




REVIEW

Patient and carer experience of living with a pressure injury: A meta-synthesis of qualitative studies

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Abstract

Introduction: Pressure injuries are a significant cause of harm, contributing to increased mortality and financial burden on the healthcare system. Significant research on pressure injury risk assessment, prevention and treatment exists, but limited research exploring the patient and carer experience of living with pressure injury.

Aims: The aim of this meta-synthesis was to describe the patient and carer experience of living with a pressure injury.

Design: Meta-synthesis.

Methods: A prospective review protocol was registered, and systematic search conducted across five electronic databases. The PRISMA 2020 checklist for reporting systematic reviews was used. Two reviewers independently undertook screening and review of articles, using the CASP checklist for evaluating qualitative research. A meta-synthesis using thematic content analysis was undertaken.

Results: Twelve studies met the inclusion criteria. Meta-synthesis led to the construction of three primary themes: *loss of autonomy and independence*, *psychological effects*, and *adjustment*. Within these primary themes, sub-themes of dependence, social isolation and social avoidance behaviours, feelings and emotions, loss, managing, physical consequences, service provision, and functional challenges, were identified.

Conclusion: The psychology and mindset of those involved, and support to navigate the challenges that arise are two unique and clinically relevant categorisations to guide provision of pressure injury care. Adaptation to a pressure injury is multifaceted and contextual, challenges to adaptation create additional psychological burden. Interventions encompassing all facets of the experience are necessary. Current research into experiences is limited, and further research to support interventions is necessary.

KEYWORDS

decubitus ulcer, meta-synthesis, patient care, pressure injury, pressure sore, pressure ulcer, systematic review

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1 | INTRODUCTION

Pressure injury, previously known as pressure ulcer or bed sore, is a long-standing problem. Globally, pressure injury is a significant issue, demonstrated by an international pooled rate of hospital-acquired pressure injury of 8.4% (95% confidence interval 7.6%–9.3%), as identified by a recent systematic review and meta-analysis (Li et al., 2020). It causes a range of physical, psychological and social burdens (Shiferaw et al., 2020), and contributes to increased mortality (Song et al., 2019). The worldwide significance of pressure injury is acknowledged globally, for example through provision of an international guideline on prevention, management and treatment (European Pressure Ulcer Advisory Panel [EPUAP], National Pressure Injury Advisory Panel [NPIAP], & Pan Pacific Pressure Injury Alliance [PPPIA], 2019), and in Australia, by inclusion as a hospital-acquired complication in the National Safety and Quality Health Service (NSQHS) Standards (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2018).

The economic burden of pressure injury cannot be underestimated, with the cost of hospital-acquired pressure injuries estimated at approximately Australian \$3332 per episode (Barakat-Johnson, Lai, Wand, White, & De Abreu Lourenco, 2019). Not only is there a direct treatment-related cost to pressure injury, there are also further opportunity costs related to, for example, lost bed days (Nguyen et al., 2015).

There is a plethora of pressure injury research, for example examining the relationship between risk assessment and preventative measures (Lovegrove et al., 2018), interventions in a variety of settings (Asimus et al., 2011; Hada & Coyer, 2021; Horn et al., 2010), treatment modalities (Walker et al., 2017; Westby et al., 2017) and strategies to support best practice (Suva et al., 2018). As well, research has been undertaken about the role of the patient in the development of risk assessment tools (Coleman et al., 2015), about pressure injury prevention (McInnes et al., 2014), the patient experience of chronic wounds (Squitieri et al., 2020) though not specifically of pressure injury, and of patient perceptions of interventions (Roberts et al., 2017) but not of the patient experience of interventions for a pressure injury.

Pressure injuries are known to generate a range of psychological, social and economic effects for the patient and their carer. Research has shown that management of pressure injury care is contingent on a complexity of patient factors, such as comorbidities and resistance to care involvement (Barakat-Johnson, Lai, Wand, & White, 2019; Barakat-Johnson, Lai, Wand, White, & De Abreu Lourenco, 2019), patient involvement in decision-making, pain and individual lifestyle considerations (Ledger et al., 2020). Understanding the experience from the patient and carer perspective is critical to improving the quality-of-care provision and reducing the effects of pressure injury.

2 | AIM

The aim of this meta-synthesis was to describe the patient and carer experience of living with a pressure injury.

What does this paper contribute to the wider global community?

- This review consolidates current research exploring the experience of people living with a pressure injury, providing justification for further exploratory and intervention work.
- Further research to improve capacity of the patient's and caregiver's psychology and mindset towards a pressure injury, and to improve mechanisms that support management of the pressure injury episode are needed.

3 | METHODS

3.1 | Design

A qualitative meta-synthesis was designed and conducted. Meta-synthesis is a recognised approach for exploring the experiences of healthcare consumers (Berry et al., 2021; Mbuzi et al., 2017). The value of meta-synthesis lies in the ability to garner new insights that cannot be identified using other research methods (Lachal et al., 2017).

The meta-synthesis approach was selected here for this study exploring the experience of living with a pressure injury due to the interpretive nature of the method (Walsh & Downe, 2005). This interpretive element was necessary as the goal was to produce new findings and develop a unique interpretation of the experience (Fingfeld-Connett, 2014), to inform further research and elements of clinical practice (Leary & Walker, 2018).

A systematic approach to literature identification, screening and appraisal based on the Joanna Briggs Institute (JBI) approach to qualitative synthesis was conducted (Aromataris & Munn, 2020). This approach was used as a guide to facilitate identification of appropriate studies, and included development of search terms, a systematic literature search, review and selection of studies, quality appraisal of included studies, data extraction and synthesis of findings.

The Preferred Reporting Items for Systematic Reviews (PRISMA) 2020 checklist (Page et al., 2021) for reporting systematic reviews was used (Data S1).

