**TITLE**

Patient involvement in pressure ulcer prevention and adherence to prevention strategies: An integrative review

**ABSTRACT**

Background: Chronic wounds including pressure ulcers represent a significant burden to patients and healthcare providers. Increasingly patients are required to self-manage their care but patient adherence to prevention strategies is a significant clinical challenge. It is important to increase understanding of the factors affecting patients’ ability and willingness to follow pressure ulcer prevention interventions.

Objectives: To investigate from a patient perspective the factors affecting adherence to pressure ulcer prevention strategies.

Design: Integrative Literature Review

Data Sources: A systematic search of electronic databases (Athens, Pub Med, Web of Science, Science Direct, AMED, CINAHL, Cochrane Library, PsychInfo, Google Scholar, Delphis) was initially conducted in May 2017 (repeated August 2018).

Review Methods: The methodological quality was assessed using the Critical Appraisal Skills Programme (CASP) principles. The Noticing, Collecting, Thinking (NCT) model of qualitative data analysis was used to identify key themes.

Results: A total of twelve studies met the inclusion criteria and were included in the review. The majority of studies were qualitative and three key themes were identified: i) individual/daily lifestyle considerations, ii) patient involvement in the decision-making process, and iii) pain and/or discomfort.

Conclusion: There is limited research that focuses on the patient view of factors affecting adherence to prevention measures, particularly in community settings. Individual and daily lifestyle considerations and involvement in decision-making around pressure ulcer care are important aspects from the patient perspective. Further research is necessary to explore which factors affect patient adherence in order to improve clinical practice and support patient involvement in preventative strategies.

**Key words:**

Adherence

Decision-making

Non- adherence

Patient involvement

Pressure ulcer

Community

**Contribution of the paper**

What is already known?

* Pressure ulcers can cause significant harm and have a detrimental effect on quality of life
* Risk of developing pressure ulcers and associated co-morbidities is a complex phenomena with immobility, skin status and poor perfusion identified as direct causal factors
* Pressure ulcer prevention is challenging in community settings where there are issues with continuity of care

What this study adds

* Patient involvement in decision-making in pressure ulcer prevention is important
* There is a research gap in the understanding of how patients understand and follow the advice given in community settings
* Factors affecting patient adherence are multifactorial, with lifestyle, behavioural and pain issues identified

**1. BACKGROUND**

The prevention of pressure ulcers remains a key priority area for healthcare providers and a patient safety issue, despite international campaigns to increase awareness and education (NICE, 2014). Pressure ulcers are defined as ‘localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear’ (NPUAP/EPUAP/PPPIA, 2014). They are associated with ill health and poor mobility and can have a severe effect on an individual’s quality of life (Gorecki et al. 2012). Detrimental effects may include reduced mental and physical function, and increased pain (Essex et al. 2009). Pressure ulcers are also costly, both in terms of health care professional time and resources (Dealey et al. 2012). In a systematic review considering the cost of prevention and treatment of pressure ulcers, it was estimated that prevention cost per patient per day ranged between €2.65-87.57, while pressure ulcer treatment cost per patient per day ranged between €1.71-470.49 (Demarre et al. 2015). Subsequent studies have estimated the annual cost of managing wounds, including pressure ulcers was approximately £5.3 billion in the UK alone (Guest et al. 2015).

Despite the international efforts to reduce pressure ulcers, their prevalence and incidence has remained unacceptably high. An international review across European countries reported mean pressure ulcer prevalence of between 8.9-25% in a range of healthcare settings including acute and community care (Moore et al. 2013). Within the UK, a study that considered pressure ulcers and wound reporting in acute hospitals identified between 7.1 – 8.4% of patients with an existing pressure ulcer (Smith et al, 2016). The limited evidence to date suggests a potentially higher rate in the community (Stevenson et al. 2013). There are, however, issues with the reporting of prevalence and incidence, with consensus needed around definitions and reporting of pressure ulcers (Coleman et al. 2016).

