

**Review Article**

# Patient-Reported Pressure Ulcer Pain: A Mixed-Methods Systematic Review

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## Abstract

**Context.** Pressure ulcers (PUs) can cause patients considerable pain and discomfort; however, little is known about how PU pain affects patients' everyday lives. To improve outcomes for patients and to help clinicians manage PU pain, the existing qualitative and quantitative research bases were systematically reviewed.

**Objectives.** The aims were to identify and synthesize all research that obtained verbal patient reports of PU-associated pain, including descriptions of the pain experience, intensity, quality, and impact to interpret the complexities of the pain experienced from PUs; describe specific characteristics of PU pain; and determine how it affects patients' lives.

**Methods.** We searched eight electronic databases (from inception to January 2010), hand searched and cross-referenced. Research studies that addressed the experience of PU-associated pain by direct patient reports were included. Two reviewers independently applied inclusion criteria and extracted findings, allocating findings to defined categories. Synthesis of findings and categories were reviewed by three reviewers until reaching consensus.

**Results.** Ten studies were included: six qualitative and four quantitative. These included 108 adults with PUs. The PU pain experience was mapped, producing a conceptual framework of five domains: communicating the pain, feeling the pain, impact of pain, self-management, and professional management, and represented by 23 subdomains and five mediating factors (four psychological well-being plus comorbidity).

**Conclusion.** A biopsychosocial model of pain experienced from PUs is presented. Improved communication of pain experienced between the individual and health care professionals is needed to promote more effective PU pain management in the future. *J Pain Symptom Manage* 2011;42:443–459. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

## Key Words

Systematic review, pain, pressure ulcer, conceptual model, patient reported

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## Introduction

Pressure ulcers (PUs) are painful wounds of the skin and deeper soft tissue that occur primarily in areas of bony prominence and in

individuals who are immobile.<sup>1,2</sup> They range in severity from nonblanchable skin erythema (Category I) and superficial skin loss (Category II) to large wounds involving fat, muscle, and bone (Category III/IV).<sup>1</sup> These wounds have widespread prevalence and incidence in all health settings,<sup>3</sup> occur at home,<sup>4</sup> are associated with high health care costs and longer hospitalization,<sup>5</sup> and have a substantial impact on health-related quality of life (HRQL).<sup>6</sup>

A common problem for patients and the health care system is the pain and discomfort associated with these wounds.<sup>6–10</sup> Pain may be defined as an unpleasant sensory and emotional experience arising from actual or potential tissue damage.<sup>11</sup> For people with chronic wounds such as PUs, pain can be cyclic: intermittent discomfort occurring with repetitious treatments or movements; noncyclic: pain occurring during a particular event (e.g., debridement); and chronic: background pain, varying in severity, intensity, and duration (i.e., persistent or intermittent), that occurs without manipulation.<sup>12</sup> In addition, some PU pain may have a neuropathic element.<sup>6</sup> Neuropathic pain is caused by damage or dysfunction in the nervous system and commonly described as sharp, shooting, or burning.

Pain is an unpleasant, severe, and prevalent experience for people with PUs, with most patients, regardless of PU severity, experiencing some form of pain or discomfort.<sup>6,13,14</sup> A recent review of the literature<sup>13</sup> investigated the problem of PU-associated pain in terms of how it is measured, prevalence/incidence, and associated factors (i.e., PU severity, pain linked to dressing changes, age). Importantly, this review emphasizes that pain associated with PUs is poorly understood and highlights the complexity of the problem and the difficulty in measuring it. However, as the review was focused on quantitative and epidemiological studies, it failed to incorporate the patient perspective (i.e., patients' own words to describe their experience) in terms of impact, experience, and intensity.

Pain cannot be measured directly, but rather is established and determined by the person experiencing it. A challenge for patients with PUs is trying to convey the pain they feel because of their PU,<sup>10</sup> particularly finding the words to express pain experienced. This is further complicated by the fact that expression of,

tolerance to, and reporting of pain experienced is influenced by various individual factors such as beliefs, culture, coping mechanisms, knowledge, and understanding, and conflict between needing treatment for healing and the treatment causing additional pain, the patient's relationship with their health care provider (HCP) and their expectations based on previous pain experienced.<sup>6,10</sup>

PU-associated pain can be disabling and devastating to the individual. Patients have reported that PU pain: interferes with their ability to undertake daily activities and particular movements; engage in and enjoy socializing; leads to anxiety, fatigue, and decreased appetite; and contributes to emotional distress.<sup>6</sup> At best, PU pain is annoying but at its worst it can be unbearable, affecting individual emotional responses and having detrimental effects on psychological well-being.<sup>6</sup>

A recent systematic review identified three pain assessment methods used in PU research, the McGill Pain Questionnaire (MPQ), the Faces Pain Scale, and the visual analogue scale, all of which have potential problems with this population.<sup>15</sup> Those who may be at increased risk of developing PUs are older people, those who have a spinal cord injury or other neurological conditions, those facing end of life, or living with impaired cognitive ability (e.g., dementia). Although the Faces Scale appears attractive, it was noted in the recent joint guidelines from the British Pain Society (BPS) and the British Geriatrics Society (BGS) that "Even though cognitively intact older adults use the Faces Pain Scale with good test-retest reproducibility, they do not always place the faces in the correct order of pain intensity when asked to rank the faces independently, raising serious doubts about the validity of the Faces Pain Scale as a measure of pain intensity in older adults. This problem is even more marked when nursing home residents and older adults with mild cognitive impairment are asked to put the faces in the correct order. The Faces Pain Scale cannot, therefore, be recommended for general clinical use with older adults or nursing home residents."<sup>16</sup> The recommendation for this group was that a numerical rating scale of 0–10 gave the best reliability and validity in older adults. It also was noted that pain was underrecognized and undertreated in older

people, particularly in those with cognitive impairment or communication difficulties.

The evidence relating to pain associated with PUs remains limited by McGill descriptors, intensity, and occurrence (i.e., at dressing change). Very few studies have investigated the quality of PU-associated pain from the patient's perspective. The BPS/BGS guidelines suggested that a major barrier to appropriate pain management for older people was failure to recognize the pain and to assess pain adequately. This was echoed by the systematic review and National Pressure Ulcer Advisory Panel White Paper in 2009, which recommended that further research is need to answer questions such as "What is the best method to identify PU pain and how do health professionals assess PU pain for people with cognitive impairment and/or in children?" It is suggested, therefore, that to provide a foundation for further research, improve outcomes for patients, and to help clinicians manage PU pain, we need to explore and understand the nature of PU pain and map causal pathways from the patients' perspective. This work builds on the work of Girouard et al.<sup>13</sup> by adding an additional element: identifying and synthesizing studies that were qualitative in design and obtained patients' verbal reports of the PU pain experience, and quantitative studies where pain descriptors were reported using the MPQ<sup>17</sup> or the Brief Pain Inventory (BPI),<sup>18</sup> with a view to contributing to the evidence for developing methods for assessing PU pain.