3.2 | Search strategy

The research question used to frame the review was as follows: What are the patient and carer experiences of living with a pressure injury? A systematic review protocol was developed and registered with the International Prospective Register of Systematic Reviews PROSPERO (#CRD42018107610). Initially, a 10-year period from 2009 to 2018 was targeted for the search. However, the study was subsequently extended to include all publications until the end of December 2021. The initial search undertaken in

October 2018, and was repeated in October 2021, with a final search undertaken in May 2022 to ensure inclusion of all 2021 publications. No new articles were identified in the May 2022 search. Search parameters were not altered between the initial search and the updated search, except to extend the inclusion of articles published between 2018 and 2021. A modified PiCO (Population, Context and Outcome) approach was used with search terms detailed in Table 1.

Five electronic databases were searched (CINAHL, Web of Science, MEDLINE, Embase and Scopus). Qualitative research studies were targeted, with mixed-method studies also screened to determine whether the qualitative component met the inclusion criteria for this review. The inclusion criteria were peer-reviewed articles, adult patients (>18 years age) who had experienced a pressure injury (ulcer) and/or adult carers (>18 years age) providing supportive care to those with a pressure injury, and papers published in English. Peer-reviewed articles were sought to ensure the highest quality evidence on the topic was obtained. Studies from a variety of settings were sought. Quantitative studies, editorials, conference papers and non-peer-reviewed articles from Internet websites were excluded.

3.3 | Study selection and appraisal

Articles were initially screened by one author to identify and exclude duplicate studies and studies that did not target pressure injury. Full-text review of remaining articles was completed, and articles not meeting the inclusion criteria were removed. Two authors independently conducted all screening, review and assessment of full-text articles using the Critical Appraisal Skills Programme (CASP) checklist for evaluating qualitative research (Critical Appraisal Skills Program, 2018). In instances when discrepancy of scoring occurred between raters, the lower quality score was assigned to the study.

3.4 | Data synthesis

To analyse and synthesise the data, a thematic content analysis approach was used; an approach focused upon extracting central ideas or themes from the data (Willis, 2019). This inductive process of data collection and analysis (Sarantakos, 2013) was appropriate for this review analysing textual data from published studies. In this review, the data collection process was the extraction of data from included articles, while the Braun and Clarke (2006) six phase approach was used to structure the analysis: data familiarisation, initial code generation, searching for themes, reviewing themes, defining and naming themes, and producing the report.

Studies were first read several times independently by two authors to foster understanding of key results and findings. The Joanna Briggs Institute QARI Data Extraction Tool for Qualitative Research was then used by the lead author to guide the data extraction

process (Aromataris & Munn, 2020). Extracted data included details about the population, context, culture, geographical location, methods and phenomena of interest as pertaining to the review aim. The lead author manually entered data into a Microsoft Excel spreadsheet for manual analysis, identified initial codes from the extracted data, with aggregation of codes then leading to development of preliminary themes. Discussion of these preliminary themes was undertaken by two authors, with further refinement of codes and themes undertaken to reach consensus. To further improve trustworthiness, a cyclical process of re-reading the source articles and critical reflection was undertaken by the lead author. This process facilitated deep engagement and familiarity with the data, and construction of robust analytical themes (Bazeley, 2013; Braun & Clarke, 2006). Finally, a process of re-contextualising the constructed analytical themes to the source data was undertaken (Bergman, 2010). This in effect 'closed the loop' to ensure the constructed analytical themes remain representative of the source data.

4 | FINDINGS

The initial database search returned 3923 articles. Removal of duplicates and screening of titles and abstracts led to removal of 3877 articles, leaving 46 articles. Of these, full-text versions of two articles could not be identified; hence, 44 articles were included for full-text review. After full-text review, a further 35 articles were removed, primarily as they did not report qualitative findings or the patient/carer experience. One additional article for inclusion was later identified through screening of reference lists. Consequently, twelve articles were included in the analysis and synthesis (refer Figure 1: PRISMA flow diagram). Included articles are shown in Table 3.

Twelve articles were included for synthesis, of which eleven were qualitative studies (Dunn et al., 2009; Fogelberg et al., 2016; García-Sánchez et al., 2019a, 2019b; Gorecki et al., 2010; Gorecki et al., 2012; Jackson et al., 2017b; Jackson et al., 2018; Kapp & Annells, 2010; Latimer et al., 2014; Rodrigues et al., 2015), and one utilised mixed-methods (Jackson et al., 2017a) (Table 3). Semi-structured interviews ($n = 7$), in-depth interviews ($n = 1$) or unstructured/conversational interviews ($n = 4$) were used to collect data within the studies. Eleven studies were rated as high quality and one as moderate quality (Table 2).

Studies occurred in a wide variety of settings. Most were conducted in community settings with the largest proportion undertaken in Spain (see Table 3). The included studies had a variety of foci: spinal cord injury (Dunn et al., 2009; Fogelberg et al., 2016); service provision and pressure redistributing devices (Jackson et al., 2017a); pressure injury prevention (Latimer et al., 2014); impact on quality of life (Gorecki et al., 2012); care in the home (García-Sánchez et al., 2019a, 2019b; Gorecki et al., 2010; Kapp & Annells, 2010); pain (Jackson et al., 2017b); living with loss (Jackson et al., 2018); and informal caregiving (Rodrigues et al., 2015).

