Nursing Practice Innovation Patient engagement

The perspective of patients and carers proved invaluable when developing a new risk assessment instrument for pressure ulcer prevention

Patient involvement in risk tool development

In this article...

- Background on pressure ulcer risk assessment instruments
- Why carers should be involved in care and research
- How patients and carers shaped a new pressure ulcer RAI

Authors

Susanne Coleman is programme manager and risk assessment project lead; Delia Muir is patient and public involvement officer; both at Leeds Institute of Clinical Trials Research. Brian Rawson and Yvonne Rawson are members of the Pressure Ulcer Service User Network.

Abstract


Pressure ulcers are a patient safety issue and present a burden to patients, carers and healthcare organisations. Patients and carers have an important part to play in managing pressure ulcer risk alongside the input of health professionals. This article describes the value of patient and carer views, and how these were integrated into research to develop a new pressure ulcer risk assessment instrument – Pressure Ulcer Risk Primary or Secondary Evaluation Tool (PURPOSE T) – to support clinical decision-making and promote patient safety.

Risk assessment is widely accepted as being essential to pressure ulcer prevention. It allows patients at risk to be identified so preventative interventions can be put in place which reduce the risk of ulcer development (NICE, 2014; NPUAP/EPUAP/PPPIA, 2014). Risk assessment instruments (RAIs) support clinical practice by allowing nurses to inform clinical judgement by assessing patient characteristics considered important in pressure ulcer development. They are thought to convey some practical advantages, by setting minimum standards of assessment, and give some structure to the assessment process (NPUAP/EPUAP/PPPIA, 2014, NICE, 2014).

Although more than 40 RAIs have been identified (Nixon and McGough, 2001), the Norton, Waterlow and Braden Scales have undergone the most scrutiny in the literature, reflecting their widespread use in clinical practice (Gould et al, 2002; Pancorbo-Hidalgo et al, 2006, Papanikolaou et al, 2007, NICE, 2014).

The basis of existing RAI development varies, with most developed from literature reviews, expert opinion or adaptation of existing RAIs. Many were developed between 1970-80 when few studies had investigated the relative contribution of individual risk factors (Nixon et al, In press). This has led to inconsistent inclusion of risk factors and raises questions about which ones should be included in RAIs (Nixon and McGough, 2001; Gould et al, 2002; Kottner and Balzer, 2010).

Evidence of patient and carer involvement in the development of existing pressure ulcer RAIs is also lacking (Coleman, 2014). The involvement of the target population is considered important in the development of instruments that assess health status, collect patient-reported outcomes or aid decision-making (Bryant et al, 2014; FDA DHHS, 2009; Liu et al, 2006; SAC, 2002).

While clinical nurses predominantly use RAIs, assessment should be undertaken in consultation with the patient to encourage shared decision-making. Patients and carers also have an important role in managing risk as they may be the only constant at risk of pressure ulcer development. They are thought to convey some practical advantages, by setting minimum standards of assessment, and give some structure to the assessment process (NPUAP/EPUAP/PPPIA, 2014, NICE, 2014).

Keywords: Pressure ulcer/Risk assessment/Patient experience/PPI

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5 key points

1 Pressure ulcer risk assessment instruments (RAIs) enable the measurement of characteristics or important risk factors to inform clinical judgement

2 Patients and carers have an important role to play in managing risk as they may be the only constant factor in a complex journey between health professionals and settings

3 Involving patients and carers in the development of the new RAI (PURPOSE T) informed the acceptability and content of the tool

4 RAI use should facilitate communication with patients about pressure ulcer risk factors and encourage them to identify changes in their own risk

5 Pressure Ulcer Service User Network highlighted a need to adapt PURPOSE T for patient and carer use to promote self-care and education about pressure ulcer risk factors
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BOX 1. MORE ON PRESSURE ULCERS
Pressure ulcers are defined as: “localised injury to the skin and/or underlying tissue, usually over a bony prominence, resulting from sustained pressure, including pressure associated with shear (NPUAP/EPUAP/PPPIA, 2014)”. They are classified according to the severity of the ulcer and the tissue layers involved (NPUAP/EPUAP, 2009). Associated with ill health and poor mobility, they have a negative impact on patients’ quality of life (Gorecki et al, 2009) and present a financial burden to the NHS (Dealey et al, 2012). Most pressure ulcers are thought to be preventable with good assessment and care (NICE, 2014).

