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Patient perceptions and understanding of pressure ulcer risk in the community: Empirical Research Qualitative

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Abstract

Aims: To explore patient perceptions and understanding of their pressure ulcer risk and how information is communicated between a nurse and patient in the home setting.

Design: A pragmatic qualitative research design including community-dwelling patients, who were deemed at risk of developing a pressure ulcer.

Methods: Observation of routine interactions between nurse and patient regarding their pressure ulcer risk and semi-structured interviews with 15 community patients following the nursing interaction.

Results: Four key overarching themes emerged from the data analysis that were related to patient perceptions and understanding of pressure ulcer risk. These included Pressure Ulcer Awareness, Importance of Repositioning, Healthy Eating and Risk Interpretation.

Conclusion: Patient perception and understanding of pressure ulcer risk is different from the scientific, professional view. Patient risk perception was based on heuristics and wider personal factors and social influences.

Impact: The study provides important new insights into clinical practice in relation to how pressure ulcer advice and information are provided and interpreted in the community setting.

Reporting Method: Adhered to the Standards for Reporting Qualitative Research (SRQR)

Patient or Public Contribution: A small selection of patients within the NHS Trust in which the research was conducted contributed to the design of the study, in particular some of the interview questions and timing.

Keywords
communitynurse–patient interactionnursing, preventionpatient perspectivespressure ulcer

1 | INTRODUCTION

Pressure ulcers (PUs) remain a key priority area for healthcare providers around the world, representing a patient safety issue. Despite national and international campaigns around awareness and education, their incidence in hospital and community settings remains unacceptably high (Moore et al. 2019). They 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' (EPUAP/NPIAP/PPPIA, 2019).

PUs represent a significant financial burden to healthcare institutions with estimated costs ranging from €1.71 to €470.49 per patient per day (Demarre et al. 2015). Guest et al. (2017, 2020) conducted a retrospective cohort analysis of National Health Service (NHS) patient records of wound treatment and estimated that the annual cost of managing a range of wounds, including PUs, was approximately £8 billion per annum. A high proportion of the associated costs were identified in the community healthcare system. Pressure ulcers are associated with ill health and poor mobility and can have a severe and detrimental effect on an individual's quality of life (Gorecki, Nixon, Madill, Firth & Brown, 2012). Studies have shown that they result in reduced mental and physical function, reduced vitality, social restrictions, and increased pain (Jackson et al. 2017). Increasingly, the focus on prevention has become paramount, with core concepts of PU preventative interventions built into the national and international practice guidelines, which include risk assessment, skin care, nutrition, repositioning/mobilization and the use of appropriate equipment (EPUAP/NPIAP/PPPIA, 2019).

In clinical practice, it has traditionally been the nurse who has been responsible for PU risk assessment and ensuring advice is followed. However, increasingly, there has been a policy shift in emphasis from nurses instructing patients what to do, to a more partnership model with shared decision-making (Truglio-Londrigan & Slyer, 2018). This places increased responsibility on the patient to understand their own PU risk and adhere to preventative measures. This is particularly important in community settings, where due to the limited time capacity and resource of healthcare workers, contact can be episodic, and patients and their families are increasingly required to manage their own care (Wondimeneh, Akalu, Mulegeta & Aynalem, 2020). However, a recent integrative literature review revealed that there is a significant gap in the research around the patient's own understanding and context of PU risk, with the majority of studies focused on the nursing/healthcare professional view (Ledger, Worsley, Hope & Schoonhoven, 2020). Research was also largely based in acute hospital settings rather than community, focused on patients with existing, often severe (Category 3–4) PUs, rather than patients at risk who had never had a PU (Ledger et al. 2020).

Therefore, this topic of understanding how patients conceptualize PU risk and the type and manner in which information is communicated has international relevance for the clinical challenge of preventing PUs.

1.1 | BACKGROUND

Despite the increased emphasis on patient responsibility to carry out key PU prevention measures, such as skin checks, nutrition, repositioning and mobilization in the community (NWCSP, 2021), there is a paucity of literature on this topic. Effective communication with an individual regarding their PU risk and preventative strategies form a key part of enabling self-management. Self-management support has been defined as 'the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support' (Adams & Corrigan, 2003). However, communication issues feature as one of the main areas during routine root cause analysis (RCAs) of PU incidents and are often cited in patient complaints (Stephenson, 2019). A recent Cochrane review found two main types of PU patient education interventions: (i) the provision of information on prevention of PUs such as patient leaflets and (ii) the use of education programmes (O'Connor, Moore, & Patton, 2021). The review revealed some key considerations regarding use of educational materials, including the importance of active patient involvement within the decision-making process itself. The importance of patient involvement has also been evidenced in other healthcare disciplines where shared decisions were more likely to increase motivation and resulting patient adherence, alongside an established patient–nurse relationship built on trust (Shanley et al. 2021).

