'm having to rely on my sister..., 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” (Spilsbury et al., 2007).*

Hence, the diminished mobility state affects the patient’s emotional and psychological well-being.

Emotional and psychological effects

Emotional and psychological effects emerged as a predominant theme. Most participants expressed negative emotions using robust affective descriptors such as “frustrating,” “miserable,” and “unbearable” due to the duration of the wound (Langemo *et al.,* 2000; Fox, 2002; Gibson, 2002; Hopkins *et al.,* 2006; Gorecki *et al.,* 2010; Jackson *et al.,* 2017; Jackson *et al.,* 2018). This range of emotions was effectuated by a participant whose pressure injuries had lasted for over two months with no imminent hope of recovery:

> *"At this moment in time, as of today, it almost seems insurmountable. Pressure injury depresses me more than anything" (Jackson et al., 2017).*

Additional worries, such as fear and anxiety about being hospitalised and bedridden for treatment, generated feelings of "*hopelessness*" associated with depression (Gorecki *et al*., 2010; Jackson *et al.,* 2018). These findings align with Langemo *et al.* (2000), where participants stated that doctors' and nurses' intrusion into their privacy and dignity during treatment affected their autonomy and self-esteem, leading to despair and despondence (Jackson *et al*., 2017). As reported by a participant with quadriplegia and stage IV pressure injury:

> *"The only thing is I get humiliated when the doctor looks at my sores with five, sometimes six people ...sometimes they leave the door open" (Langemo et al., 2000).*

Despite the clinician's education on the prognosis of pressure injuries, a participant in Hopkins *et al.* (2006) demonstrated a sense of fatalism: *"With me, I say what will be will be."* Hence, this evidence establishes a clear consensus on the emotional and psychological burden of adapting and coping with pressure injuries.

Social effects

Social and interpersonal challenges were evident in the experiences of the participants in six of the studies (Langemo *et al.,* 2000; Fox, 2002; Spilsbury *et al.,* 2007; Gorecki *et al.,* 2010; Jackson *et al*., 2018; Gourlan *et al.,* 2020). Most participants described physical restrictions and wound treatment inflicted by pressure injuries as a hindrance to their social life, leading to social isolation (Jackson *et al*., 2018).

Social isolation

Social isolation was described as a loss of engagement in social activities, including activities previously enjoyed (Jackson *et al*., 2018). Some participants identified the impact of being bedbound and the necessity of wound care due to pressure injury as significantly affecting their social life and relationships (Fox, 2002; Gourlan *et al.,* 2020). As evidenced by Langemo *et al.* (2000), many participants referred to the unpleasant malodour and visible discharge as significant factors that restricted their social interactions. While other participants with spinal cord injury expressed similar concerns about their body image using self-evaluative terms such as *"ashamed*" and *"embarrassed*" (Gorecki *et al.,* 2010). This low self-concept affected these participants (Langemo *et al.,* 2000; Gourlan *et al.,* 2020), resulting in a reluctance to socialise or form new relationships, as encapsulated by Spilsbury *et al.* (2007):

> *“I noticed the nurses… could hardly stand the smell of it. The smell is terrible..., and to me, it's an embarrassment.”*

This sense of emotion affected their self-worth, resulting in withdrawal from social activities.

Discussion

This narrative review described individuals' vivid experiences of living with pressure injuries and the profound impact on their physical, emotional, psychological, and social domains of life.

Pain was a predominant physiological effect (Hopkins *et al.,* 2006) that negatively affected individuals (Jackson *et al.*, 2017). Despite the prescribed analgesics, the intensity of the pain was still depicted using strong evaluative and sensory descriptive terms such as "*stabbing*," which highlighted participants' subjective experience (Gorecki *et al.,* 2010). However, Chang *et al.* (2022) and Goswami *et al.* (2023) argue that individuals with ongoing chronic conditions such as Multiple Sclerosis may interpret pain in the context of their existing chronic state, leading to an ambiguous pain description. Hence, it is imperative for researchers to utilise a pain assessment tool to assess the severity of participants' pain and help plan strategies to mitigate the pain effectively.

