University of Southampton

Faculty of Environment and Life Sciences

School of Health Sciences

Patient perceptions and understanding of pressure ulcer risk and potential factors affecting adherence to prevention strategies in community settings

By

Lisa Jayne Ledger

Doctor of Philosophy

December 2021

Volume 1 of 1

Word Count: 61,653

University of Southampton

Abstract

Faculty of Environment and Life Sciences

School of Health Sciences

Doctor of Philosophy

Patient perceptions and understanding of pressure ulcer risk and potential factors affecting adherence to prevention strategies in community settings

Background: Pressure ulcers (PUs) are a key priority area for healthcare institutions, representing a patient safety issue, but despite global campaigns around awareness, incidence remains high. PUs are associated with ill health, poor mobility and reduced quality of life. Increasingly, patients are required to be aware of their PU risk and to self-manage their conditions, with a need to increase patient involvement in decision-making to promote adherence. To date, research is limited regarding patients' own understanding of their PU risk and the factors that affect adherence to prevention techniques and advice given from Health Care Professionals. This is particularly significant in community settings, where patients are increasingly expected to self-manage long-term conditions.

Aims: This study aimed to address the following research questions: 1. What are patient perceptions and understanding of their PU risk? and 2.What factors affect their adherence or non-adherence to prevention strategies in community settings?

Method: This was a qualitative study using a pragmatic research approach. Data gathered included direct observations of nurse-patient interactions during nursing visits, collation of the PU patient information leaflet provided and follow-up in-depth interviews with patients. A total of 15 participants were successfully recruited for the study.

Findings: The study revealed four key overarching themes related to patient understanding of PU risk and potential factors affecting adherence to advice as: Pressure Ulcer Awareness, Risk & Prevention Knowledge, Patient Factors & Adherence, The Nursing Encounter and The Nursing Approach. Novel findings included that whilst patients understood PU risk in a basic sense, this did not necessarily secure adherence due to other patient related factors, such as pain, mood affects, fatigue, fear of falling and carer dependency. The patient information leaflet was not sufficient to secure patient understanding and adherence. The study observed two overall nursing approaches: a closed directive and a more open participatory approach. Use of an open participatory approach was pivotal in securing trust and enabling acknowledgement of dynamic patient related factors as part of shared decision-making.

Conclusion: The study provides important new insights for clinical practice in relation to how PU information and advice is provided and how decision-making occurs between nurse and patient and the effect of this on adherence. The findings were translated into a new conceptual risk model of PU prevention that places the patient perspective alongside the nursing perspective in partnership, with an open participatory nursing approach used to support shared decision-making.

Contents

List of Tables

List of Figures

Declaration of Authorship

Author Name: Lisa Ledger

Title of Thesis: **Patient perceptions and understanding of pressure ulcer risk and potential factors affecting adherence to prevention strategies in community settings**

I declare that this thesis and the work presented in it is my own and has been generated by me as the result of my own original research.

I confirm that:

1) This work was done wholly or mainly while in candidature for a research degree at this University;
2) Where any part of this thesis has previously been submitted for a degree or any other qualification at this university or any other institution, this has been clearly stated;
3) Where I have consulted the published work of others, this is always clearly attributed;
4) Where I have quoted from the work of others, the source is always given. With the exception of such quotes, this thesis is entirely my own work;
5) I have acknowledged all main sources of help;
6) Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself.

Signature: L J Ledger

Date: December 2021

Acknowledgements

I would like to thank my family for always supporting me in all that I do, my husband Mark for his kindness and understanding, mom for being there and my dad for teaching me in life to ‘plan the work and work the plan’. To my son Ollie who inspires me every day and for putting up with ‘grumpy mom’ over the past few months.

Thanks to my supervisors, Lisette, Peter and Jo for your continual support and encouragement and for believing in me, where at times my own confidence was lacking.

Thank you to my own university and work colleagues who have supported this project through the years, I could not have done this without your support.

Huge thanks to the clinicians and patients that gave their time and shared their experiences.

Finally, to my A level Sociology lecturer all those years ago at night school, who despite me not following the traditional sixth form route onto higher education, provided the vision for me to believe anything was possible and that we write our own history…

Definitions/ abbreviations used

Clinical Appraisal Skills Programme CASP

Pressure ulcer PU

Health Care Professional HCP

Tissue Viability Society TVS

Spinal Cord Injury SCI

Randomised Control Trial RCT

Health Research Authority HRA

Thematic Analysis TA

National Health Service NHS

Noticing Collecting Thinking NCT

Integrated Research Application System IRAS

Occupational Therapist OT

Birmingham Community Healthcare Trust BCHC

European Pressure Ulcer Advisory Panel EPUAP

European Wound Management Association EWMA

Tissue Viability Society TVS

International Journal of Nursing Studies IJNS

National Wound Care Strategy Programme NWCSP

Massive Open Online Course MOOC

World Health Organisation WHO

Risk Assessment Instruments RAI

Root Cause Analysis RCA

Health belief model HBM

Social Cognitive Theory SCT

Theoretical Domains Framework TDF

Theory of Planned Behaviour TPB

Tissue Viability Nurse TVN

This document is submitted for consideration of award for Doctor of Philosophy following part-time programme of PhD study. The document will outline the background and introduction to the study, rationale for the topic under investigation, integrative literature review, methodology, results, discussion and conclusion, including future research ideas and a new emergent model for consideration within clinical practice.

Chapter 1 Introduction

1.1 Personal Context

It is important to 'locate' myself early on and throughout the research process to reflect on my positionality and to bring any individual assumptions to light. Dubnewick et al. (2018) propose that the process of reflexivity supports transparency when it begins with an autobiographical review of self.

I have been a qualified Occupational Therapist, practicing clinically for over 20 years, subsequently transferring to a career in academia 9 years ago. I am white, middle class and female which I also acknowledge brings a particular positionality to the research in terms of culture, gender and 'white privilege' born out of receiving a certain level of education and literacy. I have always held a deep value base in relation to the importance of what is meaningful for an individual, in terms of decision(s) and volition in life and I believe this is what lead me to train as an Occupational Therapist. Occupational Therapy as a profession takes a whole-person approach and is grounded in the importance of the individual's engagement in meaningful occupations and purposeful activity to allow people to live as independently as possible (RCOT, 2021).

The ethos of the importance of the individual as a whole (mental, physical, social, cultural) and what is meaningful to them with their health and life are the seeds on which the research project was built. Over many years in the National Health Service (NHS) sector, working with individuals who had acquired pressure ulcers and through listening to their narratives, I was struck by a sense of how they felt their views and perspectives had not always been listened to. Other patients described a sense of deep regret and felt they had not taken on board the advice given by the Health Care Professional (HCP) at that time.

Most of my clinical career has been within the community setting, often with individuals with posture management needs, who, in many cases had experienced pressure ulcer damage. During conversations about their past history and circumstances, several patients relayed to me their own 'experiential' knowledge and struggles to follow HCP advice within their daily lives. Often this had not been taken into account by the HCP and had compromised their situation further. Also there was a sense that they hadn't really been involved in decisions around preventative care despite being given responsibility and left to carry out the advice given, which is mirrored in qualitative research with patients with pressure injury (Pinkney et al. 2014).

In relation to PU risk assessment within clinical practice, there are possible differences in how various healthcare professional groups align risk and patient involvement. In the context of this PhD it is important to reflect on these. As an Occupational Therapist within pressure ulcer prevention, our professional focus is predominantly around maintaining patient function whilst promoting PU preventative measures (Stinson et al. 2013). Whereas, in nursing practice, the emphasis is often on prioritising patient adherence to key safety indicators and care protocols. As a result, I was actively reflexive of these professional difference throughout the research process.

Some patients that I have encountered have 'actively' chosen not to adhere to the advice given and have decided to prioritise other lifestyle factors over the PU advice given, despite knowing this would increase their pressure ulcer risk. For example, choosing to sit for longer in their wheelchair so that they can hold down a job or get a flight to go on a family holiday. Again, these anecdotal observations mirror research with patients with spinal cord injury and grade 4 PU damage that found activity and occupation influenced decision-making, with patients prioritising lifestyle choices over their PU regime (Jackson et al. 2010). These patient choices are often difficult to navigate in clinical practice, as within a professional training and lens, the emphasis is on reducing risk and avoiding patient harm, thus creating a tension between the professional and 'lay' patient perspective. There can also be a labelling process of the patient as 'non-adherent' and 'difficult' where advice has not been followed in clinical practice. However, I have felt the use of these terms to describe adherence have not necessarily been adequate to encapsulate the individual patient's reasons for not following the advice given and often had negative connotations.

Listening to patient narratives it has become apparent to me that patient interpretations of risk are different to the professional paradigm, with individualised risk decisions based on more than purely rational scientific risk. The context of how educational information and advice is provided to patients and their level of involvement in care planning seems to also be important in relation to resultant adherence to advice. Therefore, the passion and core ethos of this research study is to place patient context of risk centre stage and to contribute to new knowledge and understanding to inform clinical practice.

1.2 Background to Pressure Ulcers (PUs)

Pressure ulcers (PUs) remain a key priority area for the NHS and a patient safety issue as despite national and international campaigns around awareness and education, their incidence in primary and secondary care remains high (National Institute for Health and Care Excellence, 2014). 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’ (European Pressure Ulcer Advisory Panel/National Pressure Injury Advisory Panel/Pan-Pacific Pressure Injury Alliance, 2019). 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 et al. 2012). Whilst the cost to the patient and their families cannot be easily quantified, studies have shown that they result in reduced mental and physical function, reduced vitality, social restrictions, and increased pain (Essex et al. 2009; Spilsbury et al. 2007).

Monitoring of adverse incidents including PUs has been undertaken in healthcare institutions around the world, with prevalence and incidence data increasingly used as indicators of quality of care. An international review across Scandinavia, Iceland and Ireland reported mean PU prevalence of between 8.9% and 25% (Moore et al. 2013). Within the United Kingdom (UK), a study that considered PUs and wound reporting in 24 in-patient NHS settings identified between 7.1 and 8.4% of patients with an existing PU (Smith et al. 2016). The limited evidence to date also suggests a potentially higher rate in the community (Stevenson et al. 2013).

As a result of this prevalence, PUs represent a significant financial burden to healthcare institutions. In a systematic review to summarise the cost of prevention and treatment of PUs across a range of settings including the USA, Netherlands and Canada, the cost of prevention per patient per day ranged from €2.65 to €87.57. By contrast, the estimated range of costs to treat PUs was far higher, from €1.71 to €470.49 per patient per day (Demarre et al. 2015). Within the UK, the daily cost of treating a pressure ulcer is estimated to be around £43 to £374, which has a significant impact on NHS resources (Dealey et al. 2012; National Institute of Clinical Excellence, 2014). Guest, Fuller & Vowden (2020) conducted a retrospective cohort analysis of NHS patient records of wound treatment and estimated the annual cost of managing a range of wounds, including PUs and associated comorbidities was approximately 8 billion per annum, with much of the cost associated with community treatment. Therefore the scale of the issue is widespread, with a considerable cost to both the healthcare providers and individual and increasingly a focus on prevention, with core concepts of PU prevention built into the national and international practice guidelines including; accurate risk assessment, preventative skin care, nutrition and repositioning, mobilisation and the use of appropriate equipment (European , 2019).

1.3 Risk Assessment and Prevention in Practice

PU risk identification and patient adherence to prevention advice remain a key focus in NHS health care policy and practice (National Wound Care Strategy Programme, 2021). Equally, in clinical practice PU risk assessment is seen to be central to prevention, often with a wide range of risk scales used by Health Care Professionals (HCP) to inform individual care plans (Coleman et al. 2013). The focus by the HCP's is on accurate assessment of a patients' risk status to determine the potential for developing a harmful PU and to introduce interventions and treatment strategies to minimise harm (Demarre et al. 2015). Risk assessment tools are used across a broad range of patient groups, including acute and community, rehabilitation and residential settings. The risk assessment tools currently used in practice, including the Waterlow score (Waterlow, 1985) and Norton (Norton et al. 1985) originated in the 1970s-80s where few studies have investigated the contribution of each individual risk factor (Coleman and Muir, 2015). Following a systematic review to consider patient risk factors for pressure ulcer development, Coleman and colleagues (2014) suggest there is no one single factor to explain risk, but rather it is a complex and multifactorial process which necessitates physiological, psychological and socioeconomic considerations. More recently a new risk tool has been developed, PURPOSE T which translates PU risk factor evidence and expert opinion into a usable standard instrument that can facilitate the early identification and management of individuals at pressure ulcer risk (Coleman et al. 2017). A recent study has identified that PURPOSE T is easy to use, providing clinically useful information to HCPs and contributing to a deeper understanding of risk factors and a greater awareness of pressure ulcer prevention (Hultin et al. 2021). However, it is yet to be universally adopted in healthcare practice.

Despite their widespread adoption, there is limited evidence that the use of risk tools has reduced the incidence and prevalence of PUs. Indeed, there are limitations with all existing PU risk tools and their use in clinical practice, in specific relation to patient involvement and decision making. For example, usage is typically focussed on the initial risk assessment phase and the professional nursing role in categorising a patient's risk status (Coleman et al. 2014). The PU risk tools for community nursing practice are designed to be nursing led and form part of a process driven model to support clinical decision-making, with the patient themselves largely passive within this risk framework (see Figure 1).

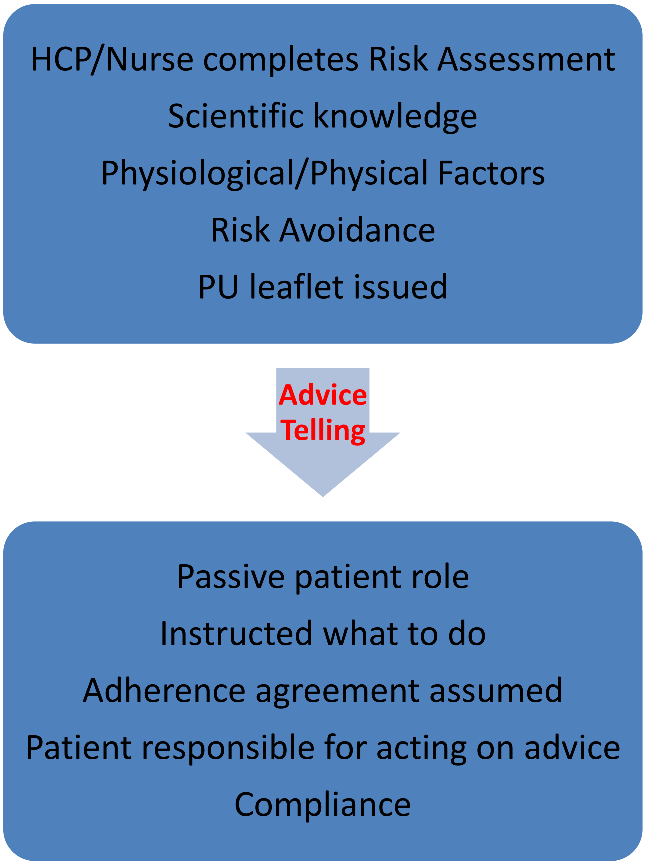


Figure 1 Existing PU Risk Assessment Framework within Birmingham Community NHS Trust District Nursing

This nursing led, risk assessment focused approach will be partly due to policies to drive down the occurrence of adverse events in the contexts of insurance premiums and the costs of malpractice (Donaldson et al. 2021). The focus on risk mitigation and responsibility placed on the HCP to minimise patient harm is endemic within existing healthcare practice, evidenced within practice guidelines such as the NHS National Patient Safety Strategy (2021). This has led to a limited focus on understanding the importance of how risk is communicated to patients themselves and patients' understanding of risk and involvement in preventative care and decision-making.

Alongside this, health care policy and guidance has shifted in recent years from professionals instructing patients what to do, to a more patient centred care model whereby patients are encouraged to be active partners in the decision-making process (Kings Fund, 2018). Increasingly, it is often the role of the patient and their carer(s) to understand and manage their own PU risk and carry out prevention strategies, particularly in community settings (Shanley et al. 2021). The patient therefore has a central role in understanding and managing their PU risk and carrying out daily prevention strategies, as they may become the only constant in a changing situation, particularly in the home setting (Coleman and Muir, 2015). Within current practice, the PU prevention strategies include risk assessment and care planning whereby patients are instructed to perform prevention strategies for example, checking their skin, regular repositioning and using pressure redistributing support surfaces (mattresses and cushions). Importantly, involving patients more in care planning and decision-making is more likely to encourage participation and adherence to the clinical advice and recommendations (Schoeps et al. 2016). In light of this, it is important to consider how PU prevention information is provided and risk communicated to patients, outlined below.

1.4 Risk Communication and Patient Education

Despite the emphasis on patient responsibility to carry out key preventative measures, such as skin checks, nutrition, repositioning and mobilization in the community (National Wound Care Strategy Programme, 2021), there is a paucity of literature on this topic. Communication of PU risk and prevention information to the patient is not effective despite communication issues featuring as one of the main areas in NHS Root Cause Analysis (RCAs) and patient complaints (Stephenson, 2019). Patient information is usually given verbally by the HCP and through the provision of a patient information leaflet, focused on the mitigation of harm (Fletcher, 2020). A recent Cochrane systematic review found two main types of PU education interventions: the provision of information on prevention of pressure ulcers such as patient leaflets and the use of different types of education programmes (O’Connor et al. 2021). The review revealed some key considerations regarding use of educational materials, including the importance of active patient involvement within the decision-making process. The importance of patient involvement has also been evidenced in other healthcare disciplines with involvement in care decisions likely to increase motivation and resultant adherence, alongside an established patient-HCP relationship built on trust (Schoeps et al. 2016; Shanley et al. 2021).

It is of note that studies evaluating the suitability of PU patient leaflets identified that for those with limited health literacy, the readability was poor (Durrant et al. 2018). In addition, even when good quality information was provided, participants were largely passive in engaging with the information provided. Despite having access to patient information leaflets, participants had limited understanding of PU causation and risk. All leaflets failed to include information relevant to different skin colour with assumptions of a white audience which may also have increased disengagement from use of the information (Durrant et al. 2018). Importantly, a more recent study which involved the evaluation of a PU prevention programme for older people in the community revealed that whilst knowledge and skills improved within the intervention group, health beliefs around lifestyle measures remained largely the same between the control and intervention group (Shanley, 2021). This suggests that whilst further consideration of aspects such as the format, style and language are important in educational materials, there are potentially wider, personal and social influences that also require investigation.

It is not yet known if HCP advice and education results in adherent behaviour to PU prevention strategies. The few studies that have focused on the role of patients in PU prevention identify that patient engagement may be influenced by a range of factors including the complexity of tasks, if the patient has a previous history of PU damage alongside the quality of HCP to patient interactions (Latimer et al. 2014; McInnes et al. 2014). There are also other considerations for varying levels of patient involvement and role depending on aspects such as ill health and cognitive ability to participate in preventative strategies (Schoeps at al. 2016).

Upon considering risk conversations in this context, the wider literature has identified that risk communication is an essential part of shared decision-making and evidence-based patient choice (Edwards, 2012). However, the communication of risk is complex, with care delivered to a range of individuals with differing health literacy in several care environments (home, residential/nursing care and hospitals). Furthermore, the current emphasis within healthcare practice of providing rational scientific knowledge may not be sufficient in itself to be acted upon by the 'lay' patient, as there are other broad personal and socioeconomic factors. Importantly, the provision of educational information may not be sufficient to secure adherence due to other contextual factors, with patients making their own day to day pragmatic decisions. A modernized empowered healthcare system should recognise citizenship and wider personal and social aspects to risk within their patient safety policy, strategies and clinical implementation (Sheridan et al. 2021). It is useful therefore to consider sociological perspectives to provide a framework in which to consider patient or 'lay' context of PU risk and how these align to the HCP view and resultant adherence.

1.5 Lay Health Beliefs, Risk and Patient-Nurse Interactions

In the professional HCP context, risk is scientific and probabilistic in nature however, the conceptualisations of risk within 'lay' interpretations are more complex and it is therefore important to understand these differences further. A risk in common lay terms, is considered an event that may be dangerous regardless of whether the probability of it happening can be predicted or not (Zinn, 2008). This blurring has resulted in ‘risk’ being used inconsistently in medical and lay discourse which is problematic as its meanings may vary significantly between patient and professional. Zinn (2008) in his work around risk and uncertainty, outlines the importance of differences between ‘lay’ and ‘professional’ context in that risks are not solely objective measures but are perceived and made sense of within social contexts that frame their meanings. In this sense risk is not the main determinant of lay experiences of carrying out preventative health measures, despite a modern culture increasingly reliant on risk-based explanations, including within the health care sphere (Zinn, 2008). The sociology of health is concerned with the social origins of and influences on health and an understanding of professional-patient interactions (Nettleton, 2013). Lay or ‘patient’ beliefs are important in the context of this study for broader consideration on conceptualising how patients interpret health and illness, risk and health-related behaviour(s). Often central to national healthcare NHS initiatives is the notion of risk ‘management’ and how health can be promoted through active lifestyle choices that patients make, such as smoking cessation and active health choices (Blaxter, 2010). However, lay ideas about health are complex and are related to culture, gender and class that permeate people’s everyday life (Stottard, 2012). Equally as discussed earlier, it is not clear that lay understanding of risk is necessarily the same as a medicalised professional view, where it is synonymous with danger and to be avoided (Blaxter, 2010). Some patients for example, may perceive taking risks as a positive and empowering experience rather than something to be avoided (Douglas, 1992). There are examples in the wider literature where fundamental differences between medical professional and lay understandings of risk perceptions have been identified.

For example, a recent systematic review of cancer risk perception identified key concepts which included:

1. Variable levels of trust in their HCPs and the health system
2. Personal relationships which shaped the ‘lay’ experience of risk through social contacts with priori experience of cancer.
3. The importance of seeking control and taking responsibility (motivational factors) including engagement with educational risk resources and information (Lipworth et al. 2010).

Other aspects identified in the review related to lay constructs of lifestyle choices such as having a healthy diet to prevent illness, with traditional meat and veg dinners seen as healthy and associated with providing rigor and strength (Lipworth et al. 2010). Likewise, other health studies investigating ‘lay’ concepts of risk, have found that patient accounts are quite different from professional when describing risk, where the use of heuristics are used to help manage uncertainty and often simplify risk in their everyday understanding (Grauman et al. 2019). There is importance attached to hope and trust that carrying out health advice is beneficial and patients present biographical accounts of their health and actively try to avoid becoming a patient ‘at risk’ through a responsible health regime (Jauho, 2019). Familial traits may also play a part in lay interpretations of risk, whereby patients view their risk according to family history of conditions, such as cancer, diabetes and cardiovascular health, rather than the professional perspective of their risk status (Vornanen et al. 2016).

Indeed, there are key differences between ‘lay’ and ‘professional’ interpretation of risk. Lay individuals’ risks are perceived and made sense of within personal and social contexts, impacting on how they are experienced (Zinn et al. 2008). As the previous studies revealed, there are a range of other factors such as trust, hope, familial traits and emotions that also play a part in shaping experiences around risk and responses to ill health and uncertainty. Zinn (2008) places uncertainty as the primary experience that pivots around these other factors, including risk and which plays an important role in shaping health behaviours and decision-making in relation to illness. In view of this, an emphasis is placed on the experiences of uncertainty and how ‘lay’ uncertainty is managed by drawing on different resources, such as risk information. These lay/professional differences are important in the context of patient information and the communication of risk. It is also not clear that lay health beliefs and professional ‘expert knowledge’ are as legitimate as each other in clinical practice in the context of risk communication and involvement in decision-making (Nettleton, 2013). This professional legitimization of knowledge relates to professional-patient interactions that reflect wider social relations and structural inequalities, with dimensions of social control and regulation. This is particularly evident within the healthcare field, where the HCP focus is on preventing harm to the patient and reducing clinical risk, with risk seen as undesirable (Nettleton, 2013). The patient on the other hand may view the risk differently. However, due to the power-relationship between patient and professional nurse ‘expert’, the patient may choose not to disclose where there is a disagreement. It is therefore important to understand further, the complex relationship and interactions between patient and HCP and how these unfold within the home setting itself.

Stottard (2012) through an ethnomethodological study focused on the social meanings and understandings in patient-nurse interactions, describes the ‘ground rules’ surrounding engagement between nurse and patient within a community setting. Within this context, there is a hierarchy of power with the nurse in a position of authority and expectations for the patient around ‘being a good patient’ and following the advice given without question. The ‘agenda’ is set in terms of the focus of the nursing visit and nurse-patient roles pre-ordained within the social meanings and understandings related to cumulative experience (Stottard, 2012). Likewise, in another study, Barnard et al. (2010) found that nurses tend to take a lead role in goal setting consultations with patients and seek to make their guidance and plans non-negotiable during interactions. In this sense, institutional roles and expertise are understood and acknowledged by co-participants with the control of the interaction(s) and how these unfold mostly exerted by nurses themselves (Barnard et al. 2010). There may be limited opportunity for patients themselves to raise concerns or feel able to question the advice or raise concerns they may have about carrying out the advice given.

Therefore, whilst acknowledging these pre-ordained nurse-patient roles exist, it is important to consider these further within an exploration of adherence as a broad concept, both in terms of how patient agreement is secured within the risk decision-making process and wider concepts in relation to patient adherence and health-related behaviour.

1.6 Concepts of Compliance, Adherence and Decision-making

In recent years, there has been a policy shift in emphasis from professionals instructing patients what to do, to a more patient centred care model whereby patients are more active partners in the decision-making process (Kings fund, 2018). Effective communication is deemed an essential element of patient centred practice and terminology has developed over time to describe the different aspects of interaction between HCP and patient around decision-making (Jordan et al. 2020). Patient involvement is at the centre of contemporary health-care policy in which quality of care improvement is emphasised, with nursing practice evolving and values transforming from biomedical to biopsychosocial aspects. This transformation includes a movement from illness orientation to health that is seen as interdependency of important physical, mental and socio-economic factors (Stottard, 2012).

Alongside this movement, the concepts have changed around health-related behaviours with important distinctions to be made between patient compliance, adherence and concordance. It is important to understand the relationships and the distinctions amongst these terms, in order to consider the impact on the HCP – patient relationship and the potential outcomes of their interactions (Zainal et al. 2021). Traditionally patient compliance has been used as a term in healthcare, which was the degree to which advice was followed, usually passively, without question. However, this was criticised for its unequal and paternalistic relationship between HCP and patient, with the patient being told what to do (Jordan et al. 2020). Subsequently, there has been a movement in more recent years from patient compliance to concepts of adherence. The World Health Organisation describes adherence as ‘the extent to which the patient follows medical instructions’ (WHO, 2003 p3). Within the concept, the quality of the professional - patient relationship is seen as an important determinant of the adherence itself, with effective relationships characterised by openness, shared negotiation and decision-making (WHO, 2003). Shared decision-making as a concept is an important cornerstone in healthcare practice, which may be defined as ‘a process in which clinicians and patients work together, sharing information about options with the aim of reaching agreement on the best course of action’ (Coulter and Collins, 2021, p130).

It could be argued that adherence is simply a developed version of compliance that requires patients to be informed before passively accepting the care plan (McKinnon, 2013). There may also be some challenges to how active patient involvement is determined and adherence agreement is reached, with underlying traditional professional-lay power relations at play (McKinnon, 2013). Equally, whilst recognising the patient’s right to autonomy and concerns in adherence, it does not necessarily recognise that in not adhering to a care plan, the patient may have exercised proper judgement from their own situation and perspective (Horne et al. 2005). In this sense, adherence as a concept may be limited in that it assumes a level of judgment from the HCP point of view concerning an individual’s health-related decision-making.

Rosenfeld and Weinberg (2011) discuss the concept of ‘situated adherence’ and the importance of recognising the home setting and the ways in which the contingencies of domestic practice may facilitate or constrain adherence. The authors suggest the importance of recognising the practical demands of daily domestic life in which the patient is ‘situated’ and how these may challenge a patient’s efforts to adhere to medical regimes. In this sense, Rosenfeld and Weinberg (2011) suggest that patient adherence as a concept may be limited in that explanations of non-compliance remain focused on patient knowledge and understanding rather than on the practical contingencies of patients’ lives. The authors suggest the importance of a research focus around the extent to which adherence to healthcare advice is governed by ‘the routines and rhythms of domestic life quite apart from more intellectual deliberations and beliefs regarding the intrinsic value of adherence (Rosenfeld and Weinberg, 2011, p3). Additionally, self and identity shape how people construct positive selves and attempt to retain control of their lives in the face of illness (Oris et al. 2018). Thus, what can appear to be non-adherence to professionals, may be a result of underlying processes occurring ‘situated’ within the patient’s own health beliefs and day-to-day life that determine their decision-making and behaviour.

More recently, the concept of concordance has been suggested within healthcare practice, which takes patient involvement further, whereby in this concept concordance is reached through a therapeutic alliance and negotiation between the HCP and patient (Jordan et al. 2020). The patient is encouraged to discuss concerns and actively participate in the decision-making process. The HCP gives evidence-based information to the patient and shares his or her clinical experience and during the negotiation process compromises are made on both sides and decisions made together. In this model, there is equal sharing of power and knowledge, including lay ‘expert’ knowledge. Jordan et al. (2020) suggested that through the process of shared decision-making and creating a therapeutic alliance, this increases patient involvement in health care decisions which in turn improves adherence to the advice given. Likewise, McKinnon (2013) on defining concordance describes ‘a partnership of equals between patients and practitioners, where patients are recognised as experts in their own life and patients’ beliefs and values together with the social context of their health inform decision-making and care planning that is shared and negotiated’ (pg766). However, in relation to healthcare practice, as discussed earlier where there are inherent traditional professional-patient roles and underlying power relations, the adoption of a more concordant approach may not be straight forwards and would require a cultural paradigm shift.

Therefore, over time there has been a conceptual movement from simply following advice that has been instructed (compliance) to more patient-centred agreement (adherence) and active involvement in decision-making (concordance). Further research is warranted to determine whether this shift to increased involvement in decisions has translated into clinical practice and its associated impact on patient adherence (Liu et al. 2021). There is also within this shift to patient involvement, an increased emphasis on self-management by the patient and responsibility to carry out the recommendations and to monitor their own health and risk status. This may create a tension between the professional ‘control’ over risk with relinquishing control to enable patients themselves to ‘self-manage’ advice and carry out prevention strategies (Chan et al. 2018). This tension is likely to be increased where there are issues around patient non-adherence and a tendency for the nursing professional to take back control over the situation and minimise risk, particularly in community settings (McKinnon, 2013). Non-adherence to healthcare advice is identified as a significant issue in community settings, where increasingly it is the patient who is responsible for carrying out advice and self-managing their condition (WHO, 2003).

In summary therefore, the main difference between compliance and adherence is that adherence is dynamic and requires the patient's agreement to the recommendations, whereas compliance is the degree to which advice is passively followed (Robinson et al. 2008). However, it is acknowledged both in the literature and empirical studies outlined that it is not entirely straightforward to ascertain if indeed, true patient agreement has been successfully achieved due to wider power relations. Therefore, it is critical to understand further how this agreement is reached within the PU risk and prevention decision-making, following the reporting of non-adherence in community settings (WHO, 2003). Equally, whilst non-adherence within clinical practice may be viewed as a negative behaviour from the HCP perspective, it may be the correct course of action from the patient perspective with pragmatic and heuristic decision-making employed. Factors that most strongly correlate with adherence are the patient's own beliefs influenced by personal knowledge and experience, as well as that of family and friends (Robinson, 2008). A patient centred approach is essential therefore to promoting adherence through communication, shared decision-making and support for self-management strategies.

Traditionally, as discussed earlier in this chapter, HCPs have relied on health information and their professional role and status alone to convince patients to engage in preventative strategies (Ingleby, 2020). Within the field of behavioural health research - for example in management of diabetic foot ulceration, it has been observed that 'knowing' about ones health and condition knowledge does not necessarily translate into 'doing' something about it. It is therefore important to understand the contribution of behavioural models of change (Zainal et al. 2021). Health-behaviour change theories suggest alternative models for accomplishing patient adherence and will be explored in the next section.

1.7 Adherence Behaviour and Self-Management

Health-behaviour change theories and models suggest more effective methods for accomplishing patient adherence and can be used to assist our understanding (Zainal, 2021). Several models currently exist, such as the Health Belief Model (HBM) and others that have been developed in an attempt to predict or explain the likelihood of adherence (Ingleby, 2020). The HBM is commonly used and is a social cognition model, with four elements that may predict an individual's behaviour (Figure 2). These are: the patient's susceptibility to the condition, the severity of how the disease will impact on the patient emotionally and functionally, the perceived benefits and barriers to adherence and the additional cues that prompt healthy behaviour.

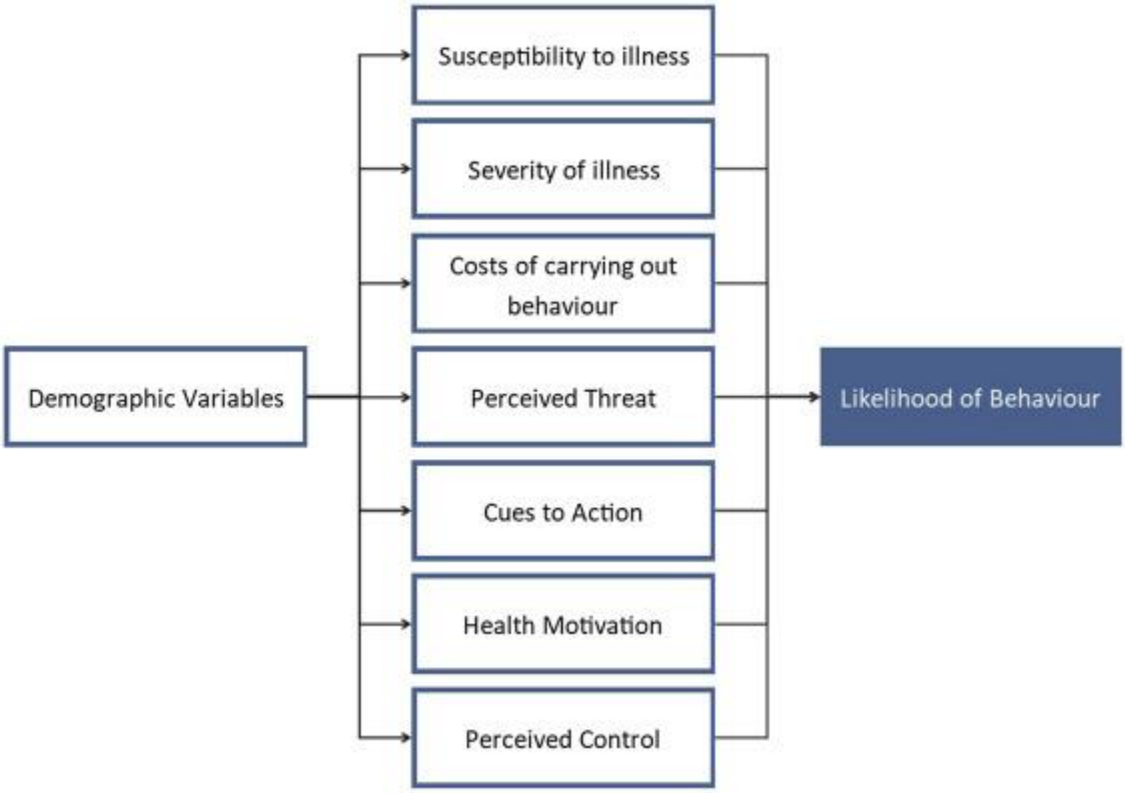


Figure 2. The Health Belief Model (Connor et al. 2021)

Through discussion with the patient of their perceptions of the pros and cons for engaging in the behaviour, this can form part of the decision-making process and plan. However, there are limitations to this model as it is based on the assumption that individuals have an understanding of their disease or condition, which may not always be the case. The Theory of Planned Behaviour (TPB) (see Figure 3) is an alternative model which states that patients determine their intention before any behaviour change, and that intention is the most accurate predictor of patient adherence (Sarafino and Smith, 2012). The TPB model acknowledges social context and that social pressures impact on adherence to treatment. This theory outlines the importance of social networks, family and more formal structures such as patient groups as social influence on adherence outcomes.

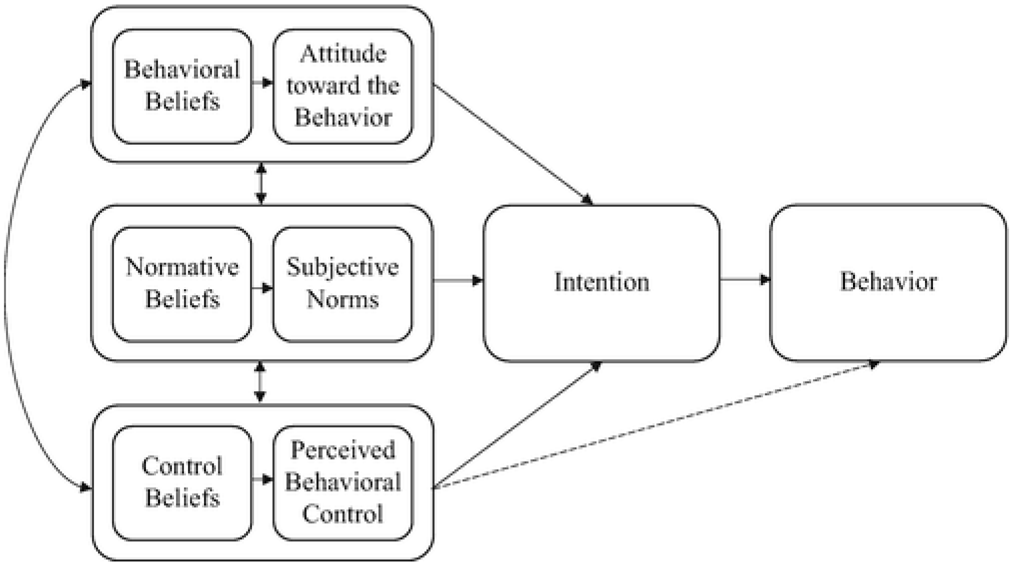


Figure 3. Theory of Planned Behaviour (Kan et al. 2017).

The Theoretical Domains Framework (TDF) as a model offers other domains to adherence, including potential barriers such as emotional and mood affects, as well as pain (Munce et al. 2017).

Therefore, there is a plethora of different conceptual models to explain health related behaviour, including Health belief Model (HBM), Theory of Planned Behaviour (TPB), Theoretical Domains Framework (TDF) and others. Many of the theories and models do share similar factors, which include:

- Intention to change behaviour
- Environmental constraints
- Skills acquisition and motivation
- Mood affect(s)
- Self confidence.

These models provide a useful framework to consider patient health behaviour, such as motivation, self-efficacy and intention to behave. However, there are some limitations to the aforementioned models. One is that they assume patients debate risk in a reductionist, probablistic way and links between disease and behaviour, which may be too simplistic particularly in the context of adherence outlined previously in the chapter (Sarafino and Smith, 2012). Within these existing behavioural models, there is also a distinct lack of acknowledgement of other factors such as role/power relations and social constraints. There has also been a gap within the existing knowledge base on the influences of patient involvement in preventative decision-making and the effect of this on resultant adherence (Van Hecke et al. 2011). The models also do not accommodate ‘situated adherence’ and how it unfolds day-to-day for individuals, creating other dynamic personal and social challenges (Rosenfeld and Weinberg, 2011). These are important considerations in the context of an increasing emphasis in clinical practice for patients to ‘self-manage’ and be responsible for carrying out advice, particularly within community settings (Brewster et al. 2017). Self-management has been defined as ‘the individual’s ability to manage the symptoms, treatment regimes, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic illness’ **(**Baron et al. 2016 p2). However, there are some challenges to the application of self-management in people’s lives, with varying priorities and social circumstances that create challenges that are more than an individual’s ‘ability’ to perform interventions. Thus, a variety of measures are often used to attempt to support patients, including training strategies, social support and targeted education programmes (Shanley et al. 2021). A recent systematic review of literature relating to self-management interventions for PU prevention, health belief and behavioural change theory in Spinal Cord Injury (SCI) found there were very few links between the behavioural change theory itself and the intervention(s). Six of the 17 interventions reviewed were reported to have a theoretical base, however failed to provide supporting evidence linking theoretical constructs of the behavioural change models used to actual self-management behaviours. Therefore, the use of such theories remain sub-optimal with further research warranted (Baron et al. 2018).

1.8 PU Prevention and Adherence

There is a paucity of evidence in relation to adherence and PU prevention. The majority of research to date has focused on other conditions such as leg ulcers. The few studies related to PU prevention have predominantly been in relation to behavioural interventions designed to improve adherence with individuals who have already experienced or have an existing PU rather than a prevention focus (Liu et al. 2021). As highlighted above, prior experience of a condition can significantly effect understanding and perception of risk.

Within the field of leg ulcer research, non-adherence to professional advice is a significant issue particularly in community settings such as a patient’s own home (Brewster et al. 2017). In a systematic review of why patients with leg ulcers do not adhere to treatment, the study found that adherence to leg ulcer treatment is influenced by a range of different factors, varying from patient related factors such as pain and discomfort to psychosocial influences and interpersonal relationships (Van Hecke et al. 2009). The authors suggest that non-adherence is a multidimensional phenomenon and importantly, whilst traditionally research has focused on interventional aspects to supporting adherence behaviour less attention is given to the decision-making process and the relationship between patient and HCP (Van Hecke et al. 2009). To address this, Van Hecke et al. (2011) conducted a follow- up qualitative study to consider the processes underlying adherence to leg ulcer treatment in community settings. The study found trust with the healthcare professional to be central to patient adherence and where trust was established with the nurse, the patient was more likely to follow the advice given. The study revealed the development of trust was established over time and fostered where patient illness narratives were acknowledged and where patients were an active part of the decision-making process. Importantly, where shared decision-making occurred, advice was more likely to be followed. Patient related factors, such as pain and discomfort, co-morbidities and fear of falling were also found to affect adherence (Van Hecke et al. 2011). The authors acknowledge a gap in a conceptual framework for adherence to leg ulcer treatment and from the study findings introduce a rudimentary framework, with trust with the HCP as the central core concept (see Figure 4) . Within this framework, the establishment of trust is secured through continuity with the HCP together with acknowledgement of facilitators and barriers to leg ulcer adherence (Van Hecke et al. 2011).

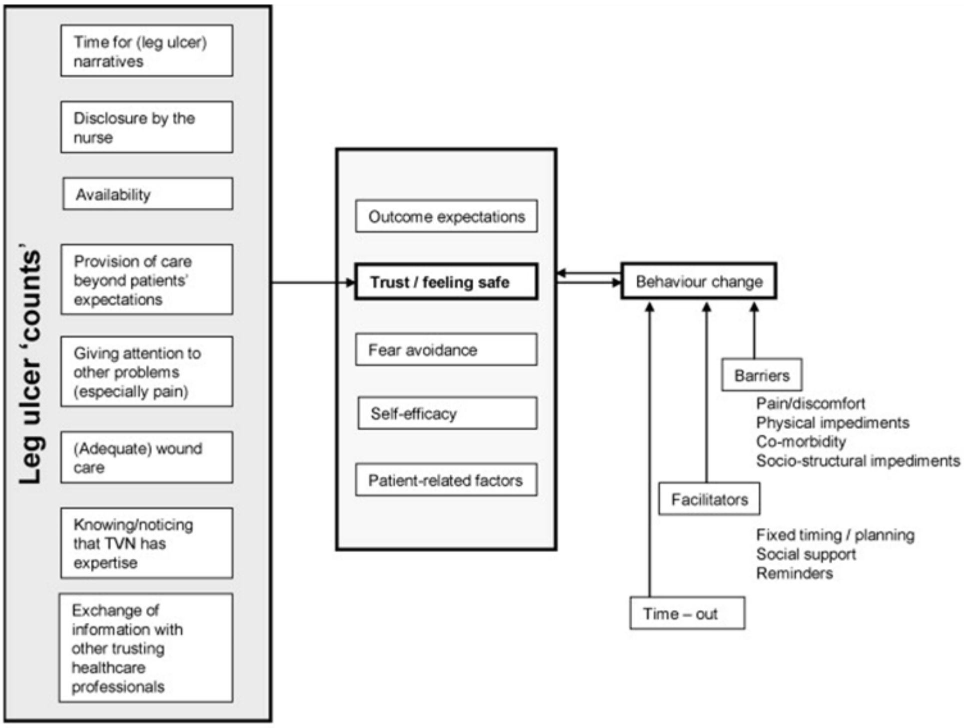


Figure 4: Theoretical framework for adherence to leg ulcer treatment (Van Hecke et al. 2011)

Weller et al. (2021) in a more recent study exploring patient explanations of adherence and non-adherence to venous leg-ulcer treatment, found there were barriers and enablers within 5 key domains:

- Knowledge (knowing what to do)
- Social influences (social support)
- Beliefs and Consequences (previous negative experiences)
- Emotions (feeling overwhelmed)
- Decision-making (difficulty remembering advice, fatigue) (Weller et al. 2021).

These were similar patient related factors to previous leg ulcer studies, reinforcing the importance of the need for further research to consider how these patient related factors may be considered within shared decision-making to improve adherence (Weller et al. 2021). These findings can be used when considering a conceptual framework for PU prevention, in particular the concepts around nurse/patient relationship and the development of trust. However, some of the other elements are less relevant to this study as they relate to a pre-existing wound and treatment aspects as opposed to a prevention focus and before a problem is evident.

In relation to studies focused on adherence in relation to pressure ulcers, research to date has largely focussed on specific subgroups of at-risk patients. For example, persons with spinal cord injury (SCI) have received particular attention due to the higher prevalence of PUs post injury. King et al. (2008) conducted a qualitative study to explore preventative skin care beliefs of 22 people with SCI using the HBM (see Figure 2) as a conceptual framework to design semi-structured interviews. The results of this study revealed four broad themes related to PU adherence:

1. taking vigilant care,
2. taking charge,
3. maintaining health and
4. passing up care. (King et al. 2008).

The theme of taking vigilant care was concerned with how participants took measures to avoid getting PUs associated with a fear of getting a PU. Importantly, the majority of the participants in the study either had an existing PU or previously had experienced one, which was likely to have influenced their perception of PUs and increased fears of a recurrence. Participants also expressed the importance in maintaining some control in their lives and although they were dependent upon others for aspects of self-care, it was important they could direct this in some way. Maintaining health included aspects such as a keeping a healthy diet and skin care and skin checks as a priority. Whereas 'passing up care' as a theme emerged from beliefs about barriers to carrying out preventative care, such as conflicting lifestyle demands therefore 'passing up' for example, not performing the PU care task. Some participants reported an ambivalence to skin care and being tired of constantly having to keep vigilant, whilst others were sceptical about the efficacy of the PU regimes and risk prevention. As a result, they chose daily lifestyle choices at times over the skin care regime. These findings are similar to other studies that have found aspects such as taking vigilant care to prevent getting PUs and passing up care with conflicting lifestyle demands affecting adherence (Hashim et al. 2020; Liu et al. 2021).