What does this paper contribute to the wider global clinical community?

- Provides novel insights into how patients contextualize their own risk in a way that is different from the nursing context and the relationship of this to adherence
- New knowledge in relation to the personal and social context in which pressure ulcer (PU) risk is communicated between nurse and patient in the community setting

Studies evaluating the suitability of PU patient leaflets identified that for those with limited health literacy, the readability was poor. In addition, even when good-quality information was provided, participants were largely passive in engaging with this information (Durrant, Taylor, Thompson, Usher & Jackson, 2018). Indeed, this study revealed that despite having access to leaflets, participants had a limited understanding of PU causation and risk. A more recent study that evaluated a PU prevention intervention including a leaflet for older people in the community revealed that whilst knowledge and skills improved within the intervention group, health beliefs around lifestyle measures remained similar between the control and intervention groups (Shanley et al. 2021). This suggests that whilst consideration of aspects such as format, style and language is important in educational materials, there are likely to be additional factors involved.

The few studies that have focused on the role of patients in PU prevention have identified that patient engagement may be influenced by a range of factors which include the complexity of tasks, history of PU damage and the quality of nurse–patient interactions (Latimer, Chaboyer & Gillespie, 2014; McInnes, Chaboyer, Murray, Allen & Jones, 2014). There are also other considerations for varying levels of patient involvement and role, such as ill-health and cognitive ability to participate in preventative strategies (Schoeps, Tallberg & Gunningberg, 2016).The wider literature has also identified that risk communication is an essential part of shared decision-making and evidence-based patient choice. However, the communication of risk is complex, with care delivered to a range of individuals with differing health literacy across several care environments, including the community setting and hospitals (Alaszewski, 2010). Furthermore, the current emphasis within healthcare of providing rational scientific knowledge and mitigation of risk may not be sufficient for action by the patient, as this does not consider wider personal and socio-economic factors (Zinn, 2008). There is a significant gap in the research evidence regarding patient understanding of PU risk and adherence to advice in community settings (Ledger et al. 2020). It is important to further understand the role of the patient within the PU risk assessment and decision-making process and its potential effect on adherence to prevention strategies (Jorgensen et al. 2019).

2 | THE STUDY

2.1 | Aim

The aim of the study was to explore patient perceptions and understanding of their PU risk and how risk is communicated between nurse and patient in the home setting.

2.2 | Design

The study used a pragmatic qualitative research design. A pragmatic perspective allows for a broad set of methods and acknowledges the most practical and appropriate means to address the research question(s), particularly useful in applied professional fields such as healthcare (Savin-Baden & Howell, 2013). Pragmatism offered an experience-based, action-orientated framework on which to address real-world issues of pressure ulcer prevention in the community, providing a descriptive account from an interpretive perspective and a richness of data from within the natural setting itself (Savin-Baden & Howell, 2013). This study utilized a range of data collection methods including observations between nurse and patient as part of routine PU care interactions within their home, semi-structured interviews with patients and collation of education material used during the care episode. This approach was necessary to investigate the different phenomena under investigation including individual experiences, processes and concepts, to add richness and depth to the study (Jamshed, 2014).

2.3 | Participants

A maximum variation sampling approach was used to purposefully select a sample of participants of different ages, ethnicities, genders and geographical locations within a single community NHS Trust (Patton, 2002). Participants were included if they were defined as living in the community and identified as 'at PU risk'. This strategy aimed at capturing data from a range of community-dwelling individuals, with the intention that any common patterns that emerge capture core experiences (Patton, 2002).

The district nurse working in each community nursing team acted as a gatekeeper to identify and recruit potential eligible participants. The district nursing teams broadly used a PU risk tool (the Walsall assessment score 4 or above, Chaloner & Franks, 2013) to determine appropriate patients at PU risk alongside contextual factors such as adult status and living in the community. Participants were excluded if they currently had a PU or lacked capacity to consent or participate in interviews (Table 1).

2.4 | Data collection

The data collection was conducted by a single researcher who was a registered occupational therapist. During the period between January 2019 and March 2020, observations of nursing visits were completed within the participants own home and as part of routine care. Interviews were completed with participants shortly after the observations (no later than 4 weeks post observation). A further three follow-up interviews occurred with three of the participants 2–3 months after the initial observations had taken place.

Observation and recording of the patient–nurse interactions was undertaken which included verbal and non-verbal cues which were documented on an observation guide alongside the use of a dictaphone. The observation guide included noting aspects such as the type of interaction, that is, instructive/directive, types of non-verbal interaction noted, for example, eye contact/ gaze and other activity observed such as demonstration. This guide was a modified version from a similar study on nurse–patient interactions (Newton, Henderson, Jolly & Greaves, 2015).