In clinical practice, pressure ulcer risk assessment is seen as central to pressure ulcer prevention, often with a wide range of risk scales used by the healthcare professional to determine a patient’s status in both hospital and community settings (Coleman et al. 2013). Pressure ulcer risk is also a constantly changing phenomenon and increasingly it is patients and often carer/s who are self-managing risk and responsible for carrying out interventions required, particularly in community settings where care is often transitory (Brewster et al. 2017).

In recent years, there has been a shift in emphasis from professionals instructing patients what to do, to a more patient centred care model whereby patients are active partners in decision-making (King’s fund, 2018). Importantly, involving patients in decision-making about their care is more likely to encourage participation in the advice and recommendations made (Schoeps et al, 2016). There is established consensus that the patient has an important role in managing their own risk and prevention strategies as they may become the only constant in a complex and changing situation, particularly in community settings (Coleman and Muir, 2015). However, very little research has been conducted regarding the patient’s understanding and role in carrying out advice and recommendations for pressure ulcer prevention (Stinson et al. 2013; Baron et al. 2016).

There is currently a significant gap in the research evidence around patient adherence to pressure ulcer advice and prevention techniques. It is crucial to further understand the effect that patient understanding of pressure ulcer risk and involvement in decision-making has on subsequent adherence to prevention strategies. Non-adherence can result in increased time with healthcare professionals, higher financial costs and greater risk of developing a pressure ulcer (Kirby et al. 2014). The aim of this integrative literature review is to investigate from a patient perspective factors affecting adherence to pressure ulcer prevention strategies in community settings.

**2. METHODS**

An integrative literature review was conducted utilising a variety of evidence sources. An integrative literature review is a distinctive form of research that generates new knowledge about a topic by critically appraising and synthesising the available literature (Torraco, 2016). It is particularly useful where new and emerging topics benefit from a holistic conceptualisation of knowledge including qualitative and quantitative methodologies and was therefore considered appropriate for this review.

 The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement (2009) were used to guide the overall process (see Figure 1).

*2.1 Inclusion/exclusion criteria*

The inclusion/exclusion criteria for the study were identified as follows:

*2.1.1 Inclusion criteria:*

Studies had to focus specifically on patients’ view or understanding of pressure ulcers and factors affecting adherence to prevention strategies. The intended focus was patients in community settings, but due to the lack of literature the search was widened to include any healthcare setting. To be included, studies also had to be empirical, full-text and published after the year 2000. Only studies written in English were included as part of the review.

*2.1.2 Exclusion criteria:*

Studies that focused on professional, medical, or nursing views of patient involvement and adherence behaviour were excluded. Studies with a specific focus on pressure ulcer products, equipment or intervention were also excluded.

*2.2 Literature Search*

The following databases were systematically searched: Athens, Pub Med, Web of Science, Science Direct, AMED, CINAHL, Cochrane Library, PsychInfo, Google Scholar and the University of Southampton search engine, Delphis. The search was carried out in May 2017 and repeated in August 2018. Three search category terms were used:

1. Pressure ulcer or bed sore or pressure sore or decubitus ulcer or pressure injury or pressure ulcer prevention or pressure ulcer management or pressure injury treatment or pressure care
2. Concordance or non-concordance or adherence or non-adherence or compliance or non-compliance
3. Patient perception or patient involvement or patient self-management or patient self-reporting or patient adherence or patient participation or patient experiences or patient role or patient narrative or patient view or patient voice or qualitative

These were all searched under Abstract (AB) and then combined using Boolean operators;

(Category 1) AND (Category 2 OR 3) with “pressure ulcer” as an overall MeSH term.

The results of the literature search are outlined and discussed in the results section.

