**MAIN TEXT File**

1. **Introduction**

The prevention of pressure ulcers remains a key priority area for healthcare providers around the world, representing a patient safety issue (Hughes, 2008). Pressure ulcers/injuries (PUs) 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). They typically occur over bony prominences and/or due to prolonged contact with medical devices (EPUAP/NPIAP/PPPIA, 2019). Despite national and international campaigns around awareness and education, their incidence in hospital and community settings remains high (Moore et al. 2019). In recent years, there has been a shift in emphasis to prevention and self-management, with increasing responsibility placed on patients to manage their own care within community settings (Wondimeneh, Akalu, Molegeta & Aynalem, 2020). Typically, this includes education and advice to the patient and/or carer around PU prevention strategies including aspects such as nutrition, repositioning and use of appropriate equipment. However, there is limited research on patient perception of pressure ulcer risk and the relationship of this to adherence.

1. **Background**.

In the UK, over 700 000 patients are affected by pressure ulcers each year, and 180 000 of those are newly acquired each year. Guest et al (2020) in a cohort study evaluating the burden of wounds in the UK, found that annual NHS cost of wound management was £8.3 billion.

Whilst the cost to the patient and their families cannot be easily quantified, studies have shown that PUs result in reduced mental and physical function, social restrictions and increased pain (Jackson et al. 2017: Gorecki et al. 2009). Increasingly the focus on prevention has become paramount, with core concepts of preventative interventions built into the national and international practice guidelines, which include PU risk assessment, skin care, nutrition, repositioning/mobilisation, and the use of appropriate pressure redistributing equipment (EPUAP/NPIAP/PPPIA, 2019).

Central to a PU prevention approach is accurate risk assessment conducted by the health care professional. This involves using standardised risk assessment instruments, including skin assessment and inspection alongside discussion with the patient. However, a recent systematic review found that it was inconclusive whether risk assessment with a common tool makes a difference to pressure ulcer incidence, when compared with training and risk assessment using clinical judgement, or risk assessment using clinical judgement alone (Moore and Patton, 2019).

In clinical practice, it has traditionally been the nurse who has been responsible for PU risk assessment and providing advice to be followed by the patient. However, increasingly there has been a policy shift in emphasis from nurses instructing patients what to do, to a partnership model with shared decision-making (Truglio-Londrigan et al. 2018). This shift places increased responsibility on the patient to understand their own PU risk and carry out 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, with patients and their families increasingly required to carry out advice and manage their own care (Durrant et al. 2018).

However, there are issues with patient non-adherence to PU advice, particularly in community settings that generate further risk to patients including further skin breakdown and other complications such as muscle wastage and reduced function (Shanley et al. 2021).A recent systematic review of the psychosocial factors impacting community-based PU preventionidentified several key influences that may affect the ability to achieve concordance between individuals and healthcare professionals, including social influences and beliefs about capabilities (Heywood-Everett et al. 2023). The review found that a concordant relationship was facilitated by the healthcare professional’s motivation to work alongside patients and their priorities and the interpersonal skills to build rapport and increase trust (Heywood-Everett et al. 2023).

The few studies that have focused on the role of patients in PU prevention in the community setting 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 et al. 2014; McInnes et al. 2014). There are also other considerations for varying levels of patient involvement such as ill health and cognitive ability to participate in preventative strategies (Schoeps at al. 2016). However, currently there is a significant gap in the research around the patient’s own understanding of PU risk, and how contextual factors such as environment and wider health status might play a role in risk perception. Indeed, most studies to date have focused on the professional nursing view (Ledger, Worsley, Hope & Schoonhoven, 2020). There is a lack of evidence around the type of nursing approach used and nurse-patient interactions within the setting itself and how PU risk is negotiated. It is important to understand this to determine the context in which PU risk information is communicated and the relationship of this to adherence behaviour.

3 **The Study**

* 1. Aim(s)

The aims of the study were to identify potential factors affecting patient adherence to preventative advice and to explore how pressure ulcer risk is negotiated between nurse and patient in the community setting.

4**. Methods/Methodology**

4.1 Design.

The study used a qualitative research design using a pragmatist approach. This involved observations of the interactions between nurses and patients during routine PU care within the patient’s home, semi-structured interviews with patients following observations, and evaluation of education material used during the interaction.