In-depth face-to-face interviews with patients within 2–4 weeks following the district nursing visit using a semi-structured approach to facilitate discussion and allow the opportunity for participants to talk freely about their experiences. An interview guide was used (Table 2) and the questions focused on key themes of patient perception and understanding of PU risk, how risk is communicated by the nurse and factors affecting uptake of advice. The interviews lasted between 30 and 60 minutes and were digitally recorded on a dictaphone. Patient-facing documentation was also collected for analysis from the setting during the observation to enhance richness of the phenomenon under investigation (Lofland, Snow, Anderson &

TABLE 1 Participant inclusion and exclusion criteria.

Sample inclusion criteria	Sample exclusion criteria
Over 18 years of age	Communication difficulties
Known to local District Nursing Team(s)	Lack capacity to consent to participation
At risk of pressure ulcer	Existing pressure ulcer

TABLE 2 Characteristics of patient sample.

	Interview guide Questions
1.	Can you tell us a bit about how you think the District Nurse visit went?
2.	What are your thoughts or concerns following the visit?
3.	How well do you feel your thoughts, ideas and concerns were addressed?
4.	How involved did you feel in the decision-making?
5.	What do you feel you learnt in relation to pressure ulcer and risk (or 'bed sore')?
6.	What is your understanding of your PU risk (or 'bed sore')?
7.	What impact do you think having a PU (or 'bed sore') would have on your life?
8.	Do you feel you have a role in PU prevention? Can you tell me more about that? How confident do you feel in your role?
9.	In what way – if any - have you acted on the advice and recommendations made?
10.	How realistic do you think the advice you have been given is?
11.	What do you feel may get in the way of you (or others) being able to carry out the advice given by the nurse?
12.	Is there anything else you would like to mention before we finish?

Lofland, 2006). This was a single document, the patient information leaflet, which was referred to by the nurse during the consultation and given to the patient in all visits observed.

2.5 | Ethical considerations

Ethical Approval was gained from the University ethics committee through the online ethics process (ERGO No. 41350) with the Health Research Authority (HRA) NHS Ethical approval granted in October 2018 (IRAS ref 248,039). The host community health Trust granted a research passport and access to approach participants for the study. Ethical considerations included consent process, anonymity and confidentiality, right to withdraw and GDPR data protection. Specific consideration was also given to the research methods used, such as the type of observation, to minimize participant burden.

2.6 | Data analysis

Audio recordings from both the observations and interview data sets were transcribed verbatim by the lead researcher. An iterative approach to analysis was undertaken, with all data sets entered into the ATLAS-ti software platform (ATLAS.ti). The data sets were collated and extracted in the following way(s):

- ***Observational data***. This data set comprised both the dictated audio transcripts and the observation guides that were completed during the observational visits. Both data sets were entered into the data analysis software package (ATLAS-ti) and included within the data analysis.
- ***Interview data*** comprised the dictated transcripts which were also entered into the ATLAS-ti data software package and included within the data analysis.
- ***Patient information leaflet***. A copy of the patient information leaflet that was collected from the observational visit(s) was manually analysed with pens and post it notes and initially coded, screenshot taken and uploaded into the data analysis software package and included within the data analysis.

All data were analysed using the principles and steps of thematic analysis to identify themes and patterns of meaning across data sets in relation to the research aim (Braun & Clarke, 2013). In terms of type of analysis, an inductive approach was used as the intention was to generate analysis from the data itself rather than pre-conceived theory or concepts. Braun and Clarke's (2013) six steps were used to guide the analysis using the following sequence: data familiarizing, generating initial codes, searching and reviewing themes, defining and naming themes and producing the report. The primary author (LL) who was also lead researcher in the study conducted the analysis. Emergent themes were discussed and reviewed by the wider research team throughout this reflexive and iterative process. These data were analysed both manually and through use of ATLAS-ti data analysis software package. Firstly, the transcription data from the research interviews were analysed and initially coded, followed by the observation transcriptions, the observation guides and, finally, the patient information leaflet. Following data transcription and uploading, ATLAS-ti was used to facilitate the creation of initial codes across and within each of the data sets. There were 52 documents analysed in total and 104 overall initial codes identified.

Data analysis occurred alongside data collection. Patients continued to be included until data saturation was achieved. For the purposes of this study, saturation was understood to have been achieved at the point at which no new themes were evident from observations or interviews that contributed to the understanding of the topic (Saunders et al. 2018).

2.7 | Rigour

The Standards for Reporting Qualitative Research (SRQR, O'Brien, Harris, Beckman, Reed & Cood, 2014) were used to guide the process to ensure rigour within the research and transparency in all aspects of the qualitative research process. To ensure reflexivity, the researcher used a reflective log throughout, to challenge any assumptions and to be aware of positionality as a white, female, healthcare professional. The researcher was not involved in patients' treatment or care decision making and was unknown to participants prior to the study. All data were transcribed verbatim by the researcher to remain close to the data and immersed in narratives that used patients' own words. Transcripts and themes were discussed within the team of researchers (JH, LS, and PW) to increase rigour.