Whilst these studies provide some useful insights into potential factors affecting PU adherence, they concern a particular subgroup of individuals with a specific comorbidity (SCI) where many participants had existing PUs or history of PU damage, which therefore limits the potential usefulness in the context of PU prevention. There is also a gap in the research on how decision-making unfolds between HCP and patient and the relationship of this to adherence in community dwelling individuals who have not experienced a pressure ulcer. Less attention has been made to preventative conversations and how the adherence 'agreement' is reached within the decision-making process between nurse and patient and the subsequent effect of this on carrying out prevention strategies (Van Hecke et al. 2011). Research to date has primarily focussed on the HCP view of the barriers and facilitators to prevention and adherence, resulting in a need to further understand the patient perspective (Lavallee et al. 2018).

The literature has revealed some important links between patient involvement within the decision-making process, trust with the nurse and resultant adherence that warrant further investigation (Deakin et al. 2020: Van Hecke et al. 2011). Likewise, the existing concepts around patient adherence and behavioural approaches have largely focused on patient knowledge and motivational aspects and failed to consider other important aspects such as the decision-making process and patient related factors to adherence such as social situation and competing lifestyle demands. The concept of 'situated adherence' is promising in understanding these more concrete and practical contingencies of patient's lives in facilitating or constraining adherence. This has been included within the conceptual framework presented below.

1.9 Introduction to the Conceptual Framework

Theoretical or conceptual frameworks can provide the underpinning of a study, built on a combination of tacit (experience) and formal (literature-based) theory on which to guide the research (Heale and Noble, 2019). A broad conceptual framework has been used to guide this study and provide a lens of focus for the research design and process, informed by a review of the wider literature outlined earlier in this chapter. Grant and Osanloo (2014) offer a useful distinction between a theoretical and conceptual framework by clarifying that a theoretical framework is usually derived from an existing theory (or theories) in the literature, whereas a conceptual framework is the researchers understanding of how the research problem will best be explored, using broad overarching concepts on which to guide the study. The intention of the research was to remain broad in order to investigate both the patient perceptions and understanding of risk as they unfold within the decision-making process, as well as the factors affecting adherence behaviour itself. The study is explorative and inductive in nature, therefore rather than a preordained rigid framework, the use of a broad conceptual framework was considered the right foundation from which to conduct this research.

A broad conceptual framework (see Figure 5) was created to address the following two research questions:

1. What are patient perceptions and understanding of PU risk in the community?
2. What factors affect adherence to PU prevention strategies in community settings?

It is important to note that currently within the field of PU prevention, a conceptual framework does not exist that encapsulates the breadth of this research focus. Likewise in relation to the adherence aspect, existing research and behavioural models have often focused on adherence in the context of treatment of an existing condition or problem. However, where relevant, elements from the existing literature and concepts have been included, such as situated adherence, the influence of family and others on adherence and the nurse-patient relationship and establishment of trust.

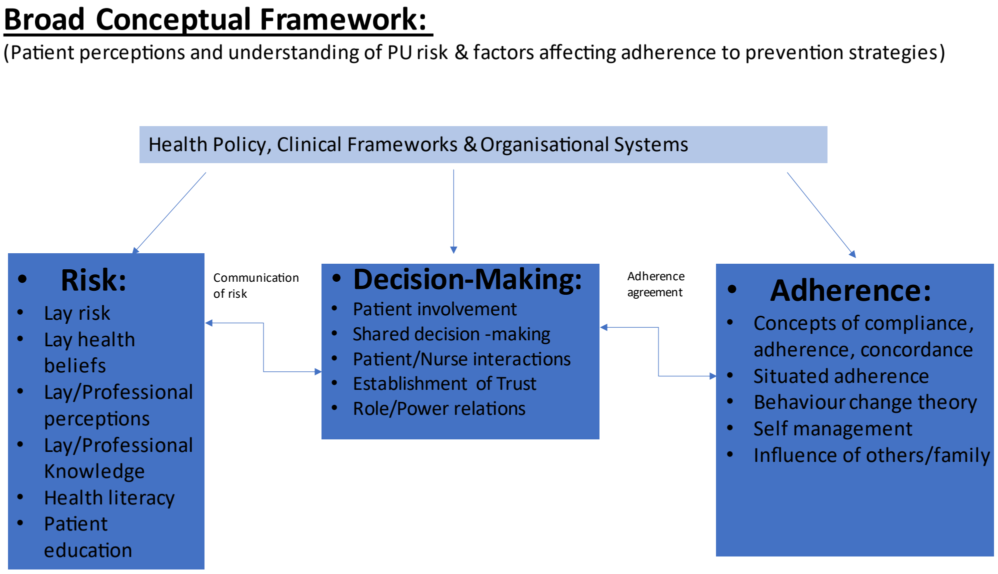


Figure 5. Broad conceptual framework of the PhD Thesis.

These concepts have been broadly used to ‘frame’ the study and visited throughout each stage of the research process, to consider how the research study ‘fits’ within the existing literature whilst also allowing consideration of new and emergent knowledge.

Through consideration of the wider literature discussed in this introductory chapter, it is evident that professional and ‘lay’ patient interpretations are not necessarily the same and it is important to understand this further in the context of how PU risk is communicated to patients and PU prevention care planning and decision-making. Likewise, the acquisition of scientific knowledge itself does not necessarily translate into adherence behaviour due to a number of other competing individual and social factors (Weller et al. 2021). There are some useful behaviour change models employed in PU research which have been considered in this chapter. However as discussed earlier, the studies to date have largely focused on adherence in the context of a pre-existing condition, such as a PU or a leg ulcer and the associated behaviour rather than prevention which this study intends to address.

1.10 Focus of the Study

There is currently a significant gap in the research evidence around the factors affecting adherence to PU advice and prevention strategies from the patient's own perspective. This includes their understanding of risk, how decision-making unfolds and subsequent adherence, particularly in community settings (Baron et al. 2016; Stinson et al. 2013). Equally, much of the literature surrounding patient adherence with PUs has focused more on the interventional aspects to adherent behaviour such as lifestyle advice and often with patients with pre-existing health condition(s). The community setting and a patient's own home is increasingly recognised as a key location for care delivery alongside increased responsibility for self-management, but it is a complex and non-standard setting which presents different challenges (Brewster et al. 2017). It is important to understand the home setting and situated adherence and how this unfolds day-to-day (Rosenfeld and Weinberg, 2011). It is important to further understand the role of the patient within the risk assessment and decision-making process and the potential effect of this on subsequent adherence to prevention strategies. Evaluating how risk knowledge and education is provided to patients within PU prevention practice and whether or not knowledge acquisition translates into preventative health behaviours is also critical (Jorgensen et al. 2019).

The focus of this study therefore was to explore how risk is communicated, patient concepts of risk and how decision-making unfolds between HCP and patient and the relationship of this to adherence. The study was also focused on situated adherence and what factor/s affect patient adherence to PU prevention strategies day-to-day, through the following broad research questions:

- ***What are patient perceptions and understanding of their pressure ulcer risk?*** *and*
- ***What factors affect adherence to pressure ulcer prevention strategies in community settings.***

Chapter 2 Literature review

2.1 Introduction

The prevention of pressure ulcers remains a key priority area for healthcare providers and a patient safety issue, as despite national campaigns to increase awareness and education, prevalence and incidence remain unacceptably high (National Institute of Clinical Excellence, 2014). Pressure ulcers (PU) are associated with ill-health and poor mobility and can have a significant detrimental effect on an individual's quality of life, including reduced mental and physical function and increased pain (Dealey et al. 2012). In clinical practice, it has traditionally been the nurse/HCP who has been responsible for PU risk assessment and ensuring advice is followed. However, increasingly there has been a policy shift in emphasis from HCPs instructing patients what to do, to a more partnership model with shared decision-making and responsibilities agreed between the patient and HCP (King's fund, 2018).

Chapter One revealed a significant gap in the research evidence around the factors affecting adherence in relation to PU advice and preventative strategies. This includes patient understanding of risk, how decision-making unfolds between nurse and patient and subsequent adherence. The integrative literature review in this chapter was specifically focused on patient perceptions, understanding of PU risk and concepts of adherence within a preventative focus for patients who do not currently have a PU, which has been understudied. The following chapter will provide a literature review which aims to integrate scientific and grey literature to synthesise themes from the patient perspective around potential factors affecting adherence to pressure ulcer prevention strategies in community settings. The rationale for the community patient focus is that increasingly within clinical practice, responsibility is placed on the individual themselves to understand their risk and implement prevention strategies, therefore it imperative to understand this more fully (Brewster et al. 2017).

To consider the existing research literature in relation to the topic under investigation, the broad concepts identified within the conceptual framework in the introduction chapter were used to inform the search. The key research questions were generated through consideration of the broader concepts of risk, patient perceptions of risk, patient understanding, decision-making and concepts of adherence and adherence behaviour.

A comprehensive and systematic integrative literature review was conducted to explore the following research questions:

'What are patient perceptions and understanding of their PU risk?'

and

***'What factors affect their adherence or non-adherence to prevention strategies in community settings*?'.**

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 research study. The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Statement (2009) were used to guide the overall process in a systematic manner (see Figure 6).

This review has been published by the author in the International Journal of Nursing Studies:

Ledger L, Worsley P, Hope J, Schoonhoven L. Patient involvement in pressure ulcer prevention and adherence to prevention strategies: An integrative review. International Journal of Nursing Studies. 2020;101:103449.

The abstract for the manuscript is detailed below:

> *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.

2.2 Inclusion/exclusion Criteria

Studies had to focus specifically on patients' view/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. Studies that focused on professional, medical, or nursing views of patient involvement and adherence behaviour were excluded. Studies with a specific focus on PU products, equipment or intervention were also excluded.

2.3 Literature Search

The following databases were 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 2019. 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 or pressure risk
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 experience or patient understanding or patient role or patient narrative or patient view or patient voice or patient view or qualitative or patient decision-making.

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.

2.4 Study Selection

A PRISMA chart depicting the selection of eligible studies is shown in Figure 6. 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 (see inclusion/exclusion criteria in 2.1 above). The full texts of the remaining 25 studies were reviewed; 10 were rejected as they focused on evaluation of a specific intervention, one study was 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 along with one additional paper from snowballing and an additional paper from the repeated search in 2019 (n=12).

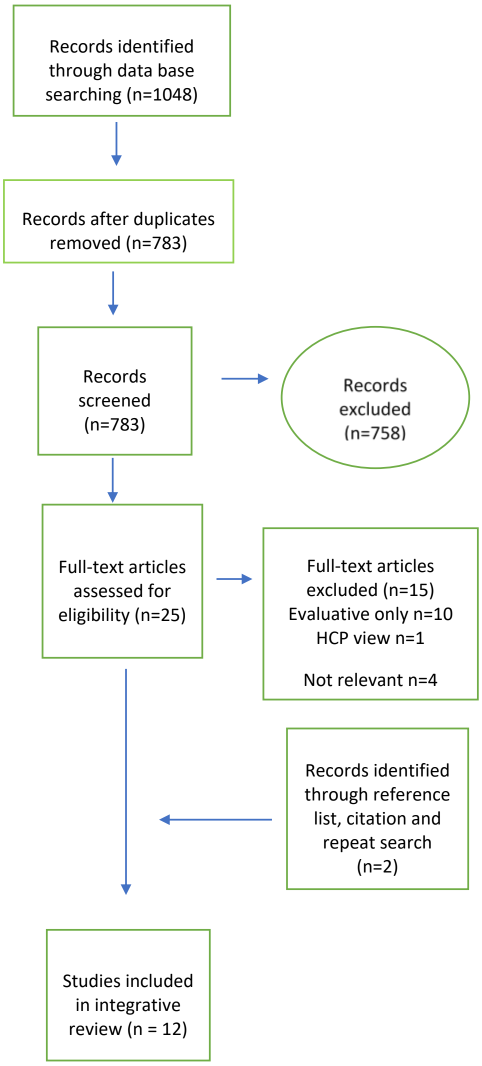


Figure 6 PRISMA flowchart of search strategy (Moyer et al. 2009)

2.5 Data Analysis

The 12 articles included in the review were analysed and the research quality assessed using the Critical Appraisal Skills Programme (CASP, 2013) tools together with qualitative synthesis of key themes. The methodological quality appraisal is described 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). Whilst this process can be completed using a data software tool such as ATLAS-ti or similar, within this review analysis was completed manually through use of highlighter pens and paper. The NCT approach is inductive in nature, with the first stage of Noticing (N) involving reading and re-reading articles. At this first stage, the lead author read, reviewed and re-read articles, highlighting words and phrases analysed. The co-authors (supervisory team) also separately highlighted words and segments of data within papers. The next stage of Collecting (C) involved collating and developing codes further, with the lead author documenting thoughts, developing codes and interpretation into a memo. This was followed by the Thinking (T) stage where all reviewers checked, re-read and reviewed emerging themes. The articles were then reviewed by all co-authors and themes checked across the researcher team to provide triangulation and ensure rigour throughout the process.

2.6 Results

An overview of the results of the studies included in the review are presented in Table 2. Of the 12 studies included, the majority were qualitative (n=9) and the others included mixed methods, systematic review and survey method. All participants were adults with either existing PU damage or a history of damage, often severe (Category 3 – 4). Only one of the studies recruited participants who were at high risk of PUs however, it was unclear whether or not they had developed a PU. Within the qualitative studies, sample size ranged from 5 – 30 patients with a variety of research approaches, including semi-structured interviews, in depth interviewing and participant observation.

Table 1 Methodological Quality Appraisal of articles (Key: Yes=Y No=N Insufficient information=?)

Study	Clear aims & focus	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	?	?	?	N	?	?
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 &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

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 Injury 19 previous history PU damage 1 PU free	Multiple complex circumstances contribute to PU development. Daily lifestyle phenomena that surrounds PU is individualised.	Participants may have misreported when ulcer damage actually occurred.
Fogelberg et al. (2016)	Qualitative Secondary analysis of previous ethnographic study	Five community dwelling Spinal Cord Injury (SCI) adults Stage 3 or 4 PU damage	Pre-existing habits are complex but can facilitate or inhibit new health-promoting habits. Education may increase knowledge but may not move patients from intent to actual behaviour.	As all 5 participants had severe PUs, the results may have been biased towards habits that exacerbated rather than mitigated PUs.
Fox (2002)	Qualitative Semi-structured interviews	Five community patients with PUs	Research identified adverse effects of having PUs in three main categories; physical, psychological and social.	Difficulty accessing participants who fulfilled study criteria.
Gorecki et al. (2009)	Systematic review Meta synthesis of	Acute, community and long-term care settings in Europe, the US,	PUs significantly affect quality of life. Pain was identified as a major concern by patients, restricting general activities of daily living. Patients	Quality of RCTs were poor and many were excluded. All RCTs used single-item

Study	Design/Data Collection	Setting/ Sample	Key Results or Recommendations	Limitations
	primary research	Asia and Australia. Included adults with PUs	expressed a keen desire to be involved in decision-making.	questioning methods rather than validated outcome measures.
Gorecki et al. (2012)	Qualitative Semi-structured interviews	Hospital, rehabilitation and home settings 30 patients with PUs	Involving patients in PU care decisions facilitated adherence. Pain was common and significant for patients.	Researcher reflexivity not evident within the study.
Guihan and Bombardier (2012)	Cross-sectional observational design Survey & checklist	Spinal Cord Injury (SCI) Centres 131 veterans with SCI and Stage 3 or 4 PU damage	Large proportions of the sample didn't follow recommended skin care guidelines. Only 42% contacted healthcare personnel when they noticed new or worsening skin. 25% of the sample were ready to or trying to change behaviours. Skin protective behaviours and adherence should be an ongoing topic of discussion.	Sample had been hospitalised with severe PUs, 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 centre 20 SCI adults with history of	Eight inter-related daily lifestyle principles that explain PU development were identified. The issue of daily activity versus health risk is a	Sample were all high PU risk. This may 'elevate' findings around how daily lifestyle

Study	Design/Data Collection	Setting/ Sample	Key Results or Recommendations	Limitations
		Grade 3 or 4 PU damage	crucial concern to individuals with SCI.	considerations affect PU development.
Jackson et al. (2017)	Qualitative Semi-structured interviews	12 community participants, five carers, existing PU damage	Having a PU negatively affected aspects such as mobility, independence, social engagement and personal autonomy.	Sample selected were identified as very high risk. This may 'elevate' findings.
King et al. (2008)	Qualitative Semi-structured interviews	Two rehabilitation hospitals 21 participants with SCI, 15 of these with history of PU damage	Four key themes emerged about skin care beliefs; taking vigilant care, taking charge, maintaining health and refusing care. Discrepancy between patient beliefs and actual performance of skin care behaviour. Individuals commonly chose non-adherence when confronted with conflicting life priorities.	Due to the cross-sectional nature of data collection, it is not known whether participants' previous experience of PU influenced their beliefs and values.
Latimer et al. (2014)	Qualitative Semi-structured interviews	Hospital setting 20 adult inpatients who required assistance to move	Patients' experience of PU is multi-faceted. Patients gather pressure injury knowledge from first-hand and vicarious experience. Patients that felt they were not listened to, disengage from PU care.	Interviews were brief due to clinical context, therefore may not have allowed deeper questioning.

Study	Design/Data Collection	Setting/ Sample	Key Results or Recommendations	Limitations
McInnes et al. (2014)	Mixed Methods Structured survey with open and closed questions	Hospital setting 51 patients participated, over half at risk of PU	86% of patients understood the concept of PU and 80% agree patients have a role in PU Prevention. Pain was related to adherence.	Small convenience sample, so results may not be generalizable.
Pinkney et al. (2014)	Qualitative Case record analysis & in-depth interviews	Patient home, acute and community hospitals and care settings Eight individuals who had developed severe PUs	Severe PUs develop in organisational contexts where there were failures in overall governance. Specifically these were characterised by clinicians failing to listen to patients.	Retrospective analysis, therefore could have created hindsight bias. Possible bias in the background of the research analysts.

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

2.6.1 Individual/daily lifestyle considerations

The first theme focused around lifestyle considerations for patients and that these are individual and often constantly changing, such physical ability, daily routines, roles and responsibilities. These factors may affect decisions around taking advice and adopting PU 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 ‘Rob’ describes a situation where advice to remain on bed rest was ignored:

“No I mean, I just, I cannot see me lying around……I love my job you see” (p574).

It is therefore important healthcare professionals are aware of these factors in their interventions and conversations with patients (Clark et al. 2006; Jackson et al. 2010). The ‘framing’ of risk from the patient perspective also needs further exploration as it appears individuals themselves may make lifestyle risk trade-off decisions on a day-to-day basis (Jackson et al. 2010). This means prevention and treatment strategies should realistically fit into a patient’s daily lifestyle (Clark et al. 2006; Fox et al. 2002; Guihan et al. 2012; Jackson et al. 2010).

Within some of the studies, patients reported that whilst they understood the importance of the PU risk and adhering to advice given, this was not always acted upon (Fogelberg et al. 2016; Gorecki et al. 2012; King et al. 2008). The reasons for this were often due to lifestyle and competing priorities. In the study by Fogelberg et al. (2016) for example, a participant explains that despite knowing and wanting to adjust his seated position, he didn’t want to miss classes as he was a student and therefore prioritised this over the PU regime:

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

Within this study pre-existing habits and routine substantially affected adherence to treatment along with competing lifestyle demands (Fogelberg et al. 2016). This highlights the dynamic and changing nature of PU risk and the decision-making process that occurs with individuals responsible for their own care on a day-to-day basis (Brewster et al. 2017). This is also an interesting finding in relation to the concept of ‘situated adherence’ and how the routine and habitual nature of daily life affects adherence decisions (Rosenfeld and Weinberg, 2011).

The studies outlined that whilst there was a genuine desire to engage in healthy skin care routines, participants reported 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 but I had just started this job and didn’t want to take time off“ (King et al. 2008, p159). This also links to the previous theme around the importance of daily lifestyle challenges.

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 they were perceived as necessary but tiresome and would therefore not always follow the advice given (King et al. 2008). This links to the concept of situated adherence outlined in the conceptual framework (Figure 5), whereby adherence is situated within the practical and social contingencies of daily life (Rosenfeld and Weinberg, 2011). These dynamic and rhythmic demands within the domestic setting may facilitate or hinder an individual’s efforts to adhere to advice.

2.6.2. Patient involvement in the decision-making process

The second theme to emerge was around the importance of shared decision-making. Patient involvement in goal setting and decisions around their PU 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; Jackson et al. 2017; King et al. 2008; Latimer et al. 2013; McInnes et al. 2014; Pinkney et al. 2014). Patients reported that they felt they were not always listened to regarding what was important to them during the PU 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, they reported that staff commonly ignored this. Three of the studies indicated a link between patient involvement in decisions and subsequent adherence to treatment behaviours (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, so what I think matters” (p8).*

It is important therefore that the patient is involved in the PU assessment and decision-making process and that their opinion and concerns are fully acknowledged (Pinkney et al. 2014). 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 that this may then result in non-adherent behaviours (McInnes et al. 2014). The importance of shared decision-making is central to the study and has therefore been added into the broad conceptual framework. However, the importance of the decision-making process between nurse and patient and its effect on adherence falls outside the adherence health-behaviour models typically used to explain patient adherence.

2.6.3 The pain factor

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. Importantly the presence of pain experienced by individuals and resultant effect upon adherence is not evident within the existing models of adherence outlined in Chapter One. 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 PU 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 advice and self-management behaviour such as turning and repositioning.

It is therefore important for healthcare professionals to be aware of pain as a significant factor in potentially contributing to restricting adherence to certain prevention strategies such as regular re-positioning (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014; Pinkney, et al. 2014). There are also other important aspects in relation to the use or non-use of pressure relieving equipment by individuals and importantly, whether these 'patient related' factors are shared with the HCP as part of preventative care planning. The reluctance to share these concerns with the HCP may relate to the concept of trust embedded within the conceptual framework, which warrants further research.

2.7 Discussion

This integrative review revealed that there is limited research regarding the patient perspective of PU risk and their involvement in the decision-making around prevention strategies. To date, research has primarily focused on the HCP view. Of the articles included in this integrative review, three key themes emerged that potentially affect adherence or non-adherence to PU prevention and advice given, namely:

- individual/daily lifestyle considerations
- patient involvement in the decision-making process
- the pain factor.

From these preliminary themes, there does appear to be interdependencies. For example, the first theme around lifestyle considerations links to patients' intention to carry out advice made versus actual behaviour and the differences around patient interpretation of risk. Within the study by Jackson et al. (2010) while participants understood PU risk and intended to follow advice, their actual behaviour was dependent upon day-to -day lifestyle choices and conflicting demands. Similarly, within the study by King et al. (2008) patients described how competing priorities affected their decisions to carry out PU advice and recommendations. This finding links to the broad conceptual framework for the study around the concept of 'situated adherence' and how lifestyle and day-to- day routine and habits affect patient adherence. The second theme around the importance of involving patients in shared decision-making about their care, may provide the means by which all the other key factors may be considered, such as lifestyle, the presence of pain or discomfort, daily routine and what matters most to a patient (Fogelberg et al. 2016). This second theme relates to the decision-making process and patient involvement in the conceptual framework proposed in Chapter One. Importantly within this, the concept of the establishment of trust with the HCP is central to patient disclosing these challenges and any concerns. The third key theme around the presence of pain that was also identified as a key factor regarding whether patients were willing or able to carry out advice given and similarly links with the intent versus actual behaviour (McInnes et al. 2014). For example, where pain or discomfort is experienced, whilst intending to move or re-position, the presence of pain may inhibit such action.

Further research is necessary to explore these 'patient related' factors further and decisions about adherence to PU prevention and treatment from the perspective of the patient. Whilst the studies included in this review have considered the patient perspective, the research has not addressed the issue of adherence within PU prevention as a primary topic for investigation, a key limitation in the research to date. The majority of the studies included in this review, involved patients who had already had a pressure ulcer or history of pressure ulcer damage. Therefore, further research is necessitated on patients who are at risk of, but do not yet have PU damage and is particularly important in community settings whereby increasingly patients are required to take significant responsibility themselves for PU prevention (Brewster et al. 2017).

The strength of the studies included in this integrative literature review are in how they begin to explore what is happening from a patient's perspective. The qualitative papers allow more in depth understanding from the patients' own perspective in order to explore what everyday factors may affect PU management (Hopkins, 2010). This is of particular importance as many healthcare institutions have limited resources including busy professionals time with individuals and/or carers increasingly required to manage their own condition's within community settings (Ghaisas et al. 2015). This review does also reveal some limitations of the studies conducted to date. More studies which include either quantitative or mixed methods approaches would broaden the evidence base. That said, due to the exploratory nature of the research question itself, it is understandable why the qualitative study design predominates. On consideration of the quality of the articles reviewed using the relevant CASP Tool (see Table 1), the overall rigor of data collection and data explanation was transparent in the majority of studies, thus increasing credibility, transferability and dependability of findings (Lincoln and Guba, 1985). Whilst acknowledging the predominant sample group were a distinct clinical population, that were spinal cord injured (SCI) who had existing PU damage, due to the 'richness' of data gathered in the studies, this does limit the transferability across a wider population with other conditions and clinical presentations. The sample used were also largely those who had existing PUs, often severe (Category 3 – 4) rather than participants who are at risk but who have not yet had a pressure ulcer. Additionally this group are a clinical population with a distinct risk status, with neurological impairments which could be a factor in physical and behavioural challenges to self-manage PU risk.

There is a need for further research to address this gap in understanding around individuals who have not yet had PU damage and who do not have such a distinct clinical risk status but are a more generalised risk such as elderly, how they understand and manage their risk. The other limitation of the research to date is a distinct lack of research within the community setting itself such as a patient's own home and how adherence to PU advice is understood and managed (Baron et al. 2016). Of the 12 studies included in this integrative review, only four studies specifically focused on the home setting.

While research into non-adherence in PUs is scarce, non-adherence has been investigated within the field of leg ulcer research and is seen as a multi-dimensional issue with factors such as patient knowledge and relationship with their healthcare professional as central to resultant behaviours (Van Hecke et al. 2009). Indeed, Van Hecke and colleagues (2011) revealed trust with the healthcare professional to be central to patient adherence. Factors such as ‘meaningful time’ spent with the patient and allowing the patient to tell his/her story facilitated the development of trust and the development of a relationship encouraged adherent behaviours. Another key factor identified within the study was self-efficacy and a patients’ confidence in their ability to carry out specific interventions. Self-efficacy was negatively influenced by experiences such as failure to follow advice given due to pain or other physical restrictions (Van Hecke et al. 2011).

We can draw from these similarities to the themes that emerged from this integrative review around the importance of patient involvement in decision-making and acknowledging other factors such as the presence of pain in whether advice can or will be followed (McInnes et al. 2014). Importantly, whilst the presence of pain was a significant factor for whether advice could realistically be followed, patients did not always disclose their concerns or difficulties with the HCP although the reasons for which are not evident (Gorecki et al. 2012). This could relate to the concept of trust with the HCP outlined in Chapter One and pre-existing power relations within the nurse-patient relationship, however this requires further investigation. Patient involvement in decision-making alongside the healthcare professional may provide the means by which other key ‘patient related’ factors important to adherence may be considered such as pain, individual lifestyle and social situation. Further research is warranted to investigate this and determine how patient understanding of PU risk and involvement in the decision-making process may affect adherence to advice and recommendations.

This integrative literature review helped to refine the overall conceptual framework and focus for the study, with patient involvement, daily lifestyle considerations and pain included (see Figure 5a).

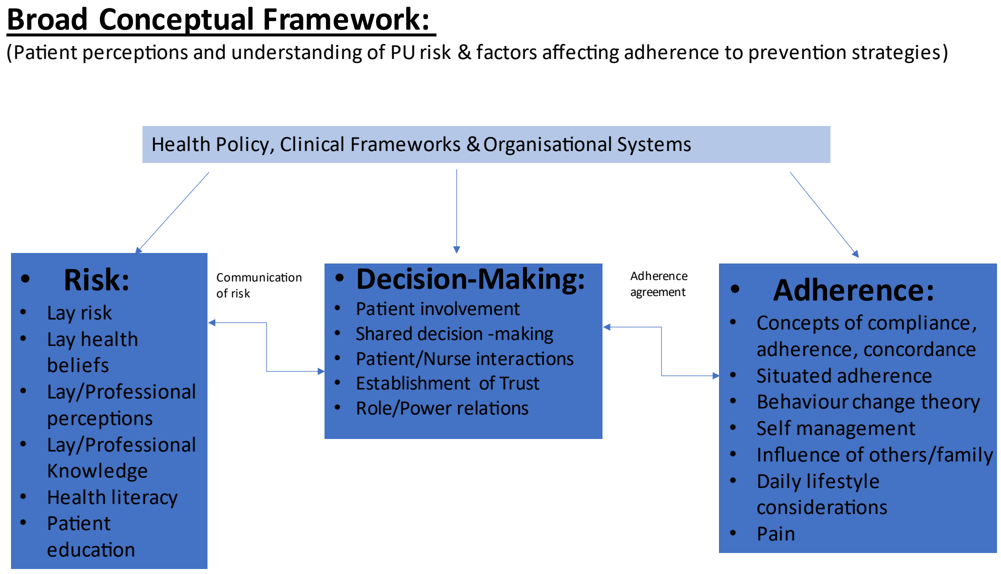


Figure 5a: Broad Conceptual Framework (refined)

There is a clear need to investigate the patient context of risk and the nature of underlying power relations and interactions between HCP and patient and observe how these unfold within the home setting. This will provide critical insights into the factors that affect adherence to PU prevention strategies. Likewise, the integrative review revealed studies so far have largely used patients who already have PU damage. To move to a more preventative focus, there is a need for this research to address individuals who have not yet had PU damage but are at PU risk. It is likely these individuals will have a unique perspective on how PU risk is interpreted and potential factor(s) affecting preventative advice being followed.

The next chapter will outline the overall research design used for the study, methodology including data collection and data analysis, practical and ethical decisions.

Chapter 3 Methodology

3.1 Overall Research Design

The themes from within the literature review and broad conceptual framework that help to frame the study (see Figure 5a) revealed the importance of how and where PU advice is provided. Also, that there may be differences in how risk as a concept is understood by professionals and patients, which may influence health behaviour. The literature also revealed the importance of the nature of interactions between nurse and patient, professional/lay roles and the decision-making process, which were also associated with patient adherence. The literature review revealed that there is limited research that has considered the patient perspective of PU risk and factors affecting their adherence to PU prevention strategies. Key themes that emerged from the literature review include the importance of patient understanding and involvement in decision-making, individual and patient lifestyle considerations and pain as a factor in adherence. It was important to further understand the wider contextual factors such as the setting itself, how risk is communicated and understood, decision-making, relationships and the potential effect of this upon the subsequent adherence behaviour of patients in relation to PU prevention advice.

In order to investigate this, two overarching research questions were formulated around patient perceptions and understanding of risk and factors affecting adherence to advice in community settings. The research design chosen needed to be open and exploratory to allow for a broad collation of data, including observation of social interactions, education materials (example, patient information leaflet) and individual experiences as phenomena. Therefore, whilst the broad conceptual framework was used to guide the methodology, it was important for the study to remain exploratory in nature. The conceptual framework influenced the broad methodology, with the use of observation to explore the process of shared decision-making and the context of PU risk assessment. The collation of the patient information leaflet was also analysed as part of the context for how educational information was provided in the setting. The interviews allowed the exploration of how patients themselves described and conceptualised their risk alongside justifications for resultant adherence behaviour.

A qualitative research design was chosen as it is an appropriate way to explore the individual's perspective around care and how decision-making is negotiated between nurse and patient within the home setting (Savin-Baden and Howell Major, 2013). The literature review and broad concepts within the overall conceptual framework outlined in the previous chapters revealed the importance in pre-ordained power relations between nurse and patient and how institutional roles and expertise are acknowledged by co-participants within nurse-patient interactions (Barnard et al. 2010). Qualitative research was therefore appropriate as it is a type of social enquiry that focuses on the way people interpret and make sense of their experiences and the world they live in (Cresswell, 2014). Therefore, rather than a preconceived theory or hypothesis, the focus of the research is on exploring, observing and interpreting multiple realities for those involved in the study and the basis of qualitative research lies in this interpretive approach to social reality (Mason, 2002). Qualitative, explorative research is particularly useful where little is known about the phenomenon under investigation and is therefore suitable for this study. Previous research has employed this explorative methodology to explore factors affecting adherence in other healthcare contexts (leg ulcers), identifying the key theme of 'trust' with the HCP and the importance of patient-HCP interactions that occur over time and relationship to patient adherence. The study also considered contextual factors such as the setting itself, time factors, decision-making and relationships (Van Hecke et al. 2011). Although the leg ulcer study was conducted in relation to leg ulcers rather than PUs, there are potential insights worth investigating further.

Within the reflexive methodological decision-making process, several different research approaches were considered and disregarded. A mixed-methods design was initially contemplated to enable qualitative and quantitative data gathering, through interviews and a potential questionnaire. However, from the literature review it became apparent there was very little research specifically within the area of enquiry and the ethos of the research needed to be more open and explorative rather than a focus on quantifying at this stage. Equally, through consideration of the conceptual framework and key concepts, it became evident the importance of observing interactions as central to the study focus. Throughout the reflective process, ethnomethodology was also considered as a potential approach as it focuses on the way people as rational actors make sense of their everyday world by employing practical reasoning rather than formal logic (Have, 2004). Ethnomethodology is a sociological approach which refers to the rules and processes by which people give meaning to their behaviour and interpret social interaction, using methods such as observation of 'routine practice' which has relevance in the nursing and healthcare field (Newton, 2015). The advantage of this is that the approach utilises data about 'real behaviour' with detailed analysis of natural occurring talk (Have, 2004). However, the focus of ethnomethodology has largely been focused on in-depth analysis of 'talk' with Conversation Analysis gaining momentum. This was felt to be limited as an overall approach to this research project as the focus was not purely on conversation and ‘talk’ to understand the phenomenon, rather a broader set of interactions, roles and also participants descriptions of their individual situations and realities.

A pragmatic perspective was taken as this allows for a broad set of methods and acknowledges the most practical and appropriate means to address the research question(s), which is particularly useful in applied professional fields such as healthcare (Savin-Baden and Howell, 2013). Pragmatic researchers adopt general beliefs of naturalists/pragmatists such as an open orientation to what they are studying and strive for unobtrusive observation in a natural setting. They fall between realist and idealist and typically take up a situational or blended philosophies orientation (Cresswell, 2014). This world view and philosophical stance aligns to my stance as researcher and the focus and intention of the research project. Therefore, for this research project, as researcher I was interested in both the ‘emic’ perspective of patients themselves around what is happening but also the processes within the interactions occurring between HCP and patient.

The aim of the research was to translate the findings to inform clinical practice within the field of PU prevention. Thus, pragmatism offered an experience-based, action orientated framework on which to address real world issues (Hothersall, 2019). Pragmatic qualitative research is particularly useful as a means to provide a descriptive account from an interpretive perspective and a richness of data from within the natural setting itself (Savin-Baden and Howell, 2013). This enabled the gathering of data from both the patient’s own perspective of PU risk together with the elements of interaction between patient and HCP as they occur within the patients’ own home. The research questions and objectives below were informed from the literature review and reflected in the broad conceptual framework outlined in the previous chapters, including patient perception of risk and lay health belief, how decision-making unfolds, patient-nurse interactions, adherence behaviour, situated adherence.

The following research aims were addressed:

1. To explore patient perceptions and understanding of their PU risk
2. To identify factors that affect patient adherence or non-adherence to prevention strategies in community settings

To achieve these aims, the following objectives were defined:

I. To recruit a cohort of community dwelling residents who were at risk of pressure ulcers

II. To conduct a qualitative study using a pragmatic research approach to understand their perception of pressure ulcer risk and adherent behaviour
III. To use a range of data collection tools to attract rich and meaningful data including interviews, observations and document analysis (PU information leaflet)
IV. To understand how some of the social processes and interactions unfold between HCP and patient within the patients' own home
V. To analyse a diverse set of data and establish key themes and concepts around individuals perceptions of pressure ulcer risk and factors affecting adherence.

3.2 Methodology

Qualitative research has a subjective and personal orientation, and this is acknowledged within the research design and methodological decisions. Within this, decisions were made along the way about what would be included or excluded within the study. Therefore, it is important to acknowledge and share the selection decisions that occurred along the way and how those decisions contributed to the design and uniqueness of the study.

Within the qualitative methodology, the study utilised a range of methods including background information, non-participant observation, analysis of the patient information leaflet and semi-structured interviews, the intention of which was to enhance both the richness and depth of the data and subsequent analysis. This approach was necessary to investigate the different phenomena under investigation such as individuals, processes and concepts. It was felt that one method such as interview for example, would not encapsulate the breadth of the topic matter. This also ensured integration of the wider overall conceptual framework throughout the study, investigating theory around patient 'lay' risk interpretation, decision-making and adherence concepts and reviewing these in light of the empirical findings of the study itself, as follows:

- Observation, to investigate the context in which risk is communicated, roles and how decision-making occurs
- Analysis of the patient information leaflet in the context of how risk is communicated within the literature provided as part of patient education and prevention strategies for self-management
- Semi-structured in-depth interviews to explore patient understanding and context of risk, knowledge acquisition and involvement in decision-making, alongside factors affecting adherence.

The study design is based on Denzin's conceptualisation of triangulation to provide alternative perspectives and richness. As Denzin (1989) describes using the analogy of a kaleidoscope, whereby each method reveals different colours and configurations of objects to the researcher. In this sense, rather than triangulation of data to determine consistency between sources, each source of data was considered as a different perspective on the same phenomena (Silverman, 2016).

Observations were used to record the nature of interactions between nurse and patient directly within the setting itself, including the relay of patient information and nurse-patient interactions. The decision to observe nursing interactions was that district nurses are predominantly those that conduct the PU risk assessment and preventative conversations with patients in the community. Within healthcare research and other disciplines, observation is a well-recognised method and is an active process by which data are collected about people, behaviour, interactions or events, which is particularly useful in providing first-hand accounts (Gerrish and Lathlean, 2015). This was important in the context of this research project, as it was evident from the literature review and wider conceptual framework, the importance of understanding further how risk is interpreted and educational information is provided to patients to aid their decision-making process (Van Hecke et al. 2011). Equally, in their work around the concept of 'situated adherence' Rosenfeld and Weinberg (2011) suggest observational methods as best suited to investigate adherence in the context of practical and domestic contingencies. This will address the gap in the literature around how knowledge and educational information is provided to patients within PU prevention practice and whether or not knowledge acquisition translates into preventative health decisions (Jorgensen et al. 2019). Therefore, the methodological decision to also collate the PU patient information leaflet as data was considered critical to evaluate patient knowledge, understanding and usage.

The decision to collect background patient information as part of the study was intended to gather cultural, ethnicity, age, gender, occupational and socio-economic information which may be important when interpreting differences in perception and adherence in the data. The decision to complete the background data information sheet before the observational phase, was to reduce the burden on study participants.

The decision to complete semi-structured interviews with participants sequentially after the nurse-patient observation was to enable exploration from participants' accounts of PU risk and prevention techniques following the nursing visit. This included their accounts of involvement in decision-making and factors affecting adherence to advice. Interviewing in the participants' own home setting was also an important methodological decision, which supported the comfort and convenience of participants to share their confidential experiences in their own personal space (Richie et al. 2014). It also enabled me as the lead researcher to see the context and environment the participant was 'situated within' which helped to build a picture of their socio and cultural reality (Mason, 2002). I also used a reflective memo as a means of collating field notes, observations and reflections throughout data gathering and as part of data analysis. Semi-structured interviews were used with participants, to facilitate targeted questioning whilst allowing some flexibility within the process. The interview schedule and development of the questions to guide the semi-structured interviews were informed by the broad conceptual framework and background literature outlined in Chapter One and Two. Therefore, the questions on the interview schedule (see **Appendix 1)** covered the following topics:

- risk,
- health belief,
- role(s) and decision-making
- and factors affecting adherence.

The rationale for doing the interview after the observation was a deliberate decision as it may generate questions for focus during the interview. Also, where a more sensitive issue warranted further exploration such as incontinence or patient challenges to following the nursing advice, the interviews could provide opportunity for exploration of these topics. The rationale for completing a further follow-up interview, where possible, a few months after the initial nursing visit was to see if there were any particular challenges or changes related to advice following after a longer period of time, balanced with consideration of participant retention of information.

To help inform the research design, a patient involvement group within the local NHS Trust where the research took place were approached and asked their feedback regarding the study design. The local research collaborator on behalf of the primary researcher, gathered feedback using a series of semi-structured questions (see **Appendix 2:** Patient Involvement Questionnaire). Although there were no formal changes to the interview schedule advised from the feedback, what was evident from the patient group was the importance they associated with not being rushed and being able to open up and talk about their experiences. The feedback informed the final design in that additional time was allowed for the semi-structured interviews to allow participants time to open up about their experiences. In addition to this, during the design phase the researcher was invited to several District 'link' Nurse network meetings in the Trust organised by the local research collaborator, that provided the opportunity to share thoughts and ideas about the evolving research design. This proved invaluable particularly in helping the researcher consider important ethical and practical considerations, such as access to participants and the challenges to nurses' time and recruitment. This resulted in changes to the organisation of the research visits, such as liaising with the nursing team rota the week prior to visit/s to establish the best order of observations to fit within the teams schedules. Equally, where there was more than one patient recruited from the nursing team, where possible these patients were seen within the same day.

3.2.1 Pilot

A pilot study was completed early on in the research process, the purpose of which was to test out the main study data collection tools including the semi-structured interview schedule (See **Appendix 1:** Interview Schedule) and the observation guide (See **Appendix 3:** Observation Guide). The pilot phase was important to determine practicalities including use of equipment such as the dictaphone, length of time for each data collection strand and opportunity to pilot key aspects of the research design. This allowed me as researcher to practice use of a dictaphone alongside making notes and noting observations using the guide. In terms of the interview schedule, the pilot was important to test out the questions and check for ambiguity, eliminating any potential closed or leading questions. The pilot phase involved two participants who were identified, consented and recruited by one of the district nursing teams in which the research was undertaken.

Whilst there were no large-scale changes deemed necessary as a result of the pilot to either the interview schedule or the observation guide itself, there were some minor changes to timing, with both the observations and interview timing(s) extended within the research protocol from 30 minutes to allow flexibility up to 60 minutes. This change would encourage a more relaxed pace and for rapport building with participants. One small change was made to the interview schedule with the addition of the question: '*What is your understanding of your Pressure Ulcer risk'.* Also one of the participants in the pilot struggled with the term 'pressure ulcer' therefore an additional term of 'bed sore' was added as a prompt for the researcher within the interview schedule. Another additional change was to have a back-up dictaphone for both the observations and interviews in case there was an issue with the recording device. The importance of this became apparent within the first pilot observation, when the dictaphone failed to record the first part of the observation. No other changes were deemed necessary following the pilot stage.

As there were very minor changes made to the research protocol following the pilot phase, the data from the pilot observations and interviews were included within the main data set for analysis as part of the overall study.

3.2.2. Data Collection Process and Tools

A broad range of data was collected, through the background information sheet, direct observations of interactions during the nursing visit, in-depth interviews with patients and through examining the patient information leaflet used by the HCP to inform patient facing decisions and involvement (see Figure 7 flowchart of data collection tools). The decision to conduct the different data gathering methods in linear sequence for each individual participant-observations followed by interviews -allowed the time to reflect and consider any key aspects that came about following the observations, including more sensitive topics to be explored with participants during interviews. However, there was a more cyclical nature to data collection overall, with data collected at different stages. For example, conducting an observation for new participants, at the same time as a follow up interview for other participants.

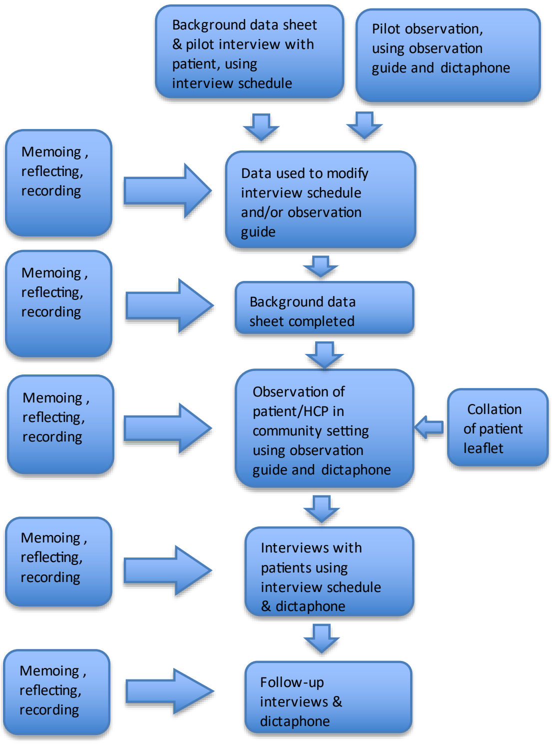


Figure 7: Flowchart of Data Collection Tools for each participant

The following data collection methods were used as follows:

1) **Background data sheet**. From the patient records and referral form, a background data sheet was used to gather an initial picture of the patient's social situation, carer involvement, equipment used, daily routine, environment prior to observations and interview (see **Appendix 4:** Background Data Sheet). The data sheet was co-designed with some of the community nurses working within the NHS Trust in which the research was conducted and was completed before each observational visit. By gathering some of the situational data beforehand, it was felt this reduced the burden of time for patients involved in the research. It also enabled the capture of some personal and socio-economic information to provide background individual context that formed part of the wider analysis, such as dependency on carer involvement, social situation and routine.