*2.3 Data Analysis*

The twelve articles included in the review were analysed and appraised together with qualitative synthesis of key themes. The methodological quality of the studies included in the review were appraised using the Clinical Appraisal Skills Programme instrument (CASP) and are summarised in Table 1. All documents were critically appraised by the first author with support from the co-authors. Of the twelve studies included, the majority were qualitative (n=9) and the others included mixed methods, systematic review, survey and quantitative methods. The principles of the Noticing, Collecting, Thinking (NCT) model of qualitative data analysis were used to analyse and synthesise the key themes that emerged from the articles (Friese, 2014). The NCT approach is inductive in nature, with the first stage of Noticing (N) involving reading and re-reading articles. At this stage, reviewers separately highlighted words and areas of interest within papers. The next stage of Collecting (C ) involved reviewers collating and developing codes, followed by the Thinking (T) stage, where reviewers checked, re-read and reviewed emerging themes. Two of the co-authors reviewed the articles and developed themes and checked across the researcher team to provide investigator triangulation and ensure rigour. Any discrepancies were overcome through consensus or the third co-author adjudicated the issue.

**3. RESULTS**

*3.1 Study Selection*

A PRISMA chart depicting the selection of eligible studies is shown in Figure 1. The titles and abstracts of studies initially identified were evaluated for eligibility (n=1048). Subsequently, 265 duplicates were removed and a further 758 studies excluded because they were not relevant to this review. The full texts of the remaining 25 studies were reviewed; 10 were rejected as they focused on evaluation of a specific intervention, one study rejected as the research was around health care professional (HCP) view and the other four studies were not relevant. The remaining 10 studies were included in the review along with one additional paper from snowballing and an additional paper from the repeated search in 2018 (n=12).

Records identified through data base searching (n=1048)

Records after duplicates removed

(n=783)

Records excluded

(n= 758)

Records screened

(n=783)

Full-text articles excluded (n=15)

Evaluative only n = 10

HCP view n = 1

Not relevant n = 4

Full-text articles assessed for eligibility (n = 25)

Records identified through reference list, citation and repeat search (n=12)

(n= )

Studies included in integrative review (n = 12)

**Figure 1 PRISMA flowchart of search strategy** from “Preferred Reporting Items for Systematic Review and Meta-Analysis: The PRISMA Statement,” by Moyer et al 2009, Journal of Clinical Epidemiology, p.1009

Footnote HCP = Health care Professional

*3.2 Methodological Quality Appraisal*

The methodological quality of the twelve studies included in the review were appraised using the Clinical Appraisal Skills Programme instrument (CASP) outlined earlier and are summarised in Table 1. The most common critique of the study papers was where researchers did not clarify why a particular research design was appropriate for the study itself and the recruitment strategy employed was unclear (Guihan and Bombardier, 2012; McInnes et al. 2014). Within these two studies, the researchers did not clearly justify the research design in addressing the overall research aims. It was also not clear why participants selected were the most appropriate to provide the knowledge sought by the study. However, overall the rigor of data collection and data explanation was transparent in the majority of studies, thus increasing credibility, transferability and dependability of findings (Kneale and Santy, 1999).

**Table 1 Methodological Quality Appraisal of articles( using CASP)**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study**  | **Clear aims & focus of study**  | **Methodology appropriate** | **Research design appropriate** | **Appropriate recruitment strategy** | **Appropriate data collection** | **Researcher role considered** | **Ethics considered** | **Data sufficiently rigorous** | **Clear statement of findings** |
| Clark et al. (2006) | Y | Y | Y | Y | Y | N | Y | Y | Y |
| Fogelberg et al. (2016) | Y | Y | Y | ? | ? | Y | N | Y | ? |
| Fox (2002) |  Y |  Y | Y | Y | Y | Y | ? | Y | Y |
| Gorecki et al. (2009) | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Gorecki et al. (2012) | Y |  Y | Y | Y | Y | ? | ? | Y | Y |
| Guihan and Bombardier (2012) | Y | Y |  ? | ? | ? | N | Y | Y | Y |
| Jackson et al. (2010) | Y | Y | ? | Y | Y | ? | Y | ? | Y |
| Jackson et al. (2017) | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| King et al. (2008) | Y | Y | Y | Y | Y | ? | Y | Y | Y |
| Latimer et al. (2014) | Y |  Y  | ? | Y | Y | Y | Y | ? | Y |
| McInnes et al. (2014) | Y | Y | ? | ? | Y | N | Y | Y | Y |
| Pinkney et al. (2014) | Y | Y | Y | Y | Y | Y | Y | Y | Y |