TABLE 1 Search terms

Population	AND	Context	AND	Outcome
("Patient*" OR "Carer*" OR "Relative*")		("Pressure injur*" OR "Pressure ulcer*" OR "Bedsore*" OR "Decubitus ulcer*")		(experience* OR view* OR perspective* OR perception*)
CINAHL (CINAHL Headings)				
((MH "Patient") OR (MH "Carer") OR (MH "Relative"))		((MH "Pressure injury") OR (MH "Pressure injuries") OR (MH "Pressure ulcer") OR (MH "Bedsore") OR (MH "Decubitus Ulcer"))		((MH "Experience") OR (MH "View") OR (MH "Perspective") OR (MH "Perception"))
Medline (MeSH)				
"Patient"[Mesh] OR "Carer"[Mesh] OR "Relative"[Mesh]		"Pressure injury"[Mesh] OR "Pressure ulcer"[Mesh] OR "bedsore"[Mesh] OR "decubitus ulcer", Combination"[Mesh]		"Experience"[Mesh] OR "View"[Mesh] OR "Perspective"[Mesh] OR "Perception"[Mesh]
Embase (Emtree)				
exp patient/exp carer/exp relative/		exp pressure injury/exp pressure injuries/exp pressure ulcer/exp bedsore/exp decubitus ulcer/		exp experience/exp view/exp perspective/exp perception/
Web of Science				
TS = ("Patient*" OR "Carer*" OR "Relative*")		TS = (Pressure injury OR pressure injuries OR pressure ulcer OR bedsore OR decubitus ulcer)		TS = (Experience* OR View* OR Perspective* OR Perception*)
Scopus				
TITLE-ABS-KEY("Patient*" OR "Carer*" OR "Relative*")		TITLE-ABS-KEY(Pressure injur* OR Pressure ulcer* OR Bedsore* OR Decubitus OR ulcer)		TITLE-ABS-KEY(experience* OR view* OR perspective* OR perception*)

Nine articles reported on the experience of the patient only (Dunn et al., 2009; Fogelberg et al., 2016; Gorecki et al., 2010; Gorecki et al., 2012; Jackson et al., 2017a, 2017b; Jackson et al., 2018; Kapp & Annells, 2010; Latimer et al., 2014), with the remaining three focused on the experiences of both patient and carer (García-Sánchez et al., 2019b) or the carer only (García-Sánchez et al., 2019a; Rodrigues et al., 2015).

Data synthesis led to the construction of three analytical themes and seven sub-themes. The three major themes constructed were *Loss of autonomy and independence*, *Psychological effects* and *Adjustment*. *Loss of autonomy and independence* included sub-themes of *dependence* (a negative impact on independence and therefore increasing dependence), and *social isolation and avoidance behaviours* (emergent upon patients and caregivers, chosen by patients, in the context of social support). *Psychological effects* included sub-themes of *feelings and emotions* (felt by patients and caregivers, varied widely, caused negative impacts for the situation, other facets of the experience such as pain contributed to challenges with feelings and emotions), and *loss* (potential loss, actual loss, vulnerability during transitional stages of care). The third theme *Adjustment* included sub-themes of *physical consequences* (*physical effects of a pressure injury forced adjustment to activity*), *service provision* (*adjusting lifestyle to accommodate provision of treatment services*) and *functional challenges* (*forced adaptation to activities of daily living and use of mobility aids*).

4.1 | Loss of autonomy and independence

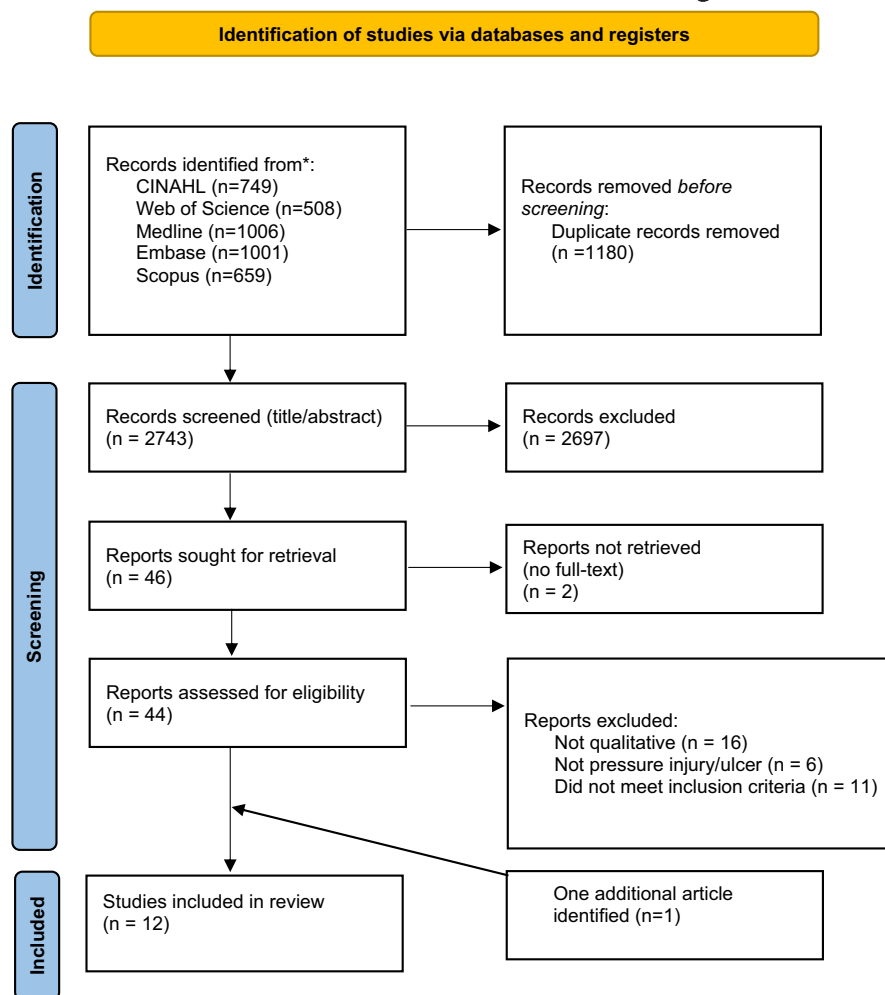
Loss of independence and negative effects on autonomy were identified in some studies. Commonly, this led to social avoidance and social isolation.