2) **Observation and recording of the interactions that occur within a district nursing visit to a patient for pressure ulcer risk assessment**. This was undertaken as part of a routine nursing visit within the patient's own home. Observations and interactions were recorded during the visit, including verbal and non-verbal cues and written onto the observation guide (See **Appendix 3: Observation Guide**) alongside the use of a dictaphone. The nurse introduced me as researcher/observer to the patient at the start of the visit and outlined the context of the visit. The observations lasted between 30 to 60 minutes. This provided a composite of 'snap-shots' of individual nurses interacting with patients in routine day-to-day practice. The observation was focused on observing and recording a number of aspects, including who was involved in the interactions, type and nature of involvement, timing and pace of involvement, where interactions are situated and the decision-making process. This guide has been used in a similar study on nurses in the workplace setting as a tool to capture a 'snap-shot' of interactions within the setting itself and is therefore seen as appropriate for this study (Newton et al. 2015). The observation guide included noting aspects such as the type of interaction observed for example, instructive / directive, types of non-verbal interaction noted, for example, eye contact/ gaze and other activity observed such as demonstration. Further field notes were completed immediately following the event in a note pad in the car to enable reflexivity and to ensure key reflections were not forgotten during the process (see **Appendix 5:** Reflective Log Extract). I also liaised closely with the

District Nursing Team(s) to ensure the visits being observed were appropriate and were timed appropriately and didn't result in any delay to usual routine care. There was awareness that my presence may have affected how both nurse and patient behaved during the observation and this was reflected on and explored through use of memoing. The observation process and data capture methods were also influenced by this reflexive process. For example, initially video recording was explored and considered, however this was discarded to minimise the intrusiveness of the observation. The use of a dictaphone and noting observations in the field does rely on skilled observation and the recording ability of the researcher (Cresswell, 2014). For the purposes of the study, I used 'non-participant observation', whereby I was present at the scene as spectator and did not engage with the situation, to remain as unobtrusive as possible by remaining silent (Cresswell, 2014). Consideration was also given to position at the setting, I therefore placed myself out of the way and usually behind the nurse during the interactions, allowing as much as possible for the visit to be conducted in the usual manner. The reason for choosing this type of observation role was so that there would be minimal disruption to usual routine care and the observation could be done relatively quickly. There are pros and cons to this 'outsider' perspective and these were fully considered prior to commencing proceedings. Cresswell (2014) suggests for example along the observer spectrum, complete participant observer allows a unique 'insider' perspective to the research but that this can be time consuming and the researcher is usually part of the setting itself. This was not the case with my research as I was an 'outsider' to the NHS Trust in which the research took place and the potential benefit to this more passive role was it allowed 'snap-shot' observational data to be gathered fairly quickly to complement the richness of the other data sets gathered such as interviews. Importantly the outsider perspective also allowed me to see things that others don't necessarily see themselves. However, as I am an Occupational Therapist and a healthcare professional I was arguably not quite insider or outsider from a professional stance. I am not a registered nurse which allowed me to observe nursing practice from an outsider perspective, whilst also acknowledging some potential challenges to observing a different profession. However, there are some similarities to my 'clinical lens' and views due to my professional background, such as the professional context of risk and the structure of community visits. Therefore, reflexivity was key throughout the research process and this was captured in the reflective log that was used to support research decisions and analysis and help mitigate bias (see **Appendix 5**: Reflective Log Extract).

3) **Initial in-depth face-to-face interviews with patients following the district nursing visit**. The semi-structured interviews were conducted as soon after the observations as practically possible, with a maximum of four weeks after the observation. Whilst there was some consideration given to issues of recall by participants, it was felt that this would be minimised within a four week window and where possible, most interviews occurred within 2 weeks. Equally, I was interested in how the knowledge gained from the nursing visit was used (or not) for patient self-management and adherence behaviour. These were an important means of checking observations and accounts of these are reflective of the participants own perspective of events, or whether there may be differences to what was observed. Where necessary, notes were made on the observation sheets to guide a particular aspect or question in the follow up interview. The focus of the research was on the patient perspective rather than the nurse (HCP) as this was acknowledged as a gap in the existing research literature outlined in Chapters one and two, hence why the interviews were conducted with patients themselves. A semi-structured approach for the interviews was used to provide some structure whilst also allowing the opportunity for participants to talk freely about their experiences and the schedule itself was informed from the broad conceptual areas of the framework outlined in Chapter 1 (see **Appendix 1**: Interview Schedule). The interviews lasted between 30 – 60 minutes each and digitally recorded on a dictaphone. Priority was given to the participant's perspective to allow deep and contextual information to be gathered (Neale, 2009). However, the process can be time consuming and a potential limitation could be suggested that the researcher's presence and positionality may bias responses participants make to questions (Cresswell, 2014). Consideration was given to this with additional time (10 minutes) given to build rapport and reassure participants that their participation was voluntary, with confidentiality maintained at all times. It was reiterated that my role was of independent researcher and not part of the clinical team to encourage participants to open up and discuss potentially sensitive areas of their care experience. To ensure researcher reflexivity throughout the process, after each interview I took notes on the encounter and how positionality may have affected interview aspects such as rapport. I made the notes in a reflective log and this was maintained throughout the study. The use of the reflective log allowed reflexivity to be explored and captured, including my positionality as a female, white, qualified Occupational Therapist within the process (See **Appendix 6:** Reflective Log Extract).

4) **Memoing** is a technique by which the researcher writes down ideas throughout the data gathering and analysis phases, which aids reflexivity and acts as an ongoing audit tool in the research process and this was used throughout the study. It is important for memoing and coding to occur simultaneously throughout data collection and analysis for rich and immersive data (Lofland et al. 2006). This use of memoing occurred directly after observations and interviews and was captured in the reflective log. I have also used the reflective log throughout the entire research process, from the beginning including formulation of ideas and development of the research design through to data analysis.

5) **Analysis of Patient information leaflet.** The patient facing document was collected for analysis from the setting itself during the observation visit, which in all visits observed was the patient information leaflet. Through including a document such as this within the data collection and analysis, this enhances richness to the phenomenon under investigation (Lofland et al. 2006).

6) **Follow-up interview with patients**. Where possible, it was intended that a follow-up interview would occur, to capture how participants were doing three months after the initial interviews, specifically around adherence to following PU advice and prevention strategies. However, in reality only three follow-up interviews were completed, for a number of reasons including patient ill-health and with some patients reluctant to continue due to other competing priorities. In addition to this, the Covid pandemic happened at the same time which halted any further follow-up interviews from March 2020 onwards (see **Appendix 7: Covid Impact Statement)**. The follow- up interviews that did occur lasted around 90 minutes and allowed patients to discuss their experiences, with a semi-structured follow-up interview schedule used as a guide (see **Appendix 8**: Follow-up Interview Schedule). It was particularly important that participants felt at ease and were able to disclose how they were finding following the advice and any challenges to this. Therefore increased time was spent reassuring participants about the confidentiality of their responses and my role as independent researcher who was not part of the clinical team.

3.3 Sample size, Population and Recruitment

There were many important sampling decisions and it proved beneficial to have involvement with the local research collaborator throughout the project. The local research collaborator was the lead nurse within the NHS Trust in which the research was conducted and provided invaluable help in encouraging wider involvement of district nurses. An example of this was inviting me to some of her clinical network meetings for District Nurses. I was invited to these early in the process and during the research itself. Through discussion with the nurses about the research design and sampling ideas, the sampling strategy and inclusion criteria were developed. For example, the district nurses felt it was important not to exclude non-English speaking participants from the research as they served a wide and ethnically diverse population. Translators were available from within the trust if required for the study, however this was not necessary within the sample recruited as all participants were able to converse in English.

The other aspect that resulted in useful discussion was acknowledgement of the challenges in recruiting enough participants for the study. The study aimed to recruit a specific cohort of community dwelling individuals who were at risk of PUs but had not sustained this condition prior to the study. Therefore the ‘preventative’ sample needed to reflect participants who had not got an existing PU or had experienced a history of PU damage. However, through discussion with the local research collaborator and nurses, it was decided that patients could also be included who had PU history previously, but ‘not recently or within the last 12 months’. This meant that recruitment was more feasible within the community healthcare trust and this history status was recorded and taken into account during analysis.

In relation to recruitment numbers, the research was qualitative in nature and therefore, rather than a focus on recruiting a large, representative sample of participants, the focus was on individuals who could provide rich and meaningful data (Savin-Baden and Howell Major, 2013). Purposeful sampling was therefore used, where people, sights and artefacts are selected that can best help to understand the phenomenon under investigation (Lofland et al. 2006). Purposeful sampling was used to identify a range of patients from different age, gender, race and different medical conditions who presented a PU risk and were living in the community. The key inclusion criteria were those identified as at PU risk but who did not currently have a pressure ulcer.

It was understood the purposive sample would need to be large enough to allow for data saturation, therefore, to ensure the richness of data gathered, a range of different data sets were captured for each participant. Data sets included a background information sheet, observations, interviews, (follow- up interviews, where possible) and collation of the patient information leaflet, therefore up to five data sets per participant. Consideration for sample size was given in terms of participants themselves agreeing to be part of the research process and sharing their experiences and time, including access to their home environment and this was factored into the design of the study. There were also important time considerations for interviewing participants for a second interview due to health, lifestyle changes or that they may choose not to be interviewed a second time. To mitigate this, the sampling strategy allowed for up to 20 participants to be recruited to the study and this was built into the ethics process. The intention was to recruit up to 20 patients for the sample who were adults or elderly (over 18) living in the community, identified as ‘at PU risk’ by the local district nursing teams. The district nursing teams used a PU risk tool, the Walsall assessment score (Chaloner and Franks, 2000) to determine appropriate patients at PU risk alongside clinical judgement and case discussion alongside broad factors such as living alone and reluctance to complying with previous advice.

Due to the exploratory nature of the research all data sets were included, even where a participant consented to be part of the whole process but then decided to only be observed and not interviewed. This retention of incomplete data was made clear in the consent process.

The ‘link’ district nurse working in each district nursing team were used as gatekeeper to identify and recruit potential participants who were suitable for the study. Link nurses are those that agreed within their Trust to be part of tissue viability initiatives and were therefore ideally located in each of the 30 district nursing teams across the geographical region. The nurses themselves were not the focus of the study and therefore were not selected based on specific characteristics other than as ‘gatekeepers’ to recruit patients suitable for the study from across the nursing patches. It was intended for this to allow a broad ‘purposive’ spread of ‘patient’ participants from across the geographical region, including inner city and more rural community dwellings, with a range of ethnicity. The nurses gave written consent and were briefed in terms of their role, the study itself, inclusion/exclusion criteria prior to the research commencing.

Patton (2002) outlines a series of different strategies for purposefully selecting information rich cases and the ‘maximum variation sampling strategy’ was chosen as best fit for the study. This strategy aims at capturing and describing the key themes that transcend across a varying group of community dwelling individuals, with the intention that any common patterns that emerge are of particular value in capturing core experiences and dimensions of a phenomena (Patton, 2002). This fitted with the aims of the study and the overall pragmatist approach, as the intention was to purposefully select a sample across a range of different age, race, gender and geographical locations across the Trust, all of whom have the key defining characteristic of being patients living in the community and identified as ‘at PU risk’.

The ‘link’ district nurses were pivotal to the recruitment of ‘patient’ participants to the study and were encouraged to participate through the clinical network meetings. Those that expressed an interest in being involved in the research were provided with further information and the contact details for the researcher. There were some challenges to recruitment and encouraging nurses to participate in the research that appeared to be around lack of confidence in taking part in research and/or time pressures due to clinical caseload. The benefit of working with a local research collaborator proved useful in supporting district nursing teams to be more involved, alongside the research collaborator running some research sessions as part of the clinical network meetings.

Once nurses had made contact with the researcher, they were consented and fully briefed regarding their role within the research, which was recruiter of potential participants and also consent to be observed as part of the study (See **Appendix 9 and Appendix 10)**. The process of consent involved either a face-to-face meeting or telephone call to go through the participant information sheet, discuss the research and ensure the nurse was fully aware of their part in consenting to the research. The consent form was then signed, dated and returned to the researcher (see Figure 8: Flowchart of recruitment process).

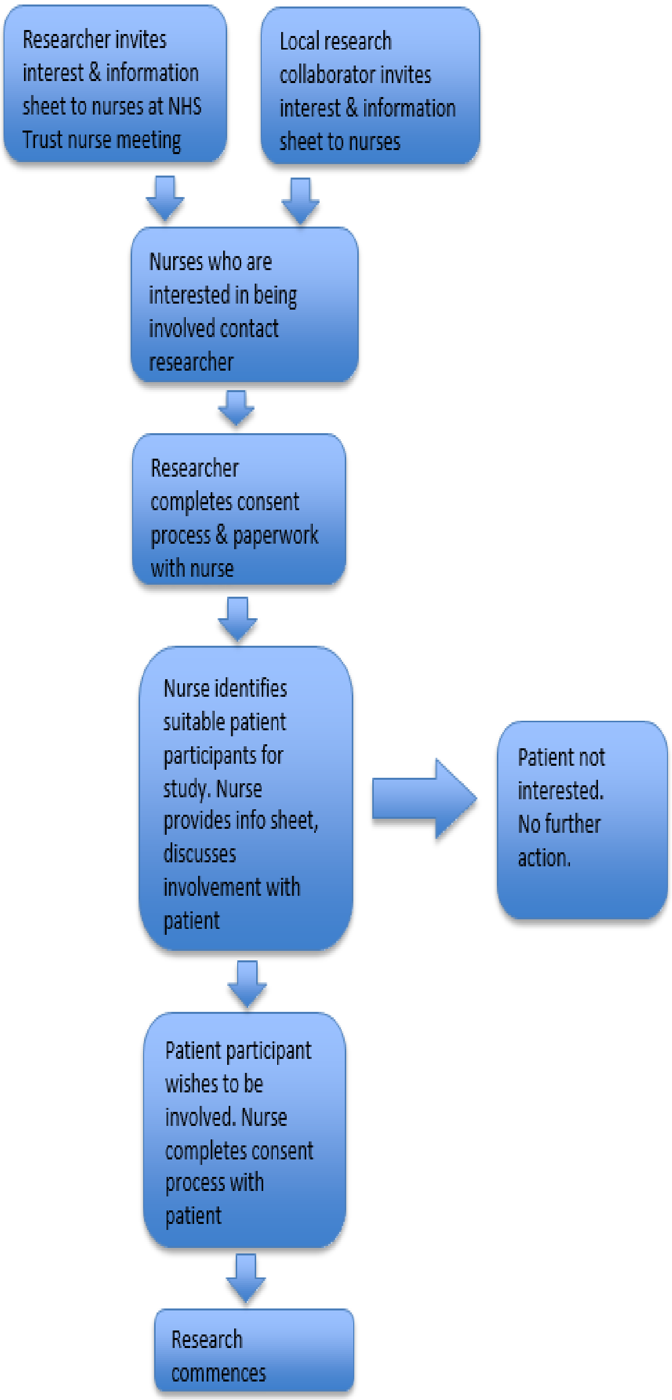


Figure 8: Flowchart of the recruitment process

The district nurse/link nurse conducting the PU assessment with the patient were part of the sample for the observational element of the study. In addition, the context, place, time and artefacts within the setting formed part of the sample under investigation (Have, 2004). Therefore, the patient facing clinical document, such as patient information leaflets that were found in the setting as part of the observation visit were also included as part of the sample.

Patient participants in the study were recruited through identification from the community district nursing teams within Birmingham Community NHS Trust, where they were identified as 'at risk' of pressure ulcer(s), adults (over 18 years) and living in the community in their own home (see Table 3).

Table 3: Participant Sample Criteria

SAMPLE INCLUSION CRITERIA:	SAMPLE EXCLUSION CRITERIA:
Over 18 years of age	Communication difficulties
Known to BCHT District Nursing Team(s)	Cognitive problems
At risk of pressure ulcer	Lack capacity
No recent history of pressure ulcer damage	Existing pressure ulcer

Table 3 provides a summary of the inclusion and exclusion criteria. Participants needed to be able to communicate effectively in order to be part of the interview process and therefore those with significant cognitive impairment were not included. Patients who were non-English speaking were not excluded as it was important in the context of the study to gain a wider sample of experiences from different cultures and ethnicity. However, it was acknowledged during the design phase the practical challenges to finding interpreters locally. This was considered and the local research collaborator confirmed there was a free interpreter to access from within the NHS Trust. Participants also needed to be able to give their consent, which would also include participation in the follow up interviews *(*See **Appendix 11**: Participant Information Sheet and **Appendix 12:** Participant Consent Form). The 'participant' district nurse managed the consent process with the patient at the pre-visit stage which occurred at least 48 hours before the observational visit.

3.3.1 Sample Characteristics

A total of 15 participants were successfully recruited to the study from 10 out of the 30 district nursing teams from across the geographical locality. Therefore, this may have affected to some degree the 'maximum-variation' spread of participants, as the majority of the teams who recruited patients were from the inner-city areas of Birmingham rather than more rural settings. This meant that there was a slight shortfall to the intended sample of 20 within the research design. However due to the depth and richness of data gathered within the different data sets, the effect of this was minimal.

Table 4 presents the sociodemographic characteristics of participants within the sample recruited for this research. * Pseudonyms are used to keep the data more personalised rather than assigning a value to each, which was felt to be important for the nature of the qualitative study.

Table 4: Characteristics of patient sample

Patient *	Age range	Occupation	Ethnicity	Gender	Medical condition	Mobility status	Lives/ with	Care input
Ann	66+	retired	Afro-caribbean	Female	Diabetic	Mobile with 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 sticks	family	wife & daughter
Belinda	30-66	unemployed	White	Female	Diabetic	Mobile	mother	mother
Colin	66+	retired	White	Male	Arthritis	Mobile with stick	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	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	retired	White	Male	Arthritis	Mobile Indoors	alone	paid carers
Eva	66+	retired	White	Female	Diabetes	Mobile indoors	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 sample comprised of mainly elderly retired, over 66 years of age and of white ethnic origin, of which eight were female and seven male. There were a range of clinical presentations including arthritis, diabetes and neurological conditions. It is significant to note that 86% (n= 13) of the patients in the study had mobility issues and 93% (n = 14) had carer input, either by relative or paid carer(s). None of the patients had an existing pressure ulcer as this was part of the exclusion criteria, however two had a previous PU history. All participants shared a common characteristic in that they were known to the district nursing team and were identified as ‘at risk’ of developing a pressure ulcer.

A total of 15 observations of nursing visits were completed within the participants own home. The patient facing document, such as the patient information leaflet was also collected as part of the data set. A total of 15 interviews were also completed with patients themselves shortly after the observations were completed and no later than four weeks post observation. A further three follow up interviews occurred with three of the participants a couple of months after the initial observations had taken place.

3.4 Ethical Considerations

Ethical Approval was gained from University of Southampton ethics committee through the ERGO online ethics process at the end of August 2018 (ERGO No. 41350). The Heath Research Authority (HRA) NHS Ethical approval was given in October 2018 (IRAS Project I.D. 248039 – **see Appendix 13)**. Following this at the end of October, Birmingham Community Healthcare NHS Foundation Trust successfully granted a research passport and access to approach participants. The process for successful NHS ethical approval and University approval was extremely rigorous and provided the opportunity to consider in detail, the key ethical considerations such as consent, anonymity and confidentiality, right to withdraw, harm and GDPR data protection considerations. The research was also required to be agreed with the NHS Trust local governance department in which the research was taking place, this required a further level of scrutiny. Within the feedback process by the NHS Trust governance department, as part of the agreement to proceed two specific elements were amended on the background data sheet, as it was felt the information was too identifiable. One change was in relation to the postcode, this was amended on the sheet to reflect only the first four digits. The second change was in relation to age, this was required to be amended to reflect broad age categories which are now reflected on the background data sheet (see **Appendix 4**).

3.4.1 Consent

As outlined earlier, for both nurse participants recruited as part of the study and patient participants a full ethical consent process was followed, including written consent forms**.** The participants were provided with a copy of the signed consent form in addition to the participant information sheet. As highlighted in the inclusion criteria, participants needed to have capacity and be able to give their consent, which also included participation in follow up interviews. At each stage of involvement in the study, participants were verbally consented again. As part of the consent process itself, there was also acknowledgment that some participants may not be comfortable being observed for the skin check carried out as part of the nursing visit. Therefore, consideration was built into the consent process and clearly stated that where necessary, the researcher would remove themselves from the room for that part of the observation.

3.4.2 Right to withdraw

All participants were made aware of their right to withdraw from the research process at any point in time. It was made clear during the consent process at each point whether they still agreed for data to be used or whether they wished for all data to be removed.

3.4.3 Anonymity and confidentiality

To protect the anonymity of participants I complied with the University of Southampton guidelines in line with Caldicott Principles, as well as The Data Protection Act (2018). Linked anonymity was maintained by using pseudonyms, linked through a password protected data sheet. All data collected was kept in a locked cabinet and separated from personal contact details at all times. All digital data were password protected and held on a university computer. The digital audio data recorded through dictaphone were kept in a locked drawer and transcribed verbatim. Once transcribed, both the digital audio files and transcripts were uploaded onto a password protected university laptop, with files then deleted from the local Dictaphone device. Once the study is fully completed, in line with the University of Southampton data management policy, all anonymized data will be uploaded onto the PURE system to be held for 10 years. There was some consideration given to specific occasions or situations where anonymity and confidentiality may need to be breached. For example, if I had observed negligence within the setting or if a patient raised a safeguarding concern that required action. This was important to consider again in terms of positionality as I am a qualified Occupational Therapist, registered with the Health Care and Professions Council (HCPC) and therefore bound by a code of practice to act on specific concerns. These such circumstances were clearly outlined to the participants as part of the consent process and paperwork.

3.4.4 Other risks

There were no direct risks involved with taking part in the research however as part of the NHS IRAS ethics process, a full risk assessment was completed. In considering the potential risk to participants it was acknowledged that some may have found recalling experiences of PU prevention and management distressing. Therefore, if participants had become distressed at any point during the interview, the interview would be paused and participants given a choice about whether they wished to proceed or not. Participants were also provided with the contact for the research governance office should they wish to discuss the project with someone independent of the researcher. Consideration was also given to the safety of myself and the patient(s) at all times, particularly the interview stage where I was conducting the research alone in the home environment. Therefore, the lone working policy and guidance for both the University of Southampton and Birmingham Community Healthcare NHS Trust were followed throughout. The University of Southampton Risk Assessment protocol was also fully completed. These are outlined in the RA3 Lone Working document completed as part of the ethics process and were agreed with the local NHS Trust where the research took place (see **Appendix 14).**

3.4.5 Researcher positionality

Throughout the research process, consideration was given to my role as researcher and the importance of critical self-scrutiny of the researcher’s effect on the research. This was particularly important due to the qualitative nature of the study and the need for active reflexivity throughout (Lofland et al. 2006). A reflective log was used throughout the research to reflect and record observations and thoughts and these shared with the research supervisory team. The background of myself as researcher in terms of role, attitudes, beliefs was also acknowledged, reflected on and considered. I am a part-time PhD student and also a qualified Occupational Therapist and for the purposes of the research was primarily introduced to participants as a PhD student with a clinical background. This may have potentially increased trust in participants knowing that I was not present in a clinical capacity but rather to act as researcher and to hear their stories. However, as part of the consent process and paperwork it was also made clear that should a specific situation arise, the researcher ‘myself’, who is also a clinician may be bound to act in accordance with their clinical duty and HCPC professional registration, for example, a safeguarding issue.

3.5 Data Analysis

An intimate knowledge of the data was achieved by the lead researcher conducting all elements of data collection, from observations to interviews to transcription and through to analysis. Repeated listening to the recordings helped to recapture the interview experience and listening, reflecting and listening again enabled me to comprehend meanings, not only in what was said, but in pauses, inflections and emphasis. The ethos of the research was inductive in nature, whereby the analysis was driven by the data itself as opposed to attempting to test a hypothesis (Lofland et al. 2006). Through gathering data from a variety of sources as described previously, this was intended to enhance both the richness and depth of the study. In this sense, rather than triangulation of data to determine consistency between sources, each source of data was considered as a different perspective on the same phenomena (Silverman, 2016). Where possible during the project, data analysis occurred simultaneously alongside data collection so that analysis could begin early on in the process and be iterative in nature. Data from the pilot observations and interviews were also subsumed within the main data set for analysis.

The dictaphone recordings from both the observations and interview data sets were all transcribed, verbatim by the lead researcher and all data sets (transcriptions, observation guide, background data sheet, patient information leaflet) were analysed using the principles and steps of Thematic Analysis (TA). Thematic Analysis is a method for identifying themes and patterns of meaning across a data set in relation to a research question (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's (2013) six steps were broadly used to guide the analysis as follows:

1) Familiarising yourself with the data
2) Generating initial codes
3) Searching for themes
4) Reviewing themes
5) Define and name themes
6) Produce the report (p202-203).

This approach acknowledges that analysis happens at an intuitive level, through immersion in the data and considering connections between codes, concepts and themes, whilst maintaining a robust process through looking for disconfirmatory data throughout (Savin-Baden and Howell Major, 2013). As Braun and Clarke (2013) describe, the process and steps above should not be used in a prescriptive way, but rather as guidelines to fit with the research question and type of data available. This flexibility was particularly important as the intention of the research design was to analyse data concurrently, both in relation to the different data sets gathered (documents, interview transcripts, observations) whilst also including new participants alongside existing participants for example, observations alongside follow-up interviews.

An iterative approach to analysis was undertaken, with all data sets entered into the ATLAS-ti software platform (ATLAS.ti, Cleverbridge, Germany). The data sets were collated and extracted in the following way(s):

- ***Background data gathering sheet***. These had been completed manually before the research observations were completed and provided a background contextual ‘picture’ of each participant. The data sheets included information such as gender, social situation, level of mobility etc., were entered in ‘raw form’ into the data analysis software package (ATLAS-ti) as individual ‘case’ information and included within the overall data analysis.
- ***Observational data***. This data set comprised of both the dictated 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 of the dictated transcripts which were also entered into the ATLAS-ti data software package and included within the data analysis.
- ***Patient information leaflet***. The patient information leaflet that was collected from the observational visit(s) was photographed and uploaded into the data analysis software package and included within the data analysis.

All data was analysed both manually and through use of ATLAS-ti data analysis software package that provided more structure and order to the mass of data collated, enabling efficient reading, reviewing, coding and refining. In addition, and alongside this reflexive process, the use of paper mind maps with coloured pens and post it notes also ensured that I was fully immersed as researcher (see **Appendix 15)**. In terms of the order of data analysis, initially the transcription data from the research interviews was analysed and initially coded (see **Appendix 16)** followed by the observation transcriptions, the observation guides (see **Appendix 17**) and finally the patient information leaflet (see **Appendix 18).** The background information data were considered in relation to developing analysis and themes to provide context such as level of mobility, carer involvement and any other cultural and social aspects. 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.

At this first data familiarisation stage, line-by-line coding was used to identify everything that could potentially be relevant to the research questions. Reading the words actively, analytically and critically to begin to understand the meaning of the data. This first level of coding involved staying close to the participants' interpretation and words, whilst using reflexive memoing this stage, to reflect on developing interpretations (Braun and Clarke, 2013). Access to the ATLAS-ti software system was shared with the supervisory team, alongside coding reports, to enable scrutiny and challenge from my supervisors at this early stage. These initial codes were further analysed within and across the data sets, with developing codes refined and/or discounted at this stage and shared alongside the data with the supervisory team. Within Atlas-ti software package, following analysis, the codes were given label names, with developing definitions and related codes then grouped into code groups. At the next step of analysis, the code groups were refined further into theoretical code groups, identifying similarities and theoretical patterns in the data whilst remaining open to disconfirmatory data in the process (Braun and Clarke, 2013). The colour coding group function was used in ATLAS-ti helped to provide a visual imagery of the developing analysis.

The next step of analysis was where visual mapping was used to capture developing analysis and potential links within and between the data sets (see **Appendix 19:** example of Visual Thematic Mapping). This later stage focused around searching for and refining themes involved more interpretive analysis of the codes and relationships between codes, subthemes and themes. It is particularly important the researcher questions, combines, challenges and refines themes at this point to build on and make connections within and between emergent themes (Braun and Clarke, 2013). This stage occurred alongside myself and closely working with the supervisory team to discuss and challenge emerging interpretation, including the use of memoing to ensure reflexivity. Visual thematic mapping was also used to aid the exploration of codes and themes, subthemes and overarching themes and to build upon the analysis (see **Appendix 20)**.

The final stages involved refining, naming and defining overarching themes, themes and subthemes within the research report itself and connections and these were captured, organised and structured both laterally (four overarching themes) and hierarchically (three layers; overarching, theme and sub-theme). The overarching themes captured an overarching idea encapsulated in a number of themes. Themes have a central organising concept and subthemes capture specific aspects of the central organising concept of the theme (Braun and Clarke, 2013).

The different data sets were initially extracted, uploaded and analysed by particular data set group, for example interview transcripts, observation data, patient information documents. However, in the later stages of data analysis there was a more fluid process of collating data, whereby different data sets from a particular patient were critically considered and analysed together, including the background data sheet. As data analysis occurred concurrently alongside data collection, it was useful in establishing when data saturation had been achieved. It is acknowledged the challenges and complexity with saturation both as a concept and operationalised, as there are different inferences and interpretations within the qualitative research field (Saunders et al. 2018). However, for the purposes of this study, saturation was understood to have been achieved at the point at which no new themes were evident from the interviews or data itself that added anything new to the understanding of the topic.

Due to the inductive nature of qualitative analysis, it was important to acknowledge my role as researcher and influence on the research process, in particular at the data stages (Lofland et al. 2006). Memoing was used a tool throughout the process in order to clarify and reflect on codes and interconnections but also importantly for me to remain active and reflexive (Lofland et al. 2006). Writing memos provided a systematic method of capturing the emergent process of my interactions as researcher with the data, emergent codes and categories (see **Appendix 20**).

The results will be described in detail in the next chapters, with chapter four considering the overall key overarching themes to emerge from the study, followed by the ‘patient-related’ overarching themes.

Chapter 4 Results: Thematic Findings and Patient Related Factors

4.1 Introduction

This chapter will introduce the overall study results and overarching themes, themes and subthemes. This will be followed by an exploration of the two key 'patient related' themes for this chapter. Throughout data analysis and interpretation, reflexive consideration has been given to what the results reveal in relation to the overall broad conceptual framework outlined in Chapter One. The results chapters consider the findings in relation to existing or new insights associated with the overall concepts and literature. Quotations have been selected and presented throughout the results to provide transparency and keep the patient narratives at the heart of the epistemological research focus (Eldh et al. 2020).

4.2 Overarching Study Themes

There were four overarching themes to emerge from the data analysis in relation to the research focus, centred around patient perceptions and understanding of PU risk and factors affecting adherence to advice, with themes subsumed within. The four overarching themes identified were;

- **Pressure Ulcer Awareness, Risk & Prevention Knowledge**
- **Patient Factors & Adherence**
- **The Nursing Encounter**
- **The Nursing Approach**.

The overarching themes, themes and subthemes are presented in Table 5 below:

Table 5: Overarching Themes, Themes and Subthemes.

Overarching Themes:	Themes:	Subthemes:
Pressure Ulcer Awareness, Risk & Prevention Knowledge	Pressure Ulcer Awareness	
	Risk Interpretation	
	Importance of Repositioning	

	Healthy Eating	
Patient Factors & Adherence	Patient Decision-making	Acting on Advice Involvement in Decision-making Fear of Falling Equipment Choices Routine & Independence
	Carer Involvement	
	Trust in the Nurse	Importance of Continuity Feeling listened to Professional advice is Right
	Difficulty Carrying out Advice	Difficulty remembering Advice Fatigue as a Factor Living with a condition Mood Affects Presence of Pain
The Nursing Encounter	Structure of visits	
	The Risk Assessment Process	Checking daily function & Repositioning Checking Equipment Incontinence Risk Nutrition Check PU Risk & Skin Vigilance
	Advice Giving	Encouraging Compliance to Advice Consequences to not following Advice Types of Patient Advice
The Nursing Approach	Type of interaction(s): Closed 'directive' style Open 'participatory' style	Acknowledging Limitations

These key overarching themes will be described in more detail in each of the results chapters. Chapter 4 will explore the first two ‘patient related’ themes and Chapter 5 will explore the two ‘nursing related’ themes. These overarching themes are not linear in order or relationship, rather they have connections and interconnections within and between, as demonstrated in the diagrammatical representation below (see Figure 9: Overarching Themes, Themes and Connections).

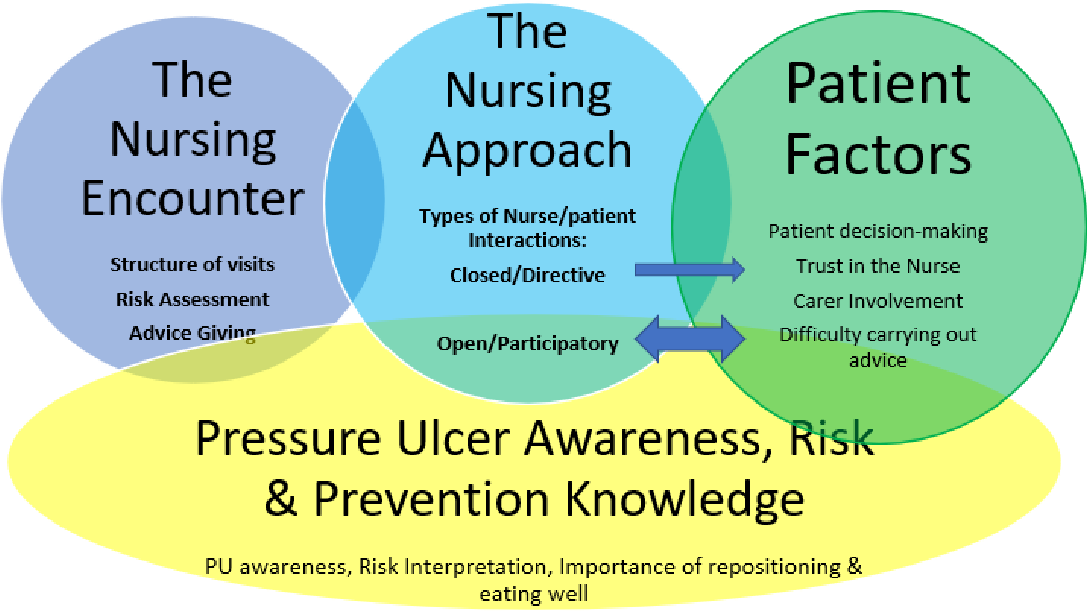


Figure 9: Overarching Themes, Themes and Connections

The overarching themes have themes and subthemes subsumed within and broadly fall into ‘patient related themes’ (PU Awareness, Risk and Prevention Knowledge and Patient Factors) and ‘nursing related themes’ (The Nursing Encounter and The Nursing Approach). Pressure Ulcer Awareness, Risk and Prevention Knowledge whilst identified as a separate overarching theme around how patients understand PUs, preventative measures and interpret their risk, this also connects under the other themes demonstrated visually in the figure above. The Nursing Encounter focuses on educating patients about these factors, the Nursing Approach has a relationship to patient understanding and the uptake of PU knowledge and preventative measures and Patient Factors affect the translation of the advice into adherence behaviour. The next section will outline the first of the two overarching themes that are ‘patient related’.

4.3 PU Awareness, Risk and Prevention Knowledge (Overarching Theme)

A key overarching theme to emerge from the study is around how patients understand their PU risk and what they understand they need to do in order to prevent them. Within this broad overarching theme, there are 4 key themes (See Figure 10). The theme '**pressure ulcer awareness'** captures the essence of how patients in the study gained PU knowledge and understanding. The theme '**importance of repositioning'** explains the physical measures that patients take to avoid getting a PU, such as regular repositioning and keeping mobile. The theme '**healthy eating'** is where a healthy diet is associated with strength and good health as a means of preventing ill health and PUs. The theme **'risk interpretation'** is how responsibility and risk is understood by patients including control and lay expertise in relation to knowledge.

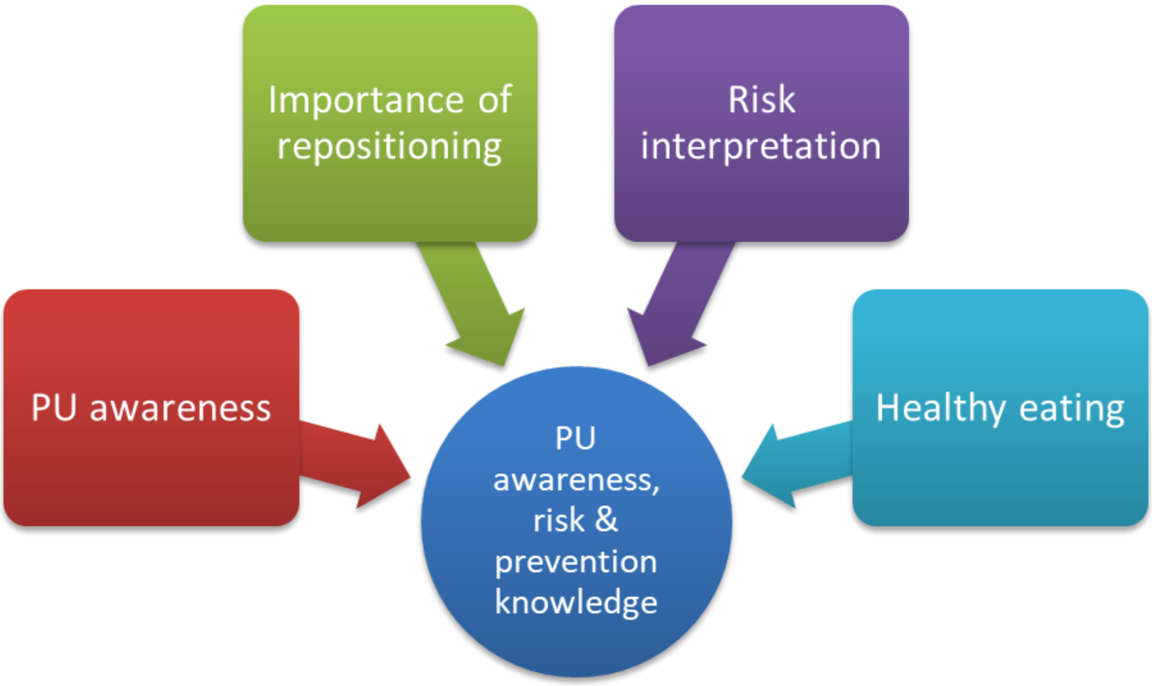


FIGURE 10: PU Awareness, Risk and Prevention Knowledge.

4.3.1 Pressure ulcer Awareness (Theme)

The theme 'pressure ulcer awareness' is how individuals gain an understanding of what a PU is, preventative measures and the potential consequences to acquiring a PU. Most patients 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 don’t want to get one’ (Beryl).

Patients gained a sense of priority 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 instead during the interviews. The use of medical terminology was therefore not helpful to patients in the study in aiding their understanding of PUs, which highlights the importance of the wider context for how health related information is communicated to patients outlined in Chapter One, including health literacy challenges and cultural aspects to knowledge translation (Durrant et al. 2018; Shanley et al. 2021).

In terms of personal understanding and context of PU knowledge, this was also influenced by the experiences of family and friends and whether participants had direct experience of having a PU themselves. Only two patients in the study had directly experienced PUs themselves, with a deep sense of foreboding and fear:

‘I don’t want to experience that ever again, the pain was so terrible you see, so now I am really careful so I don’t ever get any again’ (Frank).

For those with previous experience, there was a strong 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).

Some patients (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 hadn't known of anyone with experience of a PU or had direct experience themselves, there was a certain ambivalence towards getting one:

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

The findings reveal important differences therefore in relation to those with direct experience and those without prior experience. Patients made heuristic judgements around their understanding of PUs and whether to act on the advice given such as distancing themselves if there were no direct or perceived immediate consequences (Grauman et al. 2019) . This is an important finding for consideration as to how preventative advice and information is provided where something has not yet occurred, as compared with an established condition or visible issue such as the presence of an existing ulcer. In relation to how PU advice and information is provided, the majority of patients (12/15) reported that they gained knowledge about PUs from the nursing visit(s) through verbal instruction and demonstration by the nurse. Interestingly, only one patient stated that they had read the PU information leaflet despite being routinely handed out by the nurse as part of preventative education during the nursing visits. Several patients also described visual difficulties and other challenges such as fatigue, that made it impossible for them to access the information on the PU information leaflet:

'I've been given a very good book by one of the nurses but I couldn't 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 can't read' (Diana).

On evaluation of the patient leaflet, it revealed similar PU awareness information and key prevention messages around aspects such as importance of skin checks, nutrition and changing position. However, this was not used by the majority of patients in the study**.** 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 health care practice, particularly literacy and older adults (Chesser et al. 2016). Some of these health literacy challenges for patients around use of leaflets and hence poor update links to previous studies outlined in the literature review (Durrant et al. 2018; Shanley et al. 2021). A new finding to emerge was that the patients in the study hadn't reported these difficulties and non-use of the leaflet with the nurse. This reluctance to disclose difficulties appeared to be 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).

This relates to the nursing themes (discussed in Chapter 5) and the rigid structure and time pressures of the nursing encounter that creates challenges for wider discussion and exploration. When asked about what is most useful in terms of advice and provision of information, most patients (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 don’t 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).

'it’s like when they take the time and talk to you, they go through what they need you to do, I do tend to take that in so they could go through the leaflet then like, so for me the talking bit of instruction is really important’ (Dan).

Therefore, patients valued verbal instruction and conversation with the nurse in aiding their understanding of PUs and that discussion was more likely to encourage adherence to the advice given, as opposed to the use of a PU leaflet. The leaflet used within wider discussion with the nurse may aid some patients with their understanding, however for others, the leaflet provides no purpose. Thus, a more personalised, person-centred approach may be necessitated, targeted to different patient needs and preferences (Phelan et al. 2020). The importance associated with being seen as an individual and talking to the nurses regarding prevention strategies relates to the overarching theme of ‘the nursing approach’ which is explored in Chapter five.

4.3.2 Importance of Repositioning (Theme)

A key theme to emerge related to understanding of prevention knowledge was the importance of keeping moving and changing position. Over half of the patients understood and identified the importance of moving position and repositioning strategies (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 by several patients:

'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 I get so frustrated, it's really difficult and I do try to move as much as I can' (Colin).

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

This links to another key finding within this study with 'the presence of pain' creating a challenge for patients in carrying out the repositioning advice, also identified as a major concern by patients in the integrative literature review (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014; Pinkney et al. 2014). Therefore, whilst knowledge and patient awareness of what to do was evident, this may not translate into adherence, due to other 'patient factors' such as pain, which will be discussed further on in the chapter.

The other five patients were ambivalent to the importance of moving and repositioning, with responsibility placed on the carer to do what was needed. Three of the patients described how their acceptance of advice had also changed over time from reluctance early on, to being more accepting later in their life (3/15):

'sitting for too long I know isn't good… I am trying more now you see as I know it will stop me developing problems…I used to sit for long periods of time watching T.V. and that was my day and didn't really take it seriously…but now I can see that I do need to move' (Beryl).

There were 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, from early diagnosis to longer-term. This may be associated with acceptance of healthcare advice changing alongside longer-term acceptance of a condition, as the three patients who described their changing stance had been living with the effects of comorbidities for many years. Receptiveness for advice over time has been identified within other studies related to health adherence (Weller et al. 2021).

4.3.3 Healthy Eating (Theme)

The theme 'healthy eating' is how patients understand the importance of good nutrition and eating well. Most patients 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. These results reflect the literature explored in the introduction chapter around wider lay understanding of health, embedded within socio-cultural contexts and the fabric of everyday life including food choices related to health. Several patients in the study described an association with eating well in order to keep strong and prevent ill health, with these findings similar to the study by Lipworth et al. (2010) outlined in the introduction. The patient context therefore for healthy eating may be broader than the scientific, health professional context of nutrition.

The majority of patients 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 Ann described how in her culture, eating lots of fruit was encouraged to nourish and prevent ill health.

Similarly, another patient Dee describes 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).

It was evident from these narratives that some patients, 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 in order to stay strong and to prevent ill health. There were also perceived good and bad food choices, with some challenges to maintaining healthy eating patterns:

‘I do try to eat healthy and what they say but it isn’t 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 acknowledgement that it was not always possible however to follow the nursing advice around eating well to prevent PUs due to other factors, such as having a poor appetite and other daily commitments. These ‘patient factors’ are discussed further on in the chapter within the theme ‘difficulty carrying out advice’.

4.3.4 Risk Interpretation (Theme)

The theme 'risk interpretation' is how responsibility and risk were understood by patients, including control and lay expertise in relation to experiential knowledge about their risk of developing a pressure ulcer. The understanding of PU risk was influenced by broader lay interpretations of health and illness, with patients 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 don't 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 isn't 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 don't 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).

It is evident from some of the patient accounts, there was a relinquishing of control over decisions and actions and there was an inevitable state where some did what they were told to do, this control element had changed over the years:

'*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).

'I did used to say before, you know when I first got ill what I thought….but over the years, well I just do it now … I know it's easier to just do what the nurse said' (Ann).

In these accounts, there was an inevitability expressed by some patients around having to follow the nursing advice, with a sense that these individuals had given up trying to state to the nurse what was important to them and how this might impact on them following advice. This differed to others, who over time had become more assertive in understanding their condition and their 'lay expertise' and felt 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 didn't 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 don't 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 alot, 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' (Gwen).

These patient accounts suggest that the scientific risk information alone may not be sufficient to secure advice being followed and there are other factors that are important from the patient perspective in relation to lay risk interpretation, such as the influence of family and perceived threat of the problem patients related to themselves. This is reflective of the wider literature outlined in the introduction around lay risk interpretation according to family traits such as family history and/or experiences (Vornanen et al. 2016). Likewise there were changes over time in relation to reciprocity of advice, with patients gaining tacit expert knowledge themselves and in doing so regaining some control in their situation. There were also differences amongst patients in how much responsibility and control they favoured within preventative planning. These are outlined in the next section, within the patient related overarching theme of ‘patient factors and adherence’.

4.4 Patient Factors & Adherence (Overarching Theme)

This key overarching theme (see Figure 11) has four themes subsumed within, which are different factors that may affect whether the patient follows the nursing advice. These are complex, individualized and dynamic in nature as they are context specific and change day to day. The theme **‘patient decision-making’** captures the nature of power relations and whether the patient feels involved in decision-making and interactions with the nurse. This theme also describes how patients have other conflicting priorities such as daily routine and lifestyle choices which may take precedence over the nursing advice given and the importance associated with maintaining independence. The theme **‘carer involvement’** explains patients’ dependency on others for help with daily activities and their sense of loss of control associated with this. There is a tension between these two themes as one describes the importance of maintaining independence and doing things for oneself, whilst the other acknowledges the dependency on others to perform routine day-to-day tasks and feeling a burden. The theme ‘**trust in the nurse’** explains the relationship with the nurse and development of trust over time, with importance associated with continuity and the nurse taking time to listen and to get to know the patient. The theme ‘**difficulty carrying out advice’** explains the range of different factors that may affect adherence day to day, such as the presence of pain, fatigue, mood affects. There are also good and bad days and fluctuations as a result in levels of fatigue, mood and pain. Patient Factors was the largest overarching theme to emerge from the data analysis, with themes and subthemes subsumed within, which are outlined next.