4.2 Theoretical Framework.

The intention of the research was to remain open and inductive to investigate both patient perceptions of risk as they unfold within the decision-making process, as well as the factors affecting adherence behaviour. A broad conceptual framework was generated on which to guide the study, from the findings of an integrative literature review, evaluating patient perception of PU risk, involvement in decision-making and adherence behaviour (Ledger et al. 2020). However, within the field of PU prevention, there are limits to the current literature in informing the conceptual framework needed to address the aims of this research. Therefore, where relevant, elements from the wider literature were included, such as patient perception of risk and involvement in decision-making, health behaviour models of adherence and self-management literature.

In relation to patient perception of PU risk, wider health literature revealed important differences between lay and professional risk (Lipworth et al. 2010). Here patient ‘lay’ risk is based more broadly around priori ‘personal’ experience and the importance of family attitudes to keeping healthy and lifestyle choices (Grauman et al. 2019). Regarding patient involvement in decision-making, the importance of shared decision-making between nurse and patient was a significant theme to emerge from the integrative literature review (Ledger et al. 2020). The studies in the review revealed patients did not feel listened to as part of PU risk conversations with the nurse (Jackson et al. 2017; Latimer et al. 2013). Importantly, the integrative literature review also revealed a link between patient involvement in decision-making and subsequent adherence (Ledger et al. 2020).

Existing research and behavioural models have largely focused on adherence in the context of treatment of an existing condition or problem rather than on prevention (Liu et al. 2021). Additionally, broader concepts of adherence were also included in the theoretical framework, in particular the work of Rosenfeld and Weinberg (2011) that recognises the home setting and ways in which the practical contingencies of daily life may facilitate or constrain adherence. The authors suggest that existing concepts of adherence may be limited in their focus on patient motivation and knowledge, rather than these broader social aspects (Rosenfeld and Weinberg, 2011).

4.3 Sampling and Recruitment.

A maximum variation sampling approach (Patton, 2002) was used to purposefully select a sample of participants of different ages, ethnicities, genders, and geographical locations within a single community NHS Trust in England. 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 people living in the community 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 eligible participants. The people were sampled over time, with the intention to reflect a range of ages, ethnicities and genders.

4.4 Inclusion and/or Exclusion Criteria.

The district nursing teams used a PU risk tool (the Walsall assessment score 4 or above) 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 pressure ulcer or lacked capacity to consent to or participate in interviews.

4.5 Data collection.

Data collection was conducted by a single researcher who is a registered occupational therapist. During the period between January 2019 to March 2020 observations of nursing visits were completed within the participant’s own home and as part of routine care. Interviews were completed with participants no later than four weeks post observation.

Observation and recording of the patient-nurse interactions was undertaken to document verbal and non-verbal cues using an observation guide alongside recording audio with a dictaphone. The observation guide included recording aspects such as the type of interaction i.e., instructive / directive, types of non-verbal interaction noted e.g., eye contact/ gaze and other activity observed such as demonstration. It was adapted from a study of nurse-patient interactions (Newton, Henderson, Jolly & Greaves, 2015).

In-depth face-to-face interviews took place 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 talkfreely about their experiences. The questions focussed 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 – 60 minutes and were recorded on a digital dictaphone. Patient-facing documentation was also collected for analysis from the setting during the observation. 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.

4.6 Data Analysis.

Audio recordings from both the observations and interview data sets were transcribed verbatim by the lead researcher, and data from the observation guides entered into the ATLAS-ti software platform (ATLAS.ti, Cleverbridge, Germany). The patient information leaflet collected from the observational visit(s) was photographed and uploaded into the data software package. All data was 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 and Clarke, 2013). For the purposes of this study, inductive Thematic Analysis was used as the intention was to generate analysis from the data itself rather than pre-conceived theory or concepts (Braun and Clarke, 2013.) Emergent themes were discussed and reviewed by the wider research team throughout this iterative process.

Data analysis occurred alongside data collection, enabling an ongoing evaluation of data saturation. Patients continued to be recruited until data saturation was achieved. For the purposes of this study, saturation was understood to have been reached at the point at which no new themes were evident from observations or interviews that contributed to the understanding of the topic.

4.7 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 redacted). The host NHS Trust granted a research passport and access to approach participants for the study. Ethical considerations included informed consent, anonymity and confidentiality, right to withdraw and GDPR data protection compliance. Specific consideration was also given to the research methods used, such as the type of observation, to minimise participant burden. To ensure patient confidentiality, pseudonyms were used throughout the research process.