Developing a new RAI
Given the limitations of existing RAIs, the Pressure Ulcer Programme of Research (Purpose) developed a new evidence-based tool – Pressure Ulcer Risk Primary or Secondary Evaluation Tool (PURPOSE T) – funded by the National Institute for Health Research (RP-PG-0407-10056). This work has contributed to the body of knowledge relating to pressure ulcer risk factors and assessment for adults. It involved adapted “gold standard” instrument development methods incorporating innovative patient and carer involvement. The methods comprised five phases (Box 2).

Involving patients and carers
PPI is encouraged in consensus studies (Black, 2006) and the phase 2 consensus study was identified as a key area where patient and carer insights would be of prime importance in shaping PURPOSE T (Coleman et al, 2014a). There is evidence of patient involvement in consensus work relating to broader health priority setting. For example, the James Lind Alliance runs partnerships that bring together health professionals, patients and carers to reach consensus on research priorities (Elwyn et al, 2010).

There are also limited examples of involvement in the development of core outcome sets (Comet, www.comet-initiative.org). However, the evidence most relevant to RAI development relates to membership of the expert group (Rycroft-Malone, 2001; Jackson et al, 2009). A limitation of this approach is the small number of patient and carer participants in expert groups. The complex nature of the research evidence, and facilitating mixed groups of patients and professionals, could also be barriers for effective patient and carer involvement (Nixon et al, In press).

These limitations could lead to under-representation of patient and carer views at the development stage. In Rycroft-Malone’s (2001) study, patient and carer involvement was at the end of the process – they were asked to comment on the draft guideline before it was finalised. This approach may facilitate patient and carer endorsement, but more rigorous involvement earlier in the process may provide information to help shape the guideline and improve its acceptability to patients.

For this study, there was more value in having separate patient and carer meetings, rather than representation in the expert group. This allowed more patients and carers to be involved and more time to explore their insights. This was achieved by having facilitated meetings with the Pressure Ulcer Service User Network (PURSUN). This comprises patients and carers with direct experience of pressure ulcers or pressure ulcer risk, and was set up to improve the quality of PPI in pressure ulcer research. The views of PURSUN members were incorporated into the consensus process for consideration by the expert group alongside other evidence.

PURSUN member views were sought for the phase 4 PURPOSE T pre-test, when they co-developed realistic and clinically relevant vignettes that were used by clinical nurses (Nixon et al, In press). PURSUN also reviewed the:
» RAI after pre-testing
» Patient information leaflets for the phase 5 clinical evaluation study;
» Final version of PURPOSE T.

Impact of PPI
By involving PURSUN in this study we were able to incorporate the views of patients and carers in the development of PURPOSE T. PURSUN members were keen that the RAI would:
» Help clinical judgements;
» Facilitate conversations about risk and care with patients rather than being a “tick-box exercise”.

They also highlighted the need to consider how each risk factor would be assessed in practice and the level of burden that assessment would place on patients.

When considering assessment elements individually, PURSUN members considered risk factors, assessment items and the acceptability of collecting this information on a routine basis (Coleman et al, 2014a).