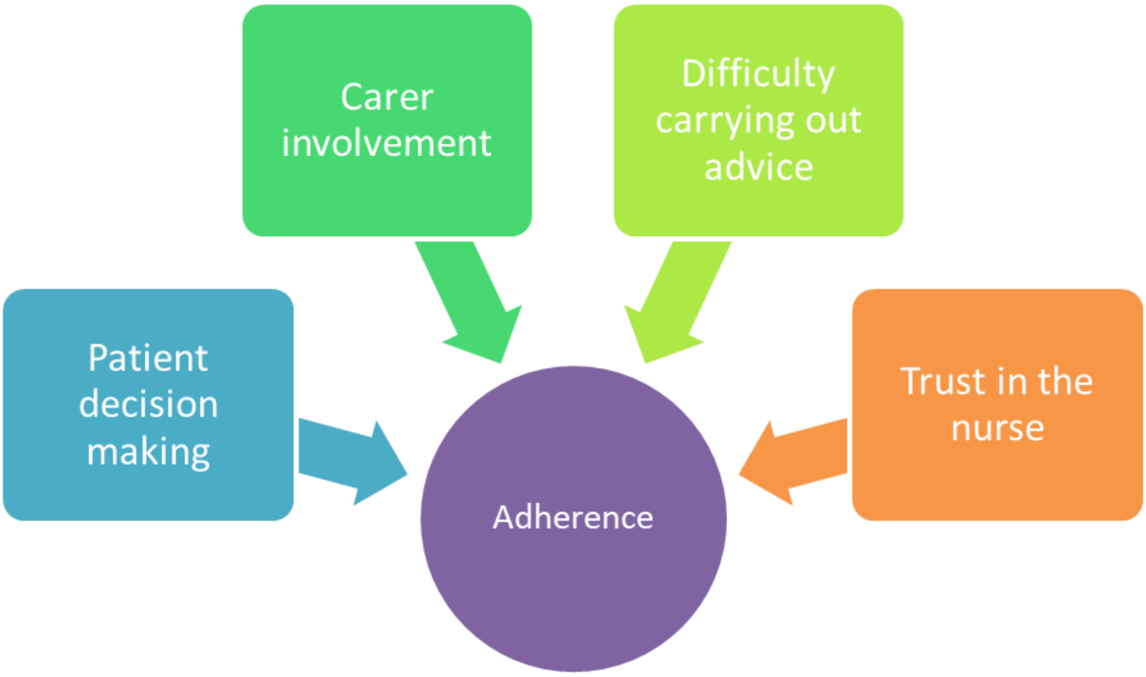


Figure 11: Patient Factors and Adherence

4.4.1 Patient decision-making (Theme)

The theme 'patient decision-making' is a large theme which captures how patients decide to act on advice, the nature of power relations and how involved the patient feels in the interactions with the nurse and the decision-making process. This theme also encapsulates other factors that impact on day to day decisions for following prevention advice, such as the fear of falling, importance of daily routine and equipment preferences. This includes the weighing up of consequences to not following advice, such as where the risk of falling was perceived as a greater threat, patients described how this would override the consequences to not following the nursing advice. Maintaining routine and independence were also paramount for patients in the study, which related to self-identity and family roles that they had held over the years and these were prioritised over the nursing advice. In this sense, decisions around the use of preventative strategies including equipment, were not based on scientific judgements, rather through broader, lay constructs related to other social determinants. Importantly, in relation to involvement in preventative care decision-making, patients stated they were more likely to follow the advice if they had been part of the decision-making process. These factors are explored more fully through the subthemes next.

Acting on Advice (subtheme)

The subtheme of 'acting on advice' focused around some of the decisions patients make on whether to act on the nursing advice given, including perceived benefits to carrying out advice. Some of the patients for example, described how they considered the potential benefits versus the disadvantages to carrying out the advice, here Beryl describes:

' I do usually follow what is said but as I say if I don't agree with it then I won't do it…I weigh it up and it all depends day to day and whether I think it will make a difference or not' (Beryl).

Eric outlined that he needed to understand and agree that the advice was right for him before he acted on it:

'I won't just do what the nurses say, I have to know its right for me, I know what works best and if it can fit with everything else going on and then all things considered l may give it a go' (Eric).

This weighing up of risk versus benefit reflects the wider lay context of risk literature around how patients manage uncertainty in their day to day lives and weigh up the potential benefits with other lifestyle considerations and consequences (Godolphin, 2003).

Some patients in their accounts described a sense of hope that carrying out the recommended advice supported a strong belief that doing the right course of action prevented bad things happening. This was identified in other studies outlined in Chapter one around lay beliefs and hope as a means of managing risk and uncertainty (Jauho, 2019; Zinn, 2008):

'you will follow the advice if you can see that it's a good thing, you know, believing in what they say and then, if I carry it out right and proper its going to stop bad things happening further down the line' (Frank).

'Im a cup half full person, you've got to in life..well if I don't believe by following what the nurse says isn't gonna work, then what hope do I have, so yes I am going to do it' (Colin).

Involvement in decision-making (subtheme)

This sub-theme is about how involved patients felt in the decision-making process when having conversations with nurses about preventative care planning. While all patients felt that they should be involved in decisions, there were differences in the reported level of involvement. This was an important finding in relation to understanding adherence, as patients who reported being involved in decision-making were more likely to adhere to the advice given. Just over half of the patients in the sample (8 out of 15) described that they did feel involved and were able to give opinions about their care:

'I think it's a deal maker or breaker, if I do feel involved more in what is being said you know and what the nurse is discussing then of course I do feel more inclined to take it on board and do it' (Belinda).

'if I am not sure, I do ask and they ask me if there is anything that I am not sure of so in that way, yes I do feel involved in the decisions and I am then more inclined to follow it' (Colin).

Conversely, where patients did not feel part of decisions this reduced adherence to PU prevention strategies. Here Dee describes a situation recently in which she had struggled to get a suitable cushion from the nurses and her daughter had eventually got involved:

'well that was quite a bone of contention as I had asked several times but I wasn't listened to and then my daughter did ring the district nursing service and we got it sorted, bit of a palaver really so then I didn't feel inclined to follow the advice' (Dee).

This echoed findings in the integrative literature review, outlined in Chapter two, where several studies highlighted the association between patient involvement in decisions and subsequent adherence to advice given (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014).

Fear of Falling (subtheme)

A significant subtheme related to patient decision-making was a fear of falling and how this affects day-to-day decisions, reported by two thirds of the participants. From the patient accounts, the risk of falling to them was perceived to be greater than the risk they associated with not following the nurse advice in relation to PU prevention. Importantly whilst the PU risk was understood, patients made pragmatic, trade-off decisions as to what was the most sensible course of action for them:

'you see I don't 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 best option so that's what I choose to do' (Diana).

'put it this way I've had at least four falls, I mean it has to be at least that as I can remember… I fell out of bed and hadn't got my pendant on and I just lay there for hours… I was scared and didn't know how to get help…luckily the carer found me…so that's it now, I won't go to bed…' (Dan).

The fear of falling therefore was a factor in some of the patients in the study actively choosing not to follow nursing advice and took priority over the potential repercussions to not following the PU advice. This is a similar finding to the leg ulcer study by Van Hecke et al. (2011) outlined in the introduction chapter whereby the fear of falling was related to leg ulcer management and lower levels of physical activity. The findings within this study provide new insights in the fear of falling and relationship to non-use of preventative equipment such as bed and pressure relieving mattress. This has important implications for clinical practice, as within the existing clinical risk assessment framework outlined in Chapter One, the risk of falling is not included. The focus from the professional perspective is on the risk of PU, with other potential risks and interrelated factors not captured. This compartmentalisation of different health related aspects is common within existing healthcare provision. However, increasingly there is acknowledgment the limitations of this in relation to preventative healthcare risk assessment and management, with more holistic assessment and treatment advocated (Sheridan et al. 2021).

Equipment Choices (subtheme)

This subtheme 'Equipment Choices' is how patients base their decisions around use of PU equipment on a wider range of factors beyond the scientific justification the nurses make. This includes aspects such as maintaining independence and the importance of comfort with equipment usage. Equally, previous history with using different types of equipment positively or negatively affected acceptance of equipment options. These choices were not based on scientific knowledge around level of risk and type of PU equipment provided by the nurses but on personal 'lay' judgements. The majority of patients described how equipment plays a significant part in their lives and decisions around how and what they use are really important to them, particularly in relation to comfort, function and aesthetics:

'*I've had a lot of different cushions but I know what I like and this one fits better in this chair you see…the other ones were too hard and I wouldn't use them, a little difference makes a big difference, so I know what works for me' (Eric).*

'I had a blue one before that and didn't like the look of, then I had another one that wasn't comfy..now I got this one and I can get out my chair much easier so that is what I do ...' (Catherine).

There were also beliefs around expert 'lay' knowledge embedded within this, with a discarding of a scientific rationale for equipment choices in favour of personal experience:

'I know I am not supposed to put a cover on the cushion as the science says no, but needs must and I know myself from years of it, I get hot and sticky otherwise. So I do put the cover even though it I shouldn't. That way if I have a bit of an accident too, then I've got all bases covered…(Colin).

Equipment usage is important in the context of clinical practice whereby the provision of PU equipment remains a core part of preventative practice (Shanley et al. 2021). However, these findings demonstrate the importance of understanding the patient perspective regarding choices around equipment usage, including preferences, function and equipment history that are based on more than the professional context of scientific and numerical risk (Grauman et al. 2019). This concurs with the findings of the study by McInnes et al. (2014) outlined in the integrative literature review around the need to include the patient perspective in relation to equipment options in order to secure adherence.

Routine & Independence (subtheme)

A key sub-theme identified in relation to decision-making was around the importance patients associated with daily routine and maintaining independence with what they can do. Many of the patients described their routine and habits as part of their day-to-day existence and identity within their family:

'and I've done that for years, I take my drink with me and I sit for a while, then I get myself and make a sandwich for me son arriving at lunchtime every day like clockwork that's what we do, so I pace myself so I can make sure I do it, it means a lot' (Ann).

'*I get myself washed and dressed and put my face on for when my daughter visits, I also cook for myself and watch the soaps and its all the same each day so if it means I can't then rest on the bed as I should, then so be it' (Gwen).*

Several patients describe how their routine dictates the priorities they choose to focus on each day. Importantly where daily routine conflicts with PU advice, patients will choose the activities that are most important to them:

‘ I can’t do much but I can still go out and dance a little, get me out of the house and go dancing which I’ve always done, even if I then miss the nursing visit and forget to follow what they said’ (Beryl).

The prioritising of routine and habits was evidenced as a key finding in the integrative literature outlined in Chapter two, with several studies highlighting the importance of acknowledging patients’ daily routines within PU regimes and the potential challenge of these to adherence itself (Fogelberg et al. 2016; King et al. 2008).

Within this, the majority of patients (14 out of 15) describe the importance of maintaining some independence for themselves, rather than having to rely on others in their daily lives. This included activities such as getting washed and dressed and cooking for themselves:

‘I’ve got the walker, they gave it to me a while ago to stop me falling and I don’t want to end up where I have to use a commode or anything, so I do, I stand up and I have a little walk to kitchen, make a drink and it means a lot to me’ (Diana).

In summary, there were several aspects to ‘patient decision-making’. This includes the ‘lay’ pragmatics that patients employ in weighing up the consequences to following advice with other concerns, such as the risk of falling. Equally maintaining routine and independence were paramount for patients in the study, which related to self-identity and family roles that they had held over the years and were prioritised over the nursing advice recommended where this conflicted with established routines. This was also a key finding from the integrative literature review (Fox 2002; Clark et al. 2006; Guihan et al. 2012; Jackson et al. 2010). In this sense, patient decisions were based on more than just professional scientific knowledge, with lay risk interpretation related to other personal and social determinants. Importantly, in relation to involvement in decision-making, patients stated they were more likely to follow the advice if they had been part of the decision-making process, which was also a key finding in the integrative literature review.

The theme ‘carer involvement’ discussed next presents a challenge to some of these concepts around wanting to maintain independence and hold onto familial roles, alongside the dependency on carers to perform certain preventative strategies.

4.4.2 Carer involvement (Theme)

The theme ‘carer involvement’ explains the dependency on others to help with daily activities and the loss of control associated with this. The dependency on others was also linked to adherence to PU advice as most patients in the study were dependent on carer input to carry out certain aspects of preventative strategies. Carer(s) were an important factor in whether preventative nursing advice is carried out, including aspects such as repositioning and potential use of equipment, with the patient themselves having varying degrees of control over what happens and when.

The majority of patients in the study (14 out of 15) identified that there was a dependency on others to provide care and do daily activities which they didn't find easy. This effected their self-identity and a loss of autonomy was evident and reflected in these accounts by Ben and Eric:

' I have to rely on them for things, to help me get a drink say…before I was ill I could do what I want and be the man of the house, but now I have to rely on family to do things for me and it's really hard, it's like a grieving process' (Ben).

' my wife she now has to do everything for me and that all there is to it…I can stand for a short time yes, but everything else now like getting washed and dressed she has to do for me' (Eric).

There was a sense of inevitability to the care help needed alongside feelings of loss and being a burden to others.

Several patients within the study also described a dislike of the carer input, whilst acknowledging they needed the help. There was a sense of wanting to maintain some control day to day and this was achieved through directing care:

'I know they are only doing their job but they drive me mad trying to make sure I am eating and drinking, what I should and this and that…so I tell them what to do I am quite firm with that' (Ben).

'I did manage just fine but now here all the time and I don't like people here if you understand what I mean, but I know I need them to help me so I tell them what time to come and what to do' (Catherine).

The desire to retain some control was evident in previous studies with 'directing care' a key finding around patient desire to maintain some control over aspects of their lives, including directing carer's to carry out PU strategies (Hashim et al. 2020; King et al. 2008). This day to day dependency on carer(s) to carry out preventative strategies is an important finding, that highlights the need for the role of carer(s) to be incorporated into PU risk and adherence frameworks, with situational and social determinants largely neglected in current models of adherence.

4.4.3 Trust in the Nurse (Theme)

The theme '**trust in the nurse'** explains the relationship with the nurse and how trust develops over time. There is importance associated with continuity of the same nurse, alongside the nurse taking time to listen to their patients. This was reported by most patients in the study (13/15) and importantly where trust was established, patients were more likely to share potential issues they faced with following advice. There were also beliefs that professional advice is right and therefore should be trusted, with the role of the nurse in a position of authority. This power imbalance inherent within pre-ordained roles of nurse and patient creates a potential challenge for the patient in disclosing conflicts and this was evident in some of the patient narratives. The subthemes relating to the theme of 'Trust in the Nurse' will be outlined next.

Importance of continuity (subtheme)

Patients associated continuity of the same nurse with the establishment of trust. This related to the nurse knowing about the patient's personal context and situation and not having to repeat information:

'it's nice when you can see the same nurses if possible because they get to know you, who you are and how you, well your know react to things and that make a big difference with trusting them…' (Belinda).

Counter to this, patients were also able to describe some of the difficulties as a result of having different nurses visit and the disruption this caused:

'because at the moment I am having to start all over again, each time with how I am and what I do or don't do or what has worked or hasn't worked…they don't know anything about me, so to be honest its exhausting having to keep repeating it' (Ben).

The presence of continuity and establishment of trust was important in allowing disclosure by patients and honesty around some of the difficulties in following advice:

'usually I would say if I was struggling to follow the advice, but then where recently I've had four or five different nurses then no, I can't say I have…I can't keep repeating things' (Frank).

Several of the patients described differences in the nursing visits and the care received and how this affects trust, including factors such as the age of the nurse, with a belief that age related to experience:

‘well some of them are good and some of them are not…so it depends who you get and how long they stay and how they treat you … it’s a bit of a lottery but it does affect how you feel about them, the young ones I am not so sure’ (Belinda).

Therefore, there were also inherent lay perceptions around age as relating to more experience and trusted more by some patients, which relates to the broader concepts around patient ‘lay’ perceptions of health outlined in the introduction. The importance of continuity with the same nurse to develop trust was a key finding of the study in relation to PU prevention and has been evidenced in broader nursing health literature (Sagsveen et al. 2018; Van Hecke et al. 2011).

Feeling listened to (subtheme)

A similar sub-theme surrounds how patients felt listened to by the nurse during the visit and understood their needs, whilst taking time to care. Several patients describe how they won’t tend to open up about any difficulties they have with following the advice if they feel the nurse is in a rush or doesn’t have time to listen. This was also influenced by non-verbal cues as well as what was said during the nursing encounter, such as the nurse’s body language and pace of discussion:

‘ like if they sit and listen to you and what you have to say rather than them just telling you, then you do feel you can say what you think about things and I am more likely to follow it…communication is key’ (Diana).

‘when the nurse sits and looks you in the eye and lets you talk, I must admit I do let go and I tell her what’s really been happening and I get such a release, I feel reassured by that (Beryl).

Conversely a few patients in the study felt rushed and not listened to, which affected their confidence and trust in the nurse, as outlined here by Eva and Colin:

‘ when it’s all rushed and you don’t feel they have got the time… and I don’t know that they are bothered and so then I tend not to say anything, I would just nod then and not say’ (Eva)

'it's not their fault, the nurses you know, but they don't have time and when they are rushed you can see they don't even sit down and look at you, I just don't feel I can say really what is going on for me…' (Colin).

Therefore, the importance of continuity and feeling listened to were important pre-requisites for the establishment of trust and increased the likelihood of the advice being followed. This concurs with the findings of the study outlined earlier around the processes underlying leg ulcer adherence (Van Hecke et al.2011) where the establishment of trust was central factor in securing adherence. The importance of patient trust with the nurse is well documented within broader nursing literature, within which trust as a relational phenomenon that is built over time and 'earned' relates to the findings of this study (Dinc and Gastmans, 2013). In this sense, trust is not simply stated, but has to be gained through continuity, time spent with the patient and familiarity with the patient as a person. The novel finding within this study is how non-verbal cues are an important factor within the nursing interactions that patients also use as an indicator of the nurse taking time to fully engage and listen. This finding links to the importance of the nursing approach and an 'openness' to understand what is important to the patient themselves, which will be discussed more fully in Chapter five around the 'Nursing-related' themes.

Professional advice is right (subtheme)

This was an interesting subtheme to emerge from the study around how patients feel that what the nurse has advised must be correct as they are in a position of authority and of professional standing and therefore, that they should trust the advice is right.

There were strongly held beliefs that 'nurse knew best' and therefore trusting the advice as the best course of action. Where patients reported difficulty with following the nursing advice, a tension was created with a sense of letting the nurse down if advice could not be followed. There was also a sense of the professional role of nurse as caring and patients wanting to do what was right by the nurse in following the advice given. Here, in the accounts of Ann and Eva, they describe what the role of nurse means to them:

'well obviously I am going to follow the advice given from the professional, I mean that's their job so they must know what they are doing' (Alan).

'you think they know best because, you know they are qualified aren't they and so they must know what they are doing…so you go with the flow' (Eva).

Later on in the interview, she goes on to describe some challenges to following the nursing advice despite believing it is correct:

'you know the nurse is always right so you do trust what they tell you to do, but sometimes I struggle and I just know that I can't do it and that's that' (Eva).

Similarly, Colin outlines how he feels a tension between needing to follow the nursing advice but not always being able to:

'I think the nurses try to understand and, well I am going to follow what they say as they are qualified and they know their stuff, but what I am saying is it's not always easy or possible to do and I find that really difficult' (Colin).

Within this, some patients described a need to please the nurse and do what's best, with the nurse seen to a caring role and vested in helping the patient, outlined here with Colin and Eva:

'they try their best, they are trying to help and they say about eating and drinking and I know what they say is right as they are professional and so I try to please them and do as they say really' (Colin).

'*you know they do their best, the nurses you know, they care don't they and that's what they are about, so I try to please them, I really do' (Eva).*

This need the patients expressed to please the nurse, and beliefs that the nurse 'knows best', creates a challenge for patient disclosure where there are practical and situational difficulties to adherence or differences in opinion. This has also been identified in other studies exploring nurse-patient interactions and the effect of inherent power relations within consultations (Barnard et al. 2010; Stottard, 2012). The patients in the study all had varying challenges and difficulty in carrying out the advice which are outlined next.

4.4.4 Difficulty Carrying out Advice (Theme)

The theme '**difficulty carrying out advice'** explains the range of different factors that may affect the advice being carried out day to day, such as the presence of pain, fatigue and mood affects and that there are 'good and bad days' which also affected the ability to follow the advice presented next. There were many different factors that patients in the study described as presenting a challenge to following the PU prevention advice, ranging from difficulty remembering advice, fatigue, living with a long-term condition, mood affects and the presence of generalised pain. There was a sense that these factors are cumulative and depending on how many are evident at any point in time, create real difficulties to following advice. Importantly, whether or not the patients shared these difficulties with the nurse were largely dependent on the nursing approach.

Difficulty remembering advice (subtheme)

Several patients described challenges to remembering the advice, which impacted on their ability to carry it out. Similarly when asked about the usefulness of the patient information leaflets, there were difficulties identified by patients including difficulty concentrating, retaining and remembering the information. Some patients described how they have difficulty remembering the advice given by the nurse, which then creates difficulties in carrying it out:

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

When asked about the usefulness of the advice given by the nurse, Ben describes how he struggles to listen and understand on the visit:

' I struggle to listen to what they say, you know, I do try but I find it hard to listen and I find it hard to always concentrate on what they are trying to tell me… depending on how long the visit goes on for is how much I can take in' (Ben).

Here, another patient Eva describes how her ability to retain information has changed over time:

'sometimes I can't remember what someone has said to me and I've always been sharp with my brain but not so sharp any more… I do worry as I can't always remember what the nurse said and I do get exhausted and then it's all the harder' (Eva).

Fatigue as a factor (subtheme)

Most patients (12 out of 15) spoke about how feeling tired and fatigue made it difficult for them to carry out the advice:

'I do try to pace myself out so I can do what they say…I get so tired it just becomes really difficult then to do what I know I should do…so I know I should get up and go a walk but I am so tired sometimes I can't' (Ann).

'it affects a lot of things, if I don't have much energy then it's difficult…and its easier said than done, I know what I need to do but I am so tired, so tired sometimes so then I just sit there' (Beryl).

This could also result in patients appearing to acquiesce to advice they knew they would not follow:

'Well, it's like this really, when I am really tired I just go along with things, you know even though I know I won't follow the advice but I just nod as I am so tired with it all' (Ben).

Living with a condition (subtheme)

Several patients expressed the day to day challenges that their condition had including physical, psychological and social effects and a sense of feeling overwhelmed with their situation, which then affected carrying out preventative strategies:

'my hands, if you look…I got arthritis and as well as the pain it's difficult to hold things…so then like holding the chair to stand up and move… well sometimes it's just not possible..'(Dan).

'I know I should and it's alright for people that can just do it, but it's not easy, it's me legs you know, it's really difficult sometimes to do the walking and I know it sounds stupid…but it really is a struggle (Eva).

The majority of patients also describe how their condition changes and likewise their ability to be able to carry out advice day to day fluctuates and this in turn affected planning:

'mostly you see I do have days when I am really tired, so it all depends on that… I don't think the nurses always understand that, it's my condition you see, I just have to see how I am each day' (Ben).

'I do know about the advice, but I have good and bad days really and it all depends on how I am feeling too, so on a good day then yes I can do stuff but on a bad day well then that's where it doesn't happen' (Colin).

The importance of this in relation to adherence was how dynamic their daily situation was in relation to fluctuating health and the effects of their condition on function. This finding is significant and highlights the dynamic aspect to adherence, shaped by different physical, psychological and social aspects that are situated within patient's day to day lives. This dynamism is not acknowledged within exiting PU risk frameworks, nor is it explicit within the behavioural models of adherence included within the conceptual framework of the study (Zainal et al. 2021).

Mood affects (subtheme)

The effects of mood on patients ability to carry out preventative strategies was a key challenge for over half of participants (7 out of 15). Low mood affected many aspects to patient's lives including the ability to plan and to be able to carry out physical activities as part of the PU prevention regime such as mobilising, repositioning and performing selfcare:

'I never knew I was going to end up like this, I mean I really down about stuff… it then takes me so much longer to do day to day things, simple things and I get upset really and then I don't want to bother doing any of it' (Eva).

Beryl describes how her mood is unpredictable and fluctuates which also makes planning difficult:

'well you see I don't know, when I am getting a low mood I don't plan for it, it just happens and then when I am on a downer I can't follow the advice that day I have to give into it' (Beryl).

This finding highlights the importance of other, non-physical factors such as low mood, that may affect the ability to carry out advice. Importantly, these psychological aspects to PU risk are not included within the current PU clinical risk frameworks, which typically focus on the more physiological and physical aspects. However, if unaddressed these may contribute to non-adherence.

Presence of pain (subtheme)

The presence of generalised pain was as significant factor for over half of the patients in the study, affecting the ability to carry out prevention advice. The detrimental effect of pressure ulcer pain on quality of life and resultant adherence has been evidenced in other studies and was a key theme from the integrative literature review (Gorecki et al. 2012; Jackson et al. 2017; McInnes et al. 2014). However, this is a new finding around the impact of generalised pain from the experience of patients living with other conditions such as arthritis and the subsequent effect on adherence.

The presence of generalised pain had a significant and detrimental affect on patients' ability to follow PU prevention advice and could be unpredictable:

'I've got pills, but I just get fed up with the whole thing.. I've had it for so long the arthritis but it's the pain…gosh it effects things really…so I just have to see day to day what is possible, I can't then do some of the activities' (Catherine).

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

Colin expresses his frustration and the way in which pain takes over:

'it's hard to explain but I can say the pain, it's just so gripping and awful and I know what the nurse said I need to do, I do try but with the pain it just takes over and then I am sorry, I cannot do anything and what I am supposed to do goes out the window'.

The presence of pain was a significant factor for whether patients were able to carry out certain preventative strategies, therefore if unaddressed increases the potential for PU development. Pain as a factor is not currently explicit within the risk assessment process related to PUs, therefore may limit their ability to support personalised care plans.

4.5 Summary

The study has shown that patients understand and have knowledge of PUs in a basic sense around the importance of eating well, moving position and skin checks and this knowledge was largely gained through the nursing visit. A few of the patients in the study didn't understand the medical term 'pressure ulcer' and were more familiar with the lay term 'bed sore', therefore terminology and language used by nurses in the translation of knowledge requires further consideration. This has also been identified in previous studies where the language used by the HCP is not always understood by the patient, which in turn may affect following the advice provided (Latimer et al. 2014; Schoeps et al. 2016).

In relation to patient perceptions and understanding of risk, patients drew on a much broader context for risk rather than purely the professional scientific knowledge provided by the nurse. Whereas the nursing focus was on scientific risk avoidance, patients in the study made risk decisions based on pragmatics within their daily life, including routine and other lifestyle commitments, alongside balancing other risks, such as fear of falling. The patient context of risk was therefore personally and socially grounded and influenced too by the experiences of family and friends, which concurs with wider health related literature (Vornanen et al. 2016). Where PUs were negatively perceived, patients had largely gained this view from others within their social circle and where two patients had direct experience, vigilance was greater. There were also other risk determinants patients described in relation to their health beliefs, such as PUs being a hospital related issue and something ‘ill people’ acquire, and that PUs were age related. In this way, patients 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 from a patient perspective and is reflective of the wider literature outlined in the conceptual framework around the influence of family and the range of other, personal factors such as hope, trust and emotions that shape ‘lay’ experiences of risk (Zinn, 2008).

The findings have important implications for clinical practice and the communication of PU risk to patients, in that scientific probabilistic information alone may not be sufficient in securing patient adherence. The study has revealed that there are other, broader lay interpretations of risk and influences that affect acceptance of knowledge and enactment of advice. However, the emphasis within current PU risk assessment frameworks and clinical practice is focused on the scientific ‘best evidence’ and instructing patients what to do to prevent harm (Donaldson et al. 2021). A significant limitation with this existing ‘linear’ model of risk is that the patient context and interpretation is missing and if unaddressed, the study findings have shown a relationship to resultant adherence. There were also some interesting findings in relation to self-efficacy and control in relation to PU prevention advice, with some patients reporting confidence in what they needed to do and asserting their lay ‘expertise’ within decision-making, whilst others took a more passive role. Where self-efficacy was greater, this appeared to relate to several years of experience and living with a health condition, which fits with some of the health-behaviour change models outlined in the conceptual framework (Zainal et al., 2021). However existing adherence models have tended to focus on adherence in relation to self-management of an existing condition, whereas this study revealed important considerations for securing patient adherence where diagnosis of a health condition is new and/or where the focus is prevention for example, before a problem is evident, which warrant further consideration.

There were important findings in relation to the type of PU information used, with patient leaflets routinely handed out by the nurse in every visit. Despite this, most patients in the study did not use them. This was, for some due to visual and/or cognitive challenges, with the majority of patients (13 out of 15) reporting that the most useful advice came from discussion with the nurse about their situation and what was meaningful to them. This is an important finding in relation to how advice is provided to patients and the efficacy of the approach used. It is common practice that patient information leaflets are used by HCP's as a means of both educating patients about their condition(s) and to encourage participation in preventative measures (Fletcher, 2020). However, this study concurs with the key findings of other studies, that patients appear to poorly engage with the materials and further consideration needs to be given to this approach, particularly in transitory settings such as the community (Durrant et al. 2018; Wynn, 2020). It is evident from the study findings that whilst provision of an information leaflet is not sufficient to warrant adherence, there is an important pre-requisite for patient participation in prevention strategies that is embedded within the nurse-patient relationship and interaction. This is discussed within the next chapter around the type nursing approach used within the context of PU prevention discussion and advice.

In relation to the second overarching theme of 'patient factors' there were many identified as presenting a challenge to following the PU prevention advice, ranging from involvement in decisions, the fear of falling, difficulty remembering advice (health literacy challenges), fatigue, living with a long-term condition, mood affects and the presence of generalised pain. There was a sense that these factors are cumulative and depending on how many are evident at any point in time, create real difficulties to following advice from the patient perspective. Importantly, these patient related factors are absent from the existing PU risk framework outlined in the introduction chapter. Routine and maintaining independence featured as a significant sub-theme in which the majority of patients described how they would prioritise daily hobbies and activities over their skin care regime and PU prevention strategies. This reflects the findings of a number of studies in the integrative literature review (Ledger et al. 2019). A new finding around patient decision-making included a fear of falling which prevented individuals following PU advice such as going to bed, with 10 out of the 15 patients in the study reported the fear of falling was greater than the potential repercussions to not following the advice. Whilst fear of falling was found to be a factor in patient adherence to leg ulcer management (Van Hecke et al. 2011) the fear of falling in relation to adherence to use of preventative PU equipment is a new finding. This has important considerations for clinical practice where a focus on falls concern is not evident within the current PU risk assessment or preventative nursing guidance. Equally, in relation to equipment choices, several patients described how they would make decisions around their equipment preference which may contravene the nursing advice, which relates to previous studies that reported equipment choices patients make that may go against professional advice including comfort, aesthetics, equipment history and for functional reasons (Jackson et al. 2010; McInnes et al. 2014). Therefore, patients in the study made pragmatic decisions around use of equipment based on different criteria to the scientific evidence used by the nurse. Failure to use PU preventative equipment places patients at increased risk of developing a PU and it is therefore paramount the patient perspective is incorporated into the decision-making process. The patient perspective however is not explicit within the existing PU risk assessment and preventative planning process.

The theme 'carer involvement' was another key finding, with the majority of patients (14 out of 15) dependent to some degree on carer input to enable the PU advice and recommendations to be carried out. Therefore, although the nursing emphasis is on educating the patient and responsibility for adhering to advice, it was not always an active choice to be able to do so. The importance of involving carer(s) in the decision-making process and treatment advice has been well documented in other health contexts (Walker and Dewar, 2001; Tambuyzer and Audenhove, 2013) and this study contributes to the existing evidence base in that it has highlighted the importance of the involvement of carer(s) in the context of PU prevention advice and strategies. Dependence on carer(s) to enact PU prevention is also absent from existing adherence models and the conceptual framework outlined in Chapter One. Trust in the nurse was a significant finding and the importance of continuity and getting to know the patient as an individual, that resulted in better adherence to advice. The importance of trust with the nurse in promoting better patient engagement in advice and treatment is well documented in other areas of nursing practice (Leslie and Lonneman, 2016; Rortveit et al. 2015). These study findings are novel with respect to PU prevention adherence, where the development of trust directly related to patients being more likely to follow PU advice and reporting any difficulties. The importance of trust was identified as a central key factor in whether patients adhered to advice in a previous study focused on leg ulcer care, which formed part of the conceptual framework outlined in the introduction. Van Hecke and colleagues (2011) revealed trust with the HCP to be central to patient adherence and factors such as 'meaningful time' spent with the patient facilitated the development of trust and encouraged adherent behaviours which concurs with the findings of this study.

The theme 'difficulty carrying out advice' was a large theme, whereby patients described a range of factors such as difficulty remembering advice, fatigue, living with a long-term condition, mood affects and the presence of pain. The presence of pain was a significant challenge for patients in carrying out prevention techniques such as repositioning and this was previously highlighted in the literature review in relation to PU pain (Gorecki et al. 2012; McInnes et al. 2014; Pinkney et al. 2014). This study has revealed a new finding with the impact of generalised pain and other health conditions such as arthritis and the subsequent effect on adherence. Therefore, there are other impacts this current study has revealed such as fatigue, mood affects and living with long-term conditions, which offer new insights into adherence. These personal, social and contextual factors were not present in the conceptual framework nor evident within the existing PU risk framework within practice and are therefore novel findings.

Within the ‘patient decision-making’ theme there were different positions adopted with some patients actively choosing whether to follow the advice, whilst others described a more passive ‘relinquishing control’ and acceptance that the nurse must be right. Patients within the study assumed different societal role characteristics expected of them as ‘patient’ and likewise the nurse, as professional. This has been identified in previous studies whereby patients may take on the role expected of them such as, dependent, and this kind of role is typically associated with different power relations assigned to the roles of ‘nurse’ and ‘patient’ within wider society (Fleisher et al. 2009; Stottard, 2012). The importance of this finding in relation to practice is that patients may not feel able to disclose issues or conflicts with advice, which links to the nursing approach outlined in the next chapter. Importantly, for the patients who felt more involved in the decision-making process, they described how it was more likely they would adhere to the advice given by the nurse. This concurs with some of the findings in the literature review whereby three of the previous studies indicated a link between patient involvement in decisions and subsequent adherence to treatment behaviours (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014). However, the importance of the nurse-patient relationship and patient involvement in decision-making with resultant adherence is not evident within existing adherence models and is a new and significant finding.

The next chapter 5 will outline the nursing related overarching themes to emerge from the study and discuss in relation to the existing literature and new, novel findings.

Chapter 5 Results: Nursing Related Themes

This results chapter will outline the key ‘nursing’ overarching themes, ‘The Nursing Encounter’ itself and ‘The Nursing Approach’ and their underlying subthemes. These will be considered in relation to existing literature and broader concepts around risk communication, role and power relations and adherence within the broad conceptual framework.

5.1 The Nursing Encounter (Overarching Theme)

This overarching theme describes the ‘architecture’ of the nursing visit. All visits observed were conducted in the patient’s own home and followed a similar structure, with the nurse checking key PU risk assessment aspects such as a skin check, nutrition, continence, mobility and repositioning. The nursing visit(s) were prescriptive, time-dependent and controlled by the nurse, with a clear purpose and order to proceedings. They were mainly task orientated including the completion of the PU risk assessment and instructing patients about preventative measures. The visits often reiterated patient responsibility to ensure the advice was acted on. The emphasis was on mitigation of risk through instruction on what to avoid, alongside provision of prevention advice and information. These findings mirror the literature and guidelines which advocate accurate assessment of a patient’s risk status and instructing patients on carrying out preventative measures (Demarre et al. 2015). This professional focus around scientific, risk management is at odds however with the findings in the previous chapter around how patients themselves interpret and understand ‘lay’ risk in the context of their daily lives.

The findings of the nursing encounter are summarised within distinct themes involving the ‘**structure of the visits’,** which summarises their formal, structured and time-limited nature **‘the risk assessment process’** captures the professional nursing emphasis on minimising risk and preventing patient harm and the theme **‘advice giving’** which describes the different ways prevention advice is given through verbal instruction, physical demonstration and written information.

5.1.1 Structure of the visit(s) (Theme)

The nurses followed a prescribed order to the visit(s) using the local NHS Trust nursing documentation and protocol to guide the visit focus, with key topics covered such as skin checks, nutrition, moving and repositioning and use of PU equipment. The predominant interaction observed was the nurse mainly asking questions, patient answering and nurse checking whether advice had been followed or not in relation to PU risk and prevention measures. There was also a reinforcing focus of the importance of the patient themselves being responsible for following the advice and negative consequences to not adhering is reinforced by the nurse. The delivery of information was largely through verbal instruction, physical demonstration and written in the form of a PU information leaflet, which was handed out in all visits observed. The results of analysis from the observation guides are summarised as follows:

Visit duration: Varied between 10 minutes to 45 minutes, with most visits lasting on average around 30 minutes.

Balance of discussion: There was some variation within the interactions between nurse and patient, particularly the amount of time overall each were talking during the interaction. Information was taken from timings recorded on the observation guide and cross referenced with the dictaphone timings for who was speaking and for how long. The data demonstrated that for eight of the visits observed, nurses spoke for the majority of the time (80% or more). In these visits where the nurse dominated the discussion, a more closed 'directive' approach was observed, with the nurse taking the lead and focused on completing tasks, such as the skin check. However, for seven of the visits where a more collaborative approach to interactions was adopted, there was a more equal balance of conversation (50%). Where a more equal amount of talk occurred, the nurse was observed to use a more open 'participatory' type approach, with patient encouraged to actively engage throughout discussion. These differences in approach will be discussed further in section 5.2. In all visits, there was an introduction, middle and closure to the overall structure and the nurse would lead with introductions and purpose of the visit and steer into the main part. The emphasis for all visits was on instructing patients how to look after their skin and how to prevent PUs with delivery of information through verbal instruction, physical demonstration and written in the form of a PU information leaflet. Within the visits where the nurse used a more open ‘participatory’ approach used, discussion with the patient on broader topics not covered as part of the PU risk assessment were evident, such as domestic and/or family circumstances.

Physical inspection: All 15 visits observed involved a skin inspection by the nurse conducted on the patient to check for any signs of damage.

Other observations/Setting: All encounters observed were in the patient’s own home, usually the living room with the patient seated. Non-verbal cues were observed to be used by patients in all visits to confirm understanding of the advice given, with the patient nodding as well as agreeing verbally to advice. Where nurses used a more ‘open participatory’ approach there was a tendency for the nurses to sit closer to the patient and increased eye-contact observed. For the visits that were more nurse directed with the nurse instructing what needed to be done and ‘telling’ the patient, it is noted these visits were where the patient was directly observed to be fatigued and not as well in themselves. These patients were physically observed as appearing unwell and exhausted with difficulty moving, as well as expressing verbally during the visits they felt exhausted to the nurse:

‘*I am so tired nurse, all the time really, just exhausted so you will have to bear with me’ (Ben).*

The visits were timed within the busy nursing teams schedule, creating a sense of time pressure to proceedings:

Nurse: ‘now we’ve got half an hour, you know why I am here to visit to make sure you understand what you need to do and why…to protect your skin of course and keep healthy ok?’

Colin: ‘ yes I do know, yes that’s right…’

Nurse: ‘so we will go through a few things and I will check your skin and we can see how you are, ok?’

Colin: ‘ok yes, let’s go for it…’

Similarly, here with Dee where the nurse outlines a known order to the visit:

Nurse: ‘and so you know the drill, so I will check your skin and go through some questions and from this see how you are doing, ok?’

Dee: ‘yes, ok, that should be fine’

Nurse:' I am going to go through with you some things and then check your skin and bottom area and then the bit at the end where I can summarise what we have discussed'.

In addition to this, there were other elements to the visits which were mainly nursing task orientated, including equipment demonstration for example use of a pressure cushion, skin checks and provision of a patient information leaflet. In a few of the visits during the interaction with the patient, the nurse was also focused on doing a task at the same time, example, dressing a leg wound. For the visits where the nurse was observed to be carrying out another task, different patterns of non-verbal communication were observed such as less eye contact with the patient and less general conversation. In relation to the PU leaflet, for the more open 'participatory' visits, the leaflet was also referred to within the nursing discussion, whereas for the closed 'directive' this was handed out at the end of the visit. The information contained in the leaflet covered the same key messages around the importance of skin check, nutrition, repositioning and equipment and consequences to the patient for advice not followed.

These observations on the structure and context of the nursing visit are reflective of the current PU clinical context outlined in the introduction chapter on risk mitigation, with scientific knowledge used to instruct the patients what to do and what situations to avoid. This emphasis on the assessment of PU risk in the context of scientific evidence and education is evident in the themes outlined below which were observed during all visits.

5.1.2 The Risk Assessment Process (Theme)

The theme **'the risk assessment process'** captures the professional nursing emphasis during the visits on minimising risk and preventing patient harm. The visit focus is driven by nursing practice protocols around PU risk and prevention. This includes 'telling' the patient what they should do and not do, for example following a healthy diet related to best clinical evidence in order to prevent PUs. This theme has been divided into a number of subthemes which are identified in Figure 12 and outlined next.

Figure 12: The Risk Assessment Process

Checking daily function and repositioning (subtheme)

This subtheme is focused on how nurses check with the patient that they follow the advice to move position and relieve pressure:

Nurse: 'Are you able to move your position?'

Colin: 'Yeah, well yeah I do that but it's not easy'

Nurse: 'But you're able to move say turn yourself in bed?'

Colin: 'just about I would say… I do'

Nurse: 'well let's move onto your diet…'.

This snapshot of the conversation with Colin demonstrates the predominant nursing focus on instructing the need to move position. However, there were some challenges to patients carrying out repositioning as identified in the previous chapter, such as the presence of pain and fatigue. The nursing approach affected whether these were picked up as part of the conversation and explored (discussed in section 5.2). In the extract above, the nurse moved to the next topic on the risk assessment which didn't allow space for Colin to expand further on any issues regarding repositioning or other functional challenges.

Checking equipment (subtheme)

The use of PU equipment and assessment of any equipment needed was considered within the nursing visit(s) as part of the conversation with patients. This subtheme is focused on how the nurse checks equipment usage as part of the risk assessment process such as the cushion and mattress, however there is less emphasis on possible reasons for non-usage, or exploration of aspects such as comfort or preference from the patient perspective:

Nurse: 'so you know about checking the cushion cover too?'

Ben: 'yes I know for wear and tear and not putting my sheet on it, but its cold you know without'

Nurse: 'right next let's have a look at your skin'.

In this extract, Ben was explaining how he finds the PU cushion temperature cold to sit on, however this element wasn't pursued further by the nurse, although it may have implications for patient adherence and use of the cushion itself. Several other patients in the study described similar preferences around equipment, some of which related to equipment history:

'*they put on the air mattress as I said before, you know in the hospital and I couldn't move then so it does me no good, I try to tell em that type are no good for me'(Frank).*

This relates to the previous literature highlighted in Chapter Two (section 2.6) and was a key theme to emerge from this study around 'equipment choices' the importance of understanding patient acceptance and use of equipment within decision-making to encourage adherence (McInnes et al. 2014). This has implications for clinical practice as it highlights the limitations to the existing professional focus on the correct 'scientific' basis for equipment, without consideration of these wider personal and social factors that are important to the patient and that affect adherence.

Nutrition check (subtheme)

During all visits observed, there was a focus by the nurse on nutrition and checking the patient was eating and drinking well to reduce PU risk:

Nurse: 'if I can check then so what about your diet and what you are eating and drinking?'

Catherine: 'I don't like all this fuss but if you are going to ask I know I need to eat and I do eat'

Nurse: 'good, so can you tell me and what sort of food do you eat?'

Catherine: 'I have a bit of fruit and I am not always hungry but I make sure I eat something, even if I am not too hungry'

Nurse: 'well you know why we ask don't you, we need to check as eating and drinking well to reduce your pressure ulcer risk?'

Catherine: 'yes I know, so I do eat what I can and fruit is good'.

However, there may be challenges to being able to ensure consistent good nutrition day to day, outlined in the previous chapter such as commitments in daily life, fatigue and mood affects.

Pressure ulcer risk & skin vigilance (subtheme)

The emphasis on checking skin, particularly key areas that may be at risk of skin damage is an integral part of current PU risk assessment and practice (National Wound Care Strategy Programme, 2021).

This was an important sub theme to emerge around the nurse ensuring patients were checking their skin regularly or by others, the emphasis by the nurse was around risk avoidance and being vigilant at all times:

Nurse: 'I am going to look at your bum for redness ok?'

Eric: 'ok then, well erm, yes ok'

Nurse: 'so I can see how things are and make sure you are not getting red ok, we need to keep checking, always?'

Eric: ' yes, that's ok, I am used to you saying about it'

Nurse: ' ok that all looks fine which is good to see it all looks ok'.

Here, with another patient Belinda, the nurse discusses the importance of skin checks:

Nurse: 'so you're ok with understanding the risk with your skin, as we say, red is bad, do you know about this and what to do?'

Belinda: 'yes I know, and my mom is here to check too and we can let you know'

Nurse: 'because it's important to keep checking the skin so that you don't get any problems'

Belinda: 'yes I am careful with that, I constantly check or mom does for me'.

Interestingly for both Eric and Belinda, they were dependant on others to carry out the skin check and therefore, whilst being receptive on what to do, performing checks were dependent on others. This relates back to the previous chapter and the importance of acknowledging the role of carers' in carrying out some of the preventative measures. Whilst the influence of family and others including the need to direct care is acknowledged within the broader adherence literature (King et al. 2008; Hashim et al. 2020) the core dependency on carer(s) to perform PU preventative strategies for some individuals is not present within the conceptual framework.

5.1.3 Advice Giving (Theme)

The theme **'advice giving'** explains the different ways in which advice is given to the patient through verbal, physical demonstration and in written form (see Figure 13). Related to this there is a separate subtheme around the emphasis of the potential negative consequences for not following the advice and encouraging compliance.