The specific review objectives were to:

1. Determine how PU pain was described.
  - a. What individual words (patients' verbal reports) were used to describe any type of PU-associated pain (i.e., impact of PU pain)?
  - b. What specific words were used to describe PU pain at varying PU severity?
2. Determine how PU pain impacted on patients with PUs.
3. Map and interpret the complexities of the PU pain experience (conceptual framework) by performing a combined qualitative and quantitative synthesis, mapping the nature and characteristics of PU pain.
4. On the basis of the PU pain map, determine whether the MPQ or the BPI are

suitable for the assessment of pain in patients with PUs or whether there is a need for adapting the existing scales or developing new ones.

5. Compare PU pain map/framework to those developed for other chronic wounds.

## Methods

### Design

This systematic review of the literature was designed to identify and synthesize all research that obtained verbal patient reports of PU pain. This included obtaining descriptions of the pain experience, intensity, pain related to PU categories, quality, and impact to interpret the complexities of the pain experienced from PUs.

### Search Strategy

The search strategy sought to identify qualitative research studies investigating patients' experiences of PU pain, and quantitative research designed to assess pain in PU patients using validated pain outcome measures that include pain descriptors (e.g., MPQ and BPI). A tried and tested search strategy consisting of PU and qualitative methodology search terms<sup>6,19</sup> was used with the addition of pain and related descriptive terms and existing pain outcome measure terms. To heighten specificity, the search was refined to exclude studies that used only rating or visual analogue scales, as these measures only provide quantified pain level/severity scores and not qualitative pain descriptors.

The following databases were searched: AMED, British Nursing Index, MEDLINE, Embase, PsycINFO, CINAHL and Cochrane Library (including the Central Register of Controlled Trials) from inception. Auto alerts via the OVID database library were set up until data analysis was completed (April 2010) to notify of any additional relevant papers that had been added to the databases since the original search was performed. In addition, the Web of Knowledge database was searched using "pressure ulcer" and "pain" topic words.

To find relevant articles not detected in the electronic bibliographic search, a hand search of relevant conference proceedings and specialist journals was undertaken (e.g., Journal

of Tissue Viability [UK]; Journal of Wound Care [UK]; Wounds Repair and Regeneration; International Wound Journal; European Wound Management Association and European Pressure Ulcer Association Proceedings). In addition, dissertation abstracts were searched using the following electronic databases: ProQuest Dissertations & Theses, Networked Digital Library of Theses and Dissertations, International Theses in Progress, Theses Canada Portal, Australian Digital Theses Program, Index to Theses, and Russian Academy of Sciences Bibliographies. Finally, a citation search was performed on all included studies and relevant systematic reviews, including Girouard,<sup>13</sup> to identify further relevant research not located through other sources.

#### *Inclusion/Exclusion Criteria*

Studies were included if the study sample was adult patients with any category of PU from any setting with any existing comorbidity and used qualitative methods to obtain patient reports of their experience of PU pain (e.g., phenomenological studies; grounded theory; descriptive; focus group; or interview). Studies using mixed-method designs were included only if PU-specific findings were reported separately from mixed wound findings or quantitative methods to assess pain used existing validated outcome measures where pain descriptors were available (e.g., MPQ and BPI). Studies that used patient-reported HRQL instruments were considered if a pain scale was included and results reported.

Studies were excluded if the study sample was mixed wounds (i.e., leg ulcers, diabetic foot ulcers, malignant ulcers), not patient reported (i.e., proxy assessment) or data collected using rating or visual analogue scales to obtain pain severity scores; numerical scores rather than pain descriptors (e.g., intensity rating scale, verbal rating scale, numerical rating scale, facial recognition scale, present pain intensity). No upper age, gender, or language restrictions were applied.

#### *Study Selection*

Abstracts from retrieved articles were screened for relevance by one reviewer (C. G.). Articles that clearly met the exclusion criteria or were not relevant to the review were rejected at this stage. Where papers were assessed as potentially relevant from their

abstracts or where their relevance was ambiguous, they were obtained in full for further scrutiny. Obtained articles were independently reviewed against the inclusion criteria by two reviewers (C. G. and M. B.). Where study details were lacking, attempts were made to contact the authors and invite them to provide additional information. Any studies that did not meet the inclusion criteria were excluded from further analysis and any disagreements were resolved through discussion with a third reviewer (J. S. C.). Decisions on final inclusion were agreed by three reviewers (C. G., M. B., J. S. C.).

#### *Quality Assessment*

Individual quality components of study methodology were not used as a threshold for the selection of primary studies. There is a little consensus about which methods to use for assessing the quality of qualitative research.<sup>20,21</sup> We took the approach of including all available data as there were so few relevant studies identified. We assessed the *appropriateness* of each study by making a judgment about whether a study used appropriate methods for addressing our review questions and for ensuring that findings about the PU pain experience were indeed from the patient perspective (e.g., Were data collection methods appropriate for helping patients express their views and how PU pain impacts on them?).<sup>22</sup>

#### *Data Extraction*

Findings were extracted by two independent reviewers (C. G. and M. B.). Findings from qualitative studies were extracted into an existing database developed by the Joanne Briggs Institute, the qualitative assessment and review instrument (QARI; Joanne Briggs Institute, Adelaide, South Australia). QARI was the chosen software, as it was developed to manage, appraise, analyze, and synthesize the findings of studies that use any qualitative approach as part of a systematic review of evidence. QARI incorporates data extraction and quality appraisal forms, and data synthesis and reporting functions. This software has been internationally peer reviewed and was successfully used recently in reviews with similar research questions.<sup>6,23</sup>

Data extraction from qualitative studies involved the reviewers reading carefully and

thoroughly through each included paper and identifying the findings in the form of either a direct quote from patients or a statement by the author that was supported by patient-reported data to establish the credibility of the author's statement. Patient-reported text and/or the authors' interpretations were identified and transferred from the original paper to produce a data set of findings that could be later categorized and synthesized.

Data extraction from quantitative studies involved extracting all descriptive words used by the patients to describe PU pain and listing them in PU classification (i.e., category) tables to enable comparison of pain descriptors by PU severity. (PU classification included any grades and stages equivalent to the most recent National Pressure Ulcer Advisory Panel and the European Pressure Ulcer Advisory Panel [EPUAP] PU classification category system.<sup>1</sup>) In addition, findings in the form of individual questionnaire items or questionnaire pain scale results were extracted. Participant characteristics, study design, and pain data collection methods were also summarized.

### *Thematic Synthesis*

Thematic analysis involved coding of all qualitative findings to defined categories. A category was determined by grouping common findings (i.e., findings that reflected similar phenomena or variables). Categories that were sufficiently similar in meaning were generated into synthesized themes. This allowed aggregating grouped findings into specific themes, providing a summary of the evidence for each particular theme and generating a working framework of the PU pain experience.

Because of the mixed methods used following thematic synthesis in QARI, all extracted findings and syntheses were transferred into tables to ease data management and incorporation of quantitative findings into the framework generated. The quantitative findings were added to the corresponding tables, with new categories and themes added if required. All findings were independently extracted and coded by two researchers (C. G. and M. B.) and then, as a team, the final framework was collectively described.