4.1.1 | Dependence

Pressure injuries were seen to impact negatively on independence. This impact extended to capacity for self-efficacy, with participants in Gorecki et al.'s (2010) study describing feeling as though '...their life had been robbed,...' (p.1531). A lack of control over who saw and touched their body, tension between what should be done for healing and what patients would prefer to do, and fear of being a burden contributed further to this (Gorecki et al., 2010). Similarly, a dependence on care workers and community services was evidenced in the study by Jackson et al. (2018), as well as pressure injury-related impact on mobility and a subsequent loss of independence attached to this.

'I'm a very independent person, all my life and I find it very hard... a couple of people do my shopping for me round here... I do hate people doing my shopping for me. Cos, I'm grateful for what they do, but it's not the same as doing your own' (Jackson et al., 2018, p. 411).

FIGURE 1 From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. 10.1136/bmj.n71



Conversely, Latimer et al. (2014) identified participation in pressure injury prevention as enabling self-determination, particularly when enablement was positively facilitated by others such as nurses and family members. A participant in Fogelberg et al.'s (2016) study described this enablement as a process of 're-training':

'...people who are newly hurt, they have to train themselves to do certain things and that's where that comes in, where you personalize a particular routine. But once you've already trained yourself to do a certain thing and it works, then... it's pretty much natural after that' (p. 473).

Motivation was identified as an important factor for involvement and regaining control and independence (Gorecki et al., 2012).

4.1.2 | Social isolation and avoidance behaviours

Social isolation as an effect of pressure injury occurrence was clearly identified. This was described as a loss of engagement and ability to engage in preferred activities (Jackson et al., 2018), and restrictions on social participation that extended to family, friends and pets

(Gorecki et al., 2010). Language such as 'captive, confined, and alienated' was used to describe this experience (Gorecki et al., 2010, p. 1531). The impacts were substantial:

'I haven't seen anybody, I haven't been out of this [hospital] room in God knows how many months. My brain is really just dying in here not having any stimulation' (Gorecki et al., 2012, p. 7).

Social support (or lack thereof) was also linked to the psychological well-being of patients with a pressure injury (Gorecki et al., 2012). Social support was welcomed, although its requirement was seen as limiting:

'One of my nieces is coming to pick me up and take me there, and sometimes I think,...I just wish I could get in a taxi and go' (Kapp & Annels, 2010, p. 3).

Participants in Dunn et al.'s (2009) study identified the treatments required for a pressure injury as causing social discomfort, leading to avoidance behaviours in two participants. This was commonly described in the context of work. One participant rationalised his reluctance to wear alternative footwear (recommended to

TABLE 2 CASP Qualitative checklist

JBI checklist criteria		Studies											
		Dunn et al., 2009	Gorecki et al., 2010	Kapp & Annells, 2010	Gorecki et al., 2012	Latimer et al., 2014	Rodrigues et al., 2015	Fogelberg et al., 2016	Jackson, 2017(a)	Jackson, 2017(b)	Jackson et al., 2018	Garcia-Sanchez et al., 2019 (a)	Garcia-Sanchez et al., 2019 (b)
1	Was there a clear statement of the aims of the research?	1	2	1	2	1	2	1	2	1	2	1	2
		Y	Y	Y	Y	Y	C	Y	Y	Y	Y	Y	Y
2	Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3	Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5	Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6	Has the relationship between researcher and participants been adequately considered?	C	C	C	Y	C	C	C	Y	Y	Y	Y	C
7	Have ethical issues been taken into consideration?	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	C
8	Was the data analysis sufficiently rigorous?	Y	C	Y	Y	Y	C	Y	Y	Y	Y	Y	Y
9	Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10	How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total score (maximum 10)		8.5	9.5	9.5	9.5	9.5	9.0	9.0	10	10	10	10	9.0
Quality rating		MED	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH	HIGH

Note: High quality 9–10; moderate quality 7.5–9; low quality <7.5; exclude <6 as described by Butler et al. (2016) <https://signapubs.onlinelibrary.wiley.com/doi/epdf/10.1111/wvn.12134>.

Abbreviations: Y, yes; N, no; C, cannot tell; NA, not applicable.