4.8 Rigor and reflexivity.

The Standards for Reporting Qualitative Research (SRQR, O’Brien et al. 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 was transcribed verbatim by the researcher to remain close to the data and immersed in narratives that used participants’ own words. Transcripts and themes were discussed within the team of researchers to increase rigour.

5. **Findings**

A total of 15 participants were recruited to the study (see **Table 1**) 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. Also, the majority had carer support (93%, n = 14). Two had a previous PU history. All participants were identified as ‘at risk’ (score of 4 or above) of developing a pressure ulcer.

**Table 1: Characteristics of patient sample**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Patient Pseudonyms  | Age Category | Occupation | Ethnicity | Gender | Medical condition | Mobility status | Lives/ with | Careinput |
| Ann | 66+ | retired | Afro-caribbean | Female | Diabetic | Mobile with trolley | alone | none |
| Alan | 66+ | retired | White | Male | ArthritisPrevious 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 -60yrs | 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 StrokeArthritis | Mobile indoors | alone | paidcarers |
| Dave | 66+ | retired | White | Male | Visual problems | Mobile with frame | alone | paid carers |
| Diana | 30-66yrs | unemployed | White | Female | Guillan BarreVisual problems | Mobile with rollator frame | alone | paid carers |
| Dee | 66+ | retired | White | Female | Arthritis | Mobile | husband | paid carers |
| Dan | 30-66yrs | 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 |

The findings of the study revealed factors that affected patient adherence to advice. These were grouped into five overarching key themes: Patient decision-making, difficulty carrying out advice, carer involvement, trust in the nurse, and the nursing approach. These factors are complex, individualised and dynamic in nature as they are context specific and varied day to day.

**5.1 Patient Decision-Making**

Patient decision-making is a central theme that captures whether patients decide to act on the nurse’s advice, and the nature of power relations between nurse and patient. Several patients in the study described how they weighed the potential benefits and disadvantages to following advice.

*I won’t just do what the nurses say, I have to know its right for me, if I can fit with everything else ok in the day and then all things considered I may give it a go (Eric).*

Importantly where patients reported more involvement in the decision-making process, they were more likely to follow the nurse’s advice:

*I feel it’s a deal breaker or maker, if I feel more involved about what is being said then of course I am more likely to take it on board and do it (Belinda).*

Within this broad theme, there were other patient-related factors that affected advice following, including fear of falling, equipment preferences and daily routine and lifestyle. Two thirds of participants reported fear of falling as significant in their decisions around the use of preventative equipment, with the risk of falling perceived as greater than the risk they associated with not following PU prevention advice:

*You see I don’t really do it, because I’m frightened of falling out of bed. So, I know I’ve been told by the nurse time and time again about my skin risk if I sleep in the chair, but I have to do what I feel is best, so that’s what I do (Diana).*

In relation to decisions around PU equipment usage, patients in the study described the importance of their comfort and ability to function whilst using it. Likewise, prior experiences with specific devices, positively or negatively affected acceptance of equipment options. These decisions around equipment used by patients were not based on scientific risk outlined by the nurse, but on personal ‘lay’ judgements and weighing up complex risks.

*you see I’ve had a lot of cushions over the years, but I know which are too hard so I wouldn’t use them and which ones I can still get in and out me chair with, a little difference makes a big difference (Eric).*

Several patients in the study described how important daily routine and maintaining independence in activities were to them. For example, Beryl here describes her love of going to the dance hall and how this takes priority over any nursing advice given:

*I can’t do much but I can watch the dancing you see and so, if it means I am all day in my wheelchair too long, well then that’s that (Beryl).*

Therefore, there were many factors patients weighed up when considering whether to follow the nursing advice, including equipment preferences, maintaining independence and daily routine and lifestyle.

**5.2 Difficulty Carrying out Advice**

This key theme describes the range of different factors that may affect patients’ ability to act on day-to-day, including the presence of pain, fatigue, mood affects, and for some individuals, difficulty remembering advice:

*I struggle to remember what she said to me, from visit to visit, it’s hard to remember and I know she said something about it, but I don’t really know so I can’t do it (Ann).*

There was a sense that these factors were cumulative, and when more were present this created greater challenges to advice following:

*it’s a lot of things, if I don’t have much energy and I’m in pain then I don’t feel like standing up like they keep telling me I should. It then gets me down and everything stacks up. I know I need to move but everything is too much so then I just sit there (Beryl).*

The effect of mood was described by over half of participants in their ability to carry out preventative strategies. Low mood affected many aspects of daily life, including planning activities and carrying out preventative aspects such as repositioning:

*when I get in a low mood I don’t plan for it, it just happens and, well, I can’t think and I struggle to move myself out the chair (Dee).*

The presence of pain was also a significant factor for over half of the patients in the study in affecting whether it was possible to carry out preventative advice:

*there it goes again, like this awful thing, it grips me and that is that for the day, I can’t move or walk around or do much for myself (Eva).*

These difficulties carrying out advice were significant in whether it was realistic for patients to be able to follow PU prevention advice. Patients in the study had multimorbidities and described how these were cumulative and affected their situation day-to-day regards the degree to which advice could be followed, meaning adherence was dynamic and changing.