## **Results**

Five hundred thirty-nine citations were retrieved electronically (minus duplicates). Of these, 30 were assessed as potentially relevant and 10 studies met the eligibility criteria and were included in the review, six qualitative<sup>7,10,14,24–26</sup> and four quantitative<sup>9,27–29</sup> in design.

The descriptive words used to describe PU pain were grouped by PU category and frequency (Table 1). No patients with Category I PUs were included in the studies. The results indicate that sensory words were used by all the patients irrespective of PU category. Common words across all Categories II–IV included tender, hurting, burning, sharp, throbbing, hot burning, and aching. Words common for PU Categories II and III included sore; for Categories II and IV: itching and stinging; for Categories III and IV: stabbing and heavy.

Previous research has explored characteristics of venous and arterial leg ulcer pain.<sup>30</sup> Compared with these other chronic wounds (Table 2), PU pain was closely associated with the sensory characteristics of pain associated with venous, arterial, and mixed ulcers. Tender was most commonly used by people with PUs and also as a term used for other chronic wounds. Other common words used for PU pain, namely sharp and throbbing, also were used to describe other chronic wounds. However, all comparisons were limited to MPQ descriptors.

The PU pain experience was mapped, producing a conceptual framework that included five main conceptual domains: communicating the pain, feeling the pain, impact of pain, self-management behaviors, and professional pain management, represented by 23 subdomains, and four psychological well-being and comorbidity mediating factors that are individual dependent (Fig. 1). All domains and descriptive components are described below from the perspective of patients with PUs.

### *Communicating the Pain*

*Evaluative Descriptors.*<sup>7,10,14,24,25,28,29</sup> An evaluation was attached to PU pain, expressed as punishment, overwhelming, never ending, strange, unbearable, troublesome, bad, mild, a nuisance, annoying, inconvenient, unbelievable, nasty, horrific, limping, excruciating,

Table 1  
Words Used to Describe PU Pain by Severity

Category II (% of 30) <sup>a</sup>	Category III (% of 47) <sup>a</sup>	Category IV (% of 30) <sup>a</sup>
<b><i>Sensory</i></b>	<b><i>Sensory</i></b>	<b><i>Sensory</i></b>
Sore (56.7)	Sharp (85.1)	Throbbing (70)
Hurting (46.7)	Tender (85.1)	Sharp (70)
Tender (40)	Aching (70.2)	Gnawing (70)
<i>Burning</i> (23.3)	Throbbing (70.2)	Aching (70)
Itching (16.7)	<i>Stabbing</i> (70.2)	Tender (70)
Sharp (13.3)	<i>Shooting</i> (70.2)	Hurting (43.3)
Throbbing (13.3)	Heavy (68.1)	Smarting (40)
<i>Hot burning</i> (13.3)	<i>Hot burning</i> (68.1)	<i>Stabbing</i> (30)
Aching (13.3)	Sore (19.2)	<i>Hot burning</i> (30)
Stinging (10)	<i>Burning</i> (19.2)	Splitting (30)
<i>Pins and needles</i> (3.3)	Hurting (17)	Heavy (30)
Flaming (3.3)	<i>Tingling</i> (4.3)	Stinging (3.3)
Pinching (3.3)	<i>Hot poker</i> (2.1)	Sharp jab (3.3)
Rhythmic beat (3.3)	Niggling (2.1)	<i>Burning</i> (3.3)
		Scalding (3.3)
<b><i>Affective</i></b>	<b><i>Affective</i></b>	<b><i>Affective</i></b>
Frustrating (10)	Confusing/scared (2.1)	Itching (3.3)
Irritating (6.7)		<i>Electric pulse</i> (3.3)
Annoying (6.7)		
Deadly (3.3)		
Excruciating (3.3)		
<b><i>Miscellaneous</i></b>	<b><i>Evaluative</i></b>	<b><i>Affective</i></b>
Nagging (3.3)	Wretched (17)	Tiring-exhausting (70)
Scream (3.3)	Extreme (2.1)	Exhausting (40)
Shivering (3.3)	Hurting (2.1)	Punishing cruel (33.3)
Uncomfortable (13.3)	<b><i>Miscellaneous</i></b>	Fearful (30)
	Discomfort (2.1)	
	<b><i>Evaluative</i></b>	
	Miserable (40)	
	Annoying (40)	
	<b><i>Miscellaneous</i></b>	
	Penetrating (40)	
	Toothache (26.7)	
	Nagging (40)	
	Torturing (40)	
	Suffering (3.3)	
	Wanting to commit suicide (3.3)	
	Spasms (3.3)	
	Takes breathe away (3.3)	
	Uncomfortable (3.3)	
	Unpleasant (3.3)	
	Grin and bear (6.7)	
	Crying (3.3)	
	Terrible (3.3)	
	Unbelievable (3.3)	
	Horrendous (3.3)	

Italics indicate words used to describe neuropathic pain.

Categories relate to the EPUAP 2009 classification system and include instances of equivalent PU classification systems.

<sup>a</sup>Combined data from multiple studies;<sup>7,9,10,27</sup> other relevant studies were identified but data could not be included as descriptors were not reported by grade, but rather combined grades. The total combined sample includes 108 patients (one patient with Grade I PU, but no descriptors reported); multiple descriptive words may be provided per ulcer.

hurtful, and unpleasant. Pain could be a dominating physical factor and, for some, the worst part of having a PU. The use of evaluative words increased as PU severity increased. One patient described "the pain from the PU...you do forget about it but then all of a sudden you'll get like a sharp, like a jab...it can kind of take your breath away...."<sup>10</sup>

*Metaphor or Simile.*<sup>7,10,14,26</sup> For many patients, PU pain is unique and the quality of the pain

is difficult to describe. Not being able to describe and express their pain was frustrating. If patients were unable to find the right words to express their pain, they would use metaphors or similes in an attempt to define their pain experience. Many examples were found in the literature including "like digging a screwdriver in," "like having an operation without anesthetic," "like sitting in a bath of scalding water," "worse than a toothache," "red hot poker," "carpet burn," "like sat on

Table 2  
Sensory Pain Descriptors for PUs and Three Other Chronic Wounds

PU (n = 107)	Venous Ulcer <sup>a</sup> (n = 30)	Arterial Ulcer <sup>a</sup> (n = 19)	Mixed Ulcer <sup>a</sup> (n = 21)
Throbbing (54%)	Throbbing (37%)	Sharp (32%)	Throbbing (38%)
Sharp (61%)	Burning (33%)	Stinging (42%)	Itchy (52%)
Hot burning (42%)	Itchy (50%)	Hurting (32%)	Sore (43%)
Aching (54%)	Stinging (33%)	<b>Tender</b> (58%)	<b>Tender</b> (52%)
<b>Tender</b> (68%)	<b>Tender</b> (43%)		
Stabbing (39%)			
<i>Heavy</i> (38%)			
<i>Shooting</i> (31%)			

Please note that multiple descriptive words may be provided per ulcer.

PU category consists of words used by 30% or more of the sample in each PU grade (regardless of PU grade).

Words in boldface are common across all chronic wounds.