TABLE 3 Characteristics of Patient Sample.

Patient pseudonyms	Agecategory	Occupation	Ethnicity	Gender	Medical condition	Mobility status	Lives/with	Care input
Ann	66+	Retired	Afro-Caribbean	Female	Diabetic	Mobilewith trolley	Alone	None
Alan	66+	Retired	White	Male	Arthritis Previous Stroke	Wheelchair user	Wife	Wife
Beryl	66+	Retired	White	Female	Amputee	Wheelchair user	Husband	Husband
Ben	66+	Retired	Asian	Male	Arthritis	Mobile with stick indoors	Family	Wife & daughter
Belinda	30 -60 yrs	Unemployed	White	Female	Diabetic	Mobile	Mother	Mother
Colin	66+	Retired	White	Male	Arthritis	Mobile with stick indoors	Partner	Partner
Catherine	66+	Retired	White	Female	Previous Stroke Arthritis	Mobile indoors	Alone	Paid carers
Dave	66+	Retired	White	Male	Visual problems	Mobile with frame	Alone	Paid carers
Diana	30-66 yrs	Unemployed	White	Female	Guillan–Barre Visual problems	Mobile with rollator frame	Alone	Paid carers
Dee	66+	Retired	White	Female	Arthritis	Mobile	Husband	Paid carers
Dan	30-66 yrs	Retired	White	Male	Arthritis	Mobile Indoors only	Alone	Paid carers
Eva	66+	Retired	White	Female	Diabetes	Mobile indoors only	Alone	Paid carers
Eric (PU history)	66+	Retired	White	Male	Arthritis	Mobile with Frame	Wife	Wife
Frank (PU history)	66+	Retired	White	Male	Paraplegia	Wheelchair user	Alone	Paid carers
Gwen	66+	Retired	White	Female	Arthritis	Mobile with Frame	Alone	Paid carers

3 | RESULTS

A total of 15 participants were recruited to the study (Table 3) from district nursing teams from across the geographical locality. Participants were mainly elderly retired individuals, who were over 66 years of age and of white ethnic origin. Eight were female and seven male with a range of clinical presentations including arthritis, diabetes and neurological conditions. The vast majority (86%, *n* = 13) of participants in the study had mobility issues and had carer support (93%, *n* = 14). Two had a previous PU history, although none had any existing skin damage. All participants were identified as 'at risk' (score of 4 or above) of developing a PU. Table 3 presents the sociodemographic characteristics of participants.

There were four overarching themes to emerge from the data analysis (Figure 1), that related to patient perceptions and understanding of PU risk and how risk is communicated between nurse and patient in the home setting, which included:

1. Pressure Ulcer Awareness
2. Importance of Repositioning
3. Healthy Eating
4. Risk Interpretation.

These will each be presented with associated quotes from participants.

3.1 | Pressure ulcer awareness

The theme 'pressure ulcer awareness' is how individuals gain an understanding of what a PU is, preventative measures and the potential consequences of acquiring a PU. Most participants in the study gained awareness and basic understanding from the nursing visits and whilst there was limited specific knowledge of PUs such as skin aetiology and level of skin damage, the importance of checking skin for redness was evident within the patient narratives:

'they go on and on about it, do you mean like a bed sore? well yes, the nurses they tell me about them and to check your skin' (Ben).

'the nurses, you know they go on about it all the time and what to do and not to do and I know I have to check my skin for red areas and I know I do not want to get one' (Beryl).

Participants gained a sense of imperative and importance from the nurses in avoiding PUs through routinely checking their skin. In relation to the language used, the majority of patients did not immediately understand the term 'pressure ulcer' and therefore the lay term 'bed sore' was used during the interviews. The use of medical terminology was therefore not helpful to patients in the study in aiding their understanding of PUs in the context of their daily lives and lay understanding.

Personal understanding and PU knowledge was also influenced by the experiences of family and friends, particularly if participants had previously had a PU. Only two participants in the study had a