**Key: Yes = Y No = N Insufficient information given = ?**

*3.3 Overview of Studies*

A summary of the twelve articles that met the inclusion criteria for the integrative review are presented in Table 2. All participants were adults with either existing pressure ulcer damage or a history of damage, often severe (Category 3 – 4). Only one of the studies recruited participants who were at high risk of pressure ulcers, however, it was unclear whether or not they had developed a pressure ulcer. Within the qualitative studies, sample size ranged from 5 – 30 patients with a variety of research approaches utilised, including semi-structured interviews, in depth interviewing and participant observation. The research context can also be seen in Table 2 with a range of settings including rehabilitation units, home settings, acute inpatient and community hospitals.

**Table 2 Overview of Studies**

| **Study** | **Design/Data Collection** | **Setting/ Sample** | **Key Results or Recommendations** | **Limitations** |
| --- | --- | --- | --- | --- |
| Clark et al. (2006) | Qualitative In-depth interviews and observations | 20 community based adults with Spinal Injury19 history of pressure damage1 pressure ulcer free | Daily lifestyle phenomena that surround pressure ulcers are individualised.Healthcare practitionerscan help individuals foster prevention behaviour by acknowledging individual and lifestyle needs. | Participants may have misreported when pressure ulcer damage actually occurred. |
| Fogelberg et al. (2016) | Qualitative Secondary analysis of previous ethnographic study | Five community dwelling Spinal Cord Injury adultsStage 3 or 4 pressure ulcer damage | Pre-existing habits are complex but can facilitate or inhibit new health-promoting habits such as prevention strategies. Education may increase knowledge but may not move patients from intent to actual behaviour. | As all 5 participants had severe pressure ulcers, the results may have been biased towards habits that exacerbated rather than mitigated damage. |
| Fox (2002) | Qualitative Semi- structured interviews  | Five community patients with pressure ulcers  | Pain may affect the ability to carry out the prevention advice given.Healthcare practitioners need to take holistic and patient centred approach to decision-making. | Difficulty accessing participants who fulfilled study criteria. |
| Gorecki et al. (2009) | Systematic reviewMeta synthesis of primary research | Acute, community and long-term care settings in Europe, the US, Asia and Australia.Adults with pressure ulcers | Incongruence between the patient need and the health care practitioner need has a negative effect on patient adherence.The therapeutic relationship is vital to build patient trust and adherence. | Quality of the randomised control trials were poor and many were excluded. All used single-item questioning methods rather than validated outcome measures. |
| Gorecki et al. (2012) | Qualitative Semi-structured interviews  | Hospital, rehabilitation and home settings30 patients with pressure ulcers  | Involving patients in pressure care decisions facilitated adherence, particularly if they believed it would help to improve their pressure ulcer. Pain was common and significant for patients and can affect ability and/or decision to follow advice. | Researcher reflexivity not evident within the study. |
| Guihan and Bombardier (2012) | Cross-sectional observational designSurvey & checklist | Spinal Cord Injury Centres 131 veterans with Spinal Injury and Stage 3 or 4 pressure ulcer damage | Large proportions of the sample didn’t follow recommended skin care guidelines. Only 42% contacted healthcare practitioner when they noticed new or worsening skin. 25% of the sample were trying to change behaviours. Prevention behaviours and adherence should be an ongoing topic of discussion between healthcare practitioner and patient. | Sample had been hospitalised with severe pressure ulcers, therefore difficult to generalise results to wider population.The screening process for assessing cognitive ability wasn’t robust.Variety of outcome measures used. |
| Jackson et al. (2010) | Qualitative In-depth interviews | Rehabilitation centre20 Spinal Cord Injury adults with history of Grade 3 or 4 pressure ulcer damage | The issue of daily activity versus health risk is a crucial concern to Spinal Injury individuals.Clinicians need to work with patients around a realistic balance between prevention strategies and daily activity. | Sample were all high pressure ulcer risk. This may ‘elevate’ findings around how daily lifestyle affected pressure ulcer development. |
| Jackson et al. (2017) | QualitativeSemi-structured interviews | Twelve community participants, 5 carers, existing pressure ulcer damage. | Patients need to be involved in decisions around pressure ulcer prevention and care that routinely occur. |  Sample selected were identified as very high risk. This may ‘elevate’ findings. |
| King et al. (2008) | Qualitative Semi-structured interviews | Two rehabilitation hospitals21 participants with Spinal Cord Injury, 15 of these with history of pressure ulcer damage | Key themes emerged about pressure ulcer and skin care; taking vigilant care, taking charge, maintaining health and refusing care.There is a discrepancy between patient beliefs and actual performance of prevention behaviour. Non-adherence was more likely when confronted with conflicting life priorities. | Due to the cross-sectional nature of data collection, it is not known whether participants’ previous experience of pressure ulcer influenced their beliefs and values. |
| Latimer et al. (2014) | QualitativeSemi-structured interviews | Hospital setting20 adult inpatients who required assistance to move | Patients gather pressure injury knowledge from first- hand and vicarious experience. Patients that felt they were not listened to disengage from pressure care and less likely to carry out advice. | Interviews were brief due to clinical context, therefore may not have allowed deeper questioning. |
| McInnes et al. (2014) | Mixed MethodsStructured survey with open and closed questions | Hospital setting51 patients participated, over half at risk of pressure ulcers | 86% of patients understood the concept of pressure ulcer and 80% agree patients have a role in prevention.Pain was related to adherence. | Small convenience sample, so results may not be generalizable.No psychometric testing was done on the survey instrument used. |
| Pinkney et al. (2014) | Qualitative Case record analysis & in-depth interviews | Patient home, acute and community hospitals.Eight individuals who had developed severe pressure ulcers | Some clinicians blamed pressure ulcer development on patients not listening to or following advice.Patients didn’t feel their concerns in relation to pressure ulcer recommendations were heard by professionals. | Retrospective analysis, therefore could have created hindsight bias.Possible bias in the background of the research analysts. |