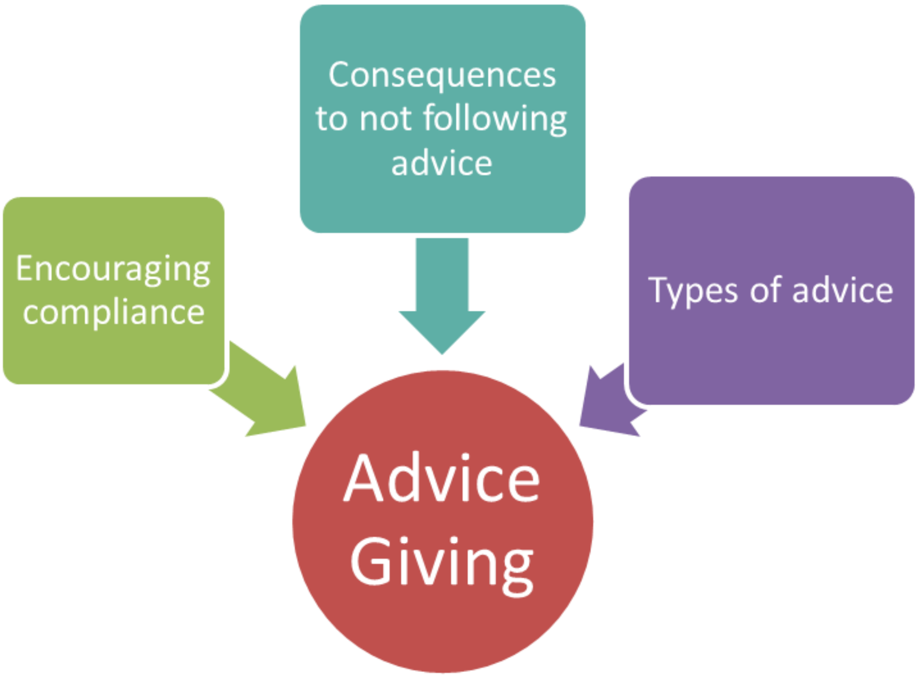


Figure 13: Advice Giving Theme

Encouraging compliance to advice (subtheme)

This subtheme within advice-giving is where the nurse encourages patients to adhere to the PU advice, including use of equipment:

Nurse: 'it's really important as they (carers) help you to move around and that's why I also gave you the cushion to try…you need to be able to move and have a good surface to protect your skin ok?'

Alan: 'yes you said before about it and I try to remember to put it on the chair'

Nurse: 'you must try to remember, it's a high pressure relief product and really good results so you must use it to protect yourself'

Alan: 'yes I know, I do see its important so will try to make sure'

Nurse: 'great as we don't want to end up with any red areas so to speak'.

Consequences to not following advice (subtheme)

In several encounters the nurse outlined the detrimental effects to the patient in not following advice:

Nurse: 'because obviously the more time you spend sitting down, the more at risk you are of developing pressure ulcers, ok?'

Ann: ' yes I do know and I try to move as much as I can'

Nurse: 'because that is what will contribute to your skin breaking you see, so you must do what I say as you don't want to end up with a problem'.

Responsibility was firmly placed on Ann to ensure the nursing advice was carried out and relay of information was largely one-way, with nurse instructing what needed to happen with negative consequences to non-adherence. This is reflective of the wider power relations between nurse and patient, with the nurse in a position of authority regarding appropriate knowledge and action required (Blaxter, 2010). However, this more paternalistic nursing role doesn't account for patient differences in choices around advice following or acknowledge situated challenges to adherence to the advice, rather it assigns blame to the patient for inaction (Jordan et al. 2020). This instructional linear approach to advice giving is reflective of the current PU risk framework and approach outlined in Chapter One.

Types of patient advice (subtheme)

This subtheme relates to the types of advice the nurse uses with the patient during the visits. A key means of providing advice was through the provision of a PU patient information leaflet:

Nurse: 'there is a nice little colourful book, it goes through and explains what pressure sores are, how they affect people, there is also a skin inspection part'

Alan: 'ok well I can take a look at that if you think it will help'

Nurse: ' yes I think it helps to explain the science rather than just talking about how to prevent the pressure problems, it shows you with pictures too'.

Here with another patient Colin, the nurse explains the different types of advice:

Nurse: 'did the nurse before mention, if you can remember about the leaflet too?'

Colin: 'I think so, and she spoke about things and what to do to avoid getting them'

Nurse: ' well that's what we do and the leaflet is good as it explains so you can read and also we can talk to you and show you where the pressure sores are likely to happen, it's important to have the best evidence'.

The PU patient information leaflet was referred to by the nurse during interactions and handed out in all visits observed. The PU leaflet content revealed similarities to the nursing focus observed in the transcripts. Indeed, the nursing emphasis on skin vigilance, moving position and healthy eating were evident in the document analysis, including the language used and emphasis on patient responsibility for ensuring advice was followed (see **Appendix 18**). The other means of providing the advice during the nurse visits were largely through verbal instruction and demonstration of equipment and how to carry out daily skin checks.

Importantly, identified in Chapter Four, only two participants had said they had read the leaflet and of these, one patient had found it useful. For the majority (n=9) that didn't read the leaflet, several had visual problems that meant it was difficult to read (Dave, Catherine and Diana) and some had difficulty retaining the information (Dee, Dan, Colin). None of the patients in the study disclosed these difficulties to the nurse which is a significant finding in itself and may be linked to the theme of ‘trust in the nurse’ outlined in the previous chapter, whereby nurse-patient interactions and the establishment of trust are the foundation by which patients in the study may open up around any challenges faced.

Therefore, it is evident from this overarching theme that the nursing encounter is largely driven by protocol and focused on PU risk assessment from a scientific basis and the provision of patient advice and risk minimisation, that mirrors the nature of existing PU nursing practice (Demarre et al. 2015). However, the results in the previous chapter reveal important differences in how patients understand and contextualise their risk and manage uncertainty, including perceived threat to self, the influence of family and others, emotions and trust and these are reflective of the wider concepts and literature around lay health beliefs within the broad conceptual framework (Zinn, 2007; Weller et al. 2021). The professional nursing emphasis on best ‘clinical’ scientific knowledge was not sufficient to secure patient adherence. Equally, the results have revealed important findings in relation to the types of information patients engaged with. Patients reported difficulties using the leaflet such as visual and memory problems. None of the patients in the study had disclosed these difficulties to the nurse themselves, an important finding in itself. This reveals underlying power relations between nurse as professional and the patient role which are embedded within traditional paternalistic relationships (Zainal et al. 2021). Traditionally, patients have been instructed what to do by HCP’s and failure to follow the advice has negative connotations with blame attached to the patient for ‘non-adherence’ to advice (Jordan et al. 2020). These wider conceptual underpinnings may offer an explanation for why the patients in the study did not wish to disclose the issues with leaflet usage directly with the nurse.

There were also considerable time pressures observed during the visits, with the average visit lasting around 30 minutes. As outlined in the previous chapter, the majority of patients in the study valued meaningful time spent and the nurse taking time to listen to them (12/15). Where time was more limited during the nursing visit(s), the nurse was more task focused with less non-verbal communication evident such as eye contact with the patient. The challenge of workload demands and time pressures are well documented in other studies and may hinder patients feeling able to open up about what is important to them and seek clarification around advice given and potential challenges to adherence (Chan et al. 2018; Stottard, 2012). However, some of the nurses within the study were able to circumvent these time pressures within the nursing visits and adopt a more open ‘participatory approach’. This links to the next important related overarching theme of ‘the nursing approach' and how this affects whether patients choose to open up about difficulties they may have with following the advice which will be discussed next.

5.2 The Nursing Approach (Overarching Theme)

The overarching theme **'the nursing approach'** captures the nature of the visit and how the nursing interactions unfold, from a more closed 'directive' style to a more open 'sharing' dialogue. The broad theme of **'type of interaction(s)'** outlines the way in which the nurse to patients interactions unfold and there are differences between a more open 'participatory' style nursing interaction to a more closed 'directive' approach. Importantly depending on which overall style is adopted is whether the subtheme of '**acknowledging limitations**' is evident within the nursing approach.

5.2.1 Types of interaction (Theme)

There were two overall styles of nursing interaction observed, a more closed 'directive' style, with the nurse taking a more directive stance (eight of the visits) and for the other seven visits, a more open 'participatory' style of interaction, with increased opportunity for patient involvement and questioning. An important finding to emerge was that the visits that were more open and collaborative also involved sense checking of understanding and 'acknowledging limitations' the patient may have in following the advice provided.

There was also some variation in conversation between nurse and patient evident from data analysis of both the observation sheets and time recorded from the dictaphone. For the more closed 'directive' interactions, nurses spoke for most of the time (80% or more), the patients less so. However, for seven of the visits where a more collaborative approach to interactions was adopted, there was a more equal balance of talk between nurse and patient (50%). For the visits where a more directive approach was observed, it was noted that the patients were also physically observed as being more unwell and/or fatigued during those visit(s).

The key results were analysed across the observations, interviews and follow-up interview data and grouped into patients that experienced a more open 'participatory' approach and those that experienced a more closed 'directive' approach, discussed next.

Summary of the closed 'directive' approach visits

From analysis of the observation sheets and transcriptions of the observations and interviews for the eight patients that were part of a more closed 'directive' approach, the patients took a more passive role in the visits and agreed to what the nurse was saying with limited responses of yes/no to questions. Whilst there was some variation noted, the nurses in the more 'directive' approach used a closed questioning style and the pace of questioning to the patient was quicker than that of the more participatory type interactions. Interestingly, the majority of patients where the nurse took this more directive approach were fatigued and/or in pain and of poor health. Therefore, it could be suggested that this may have necessitated the nurse to take a more controlled stance during the visits. The majority depended on others to do their activities of daily living and so were dependant on relatives or care staff to provide care. Whilst acknowledging they needed this help, these patients found this dependency on others challenging and there was a juxtaposition between maintaining independence with the reality of dependency upon others. Two of the patients (Gwen and Catherine) in particular found this involvement and nurse visits intrusive and therefore wanted the visit to be over as quickly as possible. This may have been a possible factor in them keeping interactions to a minimum during the visits. Two case studies are outlined below to demonstrate the more closed 'directive' approach:

Ann

The nurse was observed as directive and instructive in approach, speaking for 80% of the interaction. The nurse told Ann what she needed to do and checked this is what she has been doing with emphasis on the consequences for not following advice. The nurse talked for the majority of the time and Ann nodded agreement at intervals. The nurse was focused on the task in hand such as, the PU prevention screening checklist, skin check and demonstration, with little eye contact with Ann directly during the process. The effect of the more directive approach is evident from the analysis of the interaction data where there was much less opportunity for Ann to talk and convey potential problems:

Nurse: 'so you know you need to move around don't you and keep moving?'

Ann: 'well yes nurse, you know I try my best for you, but its hard as I get so tired'

Nurse: 'but you make sure your moving around and repositioning don't you?'

Ann: 'yes, I know I should keep myself going'

Nurse: ‘right now how are you getting on with eating well?’

The use of leading questions may have affected how Ann responded. It was also evident that Ann wanted to please the nurse and do the right thing and this was also apparent during the follow-up interview where Ann described how she agrees with the nurse and tries to do what they tell her, saying ‘*well you know the nurse knows best’.* However, when asked at the follow-up interview whether she felt she could tell the nurse any problems she may have with following advice, in this extract it is evident she is aware of time pressures the nurses have and this, alongside her struggling to concentrate, she prefers to get the visit over and done with:

Interviewer: ‘*and so tell me about how you felt the nursing visit went?’*

Ann: ‘well ok I think, you know they are so busy and give me their time’

Interviewer: ‘and do you feel you are able to say about how you feel and how you’re getting on?’

Ann: ‘well nurse knows best, I do struggle as I get so tired so it’s easier sometimes to just nod and agree’

Interviewer: ‘ok, do you feel you would be able to share any difficulties with daily functioning?’

Ann: ‘well as I say, they know best and anyway, I don’t want any more carers getting involved, I would rather try and manage as best I can’.

Ann has to depend on carers for some activities of daily living, however she is fiercely independent and tries to do as much as she can for herself. This was a factor in her not opening up during the nurse encounter about some of the difficulties she faced.

Gwen

The nurse took a directive and instructive approach and speaking for most of the time (80%). Gwen took a passive role during the visit, with mainly yes/no responses and nodding. She was observed as lethargic and low in mood having recently lost her husband and was choosing to sleep downstairs in the house in a chair. She was also afraid of falling, having previously fallen in the property. The decision to sleep in the chair was against the nurse’s advice and during the visit the nurse was observed as trying to encourage use of a pressure cushion in the chair:

Nurse: ‘so you know we don’t like you sleeping in the chair, so this cushion will be so much better for you to use’

Gwen: ‘I don’t know really’

Nurse: ‘honestly it will be great, it will protect you from pressure better so give it a go for me, go on it makes sense doesn’t it?’

Gwen: ‘well I will try to give it a go for you then’.

During the follow-up interview Gwen stated how independent she is and how she likes to do everything for herself. She resents the care input she now has since her husband died and when asked about involvement in decision-making she described the nursing visits as intrusive. At times Gwen therefore agreed to the advice to speed up the visit. However, if she doesn’t agree with what is offered she is unlikely to carry out the advice, like the example here with the cushion:

Interviewer: ‘so tell me about the cushion the nurse gave you at the visit, how are you finding that?’

Gwen: ‘I don’t really use it to be honest, I know they are only trying to help but I just won’t use it. I don’t like a cushion on my chair’.

Whilst Gwen’s rationale for not using the cushion was undetermined, it was evident her preference for non-use was not accepted during the interactions with the nurse. This is reflective of the nature of the nursing encounter and scientific focus on prescribing PU equipment to reduce patient risk and mitigate harm. It was evident during the follow up interview that Gwen had not used the cushion. However, patient non adherence to the equipment itself is a risk and highlights the importance of patient involvement and understanding preferences regarding PU equipment options.

Summary of the open ‘participatory’ type visits

Following analysis of both the observation sheets and transcripts from the observations and interviews, the seven patients that were part of a more open ‘participatory’ visit reported that they felt listened to and part of the decision-making process and this improved trust with the nurse. The patients placed value on the nurses that took more time to listen and understand what was going on for them as opposed to the nurses that were in a rush and didn’t engage with the patient as much. Patients described how they were more likely to open up about some of the challenges they were facing where they felt the nurse was not in a rush and where there was an openness to understand their perspective on things. This was observed as a difference in the more closed 'directive' approach visits where the nursing questions were more leading as opposed to open-ended style of questioning. A few of the patients described how they had increased their confidence over the years, from early diagnosis where they described less confidence to years later, being able to assert their needs and participation. This involvement in decision-making in turn increased their adherence to following the preventative advice.

Two case study examples are detailed below to demonstrate the more open 'participatory' nursing approach.

<u>Eva</u>

The interaction was a similar balance between nurse and Eva (50/50) and collaborative in nature with the nurse sense checking understanding and providing opportunity for Eva to discuss anything else that was of concern. The nurse spent considerable time reassuring Eva about her situation and offering suggestions of what may be helpful to her as she was struggling to cope. Once the physical skin check and medicine checks had been completed, the nurse sat down next to Eva and listened to what she had to say about her situation with lots of eye contact and nodding. In this extract, the nurse is encouraging her to open up:

Nurse: ' you can tell me Eva its fine, that is what I am here for its not just your skin, how are you getting on, really?'

Eva: 'to be honest nurse, it's really hard and it's getting harder, you know it used to be so much easier and I could walk better and move around, I even used to get to the shops'

Nurse: it can't be easy for you and I know moving around has become difficult, is there anything else you have noticed?

This open 'participatory' interaction and use of empathy allowed Eva to open up about what was going on for her and if she had any particular concerns.

In the follow-up interview when asked about how the nurse visits were, Eva described how '*some are better than others they are not all the same, there are good and bad you see'*. When asked to elaborate on this, she described how the good visits are where the nurse takes the time to listen and hear what she has to say:

Eva: 'some of them fob you off you know if I can be really honest they rush in and do what they need to and leave…the good ones listen to me and spend time checking how I am and what I think, it makes all the difference'.

She acknowledged that all the nurses were busy but described how some seemed to just focus on doing the task itself and didn't even look at her. To Eva, the visits are really important to her, the focus of her day and if she feels the nurses are too busy and not interested then she doesn't open up and share what difficulties she may be facing. Further to this, she described how, if she feels the nurse is not interested in understanding what she has to say then she is less likely to listen to their advice and follow what has been advised. Eva described how trust was developed over time with the nurse and continuity of the same nurse and openness was fundamental to the development of trust:

Eva: 'well you see it has to grow, I don't just open up straight away, it takes time does trust and it takes time to develop but it's so important, its being open to listen'.

Frank

The interaction was equal between the nurse and Frank (50/50) during the visit with a collaborative approach observed. The nurse was instructive at times, with majority of the visit sense checking and asking Frank's view on things. During the visit, Frank was observed to be directive at times, telling the nurse what to do and how to do things, which was interesting to observe. In this extract, Frank is explaining to the nurse how he likes to be moved:

Frank: 'if you come *round here…no not like that right round the side here and that way works best'.*

Later in the visit, the nurse is encouraging compliance through giving Frank the opportunity to share his ideas of the type of equipment too:

Nurse: 'so tell me Frank as I know you will have some thoughts, what do you think about your mattress, we spoke about the importance of using it before?'

Frank: 'I need to think about it as I can see the need to use a pressure ulcer type to stop me getting sores, but as you know I need to think about me still being able to move myself in lying'

Nurse: 'absolutely Frank, there's the pressure prevention mattress surface that is so important but equally I can see you independently being able to move is your priority'.

During the follow-up interview Frank described the importance of continuity with the nurse so that they understand him as an individual and what works best. He also discussed the importance of 'good nurses' having good eye contact and taking the time to listen. Interestingly, when asked about feeling involved in decisions about his care, he describes how he does feel confident now in asserting himself with what is important, but this wasn't the case years ago when he first had his injury. Early diagnosis, Frank described how he was still coming to terms with his situation and therefore, was less confident. However, over the years, he has developed confidence in his knowledge and situation. When talking about trust, Frank describes that this takes time to develop with the nurse and hence the importance of continuity with the same healthcare professional:

Frank: 'they (the nurse) got to build it, it don't just happen, they gotta earn it so it helps if it's the same person'.

<u>Acknowledging limitations (Subtheme)</u>

This subtheme sits within the open 'participatory' type approach, in which the nurse checks and acknowledges some of the patient limitations that make it challenging to follow the advice. Importantly, this sub-theme was not evident in the closed 'directive' approach.

Here the nurse is acknowledging to Beryl about her difficulties in changing position:

'so I know you cannot stand and move as such because of your legs' (Nurse)

'yes, that's right, it's really hard nurse' (Beryl)

'so due to the fact that your non-weight bearing I can understand it isn't easy for you. So it's trying to do the best that you can, if you can just tilt to the side, is that ok?' (Nurse)

'yes I can give that a go nurse' (Beryl)

'that's fine and just let me know, you know if we need to thing about something else, we can discuss together and come up with a plan' (Nurse)

Likewise here with Diana:

'so we spoke about you trying to move around more last time, how have you found doing this?' (Nurse)

'yes I do my best, the community physio were going to get some sticks sorted so I can try to practice more, I find it hard I just sometimes lose my balance and that and getting tired you know' (Diana)

'we do need to try to keep you moving around even though it isn't easy. I know it isn't always easy for you to do, I can see that, as I say just try your best and then let us know and if we need to talk again or look at something else it's no problem' (Nurse).

Here, with Eva, the nurse acknowledges it is problematic for Eva to raise her legs on a foot stool:

'it's for the lymphoedema, that is why it is important for you to raise your legs in that way but I do appreciate it isn't easy for you' (Nurse)

'oh gosh, well it really isn't nurse, if I could do it you know I would, I mean I really try my best but I am in so much pain it's agony' (Eva)

'it can't be easy for you, it really can't and I do know that you try your best, just let us know if you need anything else, we are here to help you' (Nurse).

The results revealed that with the open 'participatory' approach, there is an acknowledgement of some of the challenges the patients may have in following the nursing advice, which in turn lead to important insights into potential factors affecting patient adherence to PU advice and interventions. This relates to the concept of 'situated adherence' and that there is a dynamism to adherence that varies day to day, according to other patient related factors and social constraints. Importantly, the nurses using this approach were able to circumvent the rigid structure of the protocol driven nursing visit to allow exploration of patient related factors and social situation. This 'acknowledging limitations' subtheme wasn't evident as part of the more closed 'directive' type visit(s) therefore creating a challenge for these patients to have an opportunity to raise any concerns.

5.3 Summary

The study has revealed important and novel findings in relation to the Nursing Encounter, that is driven by protocol and focused on PU risk assessment from a scientific basis and provision of advice and instructing patients about preventative measures (Shanley et al. 2020). This mirrors the nature of the existing PU risk assessment nursing practice outlined in Chapter One, that is linear, prescribed and with the nurse directing the process (Demarre et al. 2015). However, the results in the previous chapter revealed important differences in how patients themselves understand and contextualise risk and manage uncertainty, including perceived threat to self, the influence of family and others, emotions and trust and these are reflective of the wider concepts and literature around lay health beliefs (Zinn, 2007; Weller et al. 2021). Therefore, patients may not use or understand professional scientific knowledge or risk in the same way, which may be reflected in the poor uptake of PU leaflets, whilst also acknowledging there were other health literacy challenges related to this. Failure to acknowledge these differences in the patient context of risk including decision-making around preventative strategies may affect negatively on adherence behaviour.

Overall, there were two nursing approaches observed during the study, a closed ‘directive’ approach and a more open ’participatory’ type approach. Within the more closed ‘directive’ approach, nurses spoke for the majority of the time and were seen by patients as bearers of the truth and experts in knowledge, therefore their advice was accepted as correct and not to be questioned. This relates to wider power relations and traditional hierarchies around nurse/patient role with the nurse as HCP seen in a position of authority (Stottard, 2012). Within this context, the nurse had a lead role and with institutional roles and expertise understood by both parties. Importantly though, whether this advice was actually followed through by the patient, depended on broader personal and social factors that were present in their day to day lives and ‘situated adherence’ (Rosenfeld and Weinberg, 2012). However, this more paternalistic, nursing approach may cause difficulty for the patient to challenge advice or raise concerns within the setting (Chan et al. 2018). This was a key finding in this study, whereby patients that experienced a more closed ‘directive’ approach struggled to communicate their challenges to following the nursing advice during the visit. Where a few of the patients had attempted to raise difficulties, these concerns had been shut down by the nurse, therefore ‘acknowledging concerns’ didn’t feature in these encounters. Conversely, over half of the patients in the study took a more questioning approach and were more involved in decision-making (9/15) which occurred in the visits where the nurse used a more open ‘participatory’ approach. Within these more open interactions, patient experiential knowledge was accepted alongside the nursing knowledge, with lay understanding explored and more balanced interactions and talk. Within this approach, shared decision-making was evident, with patients also more likely to disclose any difficulties to following advice. This is an important finding in that a more open ‘participatory’ style of communication leads to important insights into potential factors affecting adherence to PU advice and more realistic care planning as part of a two-way partnership approach. It is the means by which the nurse may break-out of the existing protocol and risk-based models of care and enable collaborative decision-making to occur.

In summary, an open ‘participatory nursing approach can be the channel that links the nursing encounter and relay of scientific risk information alongside patient ‘lay’ interpretation of PU risk and potential patient factors that may affect adherence behaviour. Importantly, it can provide the conduit within which the patient is able to ask questions and disclose any challenges they face in following advice. However, where some patients in the study were observed and reported to be struggling, for example not so well or fatigued during the visit, a more closed ‘directive’ approach to the interactions was necessitated. These findings suggest therefore, that there is also an element to the nurse varying approach according to how the patient presents clinically and is reflective of other studies around the level of patient participation in decision-making and nursing approach (Schoeps et al. 2016; Stottard, 2012).

This chapter has outlined the key findings around the context in which PU risk and preventative care planning occurs, the influence of the nursing encounter and in particular, the type of nursing approach on resultant patient adherence. These will be synthesised further in the next chapter alongside the patient related findings in relation to the broad conceptual framework and an emergent, new model in light of these findings.

Chapter 6 Discussion

This chapter considers the key results from the study in relation to the research questions and broad conceptual framework outlined in the introduction. The discussion will detail the contribution of new knowledge and describe a new reconceptualization of risk model considering these findings.

6.1 Key and Novel Insights

This study revealed new insights into how interactions unfold between the HCP and patient, with the nursing approach affecting whether the patient chooses to disclose important factors that may affect adherence. The importance of the quality of the communicative relationship between the nurse and patient in contributing to increased adherence in other clinical settings has been highlighted in previous studies (Chan et al. 2018; Stottard, 2012; Mayor and Bietti, 2017). However, Fleischer et al. (2009) in a systematic literature review identified a significant gap in the research regarding how nurse-patient interaction unfolds within the community setting, which this study has addressed. This is one of the few studies to capture the social processes and interactions within the community setting for PU prevention and the effect of these on adherence. The focus on understanding situated adherence and the practical contingencies and social fabric of daily life in either facilitating or constraining patient adherence to PU prevention, is distinctly different to studies which have investigated individual factors such as patient motivation (Rosenfeld and Weinberg, 2011; Fleisher et al. 2009; Weller et al. 2021).

The integrative literature review conducted at the start of the study revealed that most research on PU prevention and adherence has been from the professional standpoint, with little research exploring the patient perspective, particularly in community settings (Ledger et al. 2019; Stinson et al. 2013; Baron et al. 2016). This study has addressed this gap by identifying how knowledge and understanding of PU risk unfolds from a patient perspective revealing factors that may affect adherence. Whilst some of the findings concur with previous studies which have identified the importance of factors such as patient involvement in decision-making, daily routine and the impact of PU related pain (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014), the present study also revealed several novel findings.

In terms of new factors around patient adherence decision-making, fear of falling featured as a significant sub-theme which had not previously been identified in the PU literature. Other factors such as patient fatigue, mood affects, and generalised pain also 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 and relationship to resultant adherence. These elements have not been addressed previously in the research literature and are absent within existing conceptual models of adherence, therefore provide contribution of new knowledge in the sphere of PU prevention. The research approach used in the study enabled a kaleidoscope ‘lens’ through which to observe the nurse-patient interaction and interpret the understanding and subsequent intended action of patients. This, rich data capture provided different perspectives on the same phenomena (Silverman, 2016) and provided the foundation to develop a new co-produced model of risk and situated adherence for pressure ulcer prevention.

6.2 Summary of Original Findings:

- The patient PU information leaflet was not sufficient to secure patient understanding and engagement. For some individuals the information leaflet could not be accessed due to visual, cognitive and literacy challenges.
- Patients learn about their PU risk from the nursing encounter, where they gain a basic understanding of PU knowledge and prevention techniques.
- The patient interpretation of risk is complex and influenced more broadly than professional scientific advice through ‘lay’ heuristics and the influence of social networks such as family and friends.
- Patient understanding of PU risk does not necessarily secure adherence, due to other patient related factors and social constraints.
- There are many patient related factors that affect whether advice was followed. These are complex, individualised and dynamic. It is therefore too simplistic to suggest adherence is determined by patient motivation and knowledge translation alone.
- Different patient clinical presentations and circumstances appeared to necessitate the nurse to vary their approach. This affected the degree to which patient participation was

possible, with factors such as ill health, cognitive challenges and/or fatigue appearing to limit patient involvement.

- The approach by which nurses interacted with patients, namely an open ‘participatory’ or more closed ‘directive’ approach, affected whether the patient chose to disclose important individual ‘patient related factors’ that were affecting their adherence.
- Patient involvement in decision-making with the nurse is central to resultant PU adherence, including the uptake of preventative equipment. Equipment usage was dependent on a number of personal factors, which may impact on pressure ulcer prevention.
- Wider organisational structures such as the NHS Trust nursing protocols and resulting time pressures on ‘the nursing encounter’ create challenges to building trust and patient participation in decision-making. Despite this some nurses in the study were able to circumvent these challenges within their practice.

6.3 Key conceptual considerations in relation to the findings

The broad conceptual framework used to guide the study focused around the two overall research questions: Patient perceptions and understanding of PU risk and factors affecting adherence to PU prevention strategies in community settings. This is presented in Figure 5a and discussed below.

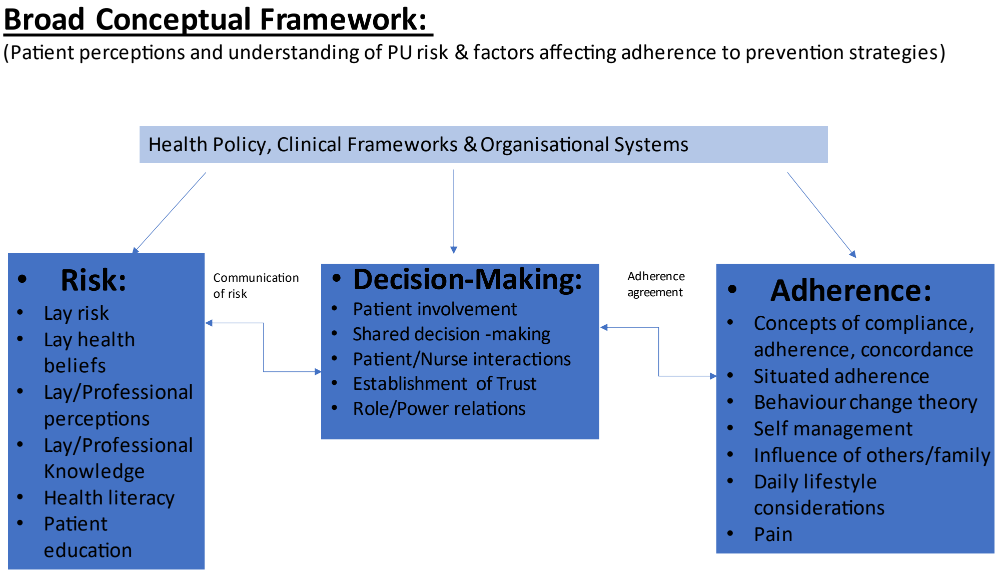


Figure 5a: Broad conceptual framework (refined)

Question 1. What are patient perceptions and understanding of their pressure ulcer risk?

The results revealed that patients drew on a much broader context for risk than the scientific knowledge provided by the nurse. Patients in the study made decisions based on pragmatics of their daily life, including routine and family roles, alongside the balancing of other risks, such as the fear of falling. The patient context of risk was more personally and socially grounded and influenced too by the experiences of family and friends. The influence of family and friends on health beliefs is similar to social pressures and the influence of family within the TPB model outlined in the introduction chapter, included within the conceptual framework (Kan et al. 2017). Where negative prior experience had occurred, the perceived threat of developing another PU was far greater so there was increased vigilance. There were also other risk determinants patients described in relation to health beliefs, such as PUs being a hospital related issue and something ‘ill people’ or elderly individuals acquire. Patients therefore distanced themselves from the perceived threat of developing a PU using heuristics to simplify risk in their everyday understanding (Grauman et al. 2019).These findings are reflective of the wider health literature shown in the conceptual framework (Figure 5a) that acknowledged important differences in lay/professional understanding and interpretations of risk, with ‘lay’ interpretation influenced by social interactions as well as personal factors such as hope, trust and emotions that shaped experiences of risk (Zinn, 2008).

The findings have important implications for clinical practice and the communication of PU risk to patients, with the provision of scientific information not sufficient to secure knowledge translation and adherence. Indeed, the study has revealed the nature of the nursing encounter follows a professional led focus on providing scientific knowledge and instructing patients regarding PU prevention, including provision of a standardised information leaflet. Although patient leaflets were handed out in every visit, most patients in the study did not use them. In part, this could be attributed to visual and/or cognitive challenges that some patients reported. Poor uptake of patient information leaflets has been reported in the literature despite this remaining the preferred method of PU patient education by HCPs (Fletcher, 2020). In most cases (13 out of 15), patients in the study valued discussion with the nurse as a means of understanding PU risk in the context of their lives. Therefore, there is a need for greater consideration within clinical practice around how healthcare information is communicated to patients and individual preferences and considerations within this (National Wound Care Strategy Programme and Skills for Health, 2021).

The findings of this study also revealed important health beliefs related to lifestyle choices that affect the translation of knowledge and resultant adherence to PU prevention, such as dietary choices in ‘staving off ill health’. These health belief constructs were deeply embedded within the patient’s life and day to day behaviour and are reflective of elements within the HBM outlined within Chapter One such as susceptibility to illness (Connor et al. 2021). These patient related health beliefs and lifestyle choices were shared with the nurse when a more open ‘participatory’ approach was used. The importance of patient health beliefs being part of PU preventative care planning alongside the nurse was also observed in a recent study by Shanley et al. (2021) whereby understanding of patient related health constructs were pivotal to adherence. Thus, there is a need to consider a more dynamic framework for PU risk communication and patient education, whereby patients are recognised as experts in their life knowledge and health beliefs, as part of shared decision-making. The concept of shared decision-making was introduced in Chapter One and included within the overall conceptual study framework (Figure 5a). Shared decision-making is inherent within NHS guidance and is a key component of person-centred healthcare. It is a process by which the HCP and patient work together to make decisions around care planning and treatment, that balances risk and expected outcomes with patient preferences and values (McCormack et al. 2021).

There were also some interesting findings around self-efficacy and control in relation to PU prevention advice, with some patients reporting confidence in asserting their lay 'expertise' within decision-making, whilst others took a more passive role. Where self-efficacy was greater, this appeared to relate to several years of experience and living with a health condition, which corresponds to some of the health-behaviour change models outlined in the introduction (Zainal et al. 2021). Within this study, patients who had several years of experience living with a health condition, were more used to navigating care conversations with the HCP. Importantly, this was not necessarily PU experience as the majority of patients did not have prior experience, but other long term health conditions, such as paraplegia and living with an amputation. Therefore, consideration is needed for differences in how patients respond to and engage with advice, with a more personalised approach to patient participation required to improve practice (Hardicre et al. 2021). There are also challenges that remain around securing patient agreement for adherence where diagnosis of a health condition is relatively new and the potential effects of managing a condition not yet experienced. This is distinct from the previous studies such as the leg ulcer work by Van Hecke et al. (2011) that focused on adherence behaviour in relation to management of an existing wound.

The overarching theme of 'the nursing encounter' revealed the context in which patients learn about their PU risk, which was time-dependent and transitory, with a strong clinical focus around risk mitigation. Within the encounter, role/power relations were assumed, with the nurse as professional in a position of authority and the patient a recipient of nursing care. This is reflected in sociological literature within the broad conceptual framework (Figure 5a) around pre-ordained social meanings and hierarchy of power between the nurse and the patient (Barnard et al.2010; Stottard, 2012, Chan et al. 2018). Within the encounter, responsibility was firmly placed on the patients in the study to adhere to the advice provided by the nurse. Patient adherence in this sense is prescribed and determined at a static point in time. However, the present study identified that in some cases there was limited opportunity for patients to raise concerns or feel able to question the advice during the nursing visit**.** As outlined in Chapter One, adherence as a concept assumes patient agreement within the decision-making process, which may be too simplistic. Importantly, this study has revealed that adherence is dynamic and situated within the practicalities of living with health conditions and social constraints. The study also revealed important tensions between those patients who were more confident acting as expert in self-management of their condition acquired over the years and their active decision-making to follow the nursing advice or not perceived as non-adherent by the nurse in a negative way. Therefore, patient involvement and expert, experiential knowledge within decision-making alongside the nurse is crucial to facilitate situated adherence.

The open ‘participatory’ nursing approach in enabling the establishment of trust with the nurse was a key finding in the study. This central concept of trust was present within the broad conceptual framework (Figure 5a), with importance in promoting better patient engagement in advice as well as treatment (Leslie and Lonneman, 2016; Rortveit et al. 2015). Trust was also a pivotal factor in the leg ulcer study which formed part of the conceptual framework, with factors such as ‘meaningful time’ spent with the patient and trust in the type of nursing wound care provided by the Tissue Viability Nurse (TVN) (Van Hecke et al. 2011). The leg ulcer study offered limited usefulness in relation to preventative PU adherence, as the findings related to patient factors associated with the management of existing wounds. The findings of this study are novel with respect to prevention, whereby patients in the study reported they were more likely to open up to the nurse and share any difficulties with preventative advice and understanding risk as part of a trusting relationship. The visit(s) themselves however were time pressured and often transitory, with different nurses visiting the patient(s) that created a tension in cultivating the right environment for trust. These organisational pressures are particularly evident within district nursing services in England. Here, there is a rising service demand alongside a falling NHS budget which has created more transitory and episodic patterns to community nursing visits (Kings Fund, 2017). The challenges to nursing time are well documented, including the time available and continuity of care episodes (Chan et al. 2018; Barnard et al. 2010; Coleman and Muir, 2015). However, despite time pressures, at least half of the nurses in the study were able to transcend these challenges and adopt an open ‘participatory’ approach with patients, which suggests time factors alone do not explain the differences in nursing approach. It is possible that clinical experience was a factor in that the nurses who were able to vary their approach and relied less on the nursing paperwork had more community nursing experience. This was not within the scope of this study and would be an important area for future research.

Question 2. What factors affect adherence to pressure ulcer prevention strategies in community settings?

There were many different factors identified by patients in the study that related to challenges they faced day-to-day. These were complex, individualized and dynamic in nature.

These factors are not included within existing models of adherence nor explicit within the current PU clinical risk and prevention practice framework.

Patient decision-making was a key theme to emerge that captures how patients navigate power relations, the degree of patient involvement in decision-making and the complexity of factors affecting patient decisions surrounding adherence. Critically, patients who felt more involved in the decision-making process, said they would be more likely to adhere to the advice. This concurs with the findings in the literature review, which indicated a link between patient involvement in decisions and subsequent adherence to treatment behaviours (Gorecki et al. 2009; Gorecki et al. 2012; McInnes et al. 2014). The importance of routine, daily lifestyle and maintaining independence also featured as a sub-theme, in which most patients described how they would prioritise daily hobbies and activities over PU prevention strategies. This was observed in several studies in the integrative literature review (Ledger et al. 2019). Important and new factors revealed in the study around patient decision-making included a fear of falling which prevented individuals following PU advice such as going to bed. This is a new and significant factor to emerge that has not been identified in previous research studies, with 10 out of the 15 patients in the study reported the fear of falling was greater than the potential repercussions to not following the PU prevention advice. Fear of falling presents a significant issue for many elderly, community patients, with prevalence around 20 -39% and associated reductions in mobility, social activity and quality of life (Whipple et al. 2018). Mobility is a primary preventative strategy for PU prevention in order for patients to off-load vulnerable skin areas and maintain function. This finding therefore has important considerations for clinical practice because fear of falling is not present within the current PU risk assessment or prevention protocols. This places patients at further PU risk, as the study has demonstrated fear of falling could limit important mobility and repositioning, including the use of preventative equipment.

In relation to equipment choices, several patients described how they would make decisions around their equipment preference which may contravene the nursing advice for comfort, aesthetics and for functional reasons. Patient decisions around use of equipment were based on different criteria to the scientific evidence used by the nurse and this is a new and important finding in the context of PU preventative clinical practice. Indeed, the provision of PU equipment is used as a primary preventative measure and non-usage increases patient risk further (European Pressure Ulcer Advisory Panel/National Pressure Injury Advisory Panel/Pan-Pacific Pressure Injury Alliance, 2019). There are also considerable cost implications for non-use of equipment, with increasing challenges to healthcare budgets and stretched resources, particularly within the community sector (Nixon et al, 2019). There may also be other factors on which community nurses base equipment decision-making, such as prioritising cost over patient suitability (Papanikolaou et al. 2007). This highlights the necessity for patient involvement within the decision-making process and the need for nurses and healthcare organisations to consider the types of equipment available, to promote adherence to their use.

Another key finding from the study was the dependency patients had on others to carry out the PU prevention advice, characterised in the theme 'carer involvement'. The majority of patients in the study (14 out of 15) were dependent to some degree on carer input, resulting in limited active choice or individual motivation to perform PU prevention activities like repositioning and skin checks. The importance of involving carer(s) in the decision-making process and treatment advice has been well documented in other health contexts and was included as part of the conceptual framework (Figure 5a) (Walker and Dewar, 2001; Tambuyzer and Audenhove, 2013). However this novel finding demonstrates the importance of the involvement of carer(s) in preventative strategies which is currently absent from PU risk frameworks that focus on the individual.

The theme 'difficulty carrying out advice' as a finding demonstrated the range of patient related factors that affected advice following such as the presence of pain, fatigue and low mood. The presence of pain was a significant challenge for patients in carrying out prevention techniques such as repositioning and this was previously highlighted in the literature review in relation to PU pain (McInnes et al. 2014; Pinkney et al. 2014; Gorecki et al. 2012). This study has revealed a new finding with the impact of chronic pain and living with other health related conditions in the community, such as arthritis and the subsequent effect on adherence. This was important, affecting over half of patients in the study. In addition to pain, other factors were revealed that are not part of PU risk assessment, such as fatigue, mood affects and living with long term conditions. These accumulated to create barriers to performing PU prevention activities and these difficulties were not present in the previous studies included in the literature review. Of the behavioural adherence models outlined in Chapter One, the Theoretical Domains Framework (TDF) is one of the few conceptual models to acknowledge some of the broader personal factors such as pain and mood affects in relation to adherence (Kan et al. 2017). They are also not included in the existing PU risk framework which do not account for the holistic health status of the individual, with a focus more on the physiological factors to PU risk such as the Waterlow, Norton and PURPOSE T outlined in Chapter One.

‘Patient-related’ factors such as fear of falling, equipment and lifestyle preferences, fatigue and low mood do not routinely form part of the current nursing focus within PU risk assessment and preventative care planning. Therefore, the type of nursing approach is fundamental to how professional/patient interactions unfold and whether patients are able to share these other, holistic challenges to carrying out the advice. The study demonstrated that a more open, participatory nursing approach allows for ‘acknowledging limitations’ the patient may have as part of the discussion with the nurse and considered within the preventative care plan. Importantly, whilst most patients in the study understood their PU risk and what they needed to do, whether this translated in adherence was dependent on their involvement in decisions and whether personal factors and social constraints were acknowledged within the decision-making process. The Theory of Planned Behaviour (TPB) outlined in Chapter One that formed part of the conceptual framework (Figure 5a) acknowledged social factors such as the influence of family and social pressures on adherence outcomes, but not other personal factors.

Likewise, the study revealed that, whilst patient involvement in decision-making is an important factor in adherence, the level of involvement cannot be assumed. Where the nurse took a more directive approach in the study, the patients were fatigued and in poorer health, which may have necessitated the nurse to take a more controlled stance. Upon consideration of the wider literature, the caution to a more closed dictated approach in practice is this may inhibit patient adherence (Merav and Hochman, 2017). This ‘chameleon’ type approach in nursing interactions has been identified in other studies that describe how the nurse may vary approach according to presentation of the patient, such as where the patient is more unwell and limited patient participation may be necessitated (Schoeps et al. 2016). There is however, a careful balance to be considered between patient participation and level of illness alongside patients maintaining some control over decisions around their care.

These findings overall reveal the importance of the patient perspective sitting firmly within the PU risk and preventative care planning and decision-making process, alongside the nursing focus, which is not currently the case. Existing adherence models largely focus on an individual’s motivation and ability to carry out advice and do not include important key factors revealed by this study, such as patient involvement in decisions, power relations, personal factors and social constraints on adherence. There is therefore a need to create a new, dynamic model that acknowledges the complexity of situated adherence, where PU risk is understood and co-created by HCP and patient and where preventative care planning is negotiated. This is presented next.

6.4 Rationale for a new model

It is evident from the findings of the study that there is a need to reconceptualise PU risk in the clinical encounter to reflect a more co-produced process that considers the personal, patient factors and social aspects of situated adherence and the carer's role.

Within the current clinical context, risk is considered probabilistic in nature, which the study has revealed may not be sufficient to address the complexity of a patient's own interpretation of risk and engagement with preventative strategies. A recent systematic review conducted into the clinical applicability of recommendations in PU guidelines and their usage, revealed that whilst guidelines are used to standardise care based on best scientific evidence, limited attention has been paid to the preferences of patients and their families and how risk is communicated (Gillespie et al. 2020). The systematic review also recommends that HCP's should also still exercise clinical judgement in the face of uncertainty and take into account the patient perspective to aid real time decision-making (Gillespie et al. 2020). This recommendation may be addressed in practice through an open 'participatory' nursing approach and shared decision-making model.

Increasing patient involvement in care planning and decision-making is gaining credence in healthcare policy and practice, with a movement away from tradition paternalistic models of care towards a more patient co-produced approach (Jordan et al. 2020). Concepts around how patients respond to health advice and the relationships between HCP and patient have changed, with a move from compliance (being told what to do) to adherence which necessitates the patient agreement within decision-making (McKinnon 2013). The challenge with adherence as this study has revealed, is how patient agreement is established at a static point in time. Therefore, concordance is considered more useful as it focuses on the patient-HCP relationship and a partnership of shared decision-making. Here, patients are recognised as experts in their own life and values and beliefs integrated into the care planning process (Liu et at. 2021). The study also revealed the concept of situated adherence as promising, as it acknowledges the dynamic nature of how adherence unfolds and that it is situated within the practical contingencies of patients' lives (Rosenfeld and Weinberg, 2011) which complements concordance.

A key finding from this study was that patient involvement in decision-making related to subsequent adherence behaviour. It is therefore important to consider a new model in which shared decision-making takes place and patient factors are acknowledged. Shared decision-making as a concept was introduced in Chapter One and formed part of the conceptual framework (Figure 5a). The new model places shared decision-making centrally and uses the principles of person-centred practice, which offers a scaffolding around the context of the patient's lifeworld, values, and beliefs, not just the illness or presenting health issue (Phelan et al. 2021). Person-centred practice has a well-established and growing research base with some demonstrable patient outcomes such as improved quality of life, maintenance of function and improved adherence (Wynia et al. 2018).

6.5 An emergent reconceptualisation 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 and a collaborative approach, whereby patients and their families bring their experiential knowledge to the table (Hower et al. 2019).The new reconceptualization model of PU risk (see Figure 14), acknowledges patient risk in the context of empowerment, choice and active decision-making, rather than traditional 'risk avoidance' parameters of patient safety policies. These principles are important in the context of contemporary healthcare, with a growing need to promote systems and risk management grounded in the experiences and involvement of patients in a variety of healthcare issues (Sheridan et al. 2021). Within this model, risk is co-constructed by HCP and patient, which provides a much broader context for risk interpretation to include scientific, personal, social and lifestyle considerations to patient safety. Co-production in healthcare has been defined as 'the interdependent work of users and professionals to design, create, develop, deliver, assess and improve the relationships and actions that contribute to the health of individuals through partnership that notices participants unique strengths and expertise' (Sheridan et al. 2021, p67). The new model is dynamic as opposed to the more traditional static model currently used in practice, acknowledging that patient preferences, risk perception and personal and social factors may change over time.

It was evident from the study that an open 'participatory' nursing approach and patient involvement in decision-making are key to patient adherence to prevention strategies. This was 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 new model. The importance of carers and family in the PU prevention and decision-making process was instrumental in carrying 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, which demonstrates the complexity and interconnectedness of the phenomenon. The model expands upon established theories and concepts around health beliefs and behaviours detailed in Chapter One, indicated using the key on the bottom left of Figure 14. The left side of the figure represents the nursing findings, with the open ‘participatory’ nursing approach, that is to some degree influenced by the nursing encounter structure and wider healthcare systems and policy. The open ‘participatory’ nursing approach allows for acknowledgement of flexibility for the level of patient involvement. This is a tentative finding in relation to level of patient engagement and is therefore indicated by the dotted line, as nurses themselves were not interviewed as part of the study but were observed to vary in approach. The nursing perspective on risk that is scientific and probablistic in nature, feeds into the centre of the model. However, the distinct difference with this new model is that risk is co-created 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. The study revealed that patient understanding of PU risk did not necessarily secure adherence, due to a range of complex patient factors situated in their daily life. Figure 14 demonstrates the multitude of these patient related factors that may affect situated adherence, and these are represented on the right-hand side. Importantly, within the new model, these patient factors feed into the centre and relate directly to the shared decision-making and concordance 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.