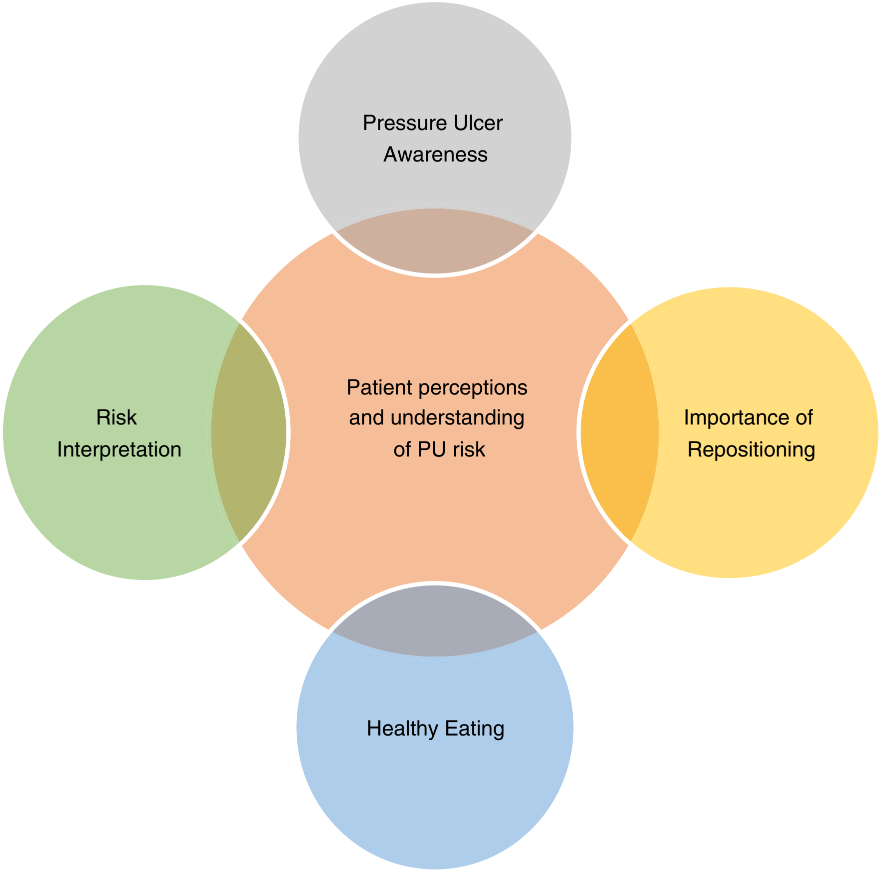

FIGURE 1 Overarching Themes from the Qualitative Analysis.

history of PU, which gave them a deeper sense of foreboding and fear:

'I do not want to experience that ever again, the pain was so terrible you see, so now I am really careful so I do not ever get any again' (Frank).

For those with previous experience, there was more vigilance in carrying out preventative measures and avoiding them at all costs:

'when I did get an ulcer years ago, you know it was really awful and then I had to stay in bed full-time, so now I follow all the advice and do everything I can to avoid them' (Eric).

Several participants (5 out of 15) described how they knew from others within their social circle that getting a PU was not a positive experience and something to be fearful of:

'I've heard about bed sores from me mates properly and what they do, nasty horrible things… try to avoid them that's what I think best' (Dave).

'I don't want any of them nasty sores…I knew a neighbour once who got them and they were horrible so no, I am not going to get them, I really am not' (Colin).

There were no reports of positive experiences of PUs either directly or through the experience of others. Where individuals did not know anyone who had had a PU or had never had one themselves, there was a certain ambivalence towards getting one:

'I do not really think I will come to harm, I've not yet and I do not know anyone who has got one' (Ann).

These findings reveal important differences between those with and without prior experience. Participants made heuristic judgements around their understanding of PUs and whether to act on the advice given. In relation to how PU advice and information are provided, most participants (12/15) reported that they gained awareness about PUs from the nursing visit(s) through verbal instruction and demonstration by the nurse for example skin checks and equipment usage. Interestingly, only one stated that they had read the PU information leaflet despite it being routinely handed out by the nurse as part of preventative education. Several participants also described visual difficulties and other challenges, such as fatigue, that made it difficult or impossible for them to access the information on the leaflet:

'I've been given a very good book by one of the nurses, but I could not read it because of my eyesight… Yeah it was all about the ulcers and how to stop them I think but it's no use when you cannot read' (Diana).

On evaluation of the patient leaflet, it revealed the same PU awareness information topics and key prevention messages around skin checks, nutrition and changing position. However, the leaflet was not used by the majority of participants in the study. Despite this, participants did not mention difficulties reading or interpreting the leaflet to the nurse. This reluctance to disclose these difficulties related to aspects such as pressured time issues alongside the lack of 'space' within the nursing encounter to discuss such matters:

'well I haven't said anything, they're so busy you see and there never seems to be a window of opportunity to say I can't read it' (Diana).

When asked what is most useful in terms of advice and information, most participants (13 out of 15) described how they felt meaningful discussion with the nurse was most beneficial, alongside physical demonstration where appropriate:

'I think properly sitting and talking to us and showing us what to do is better because you do not really sit there and read leaflets do you, but if you discuss it and shown how to do something you are more likely to do it' (Dee).

