

Improving the assessment and management of pain for people with dementia in hospital: end of project summary

Thank you for helping with the above study – your input has been essential to its success. The work is now complete and we are pleased to provide this summary of our results and our plan for taking them forward.

As you are aware, dementia and pain are common in older people and it is difficult for them to communicate their pain to healthcare professionals. Pain often has negative effects on mental and physical health and research has shown that pain is often poorly managed for people with dementia in hospital. The aims of this study were:

- i) to identify any accurate and reliable pain assessment tools available for use with hospital patients who have dementia;
- ii) to explore how pain is currently recognised, assessed and managed for people with dementia in a range of hospital wards in four Hospital organisations England and Scotland.

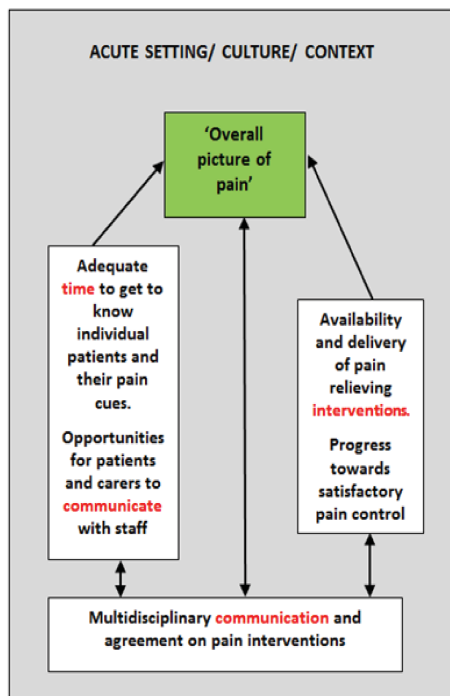
First, we reviewed systematic reviews (a 'meta-review') of existing pain assessment tools for patients with dementia and found 28 pain assessment tools which had been reviewed, but none of these had been tested rigorously. Seven had acceptable reliability and validity, but their suitability for clinical use had not been rigorously evaluated. Authors generally agreed that future work should validate existing tools rather than creating new ones, or develop a completely new approach based on different conceptual foundations. No single tool could be confidently recommended for wider use¹.

ⁱⁱ⁾ We then studied 11 hospital wards using a qualitative ethnographic approach. This included bedside observations of 31 patients with dementia, audits of patient records, semi-structured interviews with 52 staff and four carers and analysis of related hospital ward documents and policies. A thematic analysis of data collected was undertaken.

Each ward studied had its own culture and routines, with highly complex pain assessment and management practices. Elements such as time spent with patients, staff communication patterns and types of management interventions contributed to staff understanding of a patient's pain.

Information about the patient from different staff and carers were produced at different times, for different purposes, in different formats and were recorded in different documents. This information had to be integrated into an 'overall picture' of the patient's pain by each staff member for each individual patient.

This complexity was in stark contrast with the traditional 'linear' conception of pain assessment, intervention, then reassessment by a single individual.



Consequently, we have developed a preliminary specification for an electronic health record module, the PADDs (Pain And Dementia Decision Support) to support decisions about pain assessment and management. Its aim is to centralise all information about a patient's pain as part of a more rapid and effective approach to the assessment and management of pain for patients who have dementia.

The PADDs will incorporate information such as pain histories, intensity assessments, carer input, staff narratives, medication and other interventions provided, and present an *overall picture of pain* in an integrated, chronological and easily accessible visual format.

It will be designed to complement existing systems and will be developed and tested in collaboration with potential users.



The full report of this study will be available via the NIHR Journals Library <http://www.journalslibrary.nihr.ac.uk/hsdr> early in 2016.

We are in the process of applying for funds to take the development of the PADDs forward and to evaluate its effectiveness in clinical practice.

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on behalf of the pain and dementia research team,
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Reference

1. Lichtner V, Dowding D, Esterhuizen P, Closs SJ, Long AF, Corbett A, et al. Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools. BMC Geriatrics. 2014 12/17 07/29/received, 12/11/accepted;14:138. PubMed PMID: PMC4289543.