Words in italics are common only to PUs.

<sup>a</sup>From Reference 30.

something really hot,” “feels like being stabbed or sitting on a bunch of needles,” “It felt like somebody was getting a knife and really digging it in there good and hard,” “like skidding your knee on cement,” “...some days it gives me a shivering feeling...I don’t know how to explain...It is a funny feeling,” “like a real bad sunburn,” “like sticking a hot poker to you or like burning your finger playing with matches,” “Bad bee sting,” “Feels like cutting with a knife,” “...I can’t explain it. It hurts like the devil,” “PU pain is like nothing else experienced before,” “...just a touch is like getting hit in your testicles,” “a burny kind of thing,” “Feels as if the skin is being pulled backwards on it,” and “A burning, throbbing sensation that goes away for a while and then something starts it up...it starts a little beat...a rhythmic type thing, and then it keeps building and building, a crescendo, you know.”

**Cultural Differences in Reporting Pain.** Social differences in communicating PU pain were identified in one study.<sup>29</sup> Black and Asian patients reported experiencing more pain and impaired appetite because of PU pain compared with Caucasians. Others reported not always feeling able to report their pain for fear of being a burden or nuisance.

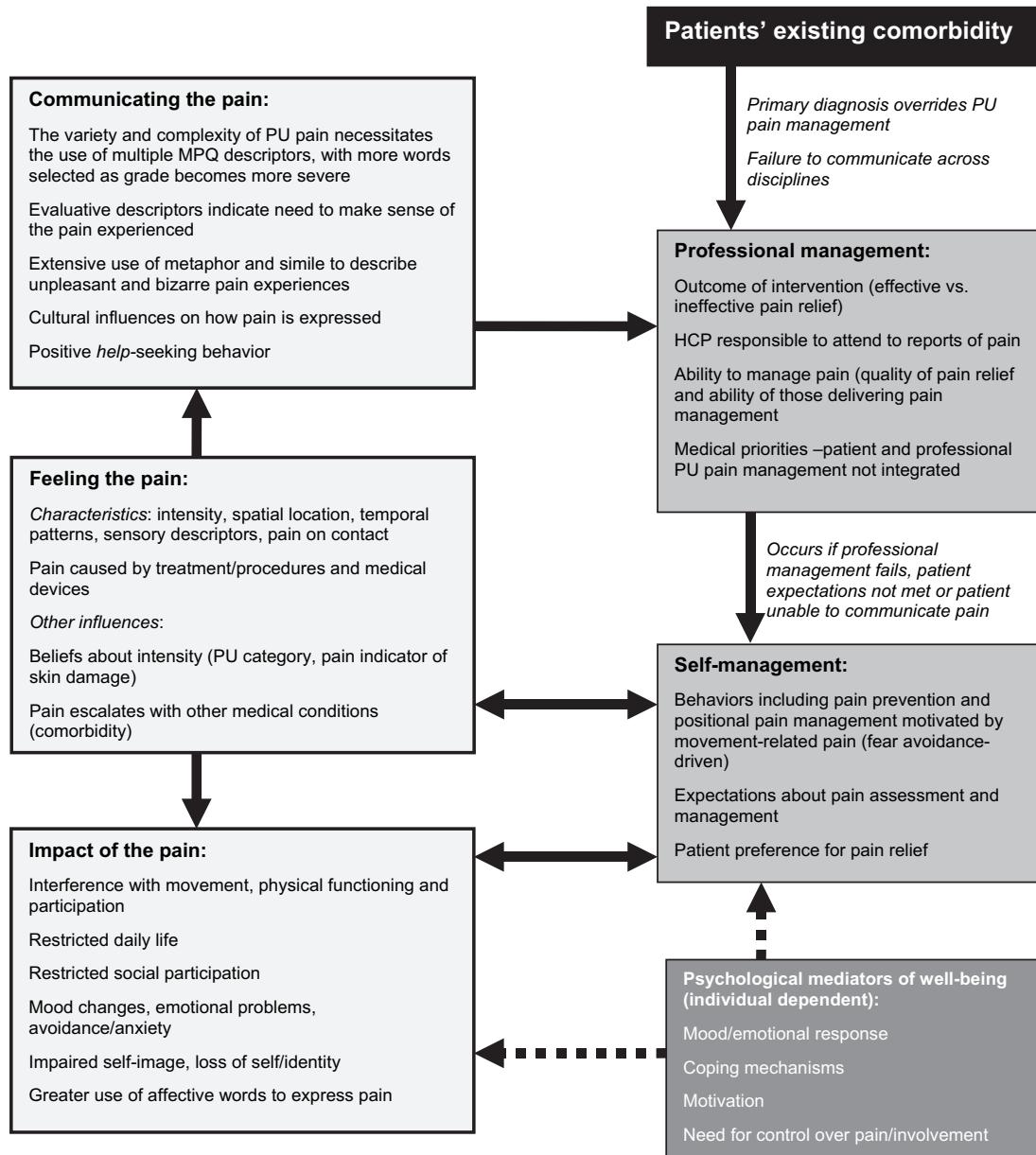
### Feeling the Pain

**Temporal Patterns.**<sup>7,9,10,14,24–29</sup> Temporal words used related to the duration and timing (e.g., frequency of occurrence and time of day) of pain. PU pain could be constant (e.g., “it hurts all the time;” “there’s always pain there but could vary in intensity;” “always aware of it;” “doesn’t go away but some days are better than others”), continuing and continuous, persistent,

intermittent (comes and goes), occurred only on movement, at rest or during repositioning, worse at night or while sleeping (e.g., lay on PU during the night), or occurred at no typical time. The majority of patients with PUs experienced some form of pain either rarely, quite often, most of the time, all the time, or it got worse as the day progressed. Some patients experienced more pain during dressing changes compared with when at rest; others experienced pain at a typical time of day, whereas some had no pattern in time of day but reported that it could be aggravated during dressing changes or depended on how long “you sit/lie on it.” Variations in timing of pain could intensify with PU contact (e.g., bed clothes).

**Intensity.**<sup>7,14,26,27</sup> Not only does PU pain vary in duration, it also varies in intensity. Extreme, tremendous, really hurt, and very painful were words used to describe PU pain intensity. Some patients rate their pain numerically (i.e., nothing under a 5 but a lot of the time it would be worse). For some, present pain intensity increased as the duration of the ulcer increased, although the number of PUs or type of dressing did not appear to influence present pain intensity. Pain levels also varied day to day, hour to hour, or intensified with contact. Patients could not always see their PU but they knew that it was there because they could feel how painful it was.

**Spatial.**<sup>7,10,14,28,29</sup> PU pain varies in location and spread. Commonly, PU pain was most painful in the actual wound or the surrounding skin; however, it also radiated elsewhere, spreading around the surrounding area, traveling up the body from the wound (i.e., travel up



#### *Patients' experience and expression of pain*

Fig. 1. Model of how the nature of PU pain influences the impact, communication, and management of that pain.

the leg or back) and back down: "It starts on the foot and can go right into your eyes, it's horrible,"<sup>10</sup> or "travel through you...if you touch it, you know like bang it, or hit it, it just goes straight through you...."<sup>7</sup> Pain was also experienced in the limbs caused by adopting positions in an attempt to avoid pain.