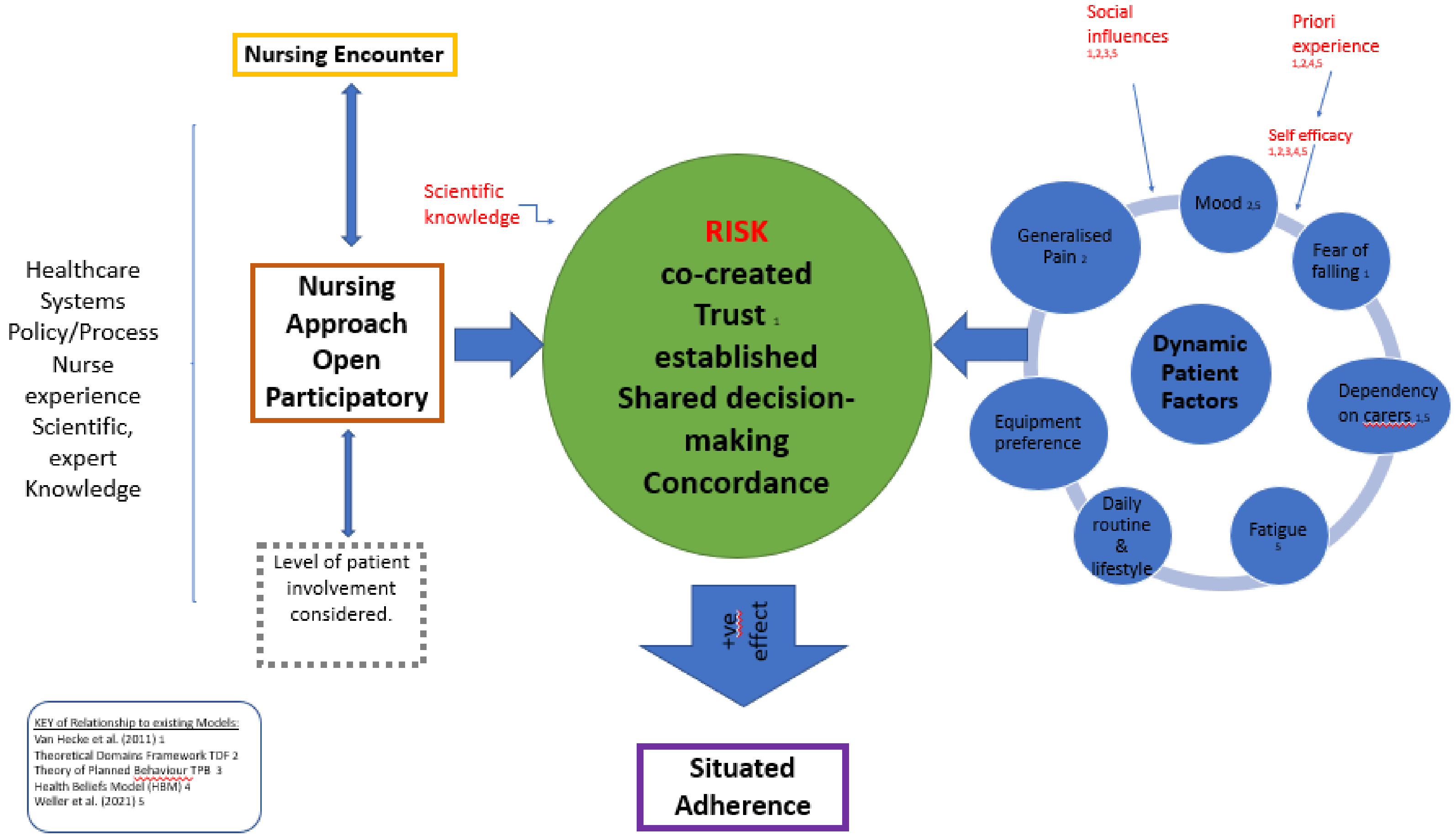

Nursing Encounter
Healthcare Systems Policy/Process Nurse experience Scientific, expert Knowledge
Nursing Approach Open Participatory
Level of patient involvement considered.
Scientific knowledge
RISK
co-created Trust 1
established
Shared decision-making
Concordance
+ve effect
Situated Adherence
Social influences 1,2,3,5
Priori experience 1,2,4,5
Self efficacy 1,2,3,4,5
Generalised Pain 2
Mood 2,5
Fear of falling 1
Dynamic Patient Factors
Dependency on carers 1,5
Equipment preference
Daily routine & lifestyle
Fatigue 5
KEY of Relationship to existing Models:
Van Hecke et al. (2011) 1
Theoretical Domains Framework TDF 2
Theory of Planned Behaviour TPB 3
Health Beliefs Model (HBM) 4
Weller et al. (2021) 5

Figure 14: New emergent Risk Model

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 application to practice. Further research would be required in terms of the implementation and 'tools' within which the model could be grounded in practice. For example, aspects such as changes or additions to the existing clinical paperwork and procedures would need to be considered (Starling et al. 2019). 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 person-centred practice (McCormack et al. 2021). There are also organisational challenges in relation to staff time and busy caseloads that create challenges for HCP to adopt a more open 'participatory' approach within their practice.

I intend to continue the evolution and testing of the model further, alongside clinical colleagues and involvement of patients and carers, as part of further post-doctoral study and development work with the local NHS trust. Some of the scoping work has already commenced with BCHC Trust colleagues and will be outlined next in the recommendations and dissemination section.

6.6 Limitations of the Study

There were some challenges with recruitment of participants to the study. The study relied on busy clinicians agreeing to help and be 'gatekeepers' for suitable patients and this remained a challenge during the recruitment phase. To mitigate this, a longer recruitment time had been built into the study and alongside this, regular contact with the nursing teams and local researcher through attendance at the monthly link nurse network meetings. This allowed momentum for involvement in the study to be sustained whilst supporting and acknowledging the time challenges the nurses faced. However poor recruitment and engagement by some nursing teams remained a challenge. An approach for future consideration to mitigate this would be to engage key stakeholders early on in the process, such as the nursing team managers who could then support nursing staff within their teams to participate.

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, which may have been a sensitive and personal aspect to their care that they may not have felt comfortable being observed. 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. This aspect of the skin inspection may still have potentially affected recruitment of particular cultural group's for participation in the study, where for example, exposure of skin may be culturally sensitive.

The intention of the study was to use a maximum variation sampling strategy sample proposed by Patton (2002) to capture and describe key themes that transcended across a varying group of community dwelling individuals all of whom have the key defining characteristic of being patients living in the community and identified as 'at PU risk'. Although the aim was that up to 20 patients would participate from across a range of different nursing teams in the Trust, only 15 in total took part in the study. Of these, the majority were elderly retired, over 66 years of age and of white ethnic origin. Therefore, a potential limitation to transferability of the results may be that the sample didn't capture a broad ethnicity and age demographic. Consideration was also given to using the nurses themselves to recruit patients for the study and potential selection bias, given they were the service provider. This potential limitation was acknowledged within the research design and balanced alongside the advantages of using nurses to identify and access suitable patients for the study. However, the study did successfully capture a range of patients with the key defining characteristic of being known to the district nursing team as 'at PU risk' and living in the community. In this sense, the results may be considered as generalisable to other settings and patient groups with similar clinical presentations and PU risk status.

Only three patients were successfully recruited for a further follow-up interview, and this was due to a range of factors including ill health, other time commitments and undisclosed reasons. The Covid pandemic also occurred from March 2020 which rendered any further follow up second interviews unviable. However, as all patients had already been interviewed once, the absence of a further interview didn't detract from the overall findings or answering the research question(s). Equally due to the depth and extent of the data already captured through the different data sets, including observation data, PU leaflet document and interviews, there was sufficient rich and meaningful data encapsulated within the study alongside the three follow-up visits that did occur.

Researcher positionality and reflexivity was considered throughout and the potential effect of ‘myself’ on the research process from beginning to end. A reflective log was used to challenge thoughts and develop analysis and discussed with the supervisory team to test assumptions and remain reflexive. A potential limitation within the interviews may have been my positionality as white, middleclass female and whether this affected rapport and the level of disclosure by some patients. This was evident with some of the older ‘male’ participants (Dan, Colin, Dave, Eric) where the interviews were quite brief and responses shorter than other participants and they didn’t really open up as much as other participants had. However, the information that they did choose to relay was still valuable to the study and was broadly in line with what others had said. Observation bias and myself being present at the nursing visit(s) as researcher/observer may also have resulted in patients responding differently. Whilst attempts were made to minimise this by the nurse reassuring the positionality of myself as researcher and consideration of where I was placed within the encounter, it is possible my presence may have affected participant interactions and responses. This could also be the case with the nurses themselves and whether my presence affected their interactions with patients.

6.7 Clinical Recommendations & Dissemination

Recommendations

Patient Information. Further consideration is needed in how patient information is provided, both in terms of the language used and the modality. This study has shown that a patient information leaflet may not be used by patient(s) due to a number of reasons including health literacy and visual/ cognitive problems. Further research therefore is needed to understand what may work best for different patient groups related to PU knowledge. Some insights from this study are around the importance of discussing advice in an open and collaborative way with patients, rather than depending on use of a patient information leaflet in isolation.

Clinical Documentation. Patient information and knowledge translation alone may not result in patient adherence to advice and recommendations. There are complex and individualised patient factors that may affect realistically whether advice is followed and these patient centred, individual factors are not explicit within the nursing PU care documents and process. The existing documents and nursing focus are around PU risk assessment and prevention measures. Healthcare practitioners working with patients in community settings around PU prevention need to consider how other important patient factors such as low mood, fatigue, daily routine and lifestyle preferences can be better acknowledged and embedded within the paperwork and routine practice.

Nursing Approach. There needs to be 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. Further research is warranted to consider how the foundations of mutuality and citizenship in health care practice can be built and true patient involvement in decision-making in clinical practice.

Dissemination

In terms of dissemination of the research ideas and knowledge translation, several different forums have been used throughout, including the regular link nursing network meetings at the local NHS Trust where the research was conducted and the University of Derby Postgraduate Research Forum in the University where I currently work. The research has received considerable interest and I have been invited to present at national and international platforms, with several successful publications as follows:

- Journal article publication in the International Journal of Nursing Studies (IJNS) (see **Appendix 27**) Reference: Ledger L, Worsley P, Hope J and Schoonhoven L (2020) Patient involvement in pressure ulcer prevention and adherence to prevention strategies: An integrative review. International Journal of Nursing Studies IJNS 101 (2020) 103449. doi.org/10.1016/j.ijnurstu.2019.103449.
- Journal article publication in the Journal of Community Nursing (JCN) (see **Appendix 28**). Reference: Ledger L and Morris L (2021) Pressure ulcer prevention and use of patient information leaflets. Journal of Community Nursing 35 (5): 42 -46.
- The European Pressure Ulcer Advisory Panel (EPUAP) verbal presentation in October 2021 **(see Appendix 21)**
- The Tissue Viability Society Conference (TVS) verbal presentation in September 2021 **(see Appendix 22)**
- The European Pressure Ulcer Advisory Panel (EPUAP) International Conference in Rome, September 2018 (see **Appendix 23**: Rome Poster)
- The National Tissue Viability Society (TVS) Conference in Southampton in May 2019 (see **Appendix 24**).

- A national multidisciplinary Pressure Ulcer Prevention Conference in Derby in November 2019 (see **Appendix 25**). I also designed, organised and led the conference, with over 200 delegates in attendance.
- The European Wound Management Conference (EWMA) in November 2020 (see **Appendix 26**).
- Expert Allied Health Professional member of the National Wound Care Strategy Programme (NWCSP). As a result of national interest in the research project I was approached to be part of the NHSi national group that are currently working on the standards and guidance around pressure ulcer(s) and wound care.
- Developed a Massive Open Online Course (MOOC) as a result of the research project and findings focused on educating and raising awareness of PU prevention to a wider audience of patient(s) carer(s) and others. At the time of submission, 3,000+ learners have accessed the platform 70% from the U.K. with 30% from an international audience. 90% of delegates reported the course has improved knowledge and changed practice.

It was important to be able to successfully publish in both scientific and clinical practice journals, in order to disseminate and reach different audiences. The Journal of Community Nursing is read by nurse practitioners in many different clinical areas including community district nursing, which has resulted in considerable interest from practice colleagues in relation to the research findings. I have also been invited to present at several conferences in 2022, including at the University of Derby Research Conference and the International Conference in Public Health Nursing.

Ongoing work with Community NHS Trust

I am continuing to work with Birmingham Community NHS Trust in which the research was conducted around key dissemination of the results into practice. To date, this has included leading a workshop in the Trust, alongside key link district nursing team leads and the Deputy Director of Nursing, to consider dissemination of the key findings into clinical practice (see **Appendix 29**). This has included a trust wide review of the timing of visit/s, nursing approach used and changes to the patient information leaflet. The key results around patient involvement have also been included into trust wide patient safety guidelines, with further workshops planned for next year. The key results of the study have also been shared within the local BCHC Trust newsletter to a wider audience (see **Appendix 30**).

Research Bid with University of Leeds

As a result of this PhD study and findings around PU risk and prevention, I have been invited to be co-applicant as part of a large scale NIHR research project with Dr Suzanne Coleman and other professors at the University of Leeds. The project is due to start next year, with a focus around PU prevention and self-management of people living with long-term conditions in the community.

6.8 Conclusion

The exploratory research findings were translated into a new conceptual risk model of PU prevention for the community setting. This model places the patient perspective alongside the nursing perspective in partnership, with an open, participatory nursing approach used to support shared decision-making. Critically, it accommodates the dynamic nature of the patient's physical, social and emotional state, which affects their ability to acquire and understand PU knowledge and adhere. 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 pressure ulcers. The study has addressed this gap in the research base around patient understanding of PU risk, in a basic physiological sense but also more broadly with personal, social and emotional aspects to risk. Importantly, knowledge translation alone doesn't ensure adherence due to other patient related factors evident from the study such as pain, fatigue, low mood, fear of falling and daily routine and lifestyle preferences. The nursing approach is the conduit within which patient participation and mutuality of shared decision-making can be navigated.

Appendices

1 Interview Schedule

2 Patient Involvement Questionnaire

3 Observation Guide

4 Background Data Sheet

5 Reflective Log Extract (Ann)

6 Reflective Log Extract (Dan/Colin)

7 Covid Impact Statement

8 Follow-up Interview Schedule

9 Participant Information Sheet (Nurse)

10 Participant Consent Form (Nurse)

11 Participant Information Sheet (Patient)

12 Participant Consent Form (Patient)

13 HRA Ethical Approval

14 RA3 Lone Working Form

15 Mind mapping Visual Extract

16 Initial Coding of Interview

17 Initial coding of Observation transcription

18 Initial Coding of Patient Information Leaflet

19 Example of Visual Thematic Mapping

20 Extract of Thematic memoing

21 EPUAP Conference Presentation 2021

22 TVS Conference Presentation 2021

23 Rome Conference Poster

24 TVS Conference 2019

25 Derby Conference 2019

26 EWMA Conference 2020

27 IJNS Journal Article Publication

28 JCN Journal Publication 2021

29 BCHC Trust workshop 2021

30 BCHC Trust Newsletter

Appendix 1 Interview Schedule

Interview Schedule

Version 01 / 30June2018

Participant research number:

Date and Time:

Researcher name and signature:

Introduction

[“Thank you for taking the time to undertake this interview”]

[“This interview will be recorded for research purposes” ‘however anonymity maintained”]

(“Purpose of the research, any questions before we start?)

Topic guide

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?

Appendix 2 Patient Involvement Questionnaire

Background:

I am going to be undertaking a research study as part of a PhD degree within the Trust. I am an Occupational Therapist and the majority of my clinical background has involved working with Nurses, T.V. Leads and Therapists who are working with patients managing their conditions within their own homes. The aim of the research is *to* find out what people think about their risk of getting pressure ulcers and what factors may influence them following the advice they are given by the Healthcare Professional within their own home. This research may create new understanding into patient involvement in pressure ulcer prevention and contribute to further developments to improve clinical practice. The research will involve me visiting and interviewing patients in their own homes, the initial visit will include an observation of them talking to a nurse, as part of a routine visit.

Before the research commences and as part of the study design, it is important to gather some initial patient/participation feedback to help inform the research design. I would therefore really appreciate your help with gathering some patient thoughts about the research process before the research commences.

Therefore, please could you ask them the following and make notes of responses below:

1) ***The research study will involve interviewing patients in their own homes and also observing a conversation with a nursing professional. This is likely to last between 30 to 90 minutes. Do you feel that this is practical and people would be comfortable with this?***

2) ***The interview with myself as researcher and the patient themselves will involve a series of informal questions such as:***

- *What are your thoughts or concerns following the nursing visit?*
- *How do you feel your thoughts, ideas and concerns were addressed at the time of the visit?*
- *How involved do you feel you are in the decision-making?*

3) ***Do you feel these questions are appropriate and would be comfortable to answer? Any suggestions for changes in wording?***

4) ***How best do you think that patient view can be considered in the research?***

5) ***How do you think patients could best be informed about the results of the research and any further information?***

Thank you very much for taking the time to ask patients their views and completing this brief questionnaire. Please do contact me: Lisa Ledger on Email: ll1d15@soton.ac.uk should you need to discuss further.

Please use the back of this sheet to include any other information.

PLEASE RETURN FORM TO Louise Morris, Prevention of Harms Practitioner (Pressure Ulcers), Tissue Viability Dept. Birmingham Community NHS Foundation Trust.

Appendix 3 Observation Guide

Observation Guide

Version Number 01 / 30June2018 *Participant research number:*

Date and Time: *Researcher name and signature:*

Time/s: ***Record timeline***	***Who:*** ***Who is instigating:***	***How:*** ***Directive/Instructed*** ***Collaborative/Demo***	***What:*** ***Training/Telling/ Asking/Sharing/ Watching/Clarify/Vicarious***	***Where:*** ***Location/ Context/***

Appendix 4

Background Data Sheet (Version 01/ 30June18)

Participant research number: *Date and time:*

Socio-economic data

Age range (please circle): 18 to 29years 30 to 65years 66 years or above

Post code (first 4 characters only):

Occupation:

Ethnicity:

Gender:

Physical Status

Primary Medical Condition/s:

Mobile:

Wheelchair user:

Transfers:

Social Situation

Type of property:

House/Bungalow/Flat/Other:

Rented/owned/other:

Lives alone/Family/Other:

Care Situation

Partner/primary carer/paid carer/s/no care input:

Frequency and type of care input:

Environment

Primary room/s utilised:

Environmental restrictions:

Primary equipment used:

Roles and Daily routine

Primary roles:

Hobbies:

Appendix 5 Reflective Log Extract

ANN – June. OBSERVATIONS. I was aware of my presence throughout and how this may have affected the nurse-patient interactions, which I tried to minimise through remaining silent throughout and sitting behind the nurse whilst the routine visit was conducted. However, despite this, there were times during the visit, where Ann tried to engage myself within the conversation and checking if I was ok and needed a drink etc. The nurse steered Ann back to the nursing encounter itself and reminded Ann that it was ok to ignore me as 'observer'. During the observation, I did feel a tension at times between myself as therapist and as researcher. For example, where Ann was describing positioning elements of care, as a therapist I would provide advice about this but I know this isn't my place to do this as researcher. I will discuss and share this tension with my supervisors as would expect this is usual to experience this. I wonder too whether in terms of my positionality that I am a HCP myself I am between an 'insider' and 'outsider' observer perspective. I am 'outsider' in the sense that I do not work for the healthcare Trust and I am not a nurse, however I am an OT therefore a HCP and therefore some of what I observe I can relate to with my clinical background and experience. I am also conscious of observing a different professions practice, such as nursing, which will have its own 'lens' in terms of professional approach within the context of patient care. I have to be reflexive and mindful of this and how I interpret the observations and data, the effect of myself and my own assumptions within the process, therefore use of these memos are key to reflect on these. For Ann, she was quite tired and in a bit of pain but did want to proceed with the interviews and I reassured should she wish at any point then I would stop the interview. When asked about what she remembered from the D/N visit she struggled to recall a bit a first but when I started questions, seemed to relax and talk more. She didn't seem to quite understand some of the questions around Pressure ulcers and I found myself varying the terms from Pressure Ulcer to Pressure sore or just sore which she understood better. I do wonder from this whether when Ann was agreeing 'nodding' to the nurse questions during the nursing encounter that she did understand all of what was being discussed or, just agreed in order to please the nurse 'professional'. She described how it was very important for her to do at least something for herself in each day, even though it was tiring for her like making her own lunch and that this helped her to move around which was important for her 'skin'. She also said she does what the nurse 'tell her to do' in terms of advice. There may be cultural reasons for this view of 'professional is right' as Ann talked quite a lot about the importance of religion in her life and being 'blessed' by having the nurse visit her and she appeared keen to please the nurse and follow the advice as she was grateful for it. It may be as a result of Ann's view of the nurse as professional and wanting to please, this may have affected disclosure to myself in the interview.

Appendix 6 Reflective Log Extract

Dan post interview Reflections – Visited later afternoon for the visit, Dan seemed pleased to be part of the interview process and warmly welcoming, clearly pleased for company as made remarks about living alone and not really seeing anyone. Went through consent again to check and reminder regarding purpose of today's interview, however Dan appeared quite tired and yawning throughout, needed lots of encouragement to be forthcoming with how things were. On reflection, not sure whether the afternoon visit timing may have affected Dan being more forthcoming with information about how things were as he did appear to struggle to keep focused. Also, not sure whether my presence as younger female may have had on his disclosure as he is elderly male. Dan frequently referred to me as 'young girl' during the interview and made references to his time in the Navy and his career many years ago and how important that employment was to him as a man. I need to remain reflexive and consider this in relation to data analysis part of the research process the effect of myself and my own positionality.

Appendix 7 Covid Impact Statement

COVID 19 Statement:

Lisa Ledger student no: 02164213

This statement will outline the impact of COVID 19 on the submitted thesis. The impacts include both limitations on data collection for the thesis and challenges to community nursing time as a result of the pandemic in care delivery, as follows:

The COVID 19 Pandemic affected access to NHS settings around March 2020, with access restricted for non-essential clinical activity, such as research. There were also restrictions placed on district nursing time, with any non-essential clinical activity ceased. Due to the ongoing situation with the impact of the COVID 19 pandemic, completion of some of the follow up research interviews on patients were restricted in the NHS community setting. The majority of research data had already successfully been collected at that point, with some remaining follow-up interviews left to do. A total of three follow-up interviews had occurred prior to March and contributed to the rich data already collected for the study.

There have also been continued impacts through 2020 as a result of the need to home school my son during this time and covering for staff absence due to some colleagues being called back into clinical practice. I have mitigated against these by flexibly working, including weekends to enable me to complete my PhD.

Appendix 8 Follow-up Interview Schedule

Follow-up Interview Schedule

Version 01 / 30June2018

Participant research number:

Date and Time:

Researcher name and signature:

Introduction

[“Thank you for taking the time to undertake this interview”]

[“This interview will be recorded for research purposes” ‘however anonymity maintained”]

(“Purpose of the research, any questions before we start?)

Topic guide

1. Can you tell us a bit about how things have gone since the last time we met?

2. What are your thoughts or concerns since the last time we spoke?

3. Do you feel your thoughts, ideas and concerns are being addressed in relation to you keeping healthy and looking after your skin?

4. How involved do you feel you are in the decisions being made regarding your skin care?
5. What do you feel you learnt about your risk of developing a pressure ulcer (if anything)?
6. In what way – if any - have you acted on the advice and recommendations made?
7. How realistic do you think the advice you have been given is?
8. What do you feel may get in the way of you (or others) being able to carry out the advice given by the District Nurse?
9. What – if anything - do you feel may help to overcome these, make it easier to follow the advice given?
10. Do you have any thoughts on what could improve these?
11. Is there anything else you would like to mention before we finish?

Appendix 9 Participant Information Sheet (Nurse)

Study Title: *Patient perceptions of pressure ulcer risk and potential factors affecting adherence to prevention strategies in the community*

Researcher: *Lisa Ledger*

Co-Investigators: *Prof Lisette Schoonhoven, Dr Peter Worsley, Dr Jo Hope*

UoS Ethics reference ERGO: 41350

Ethics reference IRAS: 248039

Version 01 / 30June18

Please read this information carefully before deciding to take part in the research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

The research aims to find out what people think about their risk of getting pressure ulcers and what things may affect advice being followed to prevent ulcers within their own home. This may create new understanding into patient involvement in pressure ulcer prevention and contribute to further developments to improve clinical practice. This research is being undertaken as part of a PhD degree. The researcher is an Occupational Therapist and doctoral student with an interest in pressure ulcer prevention.

Why have I been asked to participate?

You have been contacted as you are part of the district nursing team in Birmingham Community NHS Trust and you have indicated in a recent meeting that you would be willing to contribute and be part of further research around pressure ulcer prevention.

What should I do if I wish to take part?

Should you wish to take part, please email me ll1d15@soton.ac.uk *and I will arrange to come and see you and go through the consent process and the study in more detail.*

What will happen to me if I take part?

If you are willing to take part in the study you have the opportunity to ask further questions about the study and complete a consent form. You will be asked to consider helping to identify and recruit suitable participants for involvement in the study, which will include gaining their consent. An observation visit will then be organised where the researcher will observe a discussion between yourself and the patient within the home setting. You and the patient will be observed and a dictaphone will be used to record what is said and the researcher will also take notes. This may take between 30 to 60 minutes in total. You will also complete a basic background patient information sheet that will take up to 10 minutes to complete.

Are there any benefits in my taking part?

There is no direct benefit in taking part in the research. However participant responses may indirectly influence the future development of interventions to improve practice.

Are there any risks involved?

There are no direct risks involved however some participants may find recalling experiences difficult. This will be carefully monitored at all times and if any distress does arise, the session will be brought to a close.

Will my participation be confidential?

Yes. Confidentiality and anonymity will be maintained through compliance with the University of Southampton Data Protection Guidelines and Processes. All data collected will be stored securely and kept in a locked cabinet and separated from personal contact details at all times. All digital data collected such as audio recordings will be password protected and held on a password protected computer. All information will be treated in the strictest confidence and data will be stored for up to 10 years from study completion.

The findings of the study will be written up, published and presented without any personal identifying information. There are, however specific circumstances whereby a patient that is involved in the study may disclose something that the researcher would have a duty to share with *yourself, the nursing team or other agency and this would be made clear to you at the start of the process.*

What happens if I change my mind?

All participants have the right to withdraw at any point in the process.

What happens to the results of the research?

The results of the research will be written up and published. All information will be treated in the strictest confidence and data will be stored for up to 10 years from study completion.

The results will also be shared with the NHS Trust for dissemination in the local clinical teams and patient involvement forums and newsletters.

Where can I get more information?

Further information can be obtained from:

Lisa Ledger, PhD student, Faculty of Health Science, University of Southampton. SO17 1BJ.

Email: ll1d15@soton.ac.uk

Louise Morris, Local Research Collaborator, Prevention of Harms Practitioner.

Email: louise.morris@bhamcommunity.nhs.uk

What happens if something goes wrong?

Should there be any concern about the conduct of the research, participants can contact the Research Integrity and Governance Team at the University of Southampton:

Research Integrity and Governance Team email: researchintegrity@soton.ac.uk

Research Integrity and Governance Team telephone: 02380 595058

The University of Southampton has insurance in place to cover its legal liabilities in respect of this study.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University’s policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer (data.protection@soton.ac.uk).

Thank you

Appendix 10 Participant Consent Form (Nurse)

UNIVERSITY OF Southampton

Study title: Patient perceptions of pressure ulcer risk and potential factors affecting adherence to prevention strategies in the community

Researcher name: Lisa Ledger

Co-investigators: Prof Lisette Schoonhoven, Dr Peter Worsley, Dr Jo Hope

ERGO number: 41350

IRAS Number: 248039

Version 01 30 June 2018

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (30 June 2018, Version 01) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study .	
I understand my participation is voluntary and I may withdraw at any time for any reason without my rights being affected.	

I agree to take part in identifying and recruiting participants for the study	
I agree to take part in completing a basic background patient information sheet	
I agree to take part in the observations as part of the study	
I agree to the use of audio recording devices as part of the study	
I agree to the possible use of anonymised quotation when the study is published	
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of ethically approved research studies	

Name of participant (print name)……………………………………………………………………………

Signature of participant……………………………………………………………………………………….

Date………………………………………………………………………………………. …………………..

Name of researcher (print name)

………………………………………………………………………

Signature of researcher …………………………………………………………………………

Date……

Appendix 11 Participant Information Sheet (Patient)

Study Title: *Patient perceptions of pressure ulcer risk and potential factors affecting adherence to prevention strategies in the community*

Researcher: *Lisa Ledger*

Co-Investigators: *Prof Lisette Schoonhoven, Dr Peter Worsley, Dr Jo Hope*

UoS Ethics reference ERGO: 41350

Ethics reference IRAS: 248039

Version 01 30th June 2018

Please read this information carefully before deciding whether to take part in the research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

The research aims to find out what people think about their risk of getting pressure ulcers (commonly termed bed sores/pressure sore) and what might make it difficult to put advice into practice to prevent sores. This could help people get more involved in decisions about their care and how they are supported in the future. This research is being undertaken as part of a PhD degree. The researcher is an Occupational Therapist and doctoral student with an interest in pressure ulcer prevention.

Why have I been asked to participate?

You have been contacted as you have indicated to the nursing team that you may be interested and willing to be talk to me about pressure ulcer prevention.

What should I do if I wish to take part?

Should you wish to take part, you may contact the Nurse who provided the information by the usual telephone contact or when they visit next and say that you would like to be involved.

What will happen to me if I take part?

If you are willing to take part in the study you will be asked to complete a consent form. An observation will then be organised where the researcher will observe a discussion between yourself and the district nurse within your home setting. A dictaphone will be used to record what is said and the researcher will also take notes. This may take between 30 to 60 minutes in total. You will be also invited to be part of follow- up interviews (up to a maximum of 2 interviews) where you will be asked to talk about the district nurse's visit and your pressure care and routine. Each follow up interview may take between 30 to 90 minutes in total. Topics are likely to include your involvement in pressure sore prevention, understanding of information and use of preventative equipment such as cushions and mattresses, advice and techniques.

Are there any benefits in my taking part?

There is no direct benefit in taking part in the research. However, your answers may help us improve how people are supported in the future.

Are there any risks involved?

There are no direct risks involved however some people may find it difficult to talk about their experiences. This will be carefully monitored at all times and if any distress does arise, the interview will be paused and participants given a choice about whether they wish to continue, have a break or stop the interview.

Will my participation be confidential?

Yes. Your personal details and information will be stored securely, in accordance with the Data Protection Act and University of Southampton Data Protection Policy and your real name will not *be used or any information that would allow someone to identify you. All information will be treated in the strictest confidence and data will be stored for up to 10 years from study completion.*

The findings of the study will be written up, published and presented without any personal identifying information. There are, however, specific circumstances where you may disclose something that the researcher would have a duty to share with the nurse or other agency and this would be made clear to you at the start of the process.

What happens if I change my mind?

At any point, you can decide not to take part, to finish the interview/s at any point, or decide not to take part in any further interviews. Also, you will be asked at that point if you wish for any information you have provided to also be withdrawn at that point. Should you not wish for any data to be used, it will be confidentially destroyed.

What happens to the results of the research?

The results of the research will be written up and published. All information will be treated in the strictest confidence and data will be stored for up to 10 years from study completion.

The results will also be shared with the NHS Trust for dissemination in the local clinical teams and patient involvement forums and newsletters.

Where can I get more information?

Further information can be obtained from either the nurse who has provided the information sheet or:

Lisa Ledger, Researcher and PhD student, Faculty of Health Science, University of Southampton. SO17 1BJ. Email: ll1d15@soton.ac.uk

Louise Morris, Local Research Collaborator, Prevention of Harms Practitioner.

Email: louise.morris@bhamcommunity.nhs.uk

What happens if something goes wrong?

Should there be any concern about the conduct of the research, participants can contact the Research Integrity and Governance Team at the University of Southampton:

Research Integrity and Governance Team email: researchintegrity@soton.ac.uk

Research Integrity and Governance Team telephone: 02380 595058

The University of Southampton has insurance in place to cover its legal liabilities in respect of this study.

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page). This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it. Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed. To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect. If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet.

Appendix 12 Participant Consent Form (Patient)

CONSENT FORM (Patient)

Study title: Patient perceptions of pressure ulcer risk and potential factors affecting adherence to prevention strategies in the community

Researcher name: Lisa Ledger

Co-investigators: Prof Lisette Schoonhoven, Dr Peter Worsley, Dr Jo Hope

ERGO number: 41350

IRAS Number: 248039

Version 01 / 30 June 2018

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (30 June 2018, Version 01) and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study .	

I understand my participation is voluntary and I may withdraw at any time for any reason without my medical care or rights being affected.	
I agree to take part in the observations as part of the study	
I agree to take part in the interviews as part of the study	
I agree to take part in the follow-up interviews as part of the study	
I agree to the use of audio recording devices as part of the study	
I agree to the possible use of anonymised quotation when the study is published	
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of ethically approved research studies	

Name of participant (print name)…………………………………………………………………………

Signature of participant……………………………………………………………………………………

Date…………………………………………………………………………………….. …………………..

Name and title of person consenting (print name)

…………………………………………………………………

Signature of person consenting ……………………………………………………………………

Date……

Appendix 13: HRA Ethical Approval

From: hra.approval@nhs.net <noreply@harp.org.uk>

To: "ledgerlj@yahoo.co.uk" <ledgerlj@yahoo.co.uk>; "ledgerlj@yahoo.co.uk" <ledgerlj@yahoo.co.uk>; "rgoinfo@soton.ac.uk" <rgoinfo@soton.ac.uk>

Cc: "priti.parmar@bhamcommunity.nhs.uk" <priti.parmar@bhamcommunity.nhs.uk>; "nrescommittee.london-riverside@nhs.net" <nrescommittee.london-riverside@nhs.net>

Sent: Friday, 12 October 2018, 08:06:14 BST

Subject: IRAS Project ID 248039. Outcome of Application for HRA and HCRW Approval

Dear Mrs Ledger

RE: IRAS 248039 Patient Perceptions of Pressure ulcer risk in Community Settings. Outcome of Application for HRA and HCRW Approval

Please find attached a letter informing you of the outcome of your application for HRA and HCRW Approval.

Please also find attached your REC favourable opinion letter and the standard conditions document applicable to this study that have been passed to me by my colleagues in the Research Ethics Service. You may now commence your study at those participating NHS organisations in England and Wales that have confirmed their capacity and capability to undertake their role in your study (where applicable). Detail on what form this confirmation should take, including when it may be assumed, is provided in the HRA and HCRW Approval letter. If you have any queries please do not hesitate to contact me.

Kind regards

Andrea Bell

Health Research Authority

Ground Floor | Skipton House | 80 London Road | London | SE1 6LH

E. hra.approval@nhs.net

Appendix 14: RA3 Lone Working

Health
Sciences

UNIVERSITY OF
Southampton

Research and Enterprise Services Office

RA3 Lone Interviewing Checklist

Management of Health & Safety At Work Regulations 1999 - principles include:

avoiding risks

evaluating risks which cannot be avoided

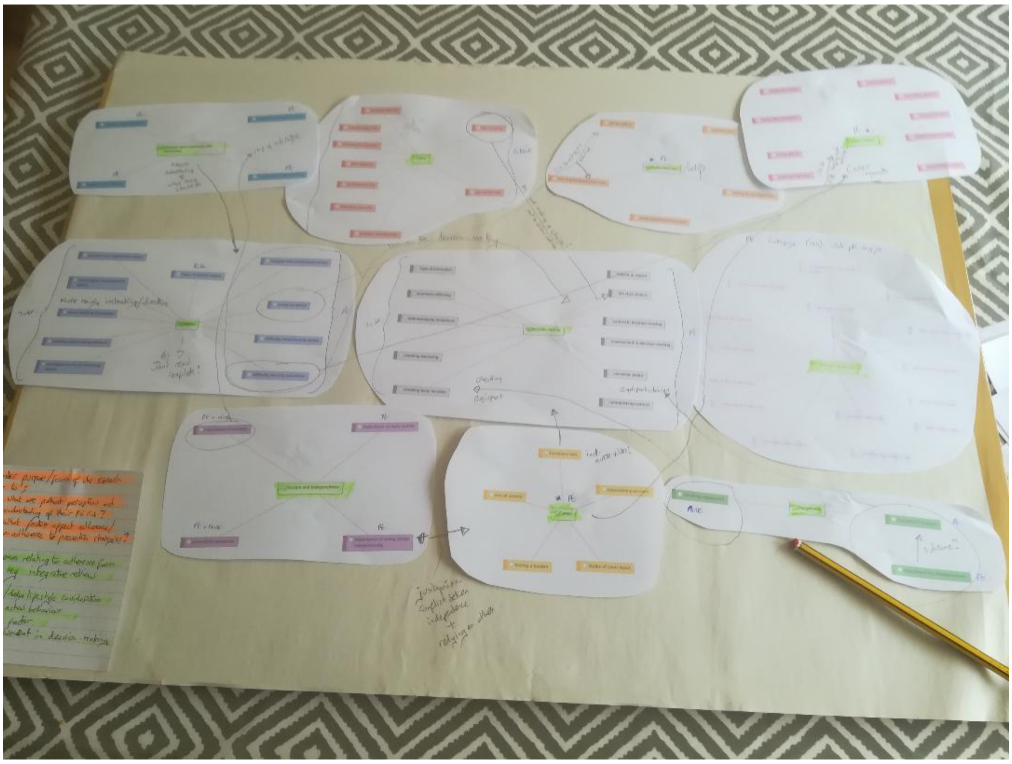
The points below are to be completed by the

researcher(s) with their research team/line manager/principal investigator/supervisor as appropriate.

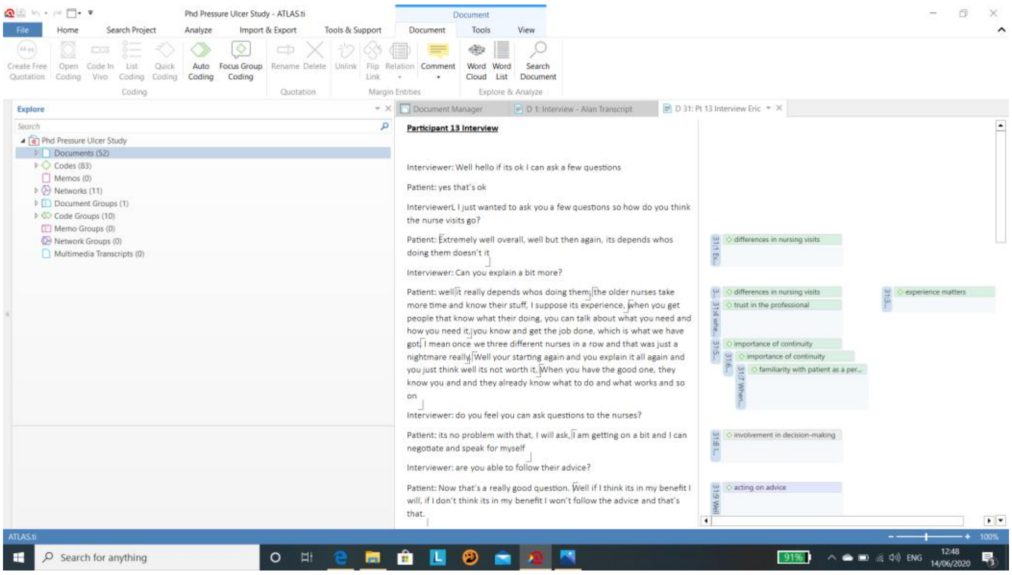
Discussion Point	**Notes & Actions from discussion with:** **Supervisors, Dr Peter Worsley, Dr Jo Hope, Professor Lisette Schoonhoven**	**Da** **Co** **d:** **23** **20**
Research Design:		

Take general risk assessment into account when designing project: Is lone working necessary? Are home interviews necessary? What time of day will interviews take place? Is it possible to complete during daylight? Clarify circumstances in which home visit is necessary (vs. more neutral environment) Could researchers conduct interviews in pairs?	Lone working may occur at the interview and follow-up interview stage. Where possible another 'buddy' will be present at the property from the Clinical Team within the NHS Trust. Where this is not possible, a full buddy system will be in place and adherence to both University of Southampton and Local NHS Trust Lone Working policy. A sealed envelope with contact details and destination will be kept with buddy (link nurse/Local District Nursing team) and if 2 hours have lapsed with no contact made by researcher, buddy will phone researcher, if no response, contact participant too, if no response instigate emergency procedure including police and research supervisor.
Take general risk assessment into account when costing project proposal	
Training:	
Researchers/Research Teams should consider whether any of the following training or other training may be required/appropriate to the research project team members: First aid Equity and Diversity ***Pre Fieldwork Checks:***	The researcher is also a trained healthcare professional and therefore has mandatory training as part of role in relation to equality and diversity, challenging behaviour etc.
Organise team meeting to agree on general level of risk,	The researcher will meet local nursing
Confirm adequate business-use insurance is in place for	Yes, in place.
Confirm professional indemnity insurance for	Will be agreed following university

Appendix 15: Mind Mapping Visual Extract



Appendix 16: Initial Coding of Interview in AtlasTi



Participant 13 Interview

Interviewer: Well hello if its ok I can ask a few questions

Patient: yes that's ok

InterviewerL I just wanted to ask you a few questions so how do you think the nurse visits go?

Patient: Extremely well overall, well but then again, its depends whos doing them doesn't it

Interviewer: Can you explain a bit more?

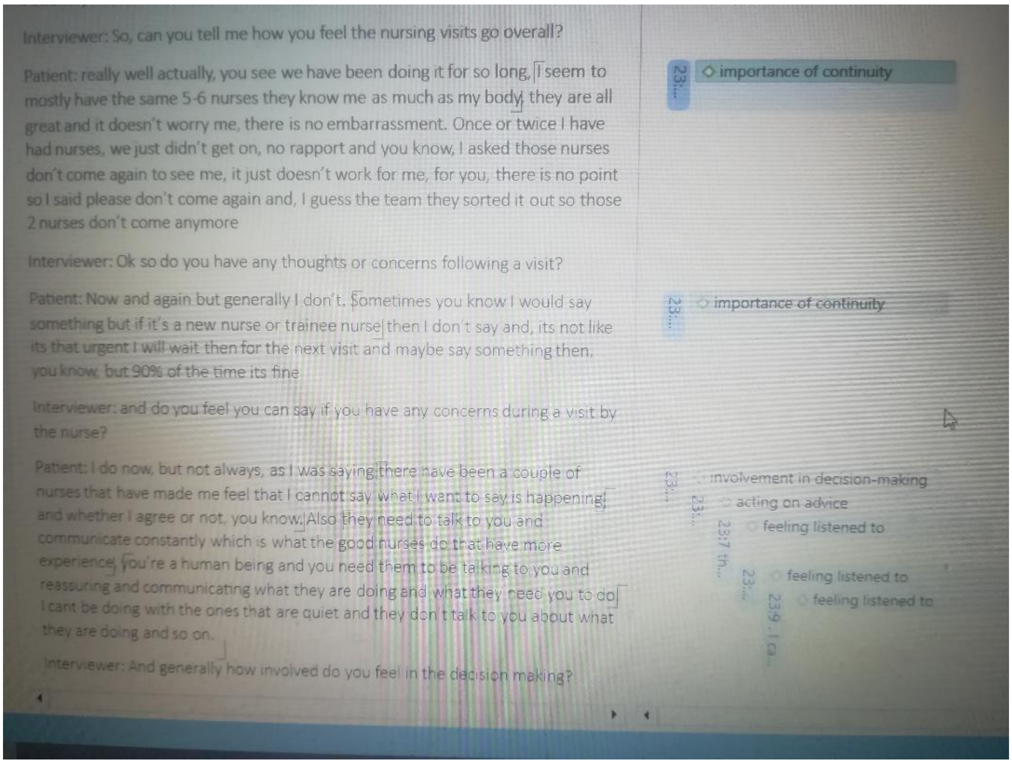
Patient: well it really depends whos doing them, the older nurses take more time and know their stuff, I suppose its experience, when you get people that know what their doing, you can talk about what you need and how you need it, you know and get the job done, which is what we have got, I mean once we three different nurses in a row and that was just a nightmare really, Well your starting again and you explain it all again and you just think well its not worth it, When you have the good one, they know you and and they already know what to do and what works and so on

Interviewer: do you feel you can ask questions to the nurses?

Patient: its no problem with that, I will ask, I am getting on a bit and I can negotiate and speak for myself

Interviewer: are you able to follow their advice?

Patient: Now that's a really good question. Well if I think its in my benefit I will, if I don't think its in my benefit I won't follow the advice and that's that.



Interviewer: So, can you tell me how you feel the nursing visits go overall?

Patient: really well actually, you see we have been doing it for so long, I seem to mostly have the same 5-6 nurses they know me as much as my body, they are all great and it doesn't worry me, there is no embarrassment. Once or twice I have had nurses, we just didn't get on, no rapport and you know, I asked those nurses don't come again to see me, it just doesn't work for me, for you, there is no point so I said please don't come again and, I guess the team they sorted it out so those 2 nurses don't come anymore

Interviewer: Ok so do you have any thoughts or concerns following a visit?