Therefore, participants valued verbal instruction and conversation with the nurse in aiding their understanding of PUs and that meaningful discussion was more likely to encourage adherence to the advice, as opposed to the use of a leaflet. The leaflet used within wider discussion with the nurse helped with their understanding for a few participants who did not have visual difficulties. However, for others who had fatigue and visual problems, it provided no meaningful purpose.

3.2 | Importance of repositioning

A key theme to emerge was the importance of moving and changing position. Over half of participants understood and identified the importance of regular movement and maintaining a good posture (10/15):

'it's about not just lying in the same position all the time, you know my chair or my bed, its knowing to move and keep moving around' (Alan).

Whilst there was understanding by most around the importance of repositioning, there were some practical challenges to carrying out strategies for several participants:

'I try you know, I try to move as I sit on this sofa all day otherwise and I know I need to move…but it's really difficult with the pain' (Colin).

'there it goes again, you see, it's like this constant awful thing, it grips me and I cannot tell you the pain, it's terrible and that's it then for that day I cannot move or walk around or do much for myself' (Eva).

The presence of pain creating a challenge for participants in carrying out the repositioning advice was a significant finding in the study. There were also other factors that affected the uptake of advice to reposition, such as the fear of falling. From the patient narratives, the risk of falling to them was perceived to be greater than the risk of developing a PU. This fear of falling was reported by two-thirds of participants in the study. Therefore, whilst the PU risk was understood, participants made pragmatic, trade-off decisions as to what was the most sensible course of action for them:

'you see I do not really like it, because I'm frightened of falling out of bed you see, so I know I've been told by the nurse time and time again my skin risk if I sleep in the chair, but for me it's the best option so that's what I choose to do' (Diana).

There were also differences around acceptance of advice in relation to the illness journey and how for some, their responses to the nursing advice had changed over time. This may be associated with acceptance of healthcare advice changing alongside longer term acceptance of a condition, with participants describing their changing stance whilst living with the effects of comorbidities for many years:

'I never really understood you see, when I was first diagnosed I was coming to terms with so much else, but as the years have gone on, well I am more accepting now of what the nurses say' (Ann).

3.3 | Healthy eating

The theme 'healthy eating' relates to how participants understand the importance of good nutrition and eating well. Most participants generally understood the importance of eating well and keeping hydrated to prevent PUs and associated eating 'proper meals' such as meat, vegetables and potatoes with strength and good health. Participants described how they ensure they eat a good meal in order to keep healthy and avoid sores:

'well I have my breakfast and I get the carers to give me the fruit…I have a sandwich later and more fruit…then my meat and two veg later, so I eat well like, makes me strong' (Ann).

When asked why this is important, she describes how particular food such as fruit gives her the strength and nutrients she needs to stay healthy:

'well I have always eaten *well, it gives me strength you know to do what I need and the vitamins they good for you…keep us healthy like me elder say…so I always do it' (Ann).*

There were also cultural aspects around diet, where a participant described how in the afro-Caribbean culture, eating lots of fruit was encouraged to nourish and prevent ill health. Similarly, another participant described how the importance of eating well was instilled in her when she was growing up:

'we were brought up on proper dinners, always have your dinner and plenty of veg…have a good dinner every day keeps you healthy' (Dee).

Some participants, whilst being aware of eating well and good hydration for PU prevention, were influenced by other, more broad health beliefs in relation to eating well to stay strong and to prevent ill health. They also described good and bad food choices and how it could be difficult to consistently choose the best option:

'I do try to eat healthy and what they say but it is not easy and sometimes I just fancy some of the wrong things if I am honest and I just have to have a bit of what I fancy, it helps my mood you see' (Beryl).

There was a sense that it was not always possible to follow the nursing advice around eating well to prevent PUs due to other factors, such as having a poor appetite and fatigue.

'mostly I do have days when I am really tired, so it all depends on that. I know I need to follow what the nurse has said with my eating, but I am so tired and just not hungry' (Ben).

3.4 | Risk interpretation

The theme 'risk interpretation' is how responsibility and risk were understood by participants, including control and lay expertise in relation to experiential knowledge. The understanding of PU risk was influenced by broader lay interpretations of health and illness, with participants associating aspects such as age and hospital admissions as factors that increased risk:

'my friend went in, you know to the hospital and she was ok before she did, but then she was sick and there for some time and then she got one and it was awful, so I do think being in hospital has something to do with it, I do not think it happens in the home' (Ann).

Another participant described older age as a risk factor in getting PUs:

'I heard a friend of mine, their old mom got one, it's an age thing is not it really, the older you are you know, chances are it's not going to happen to me' (Dan).

When asked if they felt they had a role in PU prevention, there were interesting differences between those who felt that they were responsible and others who relinquished control to the nurse. Here, Colin and Gwen describe their role in prevention and the responsibility they felt in relation to this:

'yes I mean it is me, it's my life and so it is up to me to ensure that I follow the advice and so I do keep my fluids up and eat well, it's not up to anyone else' (Colin).