Immobility and independence were another key physiological aspect. Some participants experienced more pain and discomfort with assistive devices (e.g., hoists) during movement, contributing to reduced mobility (Gorecki *et al*., 2010). This impact resulted in immobility and dependence (Hopkins *et al.,* 2006) on caregivers and family members, often leading to frustration and a loss of autonomy. Arguably, despite immobility and dependency posed by high pain levels due to pressure injuries, recent research indicates that co-morbidities are a direct causal factor of immobility (Cornish, 2023). Hence, the NICE (2014) guidelines recommend using risk assessment tools to identify and prevent pressure injuries. Therefore, educating caregivers on the importance of quality individualised care and the proper use of a valid risk assessment tool will aid in ameliorating patients' living conditions.

The emotional and psychological impacts of living with pressure injuries were evident across the reviewed studies. Many participants frequently expressed despair and despondence as emotional and psychological effects of pressure injuries (Jackson *et al*., 2017). These findings resonate with the data found in Rodriguez and Gamboa (2020), where leg ulcer patients experienced emotional turmoil caused by losing control over pain and treatment. The study suggests that clinicians adopt a care strategy that respects patients' autonomy while focusing on holistic care to promote their psychological well-being (Rodriguez and Gamboa, 2020). Therefore, this research reinforces good practice and has parallels to NICE guidelines (NICE, 2014). Altogether, a multidisciplinary approach encompassing patient-centred care is pivotal in a patient's recovery.

The lived experience of patients with pressure injuries has similarities with other reports of patients living with chronic wounds (Falanga *et al.,* 2022). Participants' accounts of social effects, such as social isolation, were evident in a study by Jackson *et al*. (2018) as one of the critical effects of living with pressure injuries. Exudate and malodour inflicted by pressure injuries created barriers to social inclusion, resulting in a reluctance to engage in social activities (Langemo *et al.*, 2000). This concern about body image, compounded by diminished mobility, led to a "restricted life" for the participants (Spilsbury *et al.,* 2007). Klein *et al.* (*2021*) described the significant impact of chronic wounds on social participation in several ways, such as social disconnection, disengagement, and feelings of loneliness. However, this review extends beyond social participation, where younger participants in a study by Gourlan *et al.* (2020) reported "closeness and interpersonal communication" as difficulties encountered in their relationships. Therefore, the convergence of these findings from various studies demonstrates the social implications of living with pressure injuries (Roussou *et al.*, 2023). Nonetheless, encouraging social support systems is crucial to reducing isolation.

Strengths

The impact of pressure injuries, as seen in the studies (Langemo *et al*., 2000; Gibson, 2002), aligns with prior research where pressure injuries extend across physical (Fox, 2002; Hopkins *et al.,* 2006), social (Spilsbury *et al.,* 2007; Gourlan *et al*., 2020), emotional (Gibson, 2002; Jackson *et al*., 2017), and psychological (Jackson *et al.,* 2018) domains of life. Hence, the research significantly contributes to the field, offering novel and profound insights into our understanding of pressure injuries.

Limitations

The absence of a second reviewer for data analysis and thematic synthesis introduces potential bias in the reliability of the results. On the other hand, increased reflexivity and peer feedback improved the credibility of the findings.

Conclusion

The cumulative evidence from nine qualitative studies using thematic synthesis provided a clear understanding of patients' experiences with pressure injuries. Pressure injuries-related pains were a significant factor that affected patients' overall quality of life. These findings align with previous research, giving newer and deeper insights into patients' experiences living with pressure injuries. The scope of this review was limited to adults aged 18 and above; however, available literature contained information only on adults aged 21 to 101, with a notable bias toward females. The financial consequences of pressure injuries, such as income loss, were also not adequately highlighted. Therefore, future research should address the experiences of younger adults living with pressure injuries and further investigate the financial implications of pressure injuries. Additionally, integrating quantitative methodologies for pain assessment should be considered as it will enhance data analysis. Undoubtedly, acknowledging and addressing patients’ concerns will aid in alleviating their living conditions, resulting in improved outcomes for both the individual and the healthcare sector.

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