*3.4 Key Themes*

Three key themes were discovered inductively in the data, all of which have a potential link to adherence to pressure ulcer prevention and management strategies from the patient perspective:

*3.4.1 Individual/daily lifestyle considerations*

The first theme was around lifestyle considerations for patients and that these are individual and often constantly changing, such as physical ability, daily routines, roles and responsibilities. These factors may affect decisions around taking advice and adopting pressure ulcer prevention and treatment strategies. Where a lifestyle trade-off was greater and impacted significantly on a patient’s function or social activity, this often resulted in non-adherence to the recommended regime. For example, in the study by Jackson et al (2010) a participant ‘Judy’ describes a situation where prevention advice to remain on bed rest was ignored;

 *“No no I mean, I just, I cannot see me lying around…I am a workaholic.…I love my job” (p574).*

In this case, although Judy had been instructed by her doctor to go onto bedrest to heal a red area of skin, she had a full-time career as an accountant that she greatly valued and therefore she ignored the advice and chose to continue to go to work.

Another example of lifestyle considerations can be seen in the study by Jackson et al (2010) where a 42 year old male ‘Rob’ is describing how a holiday trip that he chose to do last minute resulted in him developing a pressure ulcer:

“I stayed in one airport for twelve hours and I slept maybe six or seven hours in one position…by me missing a flight that was it…(p570).