**Pressure/Contact/Sheer.**<sup>7,10,14,25,28</sup> Pain was experienced from PUs having contact with clothes, floor/surface, and seating. Pain was brought on (triggered) or intensified by contact with the PU (i.e., pressure while seated/lying down, e.g., "you put a bit of weight on your heel and [it] feels as though its burst open"<sup>10</sup>).

Pain also was felt if an incontinence pad or bed sheet were not smooth (creases aggravated PU). Patients at times could not bear any contact or pressure with the PU or claimed that they did not feel any pain unless something came into contact with the PU. Rubbing could cause pain, such as when moving up and down the bed or getting in and out of a wheelchair: "rugging" at the skin caused pain. Some patients believed they had a high tolerance for pain but if anything touched or rubbed against the ulcer, the pain could be excruciating. One patient claimed that PU pain did not interfere with sleep or activities apart from when clothes touched the ulcer.<sup>7</sup>

**Sensory Descriptors.**<sup>7,9,10,14,25–29</sup> Words to describe the sensation experienced are listed in Table 1. Most commonly, patients described the pain as throbbing, burning, stabbing, aching, and tender: "It was burning, BURNING. It was like somebody taking, like a hot poker and sticking it to you."<sup>7</sup> Words used that are commonly associated with neuropathic pain include stabbing, burning, shooting, pins and needles, tingling, and electric pulse/shocks.

**PU Procedural Pain.**<sup>7,9,10,14,25,28</sup> Most commonly, pain was reported during dressing changes and was felt at the wound site or traveling along the leg, and could take as long as five or more hours to subside. The most frequent descriptors used include tender, hurting, miserable, nagging, and horrible ("grin and bear it"). Reasons patients gave for dressings causing pain were the tenderness of the PU, techniques of HCPs ("When they clean it, it is like a needle scrapping my nails. It is very painful"<sup>25</sup>), problems with application, allergy to dressing or dressing removal, particularly dressings that are overadhesive and rip the skin when removed ("...all of them [nurses] come in and take that bandage and rip it right off, it's terrible cause I don't think they really understand what you're going through"<sup>7</sup>). Pain also was reported at rest (e.g., sitting/lying on a pressure-relieving mattress, mattress cells digging into backs and aggravating the pain) or during debridement. In addition, PU treatment or handling by carers/HCP was an additional painful experience for patients.

**Pain with the Use of Medical Devices.**<sup>10</sup> Pain from the PU was experienced with the use of medical equipment (e.g., pain was felt when a patient was hoisted to get washed/dressed because of the straps on the hoist tugging on a sacral PU) and certain assistive treatment such as the wearing of sheepskin medical boots.

#### *Beliefs About Intensity and Severity*

**Pain as an Indicator of Skin Damage/Healing.**<sup>7,10,25,26</sup> First sensations and early initial discomfort or soreness indicated to patients that there might be a problem. Many were not aware that soreness was caused by skin damage or that it meant that a PU may be developing. If sensations continued, patients became aware of skin damage; however, some patients reported not to be concerned about sensations and consequently ignored them, whereas others either inspected the skin or reported the problem. Concerns about sensations resulted in behaviors to seek help and report pain.

Pain was often used as a barometer to gauge PU healing: "I could tell it was getting better by the pain."<sup>10</sup> Some patients believed that reduced frequency and intensity of pain was evidence of PU healing, whereas increased pain indicated further tissue damage or infection. For some, pain was everpresent despite evidence of healing or was still a problem even after the PU had healed: "Every now and again it still hurts. But there is nothing there. This time there is really nothing there."<sup>26</sup>

**Pain Related to Severity.**<sup>9,10,24,27</sup> Pain was experienced regardless of PU severity. Sensory descriptors such as hot burning, throbbing, sharp, and aching were all common words used across all PU Categories II–IV. For some patients, pain was a function of PU severity, as beliefs expressed about pain were dependent on PU category. Consistently across studies, patients with severe (Category III or IV) PUs were more likely to report excruciating pain, used more descriptive words to describe their pain, and the pain was often more intense and frequent (i.e., transient/intermittent vs. constant) than it was for patients with superficial PUs (Categories I and II). Some patients believed that the depth of the PU was inversely related to intensity; however, this was not always the case, as even in

instances of healing, the ulcer could actually become more painful.

**PU Pain Escalates with Other Pain/Medical Problems.**<sup>7,9,10,14,28</sup> PU pain can escalate with pain caused from treatment for other medical conditions or not be experienced, such as for those with impaired sensitivity (e.g., spinal cord injury). However, a problem occurred for those that were perceived by HCPs as unable to feel pain but who actually did feel some discomfort/pain because of PUs; their pain may have been underestimated by HCPs. In some instances, pain relief for other medical problems dulled PU pain. PU pain also was experienced as a result of other medical problems (e.g., incontinence: "...your wee going on an open sore, it is damn painful believe me"<sup>10</sup>) or caused pain from other comorbidities as a consequence of trying to avoid PU pain.

#### *Impact of PU Pain*

**Interference with Movement, Physical Functioning, and Participation.**<sup>7,9,10,14,25,28</sup> Pain was commonly experienced with movement, in the limbs because of adopting positions to promote comfort, or from prolonged sitting/lying. Experiencing pain also can compromise future movements and restrict mobility (i.e., difficulty with ability to move, walk, or sit for long periods; preventing movement in bed). Some positions in bed or chair could be uncomfortable, as were repositioning or walking. Pain could impede ambulation and ability to assume comfortable positions.

**Restricted Daily Life.**<sup>7,10,14,24,25,29</sup> Pain interfered with daily life, reduced appetite, and caused fatigue or reduced energy, suggesting that painful PUs could "radically alter one's life." Patients reported that pain affected many aspects of their lives, as daily activities were circumscribed by pain, consequently affecting overall quality of life: "When pain was at its peak you just didn't want to do anything, you didn't want to eat, you didn't want to go to sleep, you couldn't, cause you were constantly in pain."<sup>10</sup> Individuals may proceed cautiously in daily activities to avoid more pain, and needing to relieve or avoid pain interfered with doing things that they enjoyed. Others reported that PU pain restricted engagement in life: "Aside from being very uncomfortable, I

can't do any of the things that I want to do...it's just not being able to function like I was...."<sup>7</sup> PU pain also was reported to impair sleep. Patients were unable to fall asleep, had interrupted sleep or were woken during the night because of pain. They reported not always getting the quality of sleep they required, suggesting that control over pain was lost while sleeping (e.g., no control over turning in your sleep).

**Restricted Social Participation.** One study<sup>10</sup> reported that PU pain restricted social participation. Patients were unable to participate in socializing or leisure activities: "Pain interferes with doing things you enjoy such as reading or using the computer. You don't feel like going out or socialising when you're in pain, you don't enjoy it." Having to stop doing things one enjoyed to relieve pressure was annoying for some and an inconvenience in their lives.