**5.3 Carer Involvement.**

The theme ‘carer involvement’ explains the dependency on others to carry out PU advice and activities of daily living. Within the study, where participants’ referred to carer involvement, some participants’ carers were paid care staff, others family members. The majority of patients in the study (14/15) identified that they were dependent on others to carry out some of the prevention strategies:

*I have to rely on them, it’s when they visit and the shift you know, is to whether I can then get on the bed and move position (Ben).*

Therefore, the role and presence of carers was a significant factor in when and how preventative advice was enacted that was outside the control of the patient themselves. In the community the access to carers may vary depending on several factors, including funding support, social networks, and patient preference.

**5.4 Trust in the Nurse**

The theme ‘trust in the nurse’ explains the relationship with the nurse and how trust develops over time. Patients associated the importance of continuity with the same nurse and, where trust was established, they were more likely to share potential issues they had with following advice:

*when you get the same nurse, they get to know you, who you are and that makes a big difference with trusting them, so you can then be honest about what problems you might have with what they suggested (Belinda).*

Likewise, where there are different nurses visiting and a lack of continuity, this may affect the flow of information:

*recently I have had four or five different nurses so no, I can’t be repeating everything and so you know, I don’t feel they understand me so how can I trust (Beryl).*

Non-verbal cues were also identified as important in the development of trust, such as maintaining eye contact and the nurse not focusing on the paperwork. Patients reported they were more likely to discuss potential challenges they had with following the advice when the nurse made good eye contact. This links to the next key theme of the type of nursing approach used during the visit.

**5.5 The Nursing Approach**

Another key theme to emerge from the study was related to the overall ‘nursing approach’. This broad theme outlines the way in which the nurse-patient interactions unfold. Within the study there were two overall styles of nursing interaction observed, a more closed ‘directive’ style, with the nurse taking a more directive stance (8 visits) and a more open ‘participatory’ style of interaction (7 visits).

Within the open ‘participatory’ approach, patients reported that they felt listened to and part of the decision-making process and this improved trust with the nurse. They were more likely to speak freely about some of the challenges they faced with adhering to advice. Nonverbal cues were important, such as increased eye contact from the nurse and not appearing rushed during the visit:

*when they take time, you know they sit and listen I feel I can be honest about my difficulties (Eva).*

The interaction was more balanced, with nurse and patient speaking for similar amounts of time (50/50). When this approach occurred, patients in the study expressed how they were more likely to take on board the nursing advice.

Where a more closed, directive nursing approach was observed, the patients took a more passive role in the process, with the nurse taking control and talking for the majority of the time (80% of the interaction). The pace of questioning by the nurse was also quicker during these visits, with less opportunity for the patient to ask any questions. During these visits, the nurse was more focused on paperwork completion and the physical aspects of the risk assessment such as skin checks, with less direct eye contact with the patient. Patients in the study reported how this approach limited opportunity for them to seek clarification and made them aware of the time pressure the nurse was under.

Similarly, where PU equipment usage was discussed, some described how they may not admit to the nurse the reasons for not using the recommended equipment if they felt the nurse was rushed:

*well if they are busy you see, it’s easier I just say it’s working (the cushion) when I don’t really use it. I don’t like that cushion in my chair (Gwen).*

With regards to the PU patient information leaflet, this was routinely handed out in all of the visits observed. Evaluation of the leaflet revealed similar pressure ulcer preventative information and messages to those conveyed during the visits, such as nutrition, repositioning, the importance of skin checks and use of equipment. The findings revealed that, regardless of the type of nursing approach used, use of the leaflet was poor, with only one patient reporting they had read the leaflet.