TABLE 3 Overview of studies

Year	Authors	Aim	Location	Setting	Population	Sample size (n)	Design	Methods
2009	Dunn et al.	To describe how adults with SCI respond in real-life circumstances after detecting a Stage 1 or Stage 2 pressure ulcer.	USA	Rehabilitation Centre	Men and women treated for medically serious ulcers	19	Qualitative	Cross-case analysis; observation and unstructured interviews
2010	Gorecki et al.	To refine and further develop the working conceptual framework, with input from patients pertaining to the specific HRQL domains and dimensions impacted by PUs.	England, Northern Ireland	7 acute and primary care settings	Adults	30	Literature review and qualitative combined	Semi-structured interviews
2010	Kapp & Annells	To gain initial understandings of how the pressure ulcer experience may be unique to a home setting so that further relevant research of this topic could be planned.	Australia	Community	Adults	7	Hermeneutic phenomenology	Thematic analysis
2012	Gorecki et al.	To identify and define contributory factors that affect PU-related HRQL and explore patterns of association between HRQL and contributory factors.	England, Northern Ireland	7 hospitals and community services	Adults	30	Qualitative	Semi-structured interviews and literature
2014	Latimer et al.	To give patients a voice, by listening to and describing their perception of their current and future pressure injury prevention role.	Australia	4 metropolitan hospitals	Adults	20	Qualitative	Semi-structured interviews
2015	Rodrigues et al.	Understanding the experience of informal caregivers of people with pressure ulcers and perceiving the relevant aspects of the narratives emerging from the experience of those caregivers.	Azores Islands	Community	informal caregivers, adults	9	Qualitative, exploratory, grounded-based theory data analysis	Semi-structured interviews
2016	Fogelberg et al.	To examine in more detail the relationship between habits established prior to sustaining the SCI and post-injury habits and the impact of this relationship on pressure ulcer risk.	USA	Medical rehabilitation facility (SCI), PU management clinic, PU surgical unit	SCI, at least 1 PU [1 part: No PU for comparison]. Men and women, over 18	6	Ethnography	Secondary analysis
2017 (a)	Jackson et al.	Examining patients' use of community health services and pressure injury associated pressure-redistributing equipment.	UK	Community	Adults	12	Mixed methods, hermeneutic phenomenology	Case study review, narratives (conversational interviews)
2017 (b)	Jackson et al.	To provide deep insights into the pain associated with pressure injuries in home-dwelling individuals using narrative accounts.	UK	National Health Service	Adults	12	Qualitative	Semi-structured interviews, content analysis
2018	Jackson et al.	The findings are drawn from a larger study that sought to gain insights into the experiences and perceptions of life with a pressure injury from patients living and receiving care in the community.	UK	Community	Adults	12	Qualitative	Thematic content analysis
2019 (a)	García-Sánchez et al.	To explore the barriers and facilitators perceived by home caregivers regarding their involvement in the home care of people with pressure injuries.	Spain	Home caregivers district of Puertollano	Adults over 18 years age not receiving compensation for caregiving	15 caregivers	Grounded Theory, inductive analysis	Semi-structured interviews
2019 (b)	García-Sánchez et al.	To explore the conceptualisations regarding home care of pressure ulcers from the point of view of affected patients and their caregivers.	Spain	4 primary care centres	men and women, over 18, had received recent treatment for PU, and carers for same	10 patients, 15 caregivers	Grounded Theory, inductive analysis	In-depth interviews

support healing) in the workplace because 'people should look professional' (Dunn et al., 2009, p.306). More significantly, a resultant inability to work:

'I used to go to school. I used to work. I went to (name of college). I got a degree in finance. I used to work at (a major corp.). But at the moment I'm not doing great. I'm not doing anything at all at the moment' (Fogelberg et al., 2016, p. 473).

4.2 | Psychological effects

In most studies, the occurrence of a pressure injury was noted to cause a range of diverse but impactful psychological effects.

4.2.1 | Feelings and emotions

Impact on feelings and emotions was expressed by both the person with a pressure injury and caregivers. In describing the experience of the caregiver, Rodrigues et al. (2015) identified a feeling of burden associated with caring for the person with a pressure injury. This burden from a sense of duty was also evident for participants in a second study, with the family primarily viewed as having an obligation to provide this care:

'It seems like it is frowned upon if you don't take care of your parents' (García-Sánchez et al., 2019a, p. 7).

This burden was exacerbated by a sense of guilt, when the carer was involved in providing care at the time the pressure injury arose:

'I don't know if I did something wrong, I really don't know, and I wouldn't forgive myself if it were because of something I didn't do for my father' (García-Sánchez et al., 2019b, p. 595).

Participants in three studies specifically discussed the direct effect on mood for the patient (Gorecki et al., 2010; Gorecki et al., 2012; Latimer et al., 2014), with other effects associated with mood, such as unhappiness or sadness, identified more generally in most of the studies. The range of emotional responses to experiencing a pressure injury described included despair (Dunn et al., 2009; Jackson et al., 2017b), despondency (Jackson et al., 2017b), hopelessness (Gorecki et al., 2010; Jackson et al., 2017b), helplessness (Gorecki et al., 2010), frustration, anger and being forgotten (Latimer et al., 2014), anger, irritation, feeling depressed and a sense of injustice (Gorecki et al., 2010). The scope of this emotion was summarised by two participants:

'I'm scared to look at it.... When I get one, you know, I've already had so many now, you know, and I'm scared...' (Dunn et al., 2009, p. 305)

'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' (Jackson et al., 2017a, p. 3065).

Failure to heal appeared to be a common factor contributing to distress:

'I get really down because I'm 'fed-up with the time it's taking to heal...it's never ending' (Gorecki et al., 2010, p. 1530).

A participant in Latimer et al.'s (2014) study expressed this frustration at the time involved simply as 'I've had enough' (p. 652).

Pain associated with pressure injury was noted to exacerbate the emotional experience of the situation (Jackson et al., 2017b). For some, the pain was overwhelming:

'...it was 'drawing my attention to it all the time' (Latimer et al., 2014 p. 651)

'What prevailed the most was the pain and feeling so helpless, emotionally' (García-Sánchez et al., 2019a, 2019b, p. 595)

Although these effects were regularly described as a result of 'having' a pressure injury, feelings of anxiety and anger were also expressed due to having developed a preventable injury to begin with (Jackson et al., 2017a). The initial response to developing a pressure injury was expressed as a sense of denial (Dunn et al., 2009) or a belief that development of the injury was unavoidable (Dunn et al., 2009; García-Sánchez et al., 2019b). The emotion was often attributed to an apparent randomness of pressure injury development, clearly felt by one participant who expressed:

'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?' (Jackson et al., 2017a, p. 3066).

In one study, these effects directly led to a participant procrastinating and delaying treatment:

'Bout 2 months, like, like a fool. Like 2 months before I came in here [to get medical care]. And to the point that I started gettin' sick and couldn't eat' (Dunn et al., 2009, p. 305).

Pre-occupation with the injury was noted also to further contribute to anxiety, fear and emotional distress (Gorecki et al., 2012).