**Mood/Emotional Problems/Anxiety.**<sup>7,10,14,25,26</sup> PU pain impacted on psychological well-being. Pain commonly caused patients emotional problems and changes in mood such as feeling miserable, despair, frustration, and helplessness. Emotional problems were particularly caused by the restrictions imposed by PU pain (i.e., reduced activity, inability to move because of pain). When PU pain was at its worst, patients spoke of this pain in a fatalistic, resigned tone: "It's getting to me, you know. And I want it to get better...It's annoying. It does hurt. In other words, you can ignore it for a while, but it's getting old now;"<sup>7</sup> however, emotional relief was felt when their pain was eased.

PU pain-related anxiety and fear was most commonly associated with anticipation of pain (e.g., experienced pain previously during dressing changes/debridement). In some instances, anticipating pain meant that patients neglected to inform their HCP that their PU needed attending to, avoiding dressing changes or other PU treatments. Some patients feared moving (i.e., anticipation of pain when considering moving, as certain movements caused pain in the past) or becoming chemically addicted to pain medications. For some, the unexpected pain from their PU left them feeling scared and confused: "I was totally confused because it wasn't supposed to be hurting

there...I was so confused, even a little scared. I couldn't see it. All I knew it hurt bad.”<sup>7</sup>

*Impaired Self-Image/Identity.*<sup>7,25</sup> Constant and unremitting pain was voiced as “ever present” or as “existence.” Patients felt that their PU pain defined who they were, impacting on their identity and self-image. Loss of control because of restrictions imposed on their lives was a feature of PU pain, affecting self-worth. Patients reported feeling powerless to do anything about their pain, further impacting self-image. Some reported a sense of surrender: “I can’t do any of the things that I want to do. It hurts to turn over by myself or pull myself up in bed...it’s just not being able to function like I was...I get to a point where I don’t care.”<sup>7</sup>

*Affective Descriptors.*<sup>7,9,10,24,25,28,29</sup> Emotive words were used including tension, fearful, unbearable, terribly annoying, crying, tiring, exhausting, sickening, punishing, cruel, aggravating, bitterness, frustrating, tearful, unbearable, nagging, miserable, and agonizing. In extreme instances, PU pain can lead to suicidal ideation, described by one patient as “it hurt so much I wanted to commit suicide.”<sup>7</sup> Pain also was described as an overwhelming feature of living with a PU. At its worst, PU pain is horrendous, causing patients suffering that was reported by some to result in tears and screaming.

### *Self-Management*

*Postural/Positional Pain-Prevention and Management Behaviors.*<sup>7,10,14,24–26</sup> Patients reported undertaking behaviors to avoid or prevent pain. Such behaviors were motivated by movement-related pain and fear avoidance driven. Behaviors included learning to sleep in different positions, avoiding aggravating the PU by keeping off it (i.e., not sitting in a certain position) or taking care to position carefully and correctly, “creep around” to avoid putting weight on heel or elevating the foot, avoiding moving, keeping still, or going to bed if sitting starts to hurt or proceeding cautiously in daily activities. Some patients felt that there was nothing that they could do to avoid PU pain.

In addition to pain avoidance, patients practiced behaviors to relieve or reduce pain. These were predominantly positional or skin

protection behaviors (i.e., efforts to prevent clothes from sticking to ulcer, using lotions and creams to soothe, assuming positions to protect PU or relieve pain, avoiding surface contact with PU). Some patients reported leaning forward to relieve pressure while sitting or changing positions/moving around when discomfort was felt. Others reported that any movement or sitting for long periods caused pain and they had to keep adjusting themselves. For some, pain eased upon sitting and resting but eventually returned, whereas others found no relief from pain upon movement and regardless of positioning: “No matter what way they put me it hurt.”<sup>26</sup>

*Expectations About Pain Management, Relief, and Assessment.*<sup>10,14,25</sup> Patients expected their PU and associated pain would be adequately addressed and managed by HCPs. However, patients often expressed the feeling that HCPs did not fully appreciate or underestimated PU pain (“...sometimes it makes you feel like you’re crazy, because they come in and treat it so nonchalantly, so you’re in pain, what do you want me to do about it...it’s very debilitating and I hate to keep hollering that it’s there. I don’t know I never had quite this pain before so I’m dealing with how to handle it and trying to tell them what it’s like. The two just don’t mix. I know I wouldn’t wish it on an animal, let alone another human”<sup>7</sup>), or that they are not always proactive in assessing PU pain or providing appropriate analgesia. At times, complaints of pain had been ignored: “...when they drag you across the rough mattress, I can’t describe it. It’s about the worst pain I ever had...I was hurting and I told them ‘watch my back.’ They don’t listen....”<sup>7</sup>

Patients also had expectations about their pain management. Mainly, patients assumed that their pain would be recognized by HCPs, and if not, that their reports of pain would be taken seriously and attended to accordingly. However, if pain relief was not forthcoming, patients assumed they were ignored (i.e., pain reported but no pain relief provided). A related issue is the difficulty of explaining or defining PU pain. Patients’ difficulty in articulating their pain may be a reason for why it was underestimated by HCPs. The problem for patients lay with feeling ignored. Being believed was linked to patient expectations (i.e., they

expected to be believed and expected their HCP to attend to reports of pain). Optimal expectations were that pain was assessed and reports of any pain were addressed accordingly. However, more often than not, patients reported that PU pain was not assessed by nurses or other HCPs and they felt that it was not a medical priority. In some instances, pain intensity was assessed on a 0–10 scale but only in conjunction with overall pain. In addition, patients with spinal cord injury who had PUs reported that HCPs commonly assumed that PU pain was not a problem because of their impaired sensitivity. However, this was not always the case.

Other expectations related to the belief that HCPs should take care when undertaking dressing changes and that movement and repositioning should help with pain, but in reality this was not always the case: "When I'm sitting in my chair like now, then that also hurts and if I move a little it hurts even more, so I sit very still in the chair, but still it hurts."<sup>25</sup> For some, pain experienced during dressings resulted in avoidance of future dressing changes: "One nurse knew how to take it [dressing] off without making it hurt while others didn't, so sometimes I neglected to tell nurses that I needed my dressing changed."<sup>10</sup>

***Patients Preferred Choice of Pain Relief.***<sup>10</sup> Some patients had a preference for certain pain relief, choosing pain medications over none ("I'm not one for tablets but I had to take pain killers cause it was throbbing...I try to go without them but you can't because it's just there, it's burning.") or deciding to return to bed/chair rather than "bothering" with any pain relief.

### ***Professional Management***

***Outcome of Intervention (Ineffective vs. Effective Pain Relief).***<sup>7,9,10,25,26</sup> Patient satisfaction with pain relief was expressed in terms of effective or ineffective pain relief. Some topical treatments (i.e., creams or dressing) and pain medication helped with relieving or easing PU pain but varied depending on how long they sat/lay on the PU and was only effective temporarily, with pain eventually returning. In one study,<sup>10</sup> patients reported that warm water soothed/eased pain. Analgesia was rarely prescribed

for PU pain and when it was, it was seldom effective in reducing pain. Patients were most satisfied with pain relief when their pain was managed or kept under control and did not interfere with rehabilitation for other medical problems or participation in daily life. In addition to the quality of pain relief, knowledge and ability of those delivering pain management was an important factor. This links to patient expectations about their pain management.