One example of PURSUN views influencing PURPOSE T content is the inclusion of previous pressure ulcers. While the epidemiological evidence for this risk factor was low (Coleman et al, 2014a), it was considered important by the expert group and was consistent with theoretical bioengineering evidence. PURSUN members who described their experience of having had a severe pressure ulcer also explained how the possibility of a recurrence of an ulcer at that skin site was a major cause of concern, particularly if they became ill and required hospital admission. One PURSUN member said:

BOX 2. FIVE PHASES OF PURPOSE T DEVELOPMENT
The development of the Pressure Ulcer Risk Primary OR Secondary Evaluation Tool (PURPOSE T) was split into five phases:

Phase 1: Systematic review of literature relating to pressure ulcer risk factors to identify those most predictive of pressure ulcer development (Coleman et al, 2013)
Phase 2: Consensus study incorporating an international expert group, the members of which, in face-to-face meetings, considered the pressure ulcer evidence and patient and carer views to agree content (Coleman et al, 2014a)
Phase 3: Conceptual framework development to show the critical determinants of pressure ulcer development and underpin PURPOSE T (Coleman et al, 2014b)
Phase 4: Design and pre-testing with clinical nurses to confirm the content and improve ease of use (Nixon et al, In press)
Phase 5: Clinical evaluation involving 230 patients with expert and ward/community nurses to assess reliability, validity and ease of use clinically (Nixon et al, In press)
“Once you’ve had a serious pressure ulcer you will do anything to stop it happening again. When you go into hospital, it’s always on your mind. It’s important that nurses acknowledge that anxiety and discuss what can be done to stop a pressure ulcer developing again.”

It is important that nurses recognise and address this anxiety, and ensure proactive protection of the skin area.

An example of PURSUN considering the level of burden to patients to influence the content of PURPOSE T relates to albumin. The expert group had initially agreed to include albumin in the RAI on the basis of strong epidemiological evidence. However, checking this would involve a blood test. PURSUN’s views prompted the expert group to reconsider the balance between accurately assessing pressure ulcer risk and the burden on the patient. As a result, albumin was excluded from PURPOSE T.

Review

The review of the draft PURPOSE T by PURSUN led to changes. While they found the RAI easy to understand, members were concerned about the wording of the sensory perception item relating to the “ability to feel and respond”. Patients may only experience one of these, but this should still be considered in the assessment. PURSUN felt the terminology should be “feel and/or respond”. This prompted the expert group to change the wording. PURSUN also considered the results of the Purpose pain cohort study, which indicated pain at a pressure area site as a risk factor (Nixon et al, In press). Members felt the results reflected people’s personal experiences of pain (such as feeling discomfort before redness appears on the skin). Members’ views and the results of the pain cohort study were subsequently included in PURPOSE T.

Wider Implications of PPI

Involving patients and carers in the development of PURPOSE T also highlighted wider implications for assessing pressure ulcer risk. The study found that acceptability of assessment methods varied between people and could change when patients had suffered a pressure ulcer in the past. The need for sensitivity during the assessment process was also emphasised during PURSUN discussions, particularly when undertaking visual skin assessments or considering moisture-incontinence problems.

PURSUN recognised the:

- Need for effective communication about risk with patients to promote a greater awareness of pressure ulcer risk factors;
- Importance of assessment;
- Need to encourage patients to identify and report changes in their own risk.

PURSUN also highlighted the need to provide patients with details of who to contact if they are worried about their risk or skin status. They acknowledged variation in the importance placed on skin assessment in different hospital environments and felt this was a fundamental, but sometimes overlooked, aspect of care. They also suggested that PURPOSE T be adapted for use by patients and carers at home. This is being incorporated into our next programme of work.

Conclusion

Patients and carers play an important role in managing risk, so it is logical that they contribute to the design of instruments used to support risk assessment. The involvement of patients and carers with experience of pressure ulcers proved invaluable in the development of PURPOSE T. Their insights had a direct impact on the items included and they highlighted the need to balance the clinical importance of assessing risk factors with the burden it may place on patients. PURSUN also stressed the importance of effective communication, the need for sensitivity when using RAIs, and the need to encourage patients to notice and report changes in their own status. Future patient safety will consider the adaptation of PURPOSE T for patient and carer use.

References


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