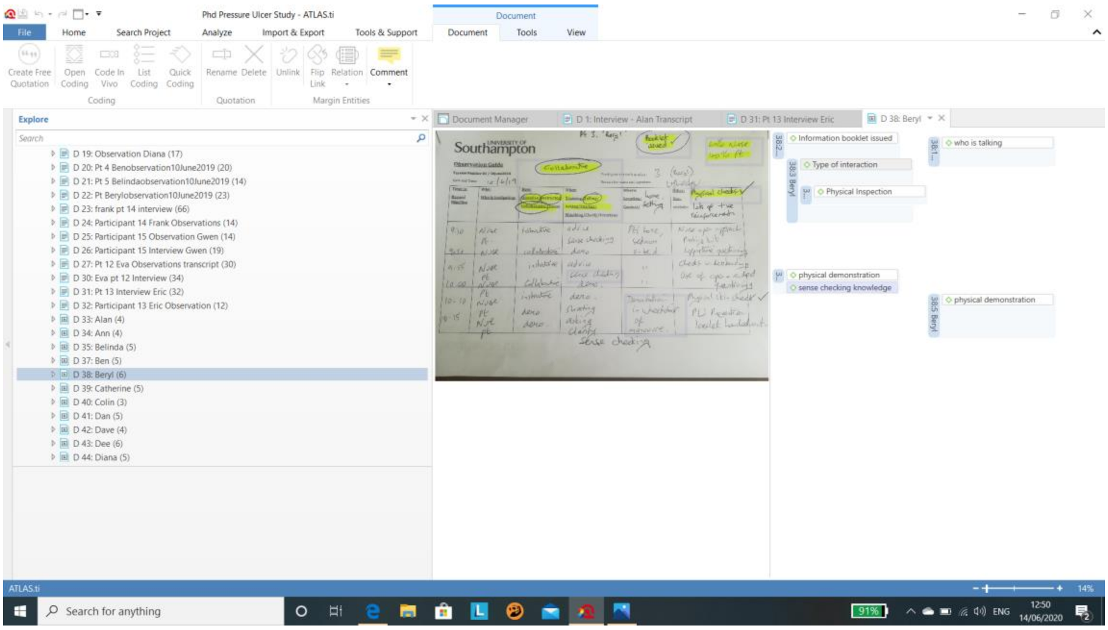
Patient: Now and again but generally I don't. Sometimes you know I would say something but if it's a new nurse or trainee nurse then I don't say and, its not like its that urgent I will wait then for the next visit and maybe say something then, you know, but 90% of the time its fine

Interviewer: and do you feel you can say if you have any concerns during a visit by the nurse?

Patient: I do now, but not always, as I was saying there have been a couple of nurses that have made me feel that I cannot say what I want to say is happening and whether I agree or not, you know. Also they need to talk to you and communicate constantly which is what the good nurses do that have more experience, you're a human being and you need them to be talking to you and reassuring and communicating what they are doing and what they need you to do I cant be doing with the ones that are quiet and they don't talk to you about what they are doing and so on.

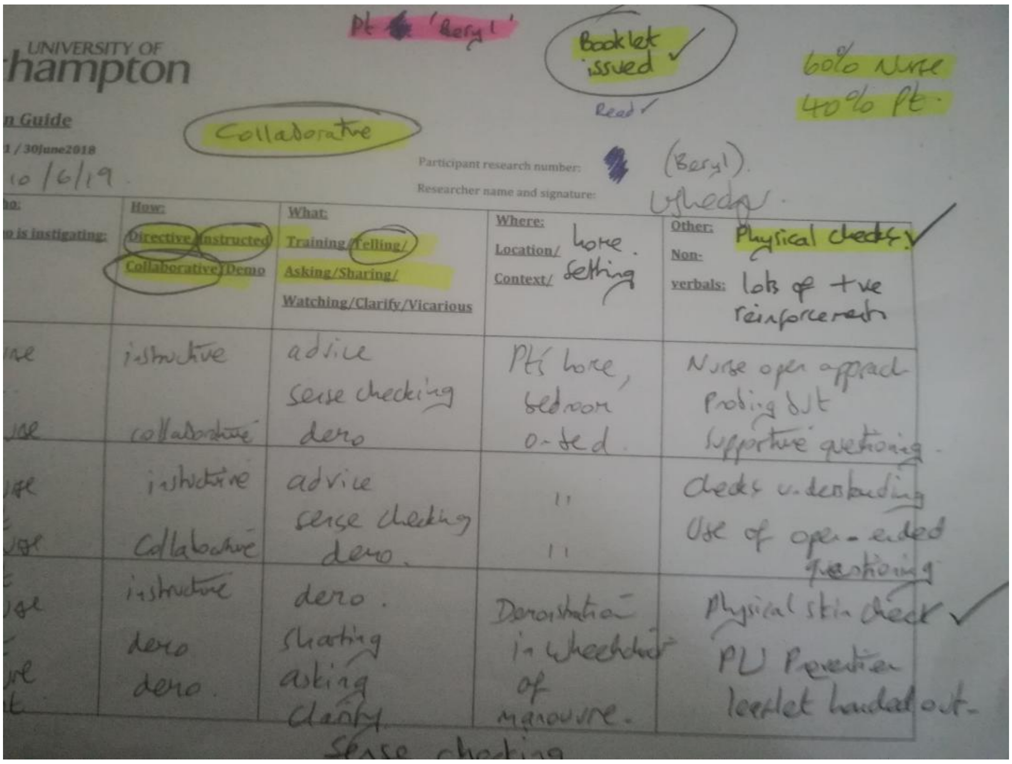
Interviewer: And generally how involved do you feel in the decision making?

Appendix 17: Initial Coding of Observation Transcript



Phd Pressure Ulcer Study - ATLAS.ti

- D 19: Observation Diana (17)
- D 20: Pt 4 Benobservation10June2019 (20)
- D 21: Pt 5 Belindaobservation10June2019 (14)
- D 22: Pt Berylobservation10June2019 (23)
- D 23: frank pt 14 interview (66)
- D 24: Participant 14 Frank Observations (14)
- D 25: Participant 15 Observation Gwen (14)
- D 26: Participant 15 Interview Gwen (19)
- D 27: Pt 12 Eva Observations transcript (30)
- D 30: Eva pt 12 Interview (34)
- D 31: Pt 13 Interview Eric (32)
- D 32: Participant 13 Eric Observation (12)
- D 33: Alan (4)
- D 34: Ann (4)
- D 35: Belinda (5)
- D 37: Ben (5)
- D 38: Beryl (6)
- D 39: Catherine (5)
- D 40: Colin (3)
- D 41: Dan (5)
- D 42: Dave (4)
- D 43: Dee (6)
- D 44: Diana (5)



Pt [redacted] 'Beryl'

UNIVERSITY OF
hampton

n Guide

1 / 30june2018

10/6/19

Collaborative

Booklet issued ✓

Read ✓

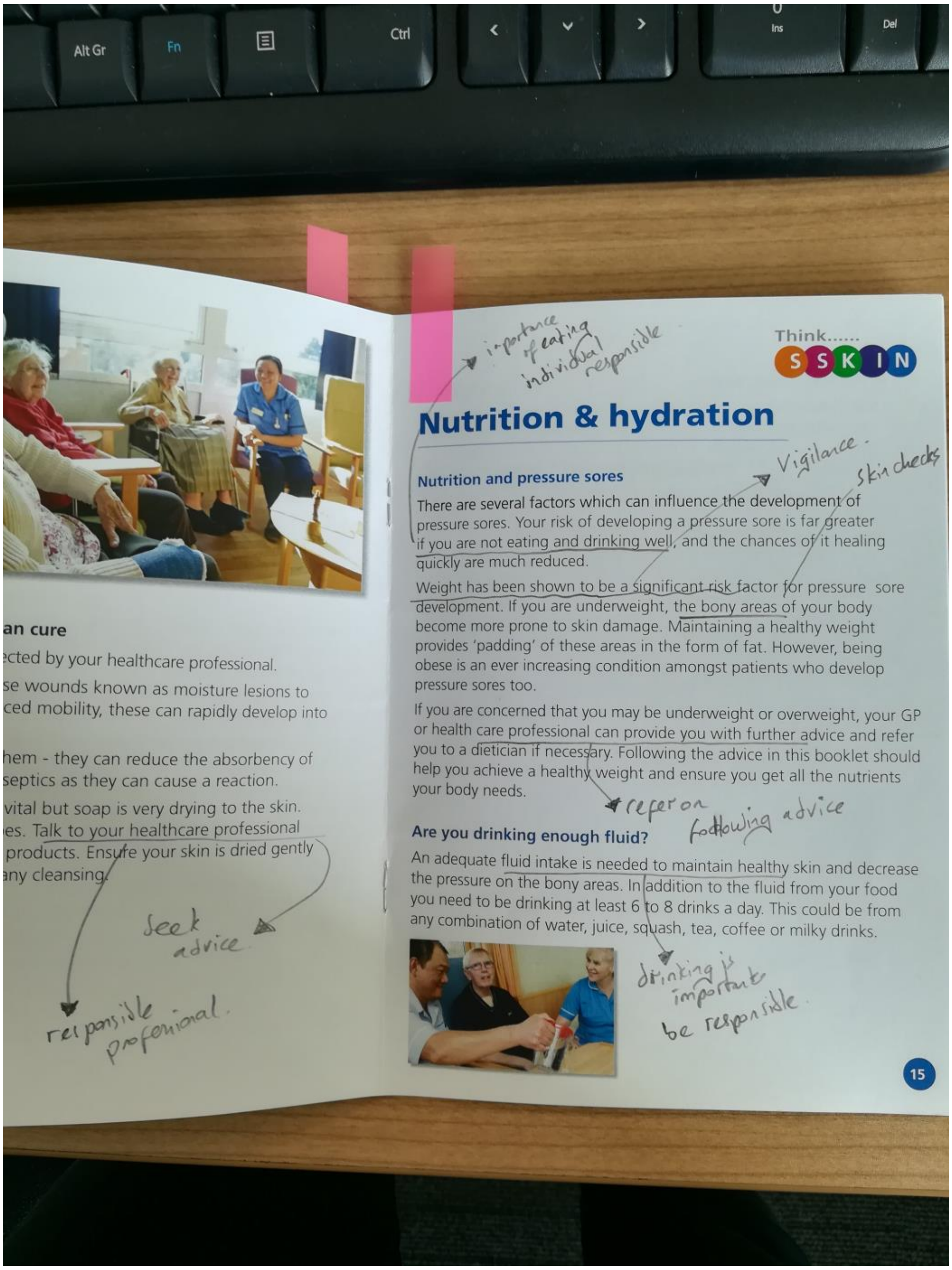
60% Nurse
40% Pt.

Participant research number: [redacted] (Beryl).

Researcher name and signature:

	How:	What:	Where: Location/ Context/	Other: Non-verbals:
ho: o is instigating:	Directive/Instructed Collaborative/Demo	Training/Telling/ Asking/Sharing/ Watching/Clarify/Vicarious	home. setting	Physical checks ✓ lots of +ve reinforcement
	instructive	advice sense checking	Pt's home, bedroom o-bed.	Nurse open approach Probing but supportive questioning.
	collaborative	demo		
	instructive	advice sense checking	"	checks understanding
	Collaborative	demo.	"	Use of open-ended questioning
	instructive demo demo.	demo. sharing asking clarify Sense checking	Demonstration in wheelchair of manouvre.	Physical skin check ✓ PU Prevention leaflet handed out.

Appendix 18: Initial Coding of Patient Information Leaflet



an cure

ected by your healthcare professional.

se wounds known as moisture lesions to
ced mobility, these can rapidly develop into

hem - they can reduce the absorbency of
septics as they can cause a reaction.

vital but soap is very drying to the skin.
es. Talk to your healthcare professional
products. Ensure your skin is dried gently
any cleansing.

Seek advice.

responsible professional.

Think......

SSKIN

importance of eating individual responsible

Nutrition & hydration

Vigilance.

Skin checks

Nutrition and pressure sores

There are several factors which can influence the development of pressure sores. Your risk of developing a pressure sore is far greater if you are not eating and drinking well, and the chances of it healing quickly are much reduced.

Weight has been shown to be a significant risk factor for pressure sore development. If you are underweight, the bony areas of your body become more prone to skin damage. Maintaining a healthy weight provides 'padding' of these areas in the form of fat. However, being obese is an ever increasing condition amongst patients who develop pressure sores too.

If you are concerned that you may be underweight or overweight, your GP or health care professional can provide you with further advice and refer you to a dietician if necessary. Following the advice in this booklet should help you achieve a healthy weight and ensure you get all the nutrients your body needs.

refer on

following advice

Are you drinking enough fluid?

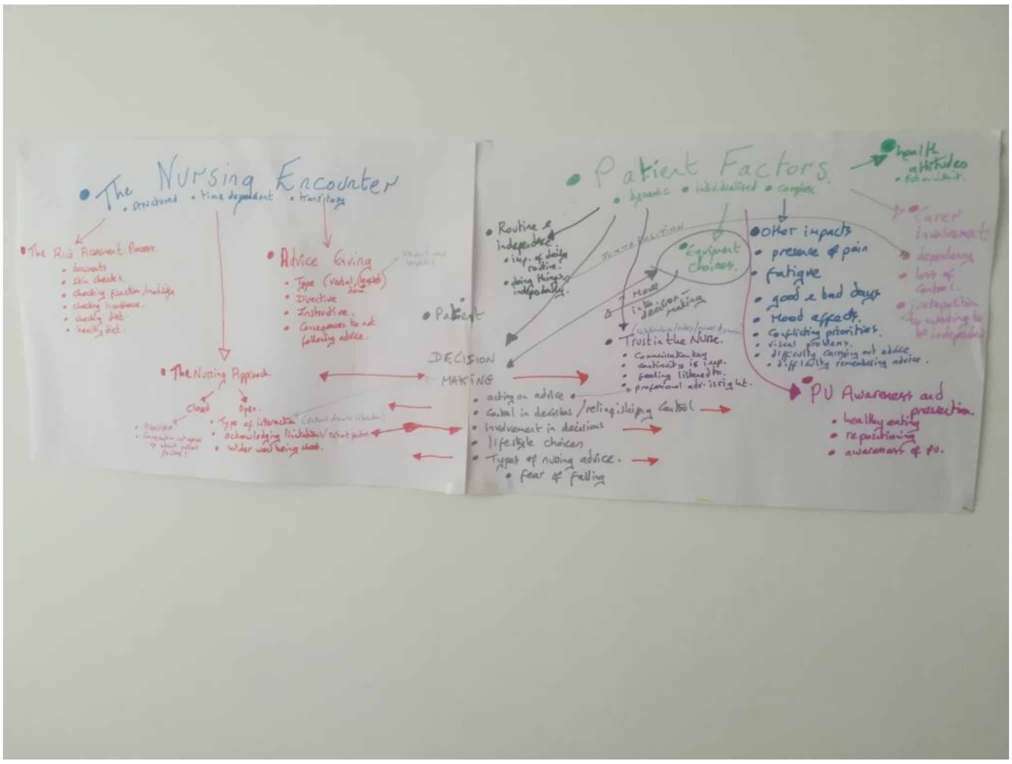
An adequate fluid intake is needed to maintain healthy skin and decrease the pressure on the bony areas. In addition to the fluid from your food you need to be drinking at least 6 to 8 drinks a day. This could be from any combination of water, juice, squash, tea, coffee or milky drinks.

drinking is important

be responsible.

15

Appendix 19: Example of Visual Thematic Mapping



Appendix 20: Extract of Thematic Memoing

19th June - Trust in the Nurse

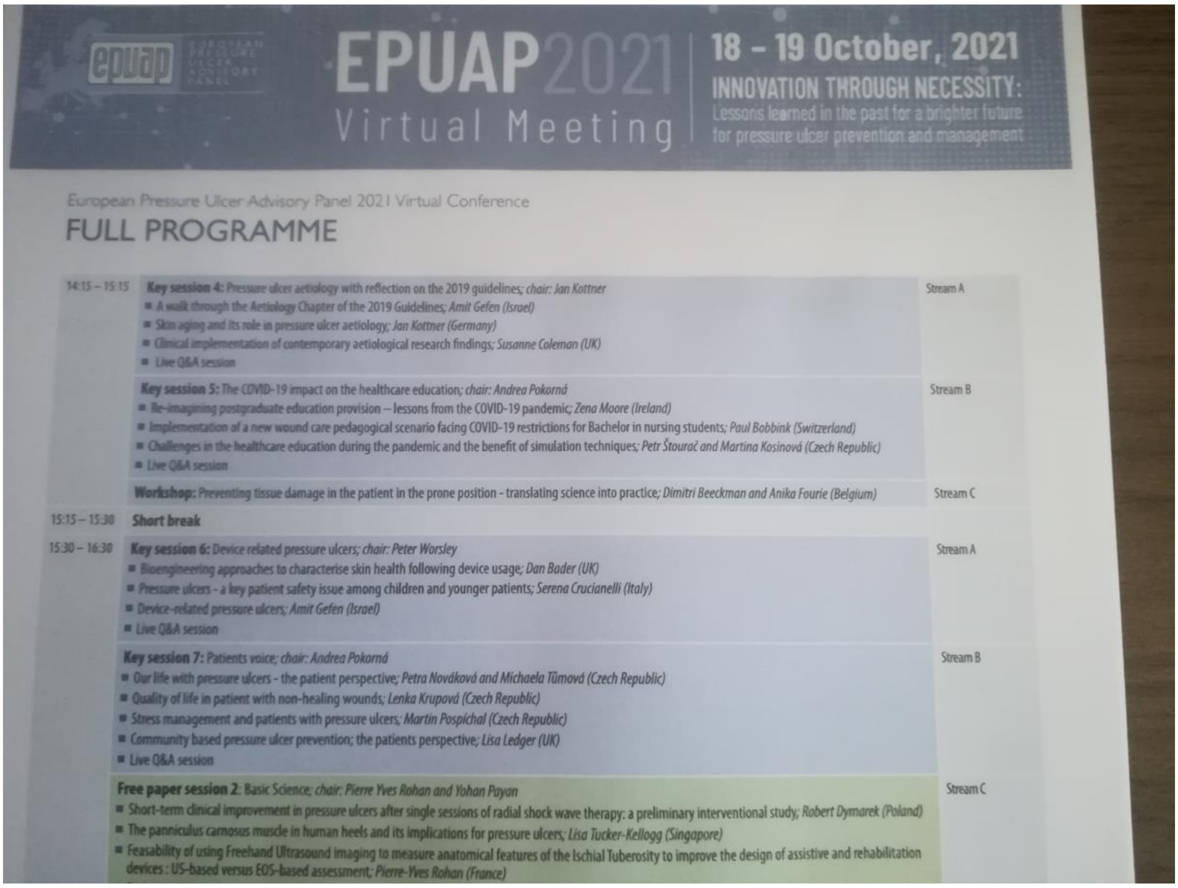
This is a significant code group as the codes begin to describe from the participants perspective the importance of aspects such as continuity and trust with the nurses and how this is developed. There are also some insightful perceptions of how patient participants 'perceive' the nursing role from their experience, for example, that nurses are always busy and have limited time during the visits. There is also a view that the nurse is always right and there is a sense of wanting to do the right thing and follow the advice being given. Trust is linked to 'taking time to care'.

From overall analysis of the key code groups and overview, it can be seen that the nurse is only one factor in the decision-making process of the patient. In that, there are a number of other complex internal and external factors that can influence whether or not the advice is followed. These effect the day-to-day decisions made by the patients themselves and whether they are able or prepared to carry out the advice.

In relation to patient perceptions and understanding of risk, patients can broadly relay what PU risk is and what prevention strategies are such as repositioning and a healthy diet. The patients gain this knowledge from the nurse advice given during the visit/s, however majority do not use the PU leaflet provided during the visits. The understanding of what needs to be done to prevent PUs also doesn't necessarily translate into actual adherence behaviour as it is influenced by a range of other 'situational' factors which are complex and dynamic.

The code group around 'trust in the nurse' is focused on the 'relationships' between nurse and patient, including roles and power imbalances. This occurs in the 'nurse/patient interactions' and how these unfold during the visit and over time.

Appendix 21 EPUAP Presentation 2021



epuap EUROPEAN PRESSURE ULCER ADVISORY PANEL

EPUAP2021
Virtual Meeting

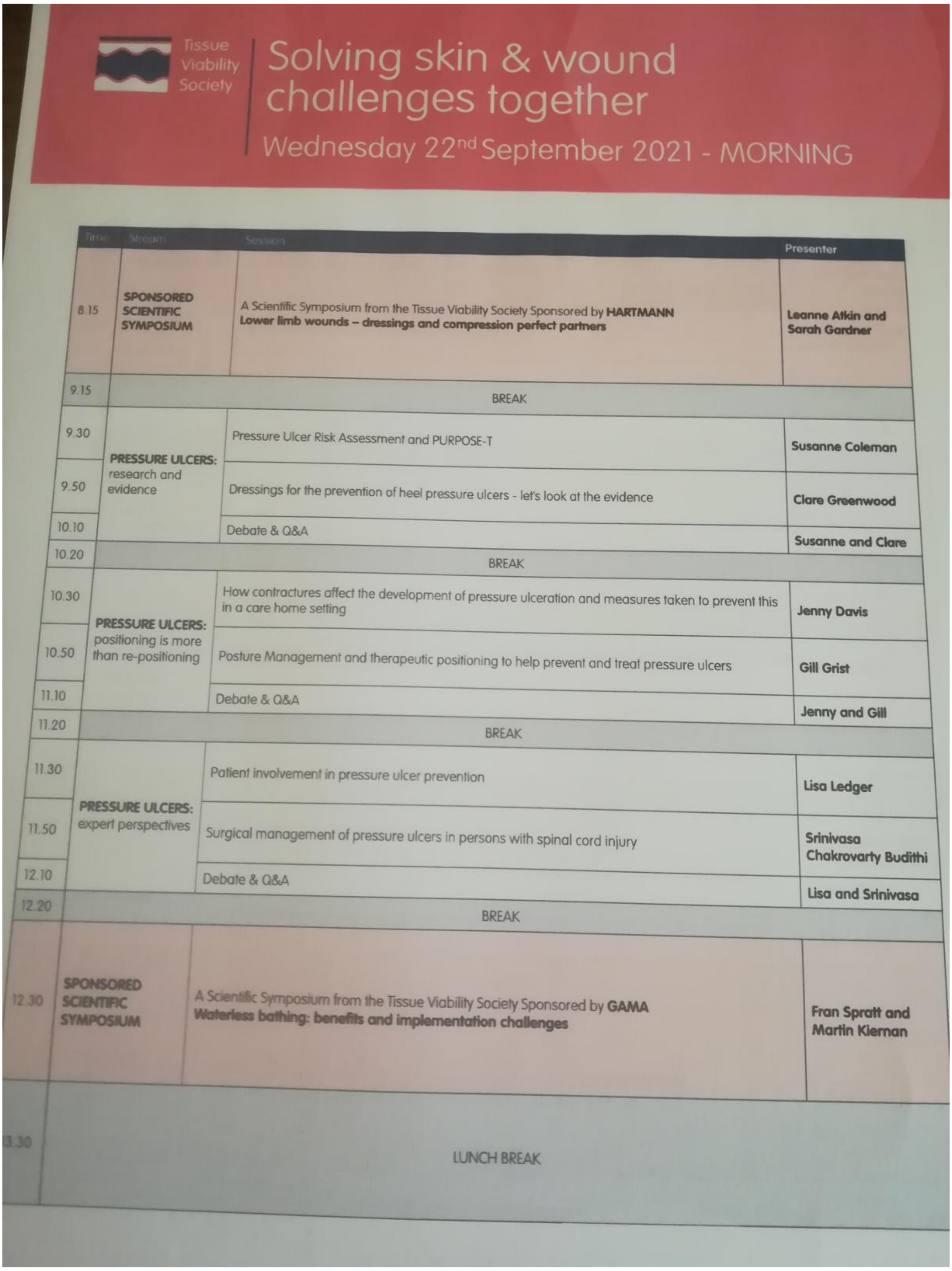
18 – 19 October, 2021
INNOVATION THROUGH NECESSITY:
Lessons learned in the past for a brighter future for pressure ulcer prevention and management

European Pressure Ulcer Advisory Panel 2021 Virtual Conference

FULL PROGRAMME

14:15 – 15:15	**Key session 4:** Pressure ulcer aetiology with reflection on the 2019 guidelines; *chair: Jan Kottner* ■ A walk through the Aetiology Chapter of the 2019 Guidelines; *Amit Gefen (Israel)* ■ Skin aging and its role in pressure ulcer aetiology; *Jan Kottner (Germany)* ■ Clinical implementation of contemporary aetiological research findings; *Susanne Coleman (UK)* ■ Live Q&A session	Stream A
	Key session 5: The COVID-19 impact on the healthcare education; *chair: Andrea Pokorná* ■ Re-imagining postgraduate education provision – lessons from the COVID-19 pandemic; *Zena Moore (Ireland)* ■ Implementation of a new wound care pedagogical scenario facing COVID-19 restrictions for Bachelor in nursing students; *Paul Bobbink (Switzerland)* ■ Challenges in the healthcare education during the pandemic and the benefit of simulation techniques; *Petr Štourač and Martina Kosinová (Czech Republic)* ■ Live Q&A session	Stream B
	Workshop: Preventing tissue damage in the patient in the prone position - translating science into practice; *Dimitri Beeckman and Anika Fourie (Belgium)*	Stream C
15:15 – 15:30	**Short break**	
15:30 – 16:30	**Key session 6:** Device related pressure ulcers; *chair: Peter Worsley* ■ Bioengineering approaches to characterise skin health following device usage; *Dan Bader (UK)* ■ Pressure ulcers - a key patient safety issue among children and younger patients; *Serena Crucianelli (Italy)* ■ Device-related pressure ulcers; *Amit Gefen (Israel)* ■ Live Q&A session	Stream A
	Key session 7: Patients voice; *chair: Andrea Pokorná* ■ Our life with pressure ulcers - the patient perspective; *Petra Nováková and Michaela Tůmová (Czech Republic)* ■ Quality of life in patient with non-healing wounds; *Lenka Krupová (Czech Republic)* ■ Stress management and patients with pressure ulcers; *Martin Pospíchal (Czech Republic)* ■ Community based pressure ulcer prevention; the patients perspective; *Lisa Ledger (UK)* ■ Live Q&A session	Stream B
	Free paper session 2: Basic Science; *chair: Pierre Yves Rohan and Yohan Payan* ■ Short-term clinical improvement in pressure ulcers after single sessions of radial shock wave therapy: a preliminary interventional study; *Robert Dymarek (Poland)* ■ The panniculus carnosus muscle in human heels and its implications for pressure ulcers; *Lisa Tucker-Kellogg (Singapore)* ■ Feasability of using Freehand Ultrasound imaging to measure anatomical features of the Ischial Tuberosity to improve the design of assistive and rehabilitation devices : US-based versus EOS-based assessment; *Pierre-Yves Rohan (France)*	Stream C

Appendix 22 TVS Conference Presentation 2021



Tissue Viability Society

Solving skin & wound challenges together

Wednesday 22nd September 2021 - MORNING

Time	Stream	Session	Presenter
8.15	**SPONSORED SCIENTIFIC SYMPOSIUM**	A Scientific Symposium from the Tissue Viability Society Sponsored by **HARTMANN** **Lower limb wounds – dressings and compression perfect partners**	**Leanne Atkin and Sarah Gardner**
9.15		BREAK	
9.30	**PRESSURE ULCERS:** research and evidence	Pressure Ulcer Risk Assessment and PURPOSE-T	**Susanne Coleman**
9.50		Dressings for the prevention of heel pressure ulcers - let's look at the evidence	**Clare Greenwood**
10.10		Debate & Q&A	**Susanne and Clare**
10.20		BREAK	
10.30	**PRESSURE ULCERS:** positioning is more than re-positioning	How contractures affect the development of pressure ulceration and measures taken to prevent this in a care home setting	**Jenny Davis**
10.50		Posture Management and therapeutic positioning to help prevent and treat pressure ulcers	**Gill Grist**
11.10		Debate & Q&A	**Jenny and Gill**
11.20		BREAK	
11.30	**PRESSURE ULCERS:** expert perspectives	Patient involvement in pressure ulcer prevention	**Lisa Ledger**
11.50		Surgical management of pressure ulcers in persons with spinal cord injury	**Srinivasa Chakrovarty Budithi**
12.10		Debate & Q&A	**Lisa and Srinivasa**
12.20		BREAK	
12.30	**SPONSORED SCIENTIFIC SYMPOSIUM**	A Scientific Symposium from the Tissue Viability Society Sponsored by **GAMA** **Waterless bathing: benefits and implementation challenges**	**Fran Spratt and Martin Kiernan**
3.30		LUNCH BREAK	

Appendix 23: Rome Conference Poster

PATIENT PERCEPTIONS OF PRESSURE ULCER RISK IN COMMUNITY SETTINGS

Authors: Lisa Ledger, University of Derby, England
Dr Peter Worsley, Dr Jo Hope and Professor Lisette Schoonhoven, University of Southampton, England

Pressure Ulcer (PU) prevention remains a key national and international priority for healthcare providers, with cost of treating PU considerable.(1) However little is known about the patients own involvement and perceptions of PU risk.

It is important to further understand patient involvement and the potential effects this may have on subsequent adherence/non-adherence to PU prevention strategies in the community.(2) Phase 1 of the research has involved an integrative literature review to consider patient involvement in PU risk assessment and decision-making.(3) A systematic search of key databases with overall search categories and related synonyms for 'pressure ulcer', 'adherence' and 'patient involvement' revealed there is very little research conducted in this area. Of the search results, 11 articles were deemed appropriate for inclusion.

KEY THEMES TO EMERGE FROM THE LITERATURE REVIEW:

DAILY LIFESTYLE

Individual needs and lifestyle factors are important considerations for pressure ulcer prevention

PATIENT INVOLVEMENT IN DECISION MAKING

Patients want to be involved in the decisions around their care and treatment

ADHERENT/ NON-ADHERENT BEHAVIOURS

Little is known about what factors affect this dynamic and constantly changing phenomena

THE PAIN FACTOR

Pain is of concern and a major factor in patients decisions around undertaking advice and strategies given

INTENTION VS ACTUAL BEHAVIOUR

The knowledge and intention to carry out advice given does not necesary translate into actual behaviour

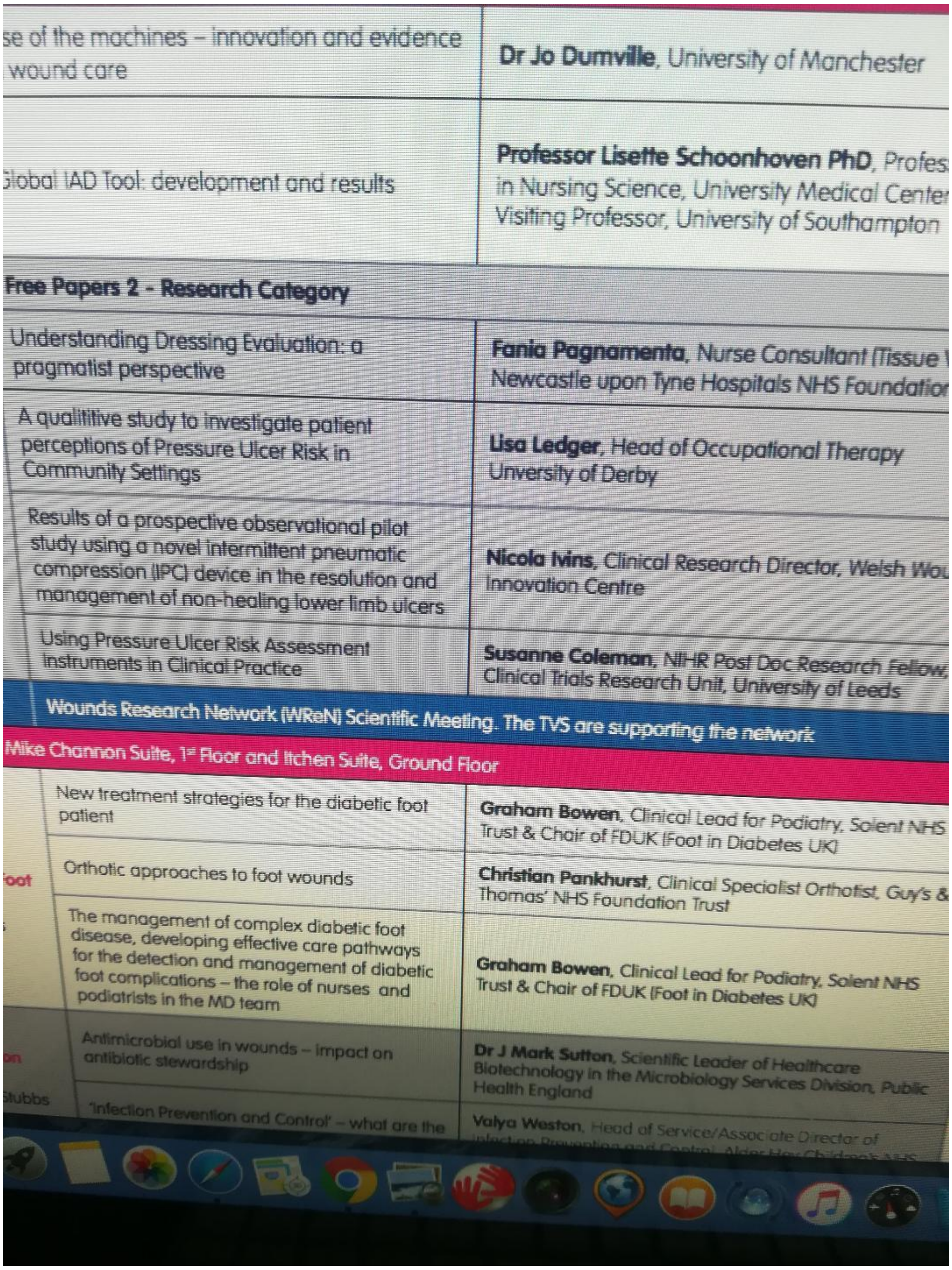
THE NEXT PHASE

The next phase of the research will involve a qualitative, enthnomethodological approach using observations (between nurse and patient), interviews and follow-up interviews with patients, together with analysis of documents naturally occurring in the home setting.

REFERENCES:

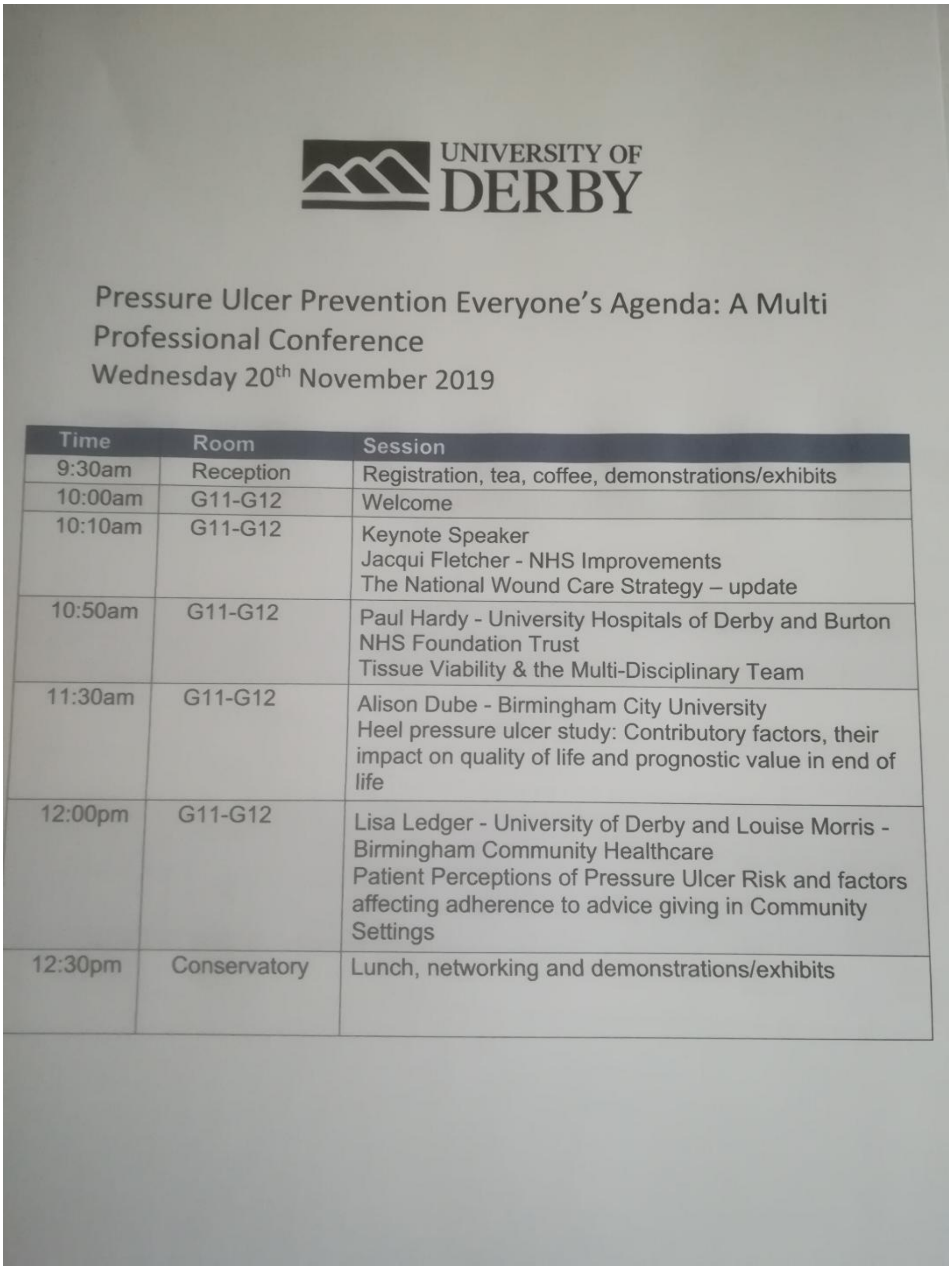
1. Demarre L et al - 2015 - Int J Nursing Studies 52:1754-1774
2. Mcinnes E et al - 2014 - BMC Nursing 13 (41) 2-3
3. Ledger L et al - 2017 - Unpublished PhD Integrative Review

Appendix 24: TVS Conference 2019



	se of the machines – innovation and evidence wound care	**Dr Jo Dumville**, University of Manchester
	Global IAD Tool: development and results	**Professor Lisette Schoonhoven PhD**, Profes in Nursing Science, University Medical Cente Visiting Professor, University of Southampton
Free Papers 2 - Research Category		
	Understanding Dressing Evaluation: a pragmatist perspective	**Fania Pagnamenta**, Nurse Consultant (Tissue Newcastle upon Tyne Hospitals NHS Foundatio
	A qualititive study to investigate patient perceptions of Pressure Ulcer Risk in Community Settings	**Lisa Ledger**, Head of Occupational Therapy Unversity of Derby
	Results of a prospective observational pilot study using a novel intermittent pneumatic compression (IPC) device in the resolution and management of non-healing lower limb ulcers	**Nicola Ivins**, Clinical Research Director, Welsh Wou Innovation Centre
	Using Pressure Ulcer Risk Assessment Instruments in Clinical Practice	**Susanne Coleman**, NIHR Post Doc Research Fellow, Clinical Trials Research Unit, University of Leeds
Wounds Research Network (WReN) Scientific Meeting. The TVS are supporting the network		
Mike Channon Suite, 1st Floor and Itchen Suite, Ground Floor		
	New treatment strategies for the diabetic foot patient	**Graham Bowen**, Clinical Lead for Podiatry, Solent NHS Trust & Chair of FDUK (Foot in Diabetes UK)
oot	Orthotic approaches to foot wounds	**Christian Pankhurst**, Clinical Specialist Orthotist, Guy's & Thomas' NHS Foundation Trust
s	The management of complex diabetic foot disease, developing effective care pathways for the detection and management of diabetic foot complications – the role of nurses and podiatrists in the MD team	**Graham Bowen**, Clinical Lead for Podiatry, Solent NHS Trust & Chair of FDUK (Foot in Diabetes UK)
on	Antimicrobial use in wounds – impact on antibiotic stewardship	**Dr J Mark Sutton**, Scientific Leader of Healthcare Biotechnology in the Microbiology Services Division, Public Health England
Stubbs	'Infection Prevention and Control' – what are the	**Valya Weston**, Head of Service/Associate Director of

Appendix 25: Derby Conference Agenda 2019



UNIVERSITY OF
DERBY

Pressure Ulcer Prevention Everyone's Agenda: A Multi Professional Conference
Wednesday 20th November 2019

Time	Room	Session
9:30am	Reception	Registration, tea, coffee, demonstrations/exhibits
10:00am	G11-G12	Welcome
10:10am	G11-G12	Keynote Speaker Jacqui Fletcher - NHS Improvements The National Wound Care Strategy – update
10:50am	G11-G12	Paul Hardy - University Hospitals of Derby and Burton NHS Foundation Trust Tissue Viability & the Multi-Disciplinary Team
11:30am	G11-G12	Alison Dube - Birmingham City University Heel pressure ulcer study: Contributory factors, their impact on quality of life and prognostic value in end of life
12:00pm	G11-G12	Lisa Ledger - University of Derby and Louise Morris - Birmingham Community Healthcare Patient Perceptions of Pressure Ulcer Risk and factors affecting adherence to advice giving in Community Settings
12:30pm	Conservatory	Lunch, networking and demonstrations/exhibits

Appendix 26: EWMA Conference 2020

TVS Stream @ EWMA

Wednesday 18th and
Thursday 19th November

Tissue
Viability
Society

09.00 - 09.15 Virtual refreshment break, networking and exhibition

Thursday 19th November cont'd...

UK Time — Subject & speakers

Digital wound care in the NHS

09.15 - 09.35 Wound care using mobile digital technology - what does good look like?

- **Eldon Macarthur,** Head of IT Operations, Systems & Business Change, Kent Community Health NHS Foundation Trust
- **Ann Jacklin,** Data & Information Lead, National Wound Care Strategy Programme

09.35 - 09.55 How secure photo sharing is transforming Tissue Viability

- **Alexandra Macfarlane**, Customer Success Manager, Pando

09.55 - 10.15 **C**reating **O**pportunities with **V**irtual **I**nterviews **D**igitally

- **Heidi Sandoz**, BSc (Hons), Tissue Viability Services Lead – Hertfordshire Community NHS Trust
- **Hayley Hanahoe**, Leg Ulcer Specialist Nurse, Hertfordshire Community NHS Trust
- **Ann Nelmes**, Tissue Viability Specialist Nurse, Hertfordshire Community NHS Trust

10.15 - 10.30 Virtual refreshment break, networking and exhibition

10.30 - 11.30 **Industry symposia**

11.30 - 12.00 Virtual refreshment break, networking and exhibition

12.00 - 12.20 The role of podiatry in the early identification and prevention of lower limb venous disease: An ethnographic study

- **Dr Peter Roberts**, Senior Lecturer in Podiatry, Division of Podiatry and Clinical Sciences, University of Huddersfield

12.20 - 12.40 Patient perceptions of pressure ulcer risk and adherence to advice giving in community settings: A qualitative study

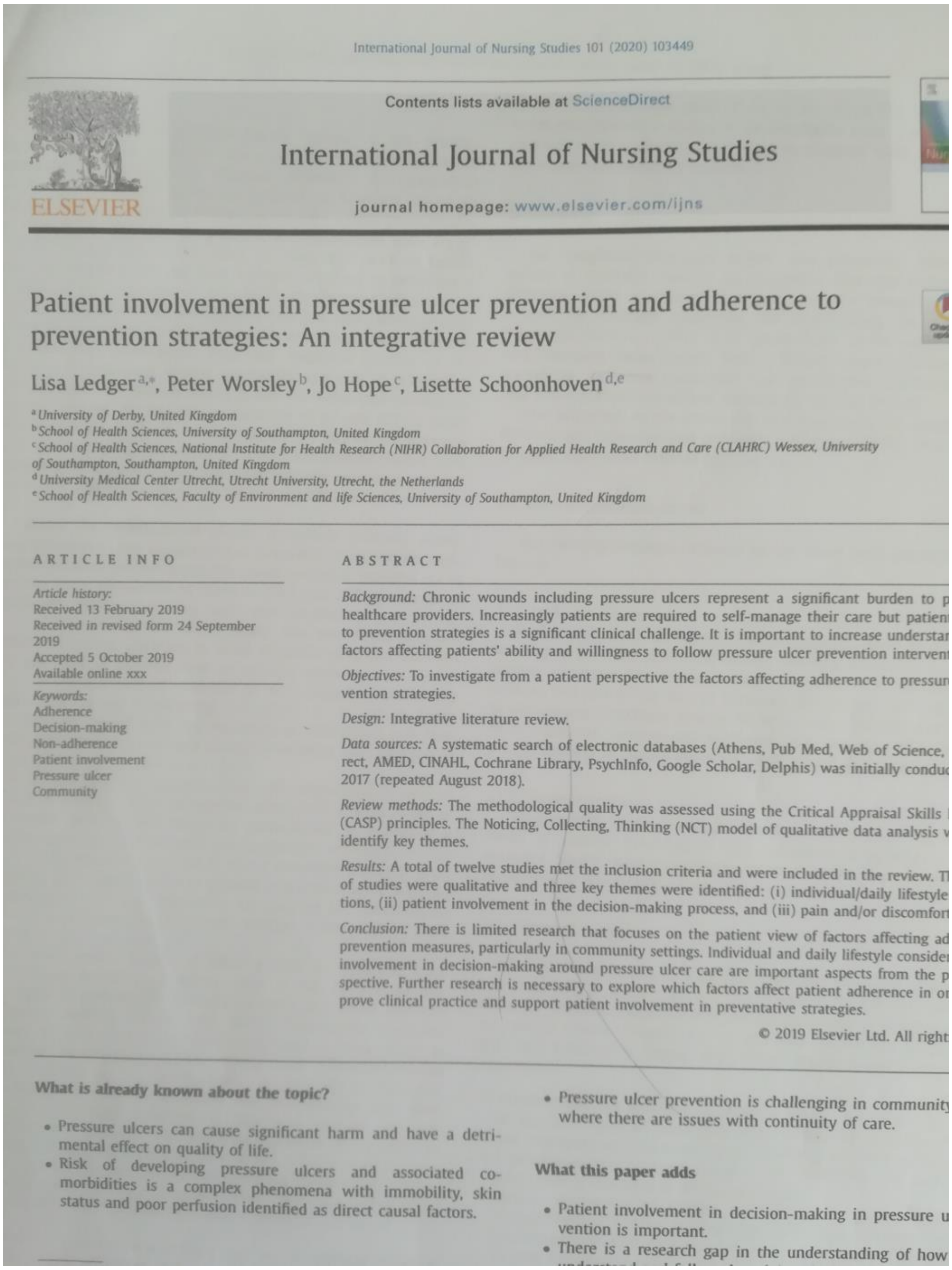
- **Lisa Ledger**, BA, BSc,MSc, FHEA, Head of Occupational Therapy, University of Derby

12.40 - 13.00 Procurement of wound dressings - the NHS Supply Chain strategy

- **Miranda Gordon,** (MCIPS) Head of Category, Wound Care and Infection Control, NHS Supply Chain

13.00 - 13.15 Virtual refreshment break, networking and exhibition

Appendix 27 IJNS Journal Article



International Journal of Nursing Studies 101 (2020) 103449

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

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

Lisa Ledger[a,*], Peter Worsley[b], Jo Hope[c], Lisette Schoonhoven[d,e]

[a] University of Derby, United Kingdom
[b] School of Health Sciences, University of Southampton, United Kingdom
[c] School of Health Sciences, National Institute for Health Research (NIHR) Collaboration for Applied Health Research and Care (CLAHRC) Wessex, University of Southampton, Southampton, United Kingdom
[d] University Medical Center Utrecht, Utrecht University, Utrecht, the Netherlands
[e] School of Health Sciences, Faculty of Environment and life Sciences, University of Southampton, United Kingdom

ARTICLE INFO

Article history:
Received 13 February 2019
Received in revised form 24 September 2019
Accepted 5 October 2019
Available online xxx

Keywords:
Adherence
Decision-making
Non-adherence
Patient involvement
Pressure ulcer
Community

ABSTRACT

Background: Chronic wounds including pressure ulcers represent a significant burden to p
healthcare providers. Increasingly patients are required to self-manage their care but patien
to prevention strategies is a significant clinical challenge. It is important to increase understar
factors affecting patients' ability and willingness to follow pressure ulcer prevention intervent

Objectives: To investigate from a patient perspective the factors affecting adherence to pressur
vention strategies.