***Medical Priorities.***<sup>7,10,25</sup> Existing medical problems and comorbidities interfered with how much and what type of pain relief patients were prescribed for PU pain. This meant that at times patients were unable to prevent experiencing pain or were unable to relieve it, as they were unable to take pain medication because of other medical problems or were prescribed only a small amount of medication. Treatment for other medical conditions was reported to override PU pain management so that when PU pain was at its peak, patients had to "grin and bear it" because they were not allowed stronger pain relief. Further, at times, PU pain prevented rehabilitation for other medical problems, or an existing condition meant that patients were unable to turn or reposition to relieve PU pain. Patients felt that this was a problem caused by failures in communicating across disciplines: "The problem really is how then information is recorded and how that information is then picked up by the staff. The problem seems to be honest, tissue viability nurse is extremely good at recording the information, the problem is... that people can't be bothered to go and read it."<sup>10</sup>

### ***Psychological Well-Being Mediators (Individual Dependent)***

***Mood/Emotional Response.***<sup>7,10,14,25,26</sup> Mood, positive vs. negative outlook on life, and emotional responses (i.e., adaptive vs. avoidance response) could affect how patients experienced and perceived the impact of PU pain. Negative mood or emotional distress may have resulted in a poor perception of PU pain impact, whereas positive emotional function may have reduced perceived impact.

***Coping Mechanisms.***<sup>7,10,25</sup> Pain coping mechanisms included comparing pain with previous

pain experienced and acceptance. An individuals' existing condition affected how they perceived their PU pain, as most commonly PU pain was compared with pain experienced from other medical problems (e.g., "It is just one of many irritations") or with previous pain experienced because of a PU (i.e., diminishing pain vs. worse pain). Patients also reported acceptance of their PU pain ("After a while you just tend to accept it, you forget what it was like being pain free"<sup>10</sup>), getting used to it, putting up with it (i.e., resignation), or surrendering to it (i.e., accept pain with an air of fatalism): "...I hate the dressing changes but they've got to be done...I've just got to grin and bear it."<sup>10</sup> Some patients become focused on their pain (i.e., hypervigilant) and the impact that it had on their lives was that they could not focus on themselves, resulting in a loss of self.

**Motivation.**<sup>7,10,25</sup> Some patients were motivated to help themselves, either as a result of their way of responding to the world (i.e., emotional response and coping mechanisms) or fear-driven motivation to avoid pain. Regardless, these patients were motivated toward help-seeking and pain-prevention behaviors.

**Control Over Pain/Involvement.**<sup>7,10,25,26</sup> Linked to motivation was patients' need to initiate and drive their pain control (i.e., pain relief/management). Some patients avoided taking analgesics unless their pain became "very bad;" otherwise, they "just coped." Most patients reported controlling their pain by self-managing the ulcer (i.e., soaking in warm water, applying cream to soothe), choosing certain positions, repositioning, or keeping still; however, control over pain was lost during sleep as patients were not always able to hold positions while sleeping.

## Discussion

Ten studies were found that reported the impact of PU pain by direct patient reports. When individuals were free to use their own words to describe their pain, as in the case of qualitative research, many rich descriptive words were used, including an array of metaphors and similes. Conversely, quantitative

research designs were limited to McGill descriptors. The number of descriptors used increased as PU severity increased. There were no evaluative words used to describe Category II PUs. Category IV PUs were associated with increasing psychological comorbidity, consistent with the belief that pain tolerance changes over time and that people try to make sense of their pain the longer that they are in pain; hence, the use of affective words increases. Further, the descriptors used suggest that PU pain is ischemic (i.e., blood supply cut off) with some neuropathic elements. The descriptors used indicate that superficial PUs have nociceptive elements while more severe PUs (e.g., Categories II/III) also have some neuropathic elements. Interestingly, the quality of neuropathic pain remains the same, as similar neuropathic descriptors were present in all PU Categories II–IV. However, because of the small sample size, we cannot say this with certainty and there is no sense of the proportion of nociceptive and neuropathic pain, only evidence to support the use of neuropathic words in each PU category. More work is needed to investigate these elements.

The word descriptors used by PU patients have important implications for existing pain assessment instruments. Descriptive words used in measures such as the MPQ are not a comprehensive list of descriptors used to describe PU pain. Some words contained in the MPQ were not used; perhaps these were not familiar words or inappropriate to describe PU pain. If the content of existing measures is not fit for purpose, this may affect response rates and data quality, and raise questions about the sensitivity and specificity of these measures for various conditions, such as PUs, to effectively assess PU pain and PU pain changes.<sup>31</sup> For example, the misery, anguish, and desperation associated with PU pain may not be captured by solely using the MPQ. It may be assumed that the MPQ is appropriate to use for all types of pain because of its popularity in research, but no validation studies for its use in PUs were identified from our searches. Researchers using the MPQ should bear in mind that it may only provide one piece of the story. Interestingly, the four quantitative studies identified all used the MPQ to describe PU pain (one study used only the MPQ and three used the MPQ plus other

methods). There may be a need to adapt the existing scales or scope for developing new ones.

Consistent with other chronic wounds, pain was a common problem for people with PUs. To better understand the complex nature of PU pain, we present a biopsychosocial model (Fig. 1) derived from studies of patients' experiences. Like other models of chronic pain,<sup>12,32,33</sup> PU pain is an interaction between somatic input (e.g., nociceptive and neuropathic elements) and physical, social, and emotional elements including pain duration, intensity, quality, and specific temporal characteristics (e.g., noncyclic acute, cyclic acute, and chronic wound pain). In addition, our model suggests that for PU pain, these specific pain elements are affected by psychological processes including individual beliefs, expectations, behaviors, mood, avoidance, coping, and motivation, which mediate how pain is experienced, how the feeling of pain is perceived, any associated impact, and how pain is communicated and managed. Further, difficulty in expressing/communicating pain; pain exacerbated or mitigated by PU treatment, other medical equipment and comorbidity; and anticipation of pain because of past pain experienced all contribute toward the nature of the PU pain experience. These factors in turn affect psychological well-being, causing distress, emotional problems, and hypervigilance. Further, patient-centered concerns can lead to pain behaviors such as self-managing pain and pain avoidance. Pain behaviors can be perpetuated by lack of forthcoming pain relief, ineffective previous treatment, or from a desire to manage or control one's pain.

Loss of self and identity can affect how patients communicate the pain experienced and how they negotiate pain management. However, for people with PUs, feeling a loss of self may be a consequence of feeling constant, intense pain over long periods of time, the impact/restrictions imposed by pain on the individual (e.g., restricted social and physical participation), inability to communicate their pain, and hypervigilance. Linked to self-image is patients' need to initiate and drive their pain control (i.e., pain relief/management). In addition, communicating and expressing PU pain is difficult for some patients. The variety and complexity of PU pain necessitates the

use of multiple descriptors comparable to MPQ classification in an attempt to describe pain experienced. Expectations about pain management influenced how pain was communicated and reporting PU pain was perceived as a positive help-seeking behavior. As such, in addition to assessment of pain duration, intensity, and specific descriptive characteristics (word descriptors) as suggested by others,<sup>12,33</sup> PU-specific patient-centered concerns need to be incorporated in pain models to ensure the most effective PU pain management.