Some participants in García-Sánchez et al.'s (2019b) study believed that their pressure injuries were caused by caregivers, while caregivers in this same study saw development of a pressure injury as a failure. Home-care setting development of a pressure injury was

expressed by caregivers as a feeling of responsibility or self-blame (García-Sánchez et al., 2019b).

4.2.2 | Loss

A sense of loss was evident in participants' stories. This was described as a loss of privacy, dignity, control and personal autonomy (Jackson et al., 2018) while loss of confidence related to altered appearance and self-consciousness was also described (Gorecki et al., 2010).

'I used to be very active, strong as a bull. Now, I've got to be honest with you, I'm virtually disabled [because of PI]. I make no bones about it' (Jackson et al., 2018, p. 411).

Periods of transition between services (e.g. hospital to home care) were times of particular vulnerability (Jackson et al., 2018). Loss of control associated with pressure injury was expressed most starkly by a participant in Jackson et al. (2018) who expressed sentiments such as

'...the pressure sore is in control, and I am not...' (p. 412).

Latimer et al. (2014) identified nursing staff disengagement contributing to lack of care involvement by the patient, with resultant feelings of disempowerment and exclusion.

'I've asked numerous times what's happening, and it's got to the point where I just stop asking 'cos it's frustrating' (Latimer et al., 2014, p. 651).

Additionally, one person living with a pressure injury also spoke of potential loss:

'...and I'm...looking at, possibly if I get a large sore or anything again, I may be bedridden for the rest of my life' (Fogelberg et al., 2016, p. 472).

4.3 | Adjustment

Developing a pressure injury necessitated a range of adjustments. These varied and included adjustments related to the physical consequences of the pressure injury, adjusting to altered physical capacity and decreased independence, obstacles within service delivery, and functional challenges.

4.3.1 | Physical consequences

The physical effects of the pressure injury were described as a central part of the experience in seven studies. Of these, pain was the most common (García-Sánchez et al., 2019b; Gorecki et al., 2010;

Gorecki et al., 2012; Jackson et al., 2017b; Kapp & Annells, 2010; Latimer et al., 2014). Pressure injury-related pain was noted to vary during the wound episode (Kapp & Annells, 2010) and in one study was identified as the '...main factor that defined the appearance, progression and treatment of...' a pressure injury (García-Sánchez et al., 2019b, p. 595).

Pain was identified as being largely unrecognised or at times ignored, with a belief expressed by one participant that '...you just have to grin and bear it' (Gorecki et al., 2012, p.7). The constancy of the pain further exacerbated the situation:

'You are at its mercy. And pressure sores are relentless.... the pressure ulcer is there 24h. And it doesn't matter where you sit, where you lie, where you turn, it's there, there's no getting away from it' (Jackson et al., 2017a, p. 3064).

Commonly, the pain was extremely debilitating:

'I can't face [activity] because of the pain' (Gorecki et al., 2010, p. 1528).

In the home-care setting, pain often occurred or was exacerbated at night, a time when access to appropriate pain management and additional nursing support was limited (Kapp & Annells, 2010).

Adapting to exuding wounds (Gorecki et al., 2012) and malodour (Gorecki et al., 2010; Gorecki et al., 2012; Latimer et al., 2014) negatively impacted on patients, as described by one participant:

'the smell was foul...you were going to vomit... it was shocking' (Latimer et al., 2014, p. 651).

4.3.2 | Service provision

Participants described many adjustments to their usual lifestyle to accommodate the needs of treatment provision. Some saw this as a need to live with differing interests between the patient and service provider (Kapp & Annells, 2010). Willingness of home carers to be involved and good communication with home service providers facilitated positive satisfaction for caregivers:

'I always communicated with them well and that's good' (García-Sánchez et al., 2019a, p. 8).

Home-based care was described as more ideal than institutional care, with García-Sánchez et al. (2019b) strongly noting avoidance of institutions by both those with pressure injuries and their caregivers. A strong association between institutionalisation and the perception of a poor prognosis was clear:

'...when they take you there it's because things are really bad'

'In the nursing homes it seems like they take you there to die and, I don't know...' (García-Sánchez et al., 2019b, p. 596).

Communication at times was less effective, with instances of disagreement between members of the healthcare team on treatment scope and responsibility causing disagreement (Kapp & Annells, 2010). This led to one participant feeling as though:

'treatment happened 'to' them, not 'with' them': (Kapp & Annells, 2010, p. s12).

In the context of a hospital admission, a reluctance to allow the usual home caregiver to be involved in care was a perceived barrier to caregiver satisfaction leading to a sense of hopelessness:

'At home, I am always willing to lend a hand, but at hospital they don't let you stay when the doctor comes by or when they care for the lesion, so you can't do anything' (García-Sánchez et al., 2019a, p. 6).

Changes in service provision and interruptions to continuity of care were detrimental (Jackson et al., 2017a), with inconsistencies in management contributing to psychological effects such as anxiety and worry (Gorecki et al., 2012). The nature of the relationship between healthcare provider and patient, and perceived competence level of the service provider was identified as critical to psychological well-being and treatment adherence (Gorecki et al., 2012). The perception of inconsistent service provision summarised by two separate participants in Jackson et al. (2017b):

'I've had nurses from three different towns this week. What worries me is they have never seen these legs before. They don't really know what they do about it. I don't mean they don't know what they're doing, but you know what I mean, they don't know what they're doing with these actual legs' (p. 385).

'If I could just see one person every time, my life would be completely different' (p. 383).

Treatment was costly (Latimer et al., 2014) with barriers to access evident (Dunn et al., 2009; Latimer et al., 2014). Financial costs for both patient and carer existed, both direct (e.g. pressure-relieving devices, footwear) and indirect (e.g. lost income) (Gorecki et al., 2012). Delays in provision of services contributed towards a perceived loss of autonomy (Jackson et al., 2018), and challenges arose when unplanned care was required at home (Jackson et al., 2017a).