6. **Discussion**

This study reveals new insights into how PU risk negotiation occurs and how interactions unfold between the nurse and patient in the community setting. The findings of the study revealed various factors affected patient perceived PU risk grouped into five overarching key themes: Patient decision-making, difficulty carrying out advice, carer involvement, trust in the nurse, and the nursing approach. The study also observed two divergent nursing approaches to communication. Where a more closed ‘directive’ nursing approach was observed, this inhibited patient involvement. Where a more open ‘participatory’ nursing approach was used, patient participation in decision-making was greater, with acknowledgement of patient related factors that may potentially affect adherence to advice. Importantly, patients reported that involvement in the risk assessment process and decision-making increased adherence, but trust alone was not sufficient for adherence.

Trust in the nurse was a key theme to emerge from the study, developed through continuity with the same nurse, alongside the type of nursing approach used. Patients placed value on the nurse spending time with them and that trust developed over time. Where trust was established, patients were more likely to share potential issues with following advice. Other studies, in the field of leg ulcer treatment, have also found trust with the healthcare professional to be central to patient adherence (Van Hecke et al. 2011). This study expands on this, with new findings that captured the importance of the type of interactions within the setting and the effect of these on the establishment of trust and adherence in relation to PU adherence. For example, the importance of non-verbal communication, such as increased eye contact with the patient and the nurse communicating at the same level (i.e., sitting down) with the patient made to the establishment of trust.

The study has also revealed new findings in relation to patient related factors affecting adherence. Some of the findings concur with previous studies, which have identified the importance of patient involvement in decision-making, daily routine, and the impact of PU related pain (Gorecki et al. 2012; McInnes et al. 2014). However, this study also revealed several novel findings including new factors such as fear of falling, which featured as a significant sub-theme which had not previously been identified in the PU literature. Other factors such as patient fatigue, mood effects and other sources of pain such as arthritis offer new insights into understanding some of the daily challenges to adherence. New findings were revealed in relation to the importance of an open ‘participatory’ nursing approach as the conduit for patient involvement, where patient factors are acknowledged as part of preventative decision-making process. This is particularly important in relation to the use of preventative PU equipment as the study revealed that without patient participation in decision-making, they were unlikely to use the equipment provided or disclose their issues with using it. This might be part of a wider challenge for nursing staff, where previous studies have identified difficulties initiating conversations with patients about risk and behaviour change (Taylor et al. 2021).

The study also revealed important findings into the nature of patient adherence as a complex, dynamic entity and individualised in nature. Patients reported how their adherence to advice varied day to day, according to cumulative and individual factors such as the presence of pain, mood, and fatigue. The patients in the study were living with multi-morbidities and having to balance competing risks and daily challenges. Equally, the majority were dependent to some degree on carer support to carry out the PU prevention advice. It is therefore too simplistic that adherence is determined by patient motivation and knowledge translation alone, as traditional models of patient adherence suggest (Liu et al. 2021)). Rather, this study has demonstrated that adherence is situated in the context of a patient’s personal situation and daily life. This aligns more with the concept of ‘situated adherence’ offered by Rosenfeld and Weinberg (2011) who highlight the importance of recognising the home setting and ways in which the practical demands of daily life may facilitate or constrain adherence. This broader focus on understanding situated adherence and the practical contingencies and social fabric of daily life is distinctly different to previous adherence studies which have investigated individual factors such as patient motivation alone (Fleisher et al. 2009; Weller et al. 2021).

6.1 A new emergent reconceptualization of risk model

There needs to be a radical paradigm shift from an approach where healthcare professionals control a hierarchical knowledge base, to citizen partnership, whereby patients and their families bring their experiential knowledge to the table. A new model of PU risk is proposed (see **Figure 1**), which acknowledges patient risk in the context of empowerment, choice and active decision-making, rather than traditional ‘risk avoidance’ parameters of patient safety policies.

**Figure 1: A new conceptual model of PU risk**



 These principles are important in the context of contemporary healthcare, with a growing need to promote risk management grounded in the experiences and involvement of patients in a variety of healthcare issues (Sheridan et al. 2021). Within this model, risk conceptualisation is co-produced by nurse and patient, which provides a much broader context for risk interpretation to include scientific, personal, social and lifestyle trade-offs. The new model presents adherence as dynamic, which is opposed to the more traditional static model currently used in practice, acknowledging that patient preferences, risk perception and personal and social factors may change from day to day.

It was evident from the study that an open ‘participatory’ nursing approach and patient involvement in decision-making provide a precursor for the establishment of trust and enabled patients to disclose any concerns and take part in shared decision-making. It therefore forms a central part of the proposed new model. The importance of carers and family in the PU prevention and decision-making process were instrumental in ability to carry out the preventative strategies, as a result it has been embedded into the dynamic patient factors in the model.