Within several studies, participant’s reported that whilst they understood pressure ulcer regimes and the importance of acting on the advice given, this was not always acted upon (King et al. 2008; Gorecki et al. 2012; Fogelberg et al. 2016). The reasons for this were complex and often due to competing priorities and day-to-day challenges. In the study by Fogelberg et al (2016) a participant explains about the prevention advice given for his wheelchair seating;

 *“ ...the doctor says I should recline…I know I should… I don’t do it … I just sit for a long time” (p471).*

In this case, the participant did not want to miss classes as he was a student and therefore whilst he understood his pressure risk and did intend on carrying out the advice, he consequently prioritised college over the pressure ulcer regime. The studies reported that whilst there was a genuine desire to engage in healthy skin care routines, participants stated that this ‘belief’ was not always acted upon (King et al. 2008). There were a number of reasons for this, primarily juggling other commitments and priorities described here;

 *“I saw the skin breakdown occurring and intended to….but I had just started this job and didn’t want to take time off “ (King et al.2008, p159).*

Similarly King et al (2008) found that even when initial changes in behaviour were made they were not maintained consistently over time;

 *“ right now skin care is my first priority because I just had surgery….but I see myself falling back into the same routine I was in before” (p159).*

Several participants in this study indicated that it was difficult to maintain care routines and prioritising pressure ulcer care alongside motivation to follow advice changed over time (King et al. 2008). These concerns were also mirrored in the studies by Gorecki et al (2012) and Fogelberg et al (2016) where participants described how the motivation to carry out advice fluctuated day to day despite the intention to follow the guidance given.

*3.4.2 Patient involvement in the decision-making process*

The second theme to emerge was around shared decision-making. Patient involvement in goal setting and decisions around their pressure ulcer care was a key concern in the majority of the studies (Fogelberg et al. 2016; Fox 2002; Gorecki et al. 2009; Gorecki et al. 2012; King et al. 2008; Latimer et al. 2013; McInnes et al. 2014; Pinkney et al. 2014; Jackson et al. 2017). Patients reported that they felt they were not always listened to regarding what was important to them during the pressure ulcer risk conversation. For example, in the study by Gorecki et al (2009) some patients felt that to be able to sleep through the night was more important to them than being repositioned regularly. However, staff commonly ignored this. Three of the studies indicated a link between patient involvement in decisions and subsequent adherence to prevention strategies (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014). In the study by Gorecki et al (2012) a patient described the importance of being involved;

 *“I’m the one suffering not them, I’m the one uncomfortable not them” (p8).*

Similarly, Pinkney et al (2014) suggest that it is important that the patient is involved in the pressure ulcer assessment and decision-making process and that their opinion and concerns are fully acknowledged. Through this involvement, the healthcare professional may become aware of factors and concerns that are important to the individual and these can be discussed and considered. Importantly, should these factors not be taken into account, there is an increased likelihood of non-adherent behaviours (McInnes et al. 2014).

*3.4.3 Pain and/or discomfort*

The third theme around the presence of pain or discomfort was identified as a major concern by patients and contributed to restricting adherence to certain prevention strategies such as moving and re-positioning (Gorecki et al 2009; Gorecki et al 2012; McInnes et al.2014, Pinkney, et al. 2014). Within these studies, participants did not always carry out advice given, for example moving position as they were in too much discomfort and lacked confidence in their ability to move. In some circumstances, the pressure relieving equipment was not always seen positively by participants and at times contributed to being uncomfortable. Participants were also reluctant to communicate to health care staff that they were in pain as they did not want to be a burden to staff. Equally, if they did mention pain or discomfort, these concerns were not always listened to or acted upon (Gorecki et al 2009; Gorecki et al 2012; McInnes et al.2014, Pinkney, et al. 2014). There was also an attitude where participants resigned themselves to put up with their situation, for example where pain relief wasn’t particularly working well;

 *“they (analgesics) didn’t do too badly but at its peak, you just have to grin and bear it…other lads were getting real, real relief, I wasn’t” (Gorecki et al. 2012 p9).*

In the same study, similar concerns were reported around pressure relieving equipment as being “too hot” and “vibrates” (p9). Importantly McInnes et al (2014) found that for many respondents if pain or discomfort factors were addressed, participants were more likely to adhere to self-management behaviour such as turning and repositioning.