The quality of patient understanding of pressure injury was identified in this review as directly related to level of participation in prevention measures, and patients voiced concerns over a lack of information. Specifically, desired with a view to increasing participation in care:

'Giving them [patients] more information about pressure sores and how to prevent them' (Latimer et al., 2014, p. 651).

Some participants in García-Sánchez et al.'s (2019b) study believed that their pressure injuries were caused by caregivers, while caregivers in this same study saw development of a pressure injury as a failure. Home-care setting development of a pressure injury was expressed by caregivers as a feeling of responsibility or self-blame (García-Sánchez et al., 2019b). Development of trust and faith in the service provider was important for patients, with good communication and positive progression and results key to cementing this faith (Kapp & Annells, 2010).

4.3.3 | Functional challenges

Development of a pressure injury created a range of attendant functional challenges for participants. Restricted mobility-limited physical activity (Gorecki et al., 2010) and forced participants to make adaptations to accommodate these limitations (Kapp & Annells, 2010). Functional challenges extended to a decreased capacity to attend to activities of daily living and negative impacts on sleep behaviours:

'I can't do things like before' (Gorecki et al., 2010 p.1530).

A restricted ability to participate in activities such as meal preparation, self-care and housework was identified (Gorecki et al., 2010):

'I could see things around the house that needed doing...and ah, I couldn't even help...' (Kapp & Annells, 2010, p.s10).

A pressure injury also necessitated adjustments to usual day-to-day activities, with physical restrictions slowing down the individual's functional activities (Kapp & Annells, 2010). Changing needs to personal items such as shoes (adjustable shoes), and bedding (hospital bed at home) (Jackson et al., 2018), and pressure-relieving devices being uncomfortable, hot, noisy, or unstable (Gorecki et al., 2012), necessitated further adaptations. Lamented one participant in Jackson et al.'s (2018) study:

'I've got a hospital bed that I don't like. When I lay on it at night-time you can hear the squeaking...' (p.412).

The inconsistent use of aids through discomfort or unsuitability was further exacerbated when no home assistance was available (Jackson et al., 2017a).

Adjustment to accommodate time spent on wound care, waiting for treatments/home visits and ineffective treatments was an additional concern raised (Gorecki et al., 2012). Enforced adaptations

often initiated a negative impact on sleep and contributed to fatigue and a lack of energy, or as one person identified:

'I haven't got the same go in me' (Gorecki et al., 2010).

Exploring pressure injury prevention, Latimer et al. (2014) identified increased awareness and a desire to avoid pressure injury as supporting greater individual participation. Active involvement was a positive in facing challenges and owning management of the situation, as described by one person:

'you have to be proactive about it. If you are not...then the decisions are made for you' (Latimer et al., 2014, p. 651)

Patients coped with these functional challenges by accepting the situation or thinking positively, with involvement in wound care decision-making improving emotional well-being (Gorecki et al., 2012). A pre-existing capacity for resilience was interpreted as supportive of maintenance of dignity and of self-worth despite pressure injury-related losses (Jackson et al., 2018). Caregivers in Rodrigues et al.'s (2015) study identified that support from the individual, family and external parties was necessary for them to appropriately assist patients with pressure injury navigate care delivery including functional challenges.

5 | DISCUSSION

This meta-synthesis sought to explore the experience of living with a pressure injury for the patient and carer. Data synthesis led to the construction of three analytical themes: *Autonomy and independence*; *Psychological effects*, and *Adjustment*, which contribute theoretical understanding to the experience of having a pressure injury. Here, these themes are discussed within the context of two unique categorisations of interventions that could be targeted to improve the experience of living with a pressure injury: *addressing psychology and mindset* and *supporting adaptation and management*.

5.1 | Addressing psychology and mindset

From this meta-synthesis, it is clear that people living with a pressure injury commonly experience a diverse range of feelings, and our findings are similar to other studies of patient experience, where psychological effects caused by the illness (Ghosh & Deb, 2017), as well as psychological effects on the illness itself (Barry et al., 2020), are reported. Clearly, anticipating these feelings and addressing the psychological experience of living with a pressure injury proactively are necessary, in addition to providing support when effects emerge.

In consideration of the psychological impact and the effects on the illness episode that generate from this, Lenzo et al. (2020) conducted a systematic review summarising evidence identifying

associations between metacognition, chronic medical conditions, and effects such as anxiety and depression. They particularly explored the suggestion that dysfunctional metacognitive beliefs could be directly related to anxiety and depression, and clearly identified metacognitive profiles characterised by negative belief factors as commonly associated with expression of anxiety and depression. Our suggestion is that improving the capacity of healthcare workers to identify dysfunctional beliefs at the metacognitive level in those living with a pressure injury would support the validity of interventions to improve the patient experience. In supporting the person living with a pressure injury, it is important to plan and implement strategies to proactively address the types of negative belief systems, rather than waiting until issues emerge to address them.

Our review identified that a person's pre-existing capacity for resilience is supportive of their ability to maintain a sense of dignity and self-worth (Jackson et al., 2018) while motivation is an important factor for regaining autonomous control and independence (Gorecki et al., 2012). Decreased mental resilience is a known outcome of impaired wound healing (Balikji et al., 2022) and supporting the development of self-awareness and having purpose would be beneficial in improving resilience. Targeting resilience could assist the person living with a pressure injury to stave off the negative pre-occupation with the situation identified by Gorecki et al. (2012), easing fear, anxiety and emotional distress. It has been demonstrated that engagement with reserve-building activities including outdoor activities or religious/spiritual activities enhances resilience in people with a chronic medical condition (Schwartz et al., 2019). Engaging those living with a pressure injury with these types of activities could support promotion of dignity and self-worth and ameliorate the sense of disempowerment and vulnerability expressed by many.

