

Title: Incorporating the patient experience into clinical guidelines: recommendations for researchers and guideline developers

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Focusing on a specific example from community care, this article argues that clinical guidelines will be better and more usable if they incorporate the findings of high quality, qualitative research. We suggest the development and adoption of guidelines which take a holistic approach to the individual and their circumstances. These should take account not only of the best available evidence in terms of which treatments, devices or lifestyle changes are most effective in a particular instance, but also how these are affected by the day-to-day life of patients. In so doing, clinical guidelines will become representative of the patient population to whom they relate and thus truly evidence-based. We offer below one particular example of where the incorporation of qualitative evidence will improve the usability of clinical guidelines.

Pressure ulcers affect nearly half a million people in the UK in any given year[1]. They can have a considerable impact on the quality of life of affected individuals[2], and are associated with an increased morbidity and mortality[3]. The burden to healthcare providers is equally significant, with costs associated with pressure ulcer care believed to comprise 4% of the annual NHS budget[4]. Evidence-based pressure ulcer prevention guidelines are available to inform clinical practice, and these recommend a range of strategies including mobilisation and repositioning, pressure redistributing support surfaces and nutritional interventions[5,6]. While the risk of pressure ulcer development can be associated with hospitalisation, community-dwelling patients who have limited mobility and chronic health conditions may equally be at risk of these ulcers. Such patients typically receive an element of care from community healthcare professionals. Nevertheless, the care received is often fragmented, as a result of being delivered by multiple providers, and there is a reliance on self-care and informal carers between formal care visits[7]. As a result, patients and their carers play a vital role in the implementation of prevention strategies, and shared decision making between the individual, their caregiver, and the healthcare professional should inform care.

Despite this, guidelines which advocate shared decision making do not necessarily address issues that are of primary importance to patients[8]. National and international guidelines highlight the importance of working in partnership with patients and their carers[5,6]. However, there is a dearth of qualitative research which examines community-dwelling patients' and caregivers' understanding of being at risk of PUs. The ability of such patients and their carers to implement the advice offered by healthcare professionals has also not been explored. In order to produce better, more usable clinical guidelines[9] for pressure ulcer prevention in the home, it is imperative that patients' perspectives are explored. Subsequently, this body of research should be incorporated into the traditional evidence-base.

A number of clinical guidelines have successfully incorporated qualitative findings. As an example, the stroke rehabilitation guidelines[10] undertook further work following stakeholder consultation to incorporate the patient experience and holistic approaches to care. More recently, NICE dementia guidance regarding shared decision making was derived solely from findings of qualitative research[11]. Drawing on qualitative research conducted with patients with existing pressure ulcers, in the absence of research concerning patients at risk of pressure ulcers, Box 1 demonstrates how patients' perspectives may be incorporated into current pressure ulcer guidelines.

Box 1: Suggestion of how pressure ulcer guidelines[5] could be enhanced using the findings of qualitative research

Current NICE guideline recommendation on pressure redistributing devices in pressure ulcer management

- Use high-specification foam mattresses for adults with a pressure ulcer. If this is not sufficient to redistribute pressure, consider the use of a dynamic support surface.

Themes from qualitative research, concerning patients with existing pressure ulcers

- Pain and discomfort associated with pressure redistributing equipment: *Individuals describe pain, noise and restricted movement associated with use of specialist mattresses[12,13]*

Possible enhanced recommendation

- Consider the use of specialist mattresses (high-specification foam or dynamic support surfaces). Ensure that the person with the pressure ulcer/ their caregiver is provided with sufficient information about the benefits and risks of pressure redistributing equipment to make an informed decision. If a specialist mattress is provided, review its acceptability to the patient at frequent intervals.

It is apparent that the number of NICE guidelines incorporating qualitative evidence is increasing over time[14]. However, with reference to our particular example, qualitative research with the patient group in question needs to be undertaken in the first instance. Qualitative research can offer a depth and context absent from quantitative studies, but importantly can also offer explanations which are difficult to explicate through other research approaches[15]. Once a body of such research is available, qualitative synthesis can appraise individual studies and collate their findings to produce a rich picture of patients' perspectives and experiences, filling in the gaps left by quantitative research[8]. Guideline developers are then tasked with considering such findings alongside quantitative research. This is particularly relevant in the holistic management of conditions where understanding the patient perspective is essential, as is the case for pressure ulcer prevention and management among patients residing in the community.

There should be representation from patients and carers in guidelines development groups [16]. Whilst this is challenging for conditions affecting 'seldom heard' patient groups, such as community-dwelling patients in receipt of home-care, every effort should be made to ensure real representation of these individuals in guideline development. Thus, the views of patients and their carers will form a fundamental element of clinical guidelines[10].

Conclusion

It is imperative that those developing guidelines recognise and incorporate research concerning patients' or carers' perspectives of the topic under consideration. This has the potential to improve patient care, particularly in community care, by making recommendations which patients themselves have identified as being feasible and acceptable. We call upon the relevant parties, namely researchers and guideline developers,

to address the significant failing of existing guidelines to take account of the patient perspective. In the first instance, methodologically robust research should be conducted with the patient group in question to understand their perspectives. Thereafter, developers should incorporate these findings into future guidelines to ensure that these are better and more usable for those who count, namely patients.

Competing Interests

None declared (J Roddis)

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Contributorship

All authors contributed equally to: the conception or design of the work; drafting the work or revising it critically for important intellectual content; final approval of the version published. All agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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