The new model is rooted in the novel findings of the study. The model expands upon established theories and concepts around health beliefs and behaviours, indicated using the key on the bottom left of Figure 1 (Connor et al. 2021; Munce et al. 2017; Kan et al. 2017). The figure depicts the open ‘participatory’ nursing approach which allows for acknowledgement of flexibility for the level of patient involvement. This new model identifies that risk is co-constructed alongside the patient as part of shared decision-making. The patient perspective of risk sits on the right of the figure, influenced by wider lay constructs such as social influences and prior experiences. This demonstrates the multitude of patient related factors that may affect situated adherence (represented on the right-hand side of Figure 1). Importantly, within the new model, these patient factors feed into the centre and relate directly to the shared decision-making between nurse and patient. The expected outcomes of the new model are improvements in patient adherence, including aspects such as the use of preventative equipment and more realistic PU preventative planning that takes account of patients’ complex health and social issues. While there are some useful parallels to be drawn from the work of Van Hecke et al. (2011) on leg ulcer treatment and adherence and the importance of trust with the nurse, this study’s findings are novel as the previous studies focused on adherence in relation to treatment of existing wounds, as opposed to prevention. Additionally, this model adds the new elements of presence of pain, fear of falling and social influences.

It is important to acknowledge the potential challenges to the adoption of a new model. Firstly, this is a new and emergent model and as yet untested in terms of translation to practice. Further research would be required to assess its implementation and ‘tools’ within which the model could be grounded in practice. Likewise, the cultural shift to person-centred practice would require consideration in terms of engaging key stakeholders and the training of staff to understand and apply the principles of genuinely person-centred practice (McCormack et al. 2021). There are also organisational challenges in relation to staff time and high caseloads that create challenges for HCPs to adopt a more open ‘participatory’ approach within their practice (Taylor et al. 2021).

 6.2 Strengths and Limitations of the study

The strengths of the study are in the pragmatic mixed methods approach, which enabled a kaleidoscope ‘lens’ through which to observe the nurse-patient interaction and interpret the understanding and intended action of patients. This rich data capture provided different perspectives on the same phenomena and provided the foundation to develop a new co-produced model of risk and situated adherence for PU prevention.

It is important to note that observation bias may have resulted in nurses acting differently and patient responses within the encounter. Whilst attempts were made to minimise this by the nurse’s explanation of the role as researcher and consideration of where the researcher was positioned, it is possible this may have affected interactions, however it is important to note that suboptimal involvement of patients in care was observed. There may also have been reluctance by some patients to participate in the study as a skin inspection was routine in most of the visits. This had been acknowledged and built into the ethics and consent process where patients were reassured that for that aspect of the observation visit, the researcher would remove themselves from the room.

6.3 Recommendations for further research and practice

Patient information and knowledge translation alone may not result in patient adherence to PU advice and recommendations. There are complex and individualised patient factors that may affect adherence to advice and these patient centred, individual factors are not explicit within current nursing care documents and processes. Healthcare practitioners need to consider how important patient factors such as low mood, fatigue, daily routine, and lifestyle preferences can be better acknowledged and embedded within routine practice. Sufficient time and resource are needed to enable nurses to provide person-centred care where new solutions are sought in open discussion. This reflects the wider need for a paradigm shift from a focus on patient adherence to a focus on concordance which emphasises patient participation and partnership working within the decision-making process. To effect meaningful practice change, a move away from a medical model of scientific risk stratification is needed, working with patients to co-produce interventions and personalise strategies to prevent debilitating PUs.

7. **Conclusion**

The findings of the study revealed various factors affected patient perceived PU risk and adherence. This included overarching key themes of patient decision-making, difficulty carrying out advice, carer involvement, trust in the nurse, and the nursing approach. These factors were complex, individualised, and dynamic in nature. The observed communication style of the nurse had a direct impact on adherence to PU prevention strategies, impacting trust and openness of discussion around PU risk. Importantly, knowledge translation alone didn’t ensure adherence due to the impact of other patient factors such as pain, fatigue, low mood, fear of falling and daily routine and lifestyle preferences.The research findings were translated into a new conceptual risk model of PU prevention for the community setting. This model places the patient perspective of risk alongside the nursing perspective in partnership, with an open, participatory nursing approach used to support shared decision-making.

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