'it's my job to do it, I mean they (Nurse) remind me how to look after myself and all that but I take the role seriously on my shoulders (Gwen).

There was also a sense of autonomy in how the advice given manifested itself in their day-to-day decisions:

'I know I should, I should be eating well to look after my skin and the nurses keep telling me that I should eat well and I do take my part seriously but put it this way, I do not always follow it to the letter, I do what I feel is best' (Eva).

'I can do it, too right, I struggle but always get there in the end so the walking and making sure I move, yes I do it and it feels good' (Colin).

In contrast, some participants described a relinquishing of control over decisions and actions where some participants reported doing what they were told to do, even if they had initially been reluctant:

'they tell me about my legs and me and what I need to do and I end up, well I just do it, I just do what they tell me' (Gwen).

'if I take the cushion for example, I did try to say but over the years its always the same so to speak, so I've given up really and now I just use the one they said to use all this time' (Dee).

In these accounts, there was an inevitability expressed by some participants around having to follow the nursing advice, where individuals had given up trying to state what was important to them and how this might impact on them following advice. This differed from others, who over time had become more assertive in understanding their condition and their 'lay expertise' and felt that their contribution of knowledge was equally valid to the nurses. Here, Frank describes his changing stance:

'I guess early on in my diagnosis if you ask me then I did not really know any different you see so I went with what the nurse said, but now, well over the years I get to know what is right for me, if you like I am an expert about my situation and so in that sense, I do now speak up if I do not agree' (Frank).

Similarly, with Beryl where she describes how the knowledge she had developed over the years about her condition is as important as the professional nursing information:

'the nurses do know a lot, of course they do with all their fancy numbers and stats and that, but all of it don't mean anything if they don't understand me, I have lived with this for years and I know what I am talking about' (Beryl).

These participant accounts suggest that the scientific risk information alone may be insufficient to secure adherence and there are other factors that are important from the patient perspective in relation to lay risk interpretation. This includes the influence of family and sense of control over healthcare decision making.

4 | DISCUSSION

The study has explored patient perceptions and understanding of risk using a qualitative study of community-dwelling adults at risk of PUs. The findings revealed four core overarching themes relating to patient perception of risk and factors associated with adherence to advice. The findings revealed that community-dwelling individuals at risk of PUs understand and have knowledge of basic PU prevention, which included the importance of eating well, moving position and skin checks. However, the study revealed limitations in medical terminology and the use of scientific risk language which inhibit patient understanding. This is reflective of other studies where language used by the nurse around risk is not always understood by the patient which in turn affects the interpretation and adherence to preventative advice (Schoeps et al. 2016).

In relation to patient perceptions and understanding of risk, participants drew on a much broader context for risk than the scientific knowledge provided by the nurse. Whereas the nursing focus was on scientific risk avoidance, participants in the study made risk decisions based on heuristics within their daily life, including routine and other lifestyle commitments, often balancing other health risks. For example, when discussing the importance of repositioning, whilst many of the participants understood the importance of this, factors such as the presence of pain and fear of falling were significant barriers to changing position. The presence of pain caused by PUs has been shown to create a challenge for patients in carrying out prevention strategies such as repositioning (Ledger et al. 2020). However, this study has revealed new insights into how chronic pain and the impact of living with other long-term conditions also have an impact on repositioning in individuals at PU risk. The fear of falling is also an important finding, which can draw parallels with other studies which have cited fear of falling, for example, in patient adherence of leg ulcer management (Van Hecke, Vergaegh, Grypdonck, Beele & Defloor, 2011). However, to the authors' knowledge, the present study is the first to identify this factor in the context of PU prevention in the community.

The patient context of risk was personally and socially grounded, influenced by the experiences of family and friends. Where PUs were negatively perceived, participants had largely gained this view from others within their social circle and where participants had a direct experience themselves. This created a heightened sense of fear and vigilance was greater. This was also reported within other studies that have shown that patient perception of health risk appears to be influenced by wider personal and social perceptions, such as prior experience and existing knowledge and beliefs (Roberts et al. 2017, Grauman, Hansson, James, Veldwijk & Hoglund, 2019). There were also other risk determinants participants described in relation to their wider health beliefs, such as PUs being a hospital-related issue and associated with 'ill people' or the elderly. In this way, participants distanced themselves from the perceived threat of developing a PU through the use of heuristics. These findings therefore reveal the importance of the influence of others, such as family and friends and lay health beliefs on the interpretation of PU risk. This also highlights the importance of the wider context for how health-related information is communicated to patients, particularly cultural considerations in knowledge translation, identified in other studies (Shanley et al. 2021). There were also interesting findings in relation to self-efficacy and control, with some participants reporting confidence in what they needed to do and asserting their lay 'expertise' within decision making, whilst others took a more passive role.