PU pain is inconsistently assessed, administered, and managed by HCPs. Patients reported variable success in conventional analgesics reducing or eliminating PU pain. Patients who received analgesics were usually prescribed analgesics for other painful conditions so any experienced relief from PU pain was often by default. Some HCPs may not have the ability or training to recognize and effectively manage PU pain, whereas others may work within health care systems that do not enable them to engage with patients holistically (i.e., focus is on primary diagnoses). Importantly, the problem seems to lie with professional systems and not individual processes (e.g., negotiating PU pain relief vs. pushing through professional systems that tissue viability specialists work in). Further, there appear to be common assumptions from patients that HCPs will know that they are in pain and know how to effectively manage it, while HCPs might assume that patients will always report pain. As seen extensively from the qualitative work, if asked, patients have the ability to describe and communicate their PU pain descriptively or by similes; however, they do not appear to do this so well clinically. The problem may be that patients are not given the opportunity and are blocked in being able to discuss PU pain with HCPs. We need to help tissue viability and community nurses link in with other pain management systems to enable them to engage with patients holistically and provide the most effective PU pain management.

Not having PU pain managed, ineffective analgesics and failure of HCPs to mitigate the impact of the pain caused patients extreme frustration. Inadequate pain management or not being believed may result in the patient giving up on HCPs and developing their own

self-management behaviors to reduce or prevent pain. Further, as current professional systems may not always allow HCPs to effectively manage PU pain, patients may use their own self-management strategies, resulting in patients filling in gaps in health care with their own behaviors, which are not necessarily behaviors that will give the best patient outcomes (e.g., avoid the pain experience by not moving, which may not be the best thing for the PU). Self-management is further mediated by individual beliefs, expectations, motivation, and coping. Consistent with other disease areas,<sup>34</sup> the quality of self-management is reduced as PU pain becomes chronic; the worse the pain gets, the less able patients are to self-manage their pain. People with PUs, predominantly younger ones, appear particularly motivated to self-manage their pain but when their pain becomes chronic, this threatens their ability to self-manage, as the longer the duration of pain, the greater the effect this has on their psychological well-being.

#### *Key Messages*

The nature of the PU pain experience is extremely complex. PU pain can be chronic, impacting on patients' lives and their ability to manage. Closely related are various psychological mediators that influence how pain experienced is perceived and individuals' desire to self-manage pain. The myriad nature of PU pain and how it is experienced also means that communicating PU pain is very complex and often patients are unable to express and explain their pain to HCPs. Other patient-specific barriers to pain management include beliefs about the quality of pain relief and comorbidity. Existing pain assessment tools may not capture the negative impacts, misery, anguish, and desperation associated with PU pain.

In addition to patient-specific barriers, there are health professional barriers to pain management including lack of communication across disciplines and the skills and ability of those delivering PU pain management. PUs are often secondary outcomes of primary diagnoses; therefore, existing conditions may determine what pain relief is provided; PU specialists are unable to endorse analgesic changes without consultation with the primary specialist. This highlights the need for

effective cross-discipline communication to enable decisions about the best course of pain management. Further, improved communication of pain experienced by patients and priority setting on the part of the patient with their HCP are also needed.

Barriers to pain management result in the pain experienced not being reported and consequently being poorly managed. As such, patients are left to their own devices to minimize their pain experience. Patients appear motivated to engage in positive health-seeking behaviors; however, the self-management behaviors, particularly pain avoidance, that patients have worked out for themselves such as staying still, keeping off the painful area or grinning, and bearing it are not always behaviors that will give the best patient outcomes. A key problem appears to be that self-management and professional management of PU pain are not integrated. This may be caused by common misconceptions about reporting and communicating pain. Patients were able to provide rich, detailed descriptions of their PU pain experience but the processes in clinical services are not always there to allow patients to communicate/express their PU pain to HCPs. Despite patients' willingness to discuss/describe PU pain and a desire to make sense of their experience, there does not appear to be a partnership model for PU pain management, suggesting that professional systems negate good/bad PU pain management. Importantly, in PUs, initial pain or discomfort is more than a symptom; it adds value as an indicator of skin damage. However, this is hampered by patients' difficulty in communicating their pain, lack of knowledge surrounding skin damage, and by professional attitudes and their inability to recognize and effectively manage PU pain. If patients had better education about skin health and prevention of pressure damage, and were encouraged to report any early experienced pain or discomfort instantly rather than ignore it or self-manage without professional health care input, then this might prevent future skin damage or at least prevent superficial damage deteriorating further. Exploration of the benefits of health promotion advice and a pain management program is needed.

### *Strengths and Limitations*

This review is the first synthesis of information derived from a combination of both qualitative and quantitative research about PU pain using robust methods. We have included 10 studies with varying methodologies. Some of these had poorly described theoretical perspectives and each had a different research question, making a conventional meta-synthesis difficult. However, including mixed methodology studies has provided a complementary, deeper interpretation of the complexities of the pain experienced from PUs to inform future research of the most effective PU pain management. For example, quantitative measurement informed us about physical aspects of PU pain (e.g., intensity), whereas qualitative data were able to convey the nature of the pain and the emotional and psychological consequences associated with it.

We were unable to evaluate PU descriptors for Category I PUs. Only one patient from the combined sample had a Category I PU, whereas the majority had multiple PUs with mixed categories. A problem with research in this field is that there is no evidence in the literature about pain associated with Category I PUs. Clinical trials of preventative interventions do not assess pain as an outcome associated with Category I PUs, whereas treatment intervention trials usually exclude patients with Category I PUs. Further, research in chronic wounds often includes mixed chronic wound samples and individual subgroup analysis is not performed. As such, some potentially relevant studies could not be included in this review as they presented descriptors for individuals with mixed chronic wounds. However, from four of the 10 included studies, we were able to isolate descriptors associated by PU severity, allowing comparison between descriptors used with other chronic wounds.

### **Conclusion**

PUs can cause patients considerable pain, discomfort, and suffering, with particularly painful times being during dressing changes or other wound care. PU pain can be debilitating, reducing the individual's ability to participate in physical and social activities, and consequently compromising psychological

well-being. The nature of the pain experienced, the impact it has on daily life and how effectively PU pain is managed will determine how patients manage their pain. Self-management behaviors are mediated by individual factors including mood, coping, and motivation. These interrelating factors are further complicated by patient-specific and HCP barriers to effective pain management. A biopsychosocial model of the PU pain experience is suggested here. To achieve the best possible outcomes important to patients, improved communication of pain experienced between the individual and cross disciplines, pain assessment by HCPs, interventions to help control or reduce PU pain, patient-centered concerns, and systemic barriers need to be considered when managing PUs to ensure more effective PU pain management in the future.

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