Design: Integrative literature review.

Data sources: A systematic search of electronic databases (Athens, Pub Med, Web of Science,
rect, AMED, CINAHL, Cochrane Library, PsychInfo, Google Scholar, Delphis) was initially conduc
2017 (repeated August 2018).

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

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

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

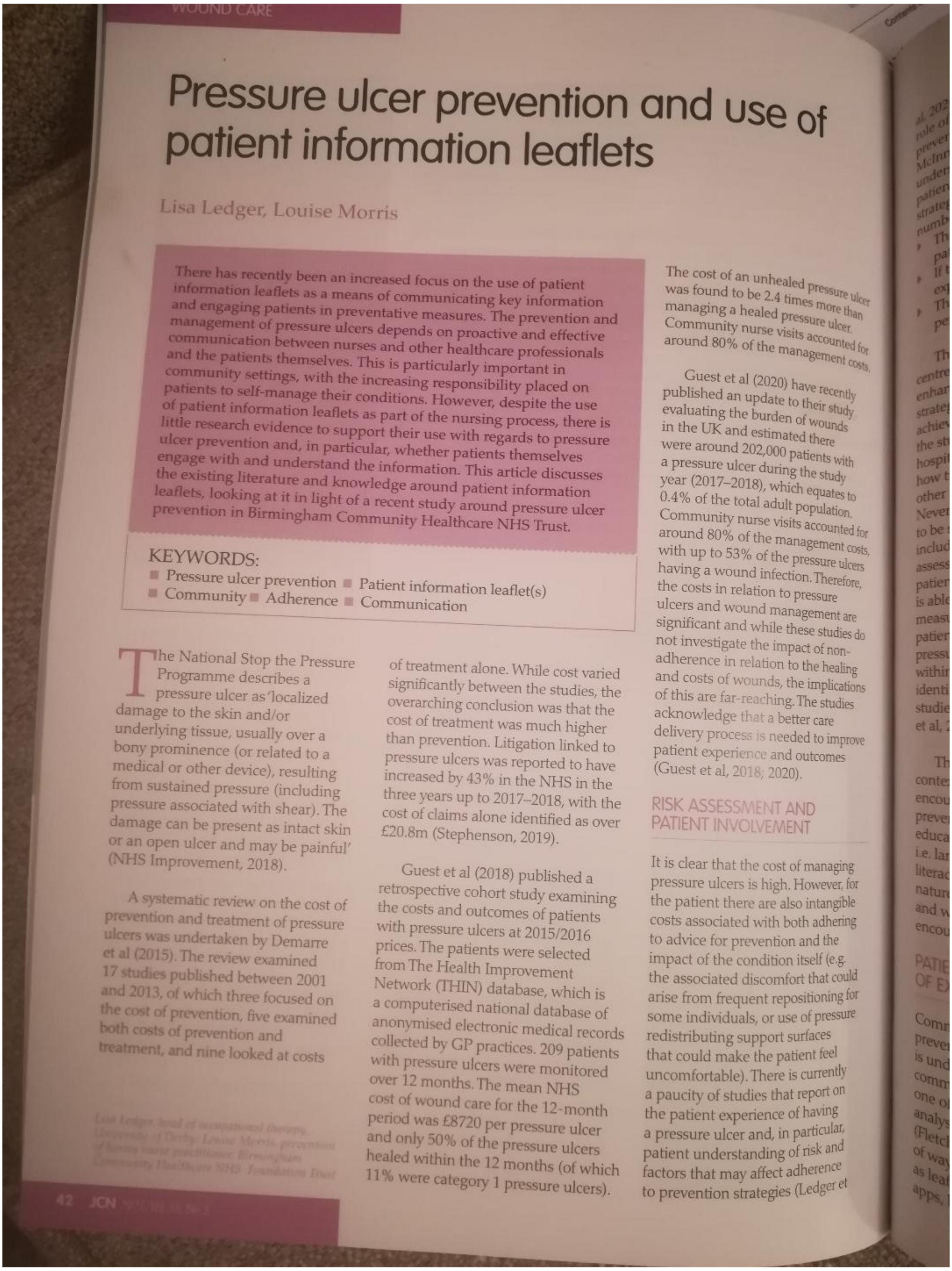
What is already known about the topic?

- 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 communit
where there are issues with continuity of care.

What this paper adds

- Patient involvement in decision-making in pressure u
vention is important.
- There is a research gap in the understanding of how

Appendix 28 JCN Journal Publication 2021



Pressure ulcer prevention and use of patient information leaflets

Lisa Ledger, Louise Morris

There has recently been an increased focus on the use of patient information leaflets as a means of communicating key information and engaging patients in preventative measures. The prevention and management of pressure ulcers depends on proactive and effective communication between nurses and other healthcare professionals and the patients themselves. This is particularly important in community settings, with the increasing responsibility placed on patients to self-manage their conditions. However, despite the use of patient information leaflets as part of the nursing process, there is little research evidence to support their use with regards to pressure ulcer prevention and, in particular, whether patients themselves engage with and understand the information. This article discusses the existing literature and knowledge around patient information leaflets, looking at it in light of a recent study around pressure ulcer prevention in Birmingham Community Healthcare NHS Trust.

KEYWORDS:
■ Pressure ulcer prevention ■ Patient information leaflet(s)
■ Community ■ Adherence ■ Communication

The National Stop the Pressure Programme describes a pressure ulcer as 'localized damage to the skin and/or underlying tissue, usually over a bony prominence (or related to a medical or other device), resulting from sustained pressure (including pressure associated with shear). The damage can be present as intact skin or an open ulcer and may be painful' (NHS Improvement, 2018).

A systematic review on the cost of prevention and treatment of pressure ulcers was undertaken by Demarre et al (2015). The review examined 17 studies published between 2001 and 2013, of which three focused on the cost of prevention, five examined both costs of prevention and treatment, and nine looked at costs of treatment alone. While cost varied significantly between the studies, the overarching conclusion was that the cost of treatment was much higher than prevention. Litigation linked to pressure ulcers was reported to have increased by 43% in the NHS in the three years up to 2017–2018, with the cost of claims alone identified as over £20.8m (Stephenson, 2019).

Guest et al (2018) published a retrospective cohort study examining the costs and outcomes of patients with pressure ulcers at 2015/2016 prices. The patients were selected from The Health Improvement Network (THIN) database, which is a computerised national database of anonymised electronic medical records collected by GP practices. 209 patients with pressure ulcers were monitored over 12 months. The mean NHS cost of wound care for the 12-month period was £8720 per pressure ulcer and only 50% of the pressure ulcers healed within the 12 months (of which 11% were category 1 pressure ulcers). The cost of an unhealed pressure ulcer was found to be 2.4 times more than managing a healed pressure ulcer. Community nurse visits accounted for around 80% of the management costs.

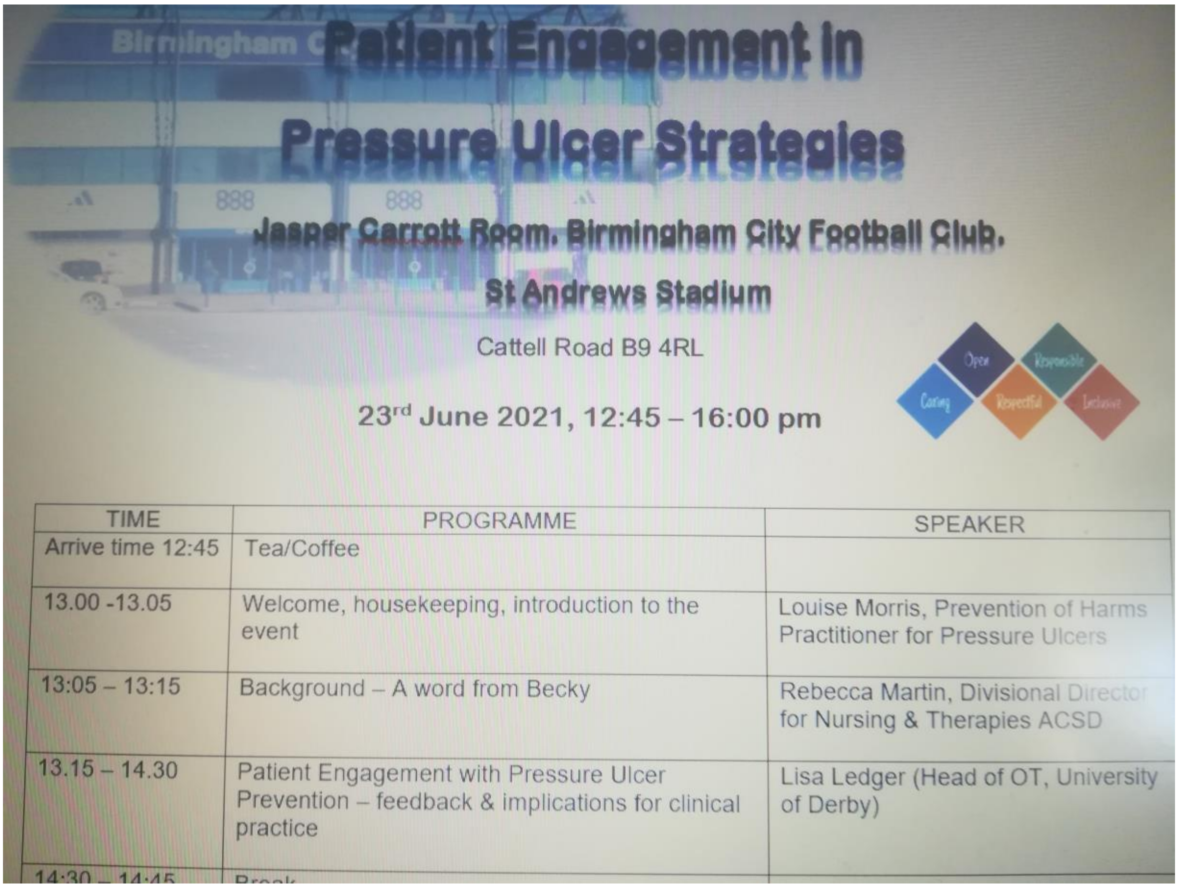
Guest et al (2020) have recently published an update to their study evaluating the burden of wounds in the UK and estimated there were around 202,000 patients with a pressure ulcer during the study year (2017–2018), which equates to 0.4% of the total adult population. Community nurse visits accounted for around 80% of the management costs, with up to 53% of the pressure ulcers having a wound infection. Therefore, the costs in relation to pressure ulcers and wound management are significant and while these studies do not investigate the impact of non-adherence in relation to the healing and costs of wounds, the implications of this are far-reaching. The studies acknowledge that a better care delivery process is needed to improve patient experience and outcomes (Guest et al, 2018; 2020).

RISK ASSESSMENT AND PATIENT INVOLVEMENT

It is clear that the cost of managing pressure ulcers is high. However, for the patient there are also intangible costs associated with both adhering to advice for prevention and the impact of the condition itself (e.g. the associated discomfort that could arise from frequent repositioning for some individuals, or use of pressure redistributing support surfaces that could make the patient feel uncomfortable). There is currently a paucity of studies that report on the patient experience of having a pressure ulcer and, in particular, patient understanding of risk and factors that may affect adherence to prevention strategies (Ledger et

Lisa Ledger, head of occupational therapy, University of Derby; Louise Morris, prevention of harms nurse practitioner, Birmingham Community Healthcare NHS Foundation Trust

Appendix 29 BHCH Trust Workshop 2021



Patient Engagement in Pressure Ulcer Strategies

Jasper Carrott Room, Birmingham City Football Club,

St Andrews Stadium

Cattell Road B9 4RL

23rd June 2021, 12:45 – 16:00 pm

TIME	PROGRAMME	SPEAKER
Arrive time 12:45	Tea/Coffee	
13.00 -13.05	Welcome, housekeeping, introduction to the event	Louise Morris, Prevention of Harms Practitioner for Pressure Ulcers
13:05 – 13:15	Background – A word from Becky	Rebecca Martin, Divisional Director for Nursing & Therapies ACSD
13.15 – 14.30	Patient Engagement with Pressure Ulcer Prevention – feedback & implications for clinical practice	Lisa Ledger (Head of OT, University of Derby)

Appendix 30 BCHC Trust Newsletter

Top Tips for Supporting Patient Engagement

One of the recurring themes noted in Pressure Ulcer Root Cause Analysis investigations includes patient non-concordance. Lack of patient & family engagement in prevention strategies is a major risk factor for pressure ulcer development. There is also a correlation between this & complaints & litigation.

Definitions

Compliance is defined as the extent to which the patient's behaviour matches the healthcare provider's recommendations. It implies passivity, following demands & directions. Patient beliefs are not taken into account & are often seen as an obstacle to treatment.

Adherence is the extent to which the patient's behaviour matches the agreed recommendations from the healthcare professional. It implies a more active role, with collaboration with the healthcare professional & the patient is self-motivated in following advice.

Concordance focuses on the patient-healthcare professional relationship & interaction. The beliefs & preferences of both the healthcare professional & the patient are taken into consideration, with the recognition that the patient's views are paramount. Patients make an informed decision about treatment, the benefits & risks.

Research

BCHC Community have been involved in an ongoing PhD research project with Lisa Ledger as Lead Researcher, examining patient understanding & engagement with pressure ulcer prevention strategies and this has already uncovered some key information & themes. These help to give us early insight into the patient's real world & what drives them to deviate from the care that was agreed.

Top Tips for Preventing Non-Concordance:

- Identify & document the cause for non-concordance.

  - If we know the cause, we can devise a strategy to help overcome issues.
- Complete the Decisions Against Advice form as this provides a checklist to ensure we have not missed any issues or aspects of care
- Increase the frequency of visits as the patient will be more at risk of pressure damage as a result of non-concordance with care
- Enlist support from an experienced colleague – see with “fresh eyes” Sometimes it is difficult to develop a therapeutic partnership with the patient & a visit from another colleague might result in improved interactions.
- Mental capacity is often discussed at Serious Incident Assurance Panel meetings. If the patient lacks capacity, they cannot be non-concordant. The panel will often ask how capacity was checked & confirmed & when was this done. Therefore, if non-concordance is sited as a precursor for a pressure ulcer development, ensure there is documented evidence to support that the patient had capacity.
- Contact Safeguarding if you need advice or support

Research Study - Patient said:	What we can do to Help:
Unable to remember the advice Complexity of advice 	Ensure they have been given the patient information leaflet on pressure ulcer prevention Provide explanations for each relevant aspect of care Keep it simple — go through one point at a time Encourage patients to ask questions about why certain interventions are needed & how to reduce their level of risk as this will help empower them & enable greater patient satisfaction Do not interrupt or rush responses Check understanding by asking questions at each visit & reiterate information at every clinical opportunity
Not fully understood the advice 	Involve family & carers in decisions about care plans If there is a language barrier, enlist support from the Interpreting Service (contact details on the Trust Intranet) Download & use the patient information pressure ulcer **picture guide** on the Patient Safety Intranet page

Strategy doesn’t fit my lifestyle:	Discuss care & treatment options with patients in a way that allows them to make informed choices Consider any cultural beliefs & concerns
It’s inconvenient & affects/reduces ability /activities 	Fitting strategy around patient’s lifestyle/integrating with their routines, not the other way where the patient must fit their routine around the strategy. E.g. when the adverts come on the TV stand up / undertake chair tilts
The equipment is obtrusive – it makes my home look untidy; my home doesn’t feel my own; I cannot see the TV as a result of the new equipment arrangement	If a particular intervention conflicts with a patient’s concerns, allow time to discuss different options in order to get their agreement Show pictures of examples which might provide reassurance for implementation & use
Cost to the patient	Running dynamic mattresses cost no more than using an electric light bulb
Unable to tolerate equipment as it causes discomfort (e.g. makes me hot, sweaty, it’s painful to use)	May need to agree a compromise with the patient, e.g. they may dislike one piece of equipment, therefore offer alternatives
Existing pain is exacerbated by strategy. **(Pain is the most frequently reported issue for causing non-concordance)** 	Assess pain Review analgesia including type & frequency Discuss analgesia with GP/Dr so that prescription can be modified Monitor pain Consider support from OT & Physio to assist with any posture-related issues
Didn’t feel that the risk was that significant	Any healthcare intervention has an element of uncertainty as to whether it will improve the health of the patient or prevent harm

⚠

Highlight the reasons & rationale for why the patient is at risk

Involve individuals in the decisions about the strategies & care bundles & encourage them to take an active role in this care

The research study outcomes are likely to be paramount in helping us to improve the way in which we address patient non-concordance.

Ultimately, it is not about simply providing information about why pressure ulcer prevention is important but involving patients in the decisions about the strategies & care bundles used, establishing their agreement on outcomes & goals & getting them to take an active part in prevention/treatment. If time can be invested in patient-healthcare partnerships in preventing pressure ulcers it has the potential to yield reductions in time spent on treating patients who have developed pressure ulcers as a result of non-concordance.

KEY POINTS

1. Staff need to discuss care and treatment options with patients in a way that allows them to make informed choices.

2. When patients have the knowledge and confidence to help manage their own health, they do better.

References

Barnard RA, Cruice MN and Playford ED (2010) Strategies used in the pursuit of achievability during goal setting in rehabilitation. Qualitative Health Research 20 (2) doi: 1049732309358327.

Baron J, Presseau J, Grimshaw J, Swaine J, White B, Aspinall A, Jaglal S and Wolfe D (2016) Self-management interventions to improve skin care for pressure ulcer prevention in people with spinal cord injuries: a systematic review protocol. *Systematic Reviews* 5: 1-8.

Baron J, Sullivan J, Grimshaw J, Swaine J, White B, Aspinall A, Jaglal S, Presseau DW and Wolfe D (2018) Self-management interventions to improve skin care for pressure ulcer prevention in people with spinal cord injuries: A systematic review of the use of theory and quality intervention reporting. Spinal Cord 56: 837-846.

Blaxter M (2010) Health (Second Edition). Cambridge: Polity.

Braun V and Clarke V (2013) Successful Qualitative Research: A practical guide for beginners. London: Sage.

Brewster L, Tarrant C, Willars J and Armstrong N (2017) Measurement of harms in community care: a qualitative study of use of the NHS Safety Thermometer. British Medical Journal Quality and Safety. 27 (8): 625-632 doi 1136/bmjqs-2017-006970.

Chaloner DM and Franks PJ (2000) Validity of the Walsall Community Pressure Sore Risk Calculator. British Journal of Community Nursing. 5 (6) : 272-6.

Chan EA, Wong F, Cheung MY and Lam W (2018) Patients' perceptions of their experiences with nurse-patient communication in oncology settings: A focused ethnographic study. PLOS One 13(6) doi https://doi.org/10.1371/journal.pone.0199183

Chesser AK, Woods N, Smothers K and Rogers N (2016) Health Literacy and Older Adults. Gerotology Geriatric Medicine. doi 10.1177/2333721416630492.

Clark FA, Jackson JM, Scott MD, Carlson, ME, Atkins MS, Uhles-Tanaka D and Rubayi S (2006) Original article: Data-Based Models of How Pressure Ulcers Develop in Daily-Living Contexts of

Adults With Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation* 87 (11): 1516-1525.

Coleman S and Muir D (2015) Patient Involvement in risk tool development. Nursing Times. 111(25).

Coleman S, Nelson EA, Closs J, Defloor T, Halfens R, Farrin A, Brown JM, Schoonhoven L and Nixon J (2013) Patient risk factors for pressure ulcer development: A systematic review. International Journal of Nursing 50 (7):974-1003.

Coleman S, Nixon J, Keen J, Wilson L, McGinnis E, Dealey C, Stubbs N, Farrin A, Dowding D, Schols J, Cuddigan J, Berlowitz D, Jude E, Vowden P, Schoonhoven L, Bader D, Gefen A, Oomens WJ and Nelson EA (2014) A new pressure ulcer conceptual framework. Journal of Advanced Nursing. 70 (10): 2222-2234.

Coleman S, Smith IL, Nixon J, Wilson L and Brown S (2016) Pressure Ulcer and wounds reporting in NHS hospitals in England part 2: survey of monitoring systems. Journal of Tissue Viability. 25 (1): 16-25.

Coleman S., Smith IL, McGinnes E, Keen J, Muir D, Wilson L, Stubbs N, Dealey C, Brown S, Nelson E and Dixon J (2017) Clinical evaluation of a new pressure ulcer risk assessment instrument, the Pressure Ulcer Risk Primary or Secondary Evaluation Tool (PURPOSE T). WILEY JAN. doi: 10.1111/jan.13444.

Connor M and Norman P (2021) Health Belief Model. International Journal of Nursing Studies. Science Direct.com.

Coulter A and Collins A (2011) Making Shared Decision-Making a Reality. No decision about me without me. London. King’s Fund.

Cresswell JW (2014) Research Design: Qualitative, Quantitative and Mixed Methods Approaches (Fourth Edition). London: Sage.

Critical Appraisal Skills Programme (CASP) (2013) Making sense of evidence. Available from: http:://casp-uk.net (Accessed 29 November 2016).

Deakin J, Gillespie BM, Chaboyer W, Niewwehoven P and Latimer S (2020) An education intervention care bundle to improve hospitalised patients pressure injury knowledge: a before and after study. Wound Practice and Research. 28(4) 154-162.

Dealey C, Posnett J and Walker A (2012) The cost of pressure ulcers in the United Kingdom. Journal of Wound Care. 21 (6): 261-2.

Demarre L, Lancker AV, Van Hecke A, Verhaeghe S, Grypdonck, Lemey J, Annemans L and Beeckman D (2015) The Cost of prevention and treatment of pressure ulcers: A Systematic Review. International Journal of Nursing Studies. 52 (11): 1754-1774.

Denzin, NK (1989) ‘Strategies of multiple triangulation’ in The Research Act: A Theoretical Introduction, 3rd Edition. Englewood Cliffs NJ: Prentice-Hall.

Donaldson L, Riccardi W, Sheridan S and Tartaglia R (2021) Textbook of Patient Safety and Clinical Management. London: Springer Open Access.

Douglas M (1992) Risk and Blame: Essays in Cultural Theory. London: Routledge.

Dubnewick M, Clandinin D, Lessard J and McHugh T (2018) The centrality of reflexivity through narrative beginnings: Towards living Reconciliation. Qualitative Enquiry. 24 (6) 413-420.

Durrant L, Taylor J, Thompson H, Usher K and Jackson D (2018) Health literacy in pressure injury: Findings from a mixed-method study of community-based patients and carers. Nursing & Health Sciences 21: (1) 37-43. https://doi.org.1111/nhs.12429

Edwards AGK (2012) Communicating risk to patients and the public. British Journal of General Practice. 213-217.

Elder JP, Ayala GX and Harris S (1999) Theory and Intervention Approaches to Health Behaviour Change in Primary Care. American Journal of Preventative Medicine 17 (4) pp275-285.

Eldh AC, Arestedt L and Bertero C (2020) Quotations in qualitative studies: Reflections on constituents, custom and Purpose. International Journal of Qualitative Methods. doi: 10.1177/1609406920969268.

Essex HN, Clark M and Sims J (2009) Health-related quality of life in hospital inpatients with pressure ulceration: assessment using generic health-related quality of life measures. Wound Repair and Regeneration. 17(6) 797-805. doi 10.1111/j.1524-475X.2009.00544.x.

European Pressure Ulcer Advisory Panel, National Pressure Injury Advisory Panel and Pan Pacific Pressure Injury Alliance (2019) Prevention and treatment of pressure ulcers/injuries: clinical practice guideline. The international Guideline.

Ewald F (1991) ‘Insurance and risks.’ In Burchell G., Gordon C and Miller P. (Eds) The Foucault Effect: Studies in Governmentality. London: Harvester.

Fleischer S, Berg A, Zimmermann M, Wuste K and Behrens J (2009) Nurse-patient interaction and communication: a systematic literature review. Journal of Public Health 17 (5) :339-353 doi 0.1007/s10389-008-0238-1.

Fletcher J (2020) Pressure ulcer education 8: giving information to patients. Nursing Times. 116 (5): 31-35.

Fogelberg DJ, Powell JM and Clark FA (2016) The role of habit in recurrent pressure ulcers following spinal cord injury. *Scandinavian Journal Of Occupational Therapy* 23(6): 467-476.

Fox C (2002) Living with a pressure ulcer: a descriptive study of patients' experiences. *British Journal Of Community Nursing* 7(6): 10.

Friese S (2014) Qualitative Data Analysis with ATLAS. Ti (Second Edition). London: Sage.

Gerrish K and Lathlean J (2015) The Research Process in Nursing (Seventh Edition). Chichester: Wiley Blackwell.

Ghaisas S, Pyatak E, Blanche E, Blanchard J and Clark F (2015) Lifestyle Changes and Pressure Ulcer Prevention in Adults with Spinal Cord Injury in the Pressure Ulcer Prevention Study Lifestyle Intervention. American Journal of Occupational Therapy. 69(1): 1-10.

Gillespie BM, Latimer S, Walker R, McInnes E, Moore Z, Estes AM, Zhaoyu Li, Schoonhoven L, Boorman RJ and Chaboyer W (2020) The quality and clinical applicability of recommendations in pressure injury guidelines. International Journal of Nursing Studies. doi:10.1016/j.ijnurstu.2020.103857.

Green J and Thorogood N (2017) Qualitative Methods for Health Research: 4th Edition. London: SAGE.

Grenier A, Phillipson C, Rudman DL, Hatzifilalithis S, Kobayashi K and Marier P (2017) Precarity in later life: Understanding new forms of risk and insecurity. Journal of Aging Studies. 43 (9-14) doi: 10.1016/j.jaging.2017.08.002.

Gluyas H (2015) Patient-centred care: Improving healthcare outcomes. Nursing Standard. 30 (4) 50-59 doi: 10.7748/ns.30.4.50.e10186.

Gorecki C, Brown JM, Nelson EA. Briggs M, Schoonhoven L, Dealey C, Defloor T and Nixon J (2009) Impact of Pressure Ulcers on Quality of Life in Older Patients: A Systematic review. Journal of American Geriatric Society. 57:1175-1183.

Gorecki C, Nixon J, Madill A, Firth J and Brown JM (2012) What influences the impact of pressure ulcers on health-related quality of life? A qualitative patient focused exploration of contributory factors. Journal of Tissue Viability. 21 (1):3-12.

Grant C and Osanloo A (2014) Understanding, selecting and integrating a theoretical framework into dissertation research: creating the blueprint for your house. Administrative Issues Journal. doi: 10.5929/2014.4.2.9

Grauman A, Hansson M, James S, Veldwijk J and Hoglund A (2019) Exploring research participants perceptions of cardiovascular risk information – Room for improvement and empowerment. Patient Education and Counselling. 102: 1528-1534 doi: 10.1016/j.pec.2019.03.010.

Guihan M and Bombardier CH (2012) Potentially modifiable risk factors among veterans with spinal cord injury hospitalized for severe pressure ulcers: a descriptive study. *The Journal Of Spinal Cord Medicine*. 35(4): 240-250.

Guest JF, Fuller GW and Vowden P (2020) Cohort study evaluating the burden of wounds to the UK's National Health Service in 2017/2018: Update from 2012/13. British Medical Journal. Open 10 doi:10.1136/bmjopen-2020-045253.

Hardicre N, Murray J, Shannon R, Sheard L, Birks Y, Hughes L, Cracknell A and Lawton R (2021) Doing involvement: A qualitative study exploring the work of involvement enacted by older people and their carers during transition from hospital to home. Health Expectations. doi:10.1111/hex.13327.

Hashim NM, Yosof AN, Engkasan J and Hasnan N (2020) Factors affecting adherence to behaviours appropriate for the prevention of pressure injuries in people with spinal cord injury from Malaysia: a qualitative study. Spinal Cord 59: 777-786.

Have P (2004) Understanding Qualitative Research and Ethnomethodology. London: SAGE.

Heale R and Noble H (2019) Integration of a theoretical framework into your research study. Evidence Based Nursing. 22 (2) doi: 10.1136/ebnurs-2019-103077.

Hopkins A (2010) Using qualitative research to improve tissue viability care. Nursing Standard 24 (32): 64-67.

Horne R, Weinnman J, Barber N, Elliott R and Morgan M (2005) Concordance, Adherence and Compliance in Medicine Taking. National Co-ordinating Centre for NHS Service Delivery and Organisation R &D. London: Sage.

Hothersall SJ (2018) Epistemology and social work: enhancing integration of theory, practice and research through philosophical pragmatism. European Journal of Social Work. 22 (5).

Hower KI, Bennedey C, Hillen HA, Kuntz L, Stock S, Pfaff H and Ansman L (2019) Implementation of patient-centred care: which organisational determinants matter from a decision makers perspective? Results from a qualitative interview study across various health and social care organisations. BMJ Open. doi: 10.1136/bmjopen-2018-027591.

Hultin L, Gunningberg L, Coleman S and Christin K (2021) Pressure ulcer risk assessment – registered nurses' experiences of using PURPOSE T: A focus group study. Journal of Clinical Nursing. Wiley. doi:10.1111/jocn.15901.

Ingleby A (2020) Knowledge, pain and depression: impact on adherence in individuals with venous leg ulceration. Wounds UK. 16 (3).

Jackson J, Carlson M, Rubayi S, Scott MD, Atkins MS, Blanche EI, Saunders-Newton C, Mielke S, Wolfe MK and Clark FA (2010) Qualitative study of principles pertaining to lifestyle and pressure ulcer risk in adults with spinal cord injury. *Disability And Rehabilitation.* 32(7): 567-578.

Jackson DE, Durrant L, Bishop E, Walthall H, Betteridge R, Garner S, Coulton M, Hutchinson M, Neville S, Davidson P and Usher K (2017) Pain associated with pressure injury: A qualitative study of community-based, home dwelling individuals. Journal of Advanced Nursing. 3 doi: 10.1111/jan.13370.

Jackson DE, Durrant LA, Hutchinson M, Ballard CA, Neville and Usher K (2017) Living with multiple losses: Insights from patients living with pressure injury. Collegian 25 (4): 409-414 https://doi.org/10.1016/j.colegn.2017.10.008 .

Jauho M (2019) Patients in waiting or chronically healthy individuals? People with elevated cholesterol talk about risk. Sociology of Health and Illness. 41 (5): 867-881.

Jorgensen M, Kamstrup-Larsen N, Dorrit-Guassora A, Reventlow and Dalton S (2019) It can do no harm: A qualitative exploration of accounts of participation in health checks. Health Risk and Society. Vol 21 (2) 57-73 doi: 10.1080/13698575.2019.1602251.

Jordan JL, Ellis SJ and Chambers R (2020) Defining shared decision-making and concordance: are they one and the same. Postgraduate Medical Journal. 10 (3): 296-303.

Kan M and Fabrigar L (2017) Theory of Planned Behavior. Encyclopedia of Personality and Individual Differences. SpringerLink. doi:10.10072978-3-319-28099-8.

King RB, Porter SL and Vertiz KB (2008) Preventive skin care beliefs of people with spinal cord injury *Rehabilitation Nursing: The Official Journal Of The Association Of Rehabilitation Nurses.* 33(4): 154-162.

Kings Fund (2017) Understanding NHS Financial Pressures: how are they affecting patient care? Available from: Understanding NHS financial pressures | The King's Fund (Accessed 6 October 2020).

Kings Fund (2018) Implementing the five year forward view. Available from: https://www.kingsfund.org.uk/publications/implementing-nhs-five-year-forward-view (Accessed 6 October 2020).

Latimer S, Chaboyer W and Gillespie B (2014) Patient participation in pressure injury prevention: giving patient's a voice *Scandinavian Journal of Caring Sciences.* 28(4): 648-656.

Lavallee JF, Gray TA, Dumville J and Cullum N (2017) Barriers and facilitators to preventing pressure ulcers in nursing home residents: A qualitative analysis informed by the Theoretical Domains Framework. International Journal of Nursing Studies. Vol 82: 79-89 doi: 10.1016/j.ijnurstu.2017.12.015.

Ledger L, Worsley P, Hope J and Schoonhoven L (2020) Patient involvement in pressure ulcer prevention and adherence to prevention strategies: An integrative review. International Journal of Nursing Studies IJNS 101 (2020) 103449. doi.org/10.1016/j.ijnurstu.2019.103449.

Ledger L and Morris L (2021) Pressure ulcer prevention and use of patient information leaflets. Journal of Community Nursing 35 (5): 42 -46.

Leslie JL and Lonneman W (2016) Promoting Trust in the Registered Nurse-Patient Relationship. Home Healthcare Now. 34(1) 38-43. doi:10.1097/NHH.0000000000000000322.PMID:26645843.

Lincoln YS and Guba EG (1985) Naturalistic Enquiry. London: Sage.

Lipworth WL, Davey HM, Carter SM, Hooker C and Huw S (2010) Beliefs and beyond: what can we learn from qualitative studies of lay people’s understanding of cancer risk? Health Expectations Journal. 13. 113-124 doi:10.1111/j.1369-7625.2010.00601X.

Liu LQ, Chapman S, Deegan R, Knight SL, Traynor M, Allan HT and Gall A (2021) Development and preliminary validation of a tool measuring concordance and belief about performing pressure-relieving activities for pressure ulcer prevention in spinal cord injury. Journal of Tissue Viability. 30. 244-249 doi: 10.1016/j.jtv.2020.05.002.

Lofland J, Snow D, Anderson L and Lofland LH (2006) Analyzing Social Settings: A guide to Qualitative Observation and Analysis (Fourth Edition). United Kingdom: Wadsworth.

Mason JM (2002) Qualitative Researching. (Second Edition). London: Sage.

Mayor E and Bietti L (2017) Ethnomethodological Studies of nurse-patient and nurse-relative interactions: A scoping review. International Journal of Nursing Studies 70 (5):46-57.

McCormack B, McCance T, Bulley C, Brown D, McMillan A and Martin S (2021) Fundamentals of Person-centred Healthcare Practice. Oxford: Wiley Press.

McInnes E, Chaboyer W, Murray E, Allen T and Jones P (2014) The role of patients in pressure injury prevention: a survey of acute care patients. *BMC Nursing* 13(1): 41-41.

McKinnon J (2013) The case for concordance: value and application in nursing practice. British Journal of Nursing. 22 (13): 16-21.

McLaughlin GH (1969) SMOG grading a new readability formula. Journal of Reading. 12(8) 639-646.

Merav BN and Hochman O (2017) Patient-centred Care in Healthcare and its Implementation in Nursing. International Journal of Caring Sciences.10 (1): 596 -600.

Moore Z, Johanssen E and Van Etten M (2013) A review of PU prevalence and incidence across Scandinavia, Iceland and Ireland (Part 1). Journal of Wound Care. 22 (7):361-368.

Moyer D, Liberati A, Tetzlaff J and Douglas G (2009) The PRISMA Statement. Preferred reporting items for systematic reviews and meta-analysis. Journal of Clinical Epidemiology 6 (7).

Munce SEP, Allins W, Wolfe DL, Anjai K, Linassi G, Noonan VK and Jagal SB (2017) Using the Theoretical Domains Framework to guide development of a self-management programme for people with Spinal Cord Injury. Journal of Spinal Cord Medicine. Vol 40 (6).

National Wound Care Strategy Programme (2021) “National Wound Care Core Capabilities Framework for England” Skills for Health.

Neale J (2009) Research Methods for Health and Social Care. London: Palgrave.

Nettleton S (2013) The sociology of Health and Illness 3rd Edition. UK: Polity press.

Newton JM, Henderson A, Jolly B and Greaves J (2015) A contemporary examination of workplace learning culture: An ethnomethodological study. Nurse Education Today. 35 (5): 91-96.

NHS England (2021) The NHS Patient Safety Strategy. https://www.england.nhs.uk NHS Improvement (2018)Pressure ulcers: revised definition and measurement Summary & recommendations June 2018.

NICE (2014) Pressure Ulcers: prevention and management. National Institute for Health and Care Excellence (2014) Costing Statement: Pressure ulcers Implementing the NICE guideline on pressure ulcers (CG179). Available from: www.nice.org.uk/guidance/cg179/chapter1 (accessed November 2020).

Nixon J, Smith L, Brown S, Vargas-Palacios A, Nelson A, Coleman S, Collier H, Fernandez C, Gilberts R, Henderson V, Muir D, Stubbs N, Walker K, Wilson L and Hulme C (2019) Pressure Relieving Support Surfaces for Pressure Ulcer Prevention (Pressure 2): Clinical and Health Economic Results of a Randomised Control Trial. The Lancet. EClinical Medicine 14. 42-52. doi.org/10.10.1016/j.eclinm.2019.07.018.

Norton D, McClaren R, Exton Smith A (1975) An Investigation of Geriatric Nursing Problems in Hospital. Churchill Livingstone, Edinburgh.

NPUAP/EPUAP/PPPIA (2014) Prevention and Treatment of Pressure Ulcers Clinical Practice Guideline. Cambridge Media. Australia.

O'Connor T, Moore ZEH and Patton D (2021) Patient and lay carer education for preventing pressure ulceration in at-risk populations. Cochrane Database of Systematic Reviews. John Wiley & Sons.

Oris L, Luyckx K, Rassart J, Goubery L, Goosens E, Apers S, Arat S, Vandenberghe J, Westhovens R and Moons P (2018) Illness Identity in Adults with a Chronic Illness. Journal of Clinical Psychology in Medical Settings. Vol 25: 429-440.

Papanikolalaou P, Lyne P and Ratcliffe J (2007) Using the discrete choice experimental design to investigate decision-making about pressure ulcer prevention by community nurses. Health and Social Care in the Community. 15(6) 588-598. doi:10.1111/j.1365-2524.2007.00728.

Parsons E and Atkinson P (1992) Sociology of Health & Illness. 14 (4) ISSN 0141-988.

Patton MQ (2002) Qualitative Research and Evaluation Methods (3rd Ed) Thousand Oaks. CA: Sage.

Phelan A, McCormack B, Dewing J, Brown D, Cardiff S, Cook NF, Dickson CAW, Knetec S, Lorber M, Magowan R, McCance T, Skovdahl K, Stiglic G and Lieshout F (2020) Review of developments in person-centred healthcare. International Practice Development Journal. 10 (3) 1-28 doi:10.19043/ipdj.10Suppl2.003.

Pinkney L, Nixon J, Wilson L, Coleman S, McGinnis E, Stubbs N, Dealey C, Nelson A, Patterson M and Keen J (2014) Why do patients develop severe pressure ulcers? A retrospective case study. British Medical Journal Open. 4(1): 1-7. doi:10.1136/bmjopen-2103-004303.

Richie J, Lewis J, Nichols CM and Ormston R (2014) Qualitative Research Practice: A guide for social science students and researchers (Second Edition). London: Sage.

Riley KE, Hay JL, Waters EA, Biddle C, Schofield E, Li Y, Orom H and Kiviniemi MT (2019) Lay beliefs about risk: relation to risk behaviours and to probabilistic risk perceptions. Journal of Behavioural Medicine. 42: 1062-1072. doi: 10.1007/s10865-019-00036-1.

Robinson JH, Callister LC, Berry JA and Dearing KA (2008) Patient-centred care and adherence: Definitions and applications to improve outcomes. American Academy of Nurse Practitioners. doi: 10.1111/j1745-7599.2008.00360.

Rosenfeld D and Weinberg D (2012) Domestic practice, situated contingency and adherence to medical directives: A call for research. Social Theory and Health. 10 (1): 42-60.

Rortveit K, Hansen BS, Leiknes I, Joan I, Testad I and Severinsson E (2015) Patients' experiences of Trust in the Patient-nurse Relationship – a systematic review of Qualitative Studies. Open Journal of Nursing Vol 5 (3): 195-209. doi:10.4236/ojn.2015.53024.

RCOT (Royal College of Occupational Therapists) What is Occupational Therapy? OT Explained - RCOT https://www.rcot.co.uk accessed July 2021.

Sagsveen E, Rise MB, Gronning K, Westerlund H and Bratas O (2018) Respect, trust and continuity: A qualitative study exploring service user experience of involvement at a Healthy Life Centre in Norway. Health Expectations 22 (6) 226-234 doi: 10.1111/hex.12846.

Sarafino EP and Smith TW (2012) Heath Psychology. Biopsychosocial Interactions. London: John Wiley & Sons.

Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C (2018) Saturation in qualitative research: exploring its conceptualisation and operationalization. Quality and Quantity. 52 (4) 1893-1901 doi: 10.1007/s11135-017-0574-8.

Savin-Baden M and Howell Major C (2013) Qualitative Research: The Essential Guide to Theory and Practice. London: Routledge.

Schoeps LN, Tallberg AB and Gunningberg L (2016) Patients' knowledge of and participation in preventing pressure ulcers – an intervention study. International Wound Journal 14 (2): 344-348.

Shanley E, Patton D, Avsar P, O'Connor T, Nugent L and Moore Z (2021) The impact of the Shanley Pressure Ulcer Prevention Programme on older persons knowledge of, and attitudes and behaviours towards, pressure ulcer prevention. International Wound Journal. doi: 10.1111/iwj.13671.

Sheridan S, Sherman H, Kooijman A, Vazquez E, Kirk K, Metwally N and Cardinali F, in Donaldson L (2021) Textbook of Patient Safety and Clinical Risk Management. doi:10.1007/978-3-030-59403-9_6.

Silverman D (2016) Qualitative Research. London: Sage.

Skills for Health (2021) National Wound Care Core Capabilities Framework for England. National Wound Care Strategy Programme NWCSP. National Wound-Care-Core Capabilities Framework-2021 Skills for Health.pdf accessed November 2021.

Smith IL, Nixon J, Brown S, Wilson L and Coleman S (2016) Pressure Ulcer and wounds reporting in NHS hospitals in England part 1: Audit of monitoring systems. Journal of Tissue Viability. 25(3): 3-15.

Spilsbury K, Nelson A, Cullum N, Iglesias C, Nixon J and Mason S (2007) Pressure ulcers and their treatment and effects on quality of life: hospital inpatient perspectives. Journal of Advanced Nursing. 57: 494-504.

Starling A (2019) Implementing new models of care: Lessons from the new care models programme in England. International Journal of Care Coordination. 21 (1-2): 50-54.

Stevenson R, Collinson M, Henderson V, Wilson L, Dealey C, McGinnis E, Briggs M, Nelson E A, Stubbs N, Coleman S, Nixon J (2013) The prevalence of pressure ulcers in community settings. International Journal of Nursing Studies. 50(11): 1550-1557.

Stephenson, J (2019) https://www.nursingtimes.net/news/technology/nhs-litigation-bill-for-pressure-ulcers-soars-53-in-three-years-08-05-2019.

Stinson M, Gillan C and Porter-Armstrong A (2013) A literature review of pressure ulcer prevention: weight shift activity, cost of pressure care and the role of the occupational therapist. British Journal Occupational Therapy 76(4): 1-10.

Stottard KM (2012) Social meanings and understandings in patient-nurse interaction in the community practice setting: a grounded theory study. BMC Nursing 11 (14) http://www.biomedcentral.com/1472-6955/11/14 .

Tambuzer E and Audenhove CV (2013) Service User and Family Carer Involvement in Mental Health Care. Community Mental Health Journal. 49(6): 675-685.

The Data Protection Act (2018) Available at: http:www.Legislation.gov.uk . (Accessed October 2020).

Torraco RJ (2016) Writing integrative literature reviews: Guidelines and examples. Human Resource Development Review (4) 356. doi.org/10.1177/1534484305278283.

Vanderwee K, Clark M and Dealey C (2007) Pressure ulcer prevalence in Europe: a pilot study. Journal Evaluative Clinical Practice. 13(2):227-35.

Van Hecke A, Grypdonck M and Defloor T (2009) A review of why patients with leg ulcers do not adhere to treatment. *Journal of Clinical Nursing.* 18(3): 337-349.

Van Hecke A, Verhaeghe S, Grypdonck M, Beele H and Defloor T (2011) Processes underlying adherence to leg ulcer treatment: A qualitative field study. International Journal of Nursing Studies. 48: 145-15.

Vornanen M, Konttinene H, Kaarianinen H, Mannisto S, Salomaa V, Perola M and Haukkala A (2016) Family history and perceived risk of diabetes, cardiovascular disease, cancer and depression. Preventative Medicine. 90: 177-183.

Walker E and Dewar JB (2001) How do we facilitate carers' involvement in decisionmaking? Journal of Advanced Nursing. 34 (3):329-337.

Waterlow J (1985) Pressure sores: a risk assessment card. Nursing Times. 81(48): 49-55.

Weller C, Richards C, Turnour L and Team V (2021) Patient explanations of adherence and non-adherence to venous leg ulcer treatment: A qualitative study. Frontiers in Pharmacology. 5: 33-43 doi:10.3389/fphar.2021.663570.

Whipple M, Hamel A and Talley K (2018) Fear of Falling Among Community-Dwelling Older Adults: A Scoping Review to Identify Effective Evidence-Based Interventions. Geriatric Nursing. 39 (2) 170-177. doi: 10.1016/j.gerinurse.2017.08.005.

WHO (2003) Adherence to Long -term Therapies: Evidence for Action. World Health Organisation: Switzerland.

Wynia, K, Spoorenberg S, Uittenbroek R, Jager M, Kremer H and Reijneveld S. (2018) Long-term advantages of person-centred and integrated care: results from a longititudinal study on Embrace. International Journal of Integrated Care. Vol. 18. pp 1-2. http://doi.org/10.5334/ijic.s2362.

Wynn M (2020) Patient expectations of pressure ulcer prevention in the NHS, healthcare demand and national policy: a critical commentary. British Journal of Nursing 29 (20) 26-31.

Zainal N, Holloway S and Edney SM (2021) Health belief theories and their influence on adherence behaviours in individuals with diabetic foot ulceration: A literature review. Journal of Wound Management doi:10.35279/jowm202107.03.

Zinn J (2008) Social Theories of Risk and Uncertainty: An Introduction. Blackwell Publishing: Oxford.