The present study also revealed that although the patient information leaflet was routinely handed out to all participants during the nursing visit, participants did not use it in most cases. This was often due to visual and/or cognitive challenges. This finding is important in consideration of how health literacy challenges such as visual difficulties and fatigue affect patient uptake of health information and is well documented in other areas of healthcare practice, particularly literacy and older adults (Chesser, Woods, Smothers & Rogers, 2016). Some of these health literacy challenges for patients around use of leaflets and hence poor uptake of information leaflets link to previous studies (Durrant et al. 2018; Shanley et al. 2021). It is common practice that patient information leaflets are used by nurses as a means of both educating patients about their condition and to encourage participation in preventative measures (Fletcher, 2020). However, this study concurs with the key findings of other studies that it is a poor medium of communication for most patients and this approach should be reconsidered, particularly in transitory settings such as the community (Durrant et al. 2018; Wynn, 2020). Indeed, most participants (13 out of 15) reported that useful advice came from discussion with the nurse about their personal situation and what was meaningful to them. This is an important finding in relation to how advice is provided and the effectiveness of different approaches. It is evident from the study findings that participants valued meaningful discussion with the nurse and there is an important prerequisite for patient participation in prevention strategies that is embedded within the nurse–patient relationship and interactions.

5 | IMPLICATIONS

The provision of scientific, educational information alone may not be sufficient to secure understanding and patient adherence, due to other contextual factors and patients' use of heuristic decision making. Importantly generalized pain, fear of falling and other factors such as visual problems, fatigue and long-term conditions affected participants' ability to adhere to advice, but this was rarely discussed with the nurse during the clinical encounter. A modernized empowered healthcare system should recognize citizenship and wider personal and social aspects to risk within their patient safety approaches, policy and clinical implementation (Sheridan et al. 2021). It is evident that further research is needed to understand and support the development of shared decision making in PU prevention practice and to develop meaningful ways of communicating risk with and alongside patients. These approaches need to incorporate the broader lay interpretations of risk and constraints on the acceptance of knowledge and enactment of advice.

There needs to be a fundamental change from PU prevention strategies that are focused on the instructing patients what to do to prevent harm by appealing to scientific 'best evidence' (Donaldson, Riccardi, Sheridan & Tartaglia, 2021). If patient context and interpretation are missing from the nursing encounter, adherence to PU prevention strategies may be limited. This study also has wider relevance to securing patient adherence where diagnosis of a health condition is new or where the focus is on prevention rather than on treatment of an existing condition.

6 | STRENGTHS AND LIMITATIONS

The majority successfully recruited were elderly retired, over 66 years of age and of white ethnic origin. Therefore, it is possible that further research with a more diverse ethnicity and age demographic might add some different perspectives. However, it does provide key insights into patient understanding and context of PU risk from patients' own experience, which is extremely relevant to clinical practice. The study relied on busy clinicians agreeing to be 'gatekeepers' for suitable participants and this remained a challenge. To mitigate this, additional recruitment time was built into the study. The selection of eligible patients through the nursing team could have resulted in selection bias, although the strict inclusion and exclusion criteria mitigated this. In addition, whilst the study used a maximum variation sampling strategy (Patton, 2002) to capture and describe key themes that transcended across a varying group of participants, the sample was largely elderly, retired and of white ethnicity. Observation bias with the researcher being present at the nursing visits may also have resulted in some of the nurses and/or patients responding differently. Whilst attempts were made to minimize this through consideration of where researcher was placed within the encounter, it is possible that this may have affected participant interactions and responses.

7 | CONCLUSION

The narratives from patients in the study have shown that they had a basic understanding of PU risk and preventative measures, including the importance of repositioning, carrying out skin checks and healthy eating. New insights into how patients contextualize PU risk revealed distinct differences to the professional context, with patient risk perception based on lay heuristics and wider personal factors and social influences, which influenced adherence. Generalized pain and the fear of falling were also significant factors in patients deciding whether to follow nursing advice. Indeed, it was evident that patients interpret risk differently from healthcare professionals, including the poor uptake of medical information leaflets. This is important in the context of current clinical practice where risk conversations and education are predominately professionally led and evidence-driven. Further research is needed to understand and adopt a more person-centred approach to PU risk assessment and patient education and participation in preventative care.

AUTHOR CONTRIBUTIONS

Lisa Ledger was responsible for the study design, implementation and analysis. Lisa Ledger also led the preparation of the manuscript and is also lead author. Peter Worsley, Jo Hope and Lisette Schoonhoven were involved in the conception and design of the study and supported data analysis and manuscript preparation.

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CONFLICT OF INTEREST

There are no conflict of interest to declare.

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Research data are not available.

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