Building resilience in caregivers is also warranted. In recognition of the relational nature between the caregiver and the person living with a pressure injury, skills such as developing compassion and mindfulness have been proposed as supporting resilience in parents caring for children with chronic illness (Cousineau et al., 2019). Although with pressure injury the caring relationship tends to be of an adult-child caring for a parent, these strategies may well have usefulness for this cohort of carers.

5.2 | Supporting adaptation and management

Findings from our review also point to the requirement for those living with a pressure injury to navigate unfamiliar experiences, at times within different healthcare and community contexts. Patients and carers found themselves adapting to an evolving capacity for autonomy and self-care and managing adverse effects of the pressure injury such as pain and malodour. Of note also, these physical and functional adaptations are closely linked to the psychological challenges presented earlier.

Functional adaptation is required but is also contextually specific. This functional adaptation encompasses variants of the full range of day-to-day activities, such as hygiene, food preparation and

housework, and often occurs within the context of adapting to the use of aids for either pressure-relieving or functional support. So, in effect, a dual adaptation process is occurring here, adapting to the aid itself and adapting to altered patterns of navigating activities with the aid.

In Latimer et al.'s study (2014), an increased patient and carer awareness of pressure injury and a desire to avoid further injury were identified as supporting greater adaptation through individual participation. Patients coped by accepting the situation or thinking positively, with involvement in wound care decision-making improving emotional as well as physical well-being (Gorecki et al., 2012). In a qualitative study of patient experience measures and their relationship to quality of care for chronic wounds, Squitieri et al. (2020) found that patient-reported measures in wound care, such as care co-ordination and the patient/provider interaction, had the capacity to improve patient-centredness and care efficiency. Consequently, measures aimed at supporting adaptation to and management of the experience, such as negotiating services and collaborative care planning must include the person and carer experiencing life with the pressure injury.

Healthcare service providers are critical to the patient experience, facilitating access to services, co-ordination of services, supporting continuity of care and providing educational support. Of particular concern then is a recent empirical study aiming to give patient's a voice (Latimer et al., 2021) that identified patients reporting receipt of limited education from nurses regarding pressure injury prevention. As well, nurses' knowledge of pressure injury prevention has been shown to be quite variable and sub-optimal (Dalvand et al., 2018; Fulbrook et al., 2019). Concurrently, in a study exploring health literacy related to pressure injury, Durrant et al. (2019) identified patients engaging poorly with education leaflets and demonstrating limited health literacy in pressure injury. The capacity of a patient and their caregiver to adapt to and navigate the experience of a pressure injury is inherently bound to the nurse's service quality; hence, these findings raise concern. Given the existing body of knowledge on pressure injury generally, this is perplexing but highlights the importance of ongoing patient, carer and nurse education on this topic.

Caregiver experiences are clearly under-represented in the literature, with only three studies meeting the inclusion criteria for this review. Despite this, some findings of note were identified. In the home-care setting, caregivers felt burdened (Rodrigues et al., 2015), with a duty to care (García-Sánchez et al., 2019a), and saw circumstances where a pressure injury developed in a home-care setting as their failure (García-Sánchez et al., 2019b). Despite this, a clear desire to avoid institutionalisation by both patient and carer was identified (García-Sánchez et al., 2019b). Since the clear preference is for caregivers to provide quality care in the home, mechanisms to support this are warranted. A key element of this is ensuring the caregiver has the knowledge necessary to understand and therefore meet the needs of the person with the pressure injury.

A pilot study of a home-based education program for caregivers of elderly patients targeting pressure injury prevention was

reported as effective in increasing knowledge of pressure injury as well as compliance with prevention strategies (Chong & Lee, 2017). However, as a pilot study participant numbers were small ($n = 24$), and the study did not extend to explore changes in outcomes resulting from the increased knowledge and compliance. Given the preference for home-based care identified in this review, further research investigating carers' experience of supporting a person living with a pressure injury is necessary.

5.3 | Limitations

This review specifically targeted the experiences of people living with a pressure injury and their caregivers only. The experiences of similar types of participants within other contexts, such as chronic wound care, may provide useful understandings to further inform the recommendations proposed here. The review was limited to peer-review articles, and while providing the best level of evidence on the topic available, excluded less rigorous sources such as grey literature. Given the limited peer-reviewed evidence available particularly related to the caregiver experience, further exploration of diverse sources such as the grey literature may uncover useful data on the experiences discussed in this review.

6 | CONCLUSION

There is a lack of primary research seeking to understand the experiences of those living with a pressure injury, and those caring for a person with a pressure injury. Given the limited research literature identified and the geographical dispersity of the existing studies, further study investigating cultural influences such as expected gender roles on the experience of pressure injury care as identified by García-Sánchez et al. (2019a) is warranted. Investigation in this area may be especially useful when considering the psychological effects and adaptation processes identified in this review.

The unique theoretical categorisations of *addressing psychology and mindset* and *supporting adaptation and management* identified in this meta-synthesis provide clinically relevant concepts that can be used to scaffold the development of an intervention program to improve the experiences of patients with a pressure injury and their carers. A clear preference to provide care in the home, rather than a health institution, was identified. Interventions that simultaneously target the challenges to autonomy and independence, the psychological effects, and the adaptation required when experiencing a pressure injury, would provide a more holistic outcome.

7 | RELEVANCE TO CLINICAL PRACTICE

Nurses must recognise the individuality of the experience, and the role of psychology and mindset for patients with a pressure injury

and their caregivers, when developing plans of care. Nurses should advocate for further exploratory and interventional research to improve the patient and caregiver's psychology and mindset and improve mechanisms that support navigation of the pressure injury episode.

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CONFLICT OF INTEREST

The authors assert that no conflict of interest exists.

DATA AVAILABILITY STATEMENT

Data available on request from the authors

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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