**4. DISCUSSION**

This integrative review revealed that there is limited research regarding the patient perspective of pressure ulcer risk and their involvement in the decision-making around prevention strategies. To date, research has primarily focused on the healthcare professional view and therefore the patient view remains an important gap in the research (Baron et al. 2016). Of the articles included in this integrative review, three key themes emerged that affect adherence or non-adherence to strategies for pressure ulcer prevention, providing useful insights. These were:

* individual/daily lifestyle considerations
* patient involvement in the decision-making process
* pain and/or discomfort

By discussing the key themes identified within this review, useful implications for practice and patient care may be gained.

*4.1 Individual/daily lifestyle considerations*

The majority of studies included in this review highlighted the importance of individual and daily lifestyle considerations as part of pressure ulcer care regime. Participants in the studies described how in daily life there were dynamic and changing priorities which created challenges in carrying out clinical advice and recommendations (Clark et al.2006). Equally, whilst some participants described how they fully intended to follow advice, this did not always result in actual behaviour. Within one study in particular, there appeared to be habitual considerations, which appeared to facilitate or inhibit new health promoting behaviour (Fogelberg et al. 2016). This has important considerations for clinical practice as it indicates that patient agreement during the pressure care conversations with professionals may not translate into day-to-day practice and that habits are complex. It may be that clinicians need to go beyond educational strategies that are focused on developing patient intention and adopt strategies that are also focused on changing habits through collaborative problem solving. As Fogelberg suggests (2016) although education may increase patient knowledge, it may not reliably move patients beyond intention into actual routine habit. It is important that these factors are acknowledged and considered as part of the conversations with healthcare professionals and that a patient centred approach is adopted (Tobiano et al. 2015). This theme also has important considerations for how advice and intervention is followed up and maintained, particularly in the home community setting where clinical intervention is usually transitory with the emphasis on individuals to ensure advice is routinely followed (Baron, 2016).

*4.2 Patient involvement in the decision-making process*

The importance of involving patients in decisions around their pressure ulcer care was identified within the majority of studies included in the review. This theme linked closely to trust with the healthcare professional and where there was a strong therapeutic relationship, it was more likely to facilitate adherence (Gorecki et al. 2012). Likewise where trust wasn’t established and participants’ concerns were not heard, there was an increased likelihood of non-adherence and potentially increased PU risk (Pinkney et al. 2014; Latimer et al. 2014). The need for health professionals to provide person-centred care is becoming more recognised and accepted across the world(World Health Organisation, 2007; Kitson et al. 2013).This is critical to drive better patient outcomes with patients seen as equal partners in their care (Tobiano et al. 2015). This integrative review has revealed the importance of a patient centred approach to pressure ulcer care and prevention to empower and enable patients to be actively engaged in the decision-making process.

*4.3 Pain and/or discomfort*

The studies also revealed that the issue of pain and/or discomfort was a significant concern for individuals at risk of developing pressure ulcers. Participants described how this also was a factor in whether they were able to carry out certain advice and strategies. For example, some participants described how pressure relieving equipment was uncomfortable and where this was the case, the equipment was less likely to be used. This was also true where pain or discomfort affected the ability to move and reposition. It is therefore important for healthcare professionals to be aware of this factor potentially contributing to restricting adherence to certain prevention strategies such as regular re-positioning and equipment usage (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014, Pinkney, et al. 2014). Equally it is important that healthcare professionals acknowledge the importance of pain and work holistically alongside the patient to improve pain management (Jackson et al. 2017).

*4.4 Summary*

Although the results from the narrative review provided three overall themes, it is evident that there are interdependencies between them. For example, the first theme around lifestyle and individual considerations for carrying out pressure ulcer care regime links to the third theme of the presence of pain and/or discomfort. The presence of pain was identified as a key factor in whether patients were willing or able to carry out the advice given and if it was feasible as part of their daily routine (Gorecki et al. 2012). Equally, theme two focused around patient involvement in decision-making which links to individual/lifestyle considerations in that through a patient centred approach, these individual patient concerns and daily routine can be understood and from this realistic care decisions agreed.

This review offers some useful insights into the patient perspective of pressure ulcer risk and potential factors affecting adherence to prevention strategies. While the predominant sample group within the studies are a distinct clinical population, i.e. Spinal Cord Injury who had existing pressure ulcers, due to the ‘richness’ of data gathered in the studies, this does not limit the transferability across a wider population with other conditions who are in similar community surroundings. For example, from this review, there are useful insights around how individuals manage their pressure ulcer care within the home setting, with factors such as the transitory nature of staff and the emphasis on prevention and self-management (Baron et al 2016).

Due to the limited results and lack of studies that focused on the community home setting, this integrative review was expanded to include other settings such as hospitals and nursing homes. Each of these settings do have particular characteristics, which may limit transferability. For example, whilst many nursing homes are community based, the social context is different to that of a patient’s own home, with patients treated as recipients of care rather than taking a more active role (Lavallee et al. 2018). Likewise within the acute hospital setting, whilst there has been an increased focus in recent years around supporting inpatients to continue to be involved in their preventative pressure ulcer care, a more active role remains a challenge (McInnes et al 2014). The samples were also largely those who had existing pressure ulcer damage, often severe (Category 3 – 4) rather than participants who are at risk but who have not yet had a pressure ulcer. This does highlight an important gap in the research evidence around prevention for those individuals at risk but do not currently have wounds.

*4.5 Limitations*

This review does reveal some limitations of the studies conducted to date. More studies, which include either quantitative or mixed methods approaches, would broaden the evidence base. However, due to the exploratory nature of the research question, it is understandable why the qualitative study design predominates. The limitations of the integrative review itself are that although the initial focus was around patient understanding of pressure ulcer risk in the community setting, the search parameters had to be expanded to include all patient settings. The review therefore included community, acute and nursing homes which offers a diverse range of settings. As the majority of the studies were qualitative in nature, the review is limited to what the researchers of the studies choose to report within their findings, which does not fully overlap with the focus of this review.

*4.6 Clinical and Research Recommendations*

There are important clinical recommendations that can be gleaned from this review, particularly the importance of a patient centred approach to decision-making around pressure ulcer care. It is crucial for healthcare professionals to understand what is important to a patient in their daily life, so that shared decision-making can occur and realistic prevention strategies identified. This would enable healthcare professionals and clinical services to consider how to most effectively support and monitor community-based patients where pressure ulcer prevention decisions, daily lifestyle and individual factors are dynamic and changing.

Further research is necessary to develop a greater understanding of which factors affect decisions about adherence to pressure ulcer prevention. Whilst the studies included in this review have considered the patient perspective, the research has not addressed the issue of adherence as a primary topic for investigation, a key limitation in the studies to date. This is particularly important in community settings where the patients have limited access to healthcare professionals and have to take a significant responsibility for pressure ulcer prevention. Indeed, this is a complex and individualised setting that may affect healthcare providers’ ability to provide high-quality care (Brewster et al. 2017). It may also be useful to consider research further afield, for example in leg ulcer research, where non-adherence has been identified as a multi-dimensional issue, with factors such as patient knowledge and the relationship with their healthcare professional as central to patient behaviours (Van Hecke et al. 2009). However the strength of the studies included in this integrative review lies in how they explore what is happening from a patient’s perspective and the complex nature of PU prevention work.

**5. CONCLUSION**

From the limited research available, this integrative literature review has identified three key themes that can affect a patient’s adherence to pressure ulcer advice, including; i) individual/lifestyle considerations, ii) shared decision-making and iii) pain and/or discomfort. There were interdependencies within these factors, creating conditions that act as barriers or facilitators to pressure ulcer prevention strategies. Further research is warranted to investigate determinants regarding patients understanding and involvement in the decision-making, and its effects on adherence to prevention advice and recommendations. The lead author intends to address this important gap in the research through an ethnomethodological study focused around how community patients understand their pressure ulcer risk and factors that affect adherence to carrying out the advice given. The study will be qualitative and use a range of methods including observations, interviews and document analysis.

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