

Towards improved decision support in the assessment and management of pain for people with dementia in hospital: systematic meta-review and observational study

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FIRST LOOK DRAFT

Important

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Scientific summary

Background

Pain and dementia are common, particularly in older people. Impaired cognitive and communication abilities may make it difficult for people with dementia to express their pain clearly. If clinicians cannot recognise the presence of pain they are unlikely to assess its nature and intensity, hampering their ability to manage pain effectively. Poorly managed pain is common among people with dementia and may produce numerous adverse effects on their mental and physical health and well-being. These patients are at risk of pain not being identified while in hospital; ward staff often find it challenging to manage this group of patients; and robust methods for identifying, assessing and managing pain for people with dementia in hospital are unavailable.

Aims and objectives

The work reported here was undertaken to inform the development of a decision support tool to be used by staff in hospital settings to aid the recognition, assessment and management of pain amongst people with dementia. Two studies were undertaken.

The first study was a systematic review of systematic reviews of observational pain assessment instruments, referred to as the **meta-review**, which had three objectives:

- 1) To identify all tools which are available to assess pain in adults with dementia
- 2) To identify the settings and patient populations with which they had been used
- 3) To assess their reliability, validity and clinical utility

The second was a multi-site **observational study** of current pain assessment and management practices in a range of wards within four hospitals across the UK, with the following four objectives:

- 1) To identify what information is currently elicited and used by clinicians when detecting and managing pain in patients with dementia in acute hospital settings.
- 2) To explore the existing process of decision making for detecting and managing pain in patients with dementia in hospital settings.

- 3) To identify the role (actual and potential) of carers in this process.
- 4) To explore the organisational context in which health care professionals operate, with regard to this decision-making process.

From the findings of these studies we aimed to develop a decision support tool to improve pain assessment and management, and develop research instruments required for an economic assessment of the intervention in a follow-on study. The latter included:

- 1) identifying resource use associated with the intervention developed in this project and
- 2) exploring the use of outcome measures to assess proxy issues and generate hypotheses about the domain of impact.
- 3) developing a set of health economic data collection forms for evaluating the new decision support tool.

Meta-review

Methods

A plethora of observational pain assessment tools have been developed over the past decade, and numerous variable quality systematic reviews have considered their effectiveness. We therefore undertook a systematic review of systematic reviews (meta-review) and analysed and summarised evidence concerning the reported psychometric properties and clinical utility of observational pain assessment tools for use with adults with dementia or other cognitive impairment.

The databases searched were: Medline, All EBM Reviews (including Cochrane DSR, ACP Journal Club, DARE, CCTR, CMR, HTA, and NHSEED), Embase, PsycINFO, and CINAHL; the searches were carried out all on the same date (12 March 2013). Additional searches included the Joanna Briggs Institute (JBI) Library (The JBI Database of Systematic Reviews and Implementation Reports) and the Centre for Reviews and Dissemination database. Further data were retrieved through reference chaining. No grey literature was sought.

Criteria for inclusion followed an adapted SPICE structure. Systematic reviews were included if they reported pain assessment tools involving adults with cognitive impairment; provided psychometric data for the pain assessment tools; and were available in English. No reviews

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were excluded on the basis of setting; type, location or intensity of pain; or the outcomes of pain assessment. Narrative reviews and case reports were excluded.

Two reviewers independently screened the papers as well as extracting data from each systematic review. Quality was assessed using the AMSTAR critical appraisal tool. A third reviewer mediated when consensus was not reached. Analysis of the data was carried out collaboratively. The data within the reviews were synthesised using a narrative synthesis approach.

Findings

Four hundred and forty-one potentially eligible reviews were identified; 23 met the criteria for inclusion and 8 provided data for extraction. Reviews evaluated 8-13 tools, in aggregate providing evidence on a total of 28 tools used for the assessment of pain with patients with dementia.

The tools had been used within a wide variety of settings and with varied patient populations. They had been designed for different users, such as nursing assistants or researchers, or as decision support tools. The vast majority had been used in long term settings for older people, particularly care homes and dementia care units. Little information was available about their use in acute settings.

There was considerable variation in how tools' validity and reliability were assessed. The lack of a 'gold standard' hindered the evaluation of tools' validity. In terms of content validity, limited information was available about the conceptual foundation of tools, which were mostly developed through literature reviews and clinical or research experts. The majority of reliability and validity assessments were carried out on small samples in one or two studies, so the applicability of tools across settings is yet to be evaluated meaningfully. Most tools showed moderate to good inter-rater reliability and temporal stability, while internal consistency varied considerably between scales. Feasibility data (e.g. time to complete assessment or availability of instructions for use) were not reported for six tools and clinical utility data were absent for seven tools. The tools had all been developed for use in long-term settings, so the relevance of their clinical utility in a hospital would have been questionable even had it been available.

Importantly, the study samples included in the systematic reviews were small, providing limited evidence for the use of any of the tools across settings or populations. Of the tools included in the systematic reviews, based on limited evidence, the best candidates for clinical use

appeared to be DS-DAT, Doloplus-2, Mahoney Pain Scale, PACSLAC, PAINAD, Abbey Pain Scale and ECPA. However, no single scale stood out as clearly superior to the others.

Observational study

Methods

A qualitative, multi-site exploratory case study was undertaken using an ethnographic approach. Case sites were purposively sampled to include a range of settings and included 11 wards in four hospitals in England and Scotland. Methods included bedside non-participant observations of 31 patients, audits of patient records, semi-structured interviews with 52 staff and four carers, informal conversations with staff and carers during observations, and analysis of related hospital ward documents (e.g. pain charts), routines (e.g. comfort rounds) and policies.

One hundred and seventy hours of non-participant observations of healthcare professionals and healthcare assistants interacting with patients aged 65+ diagnosed with dementia were recorded. Observations were made of how and where pain was discussed and documented; interactions between professionals, healthcare assistants, patients and carers; interactions between members of the multidisciplinary team; and availability of resources such as pain specialists. Observations were guided with a protocol derived from the theoretical framework.

Semi-structured interviews lasting 15 - 60 minutes with a range of staff and family members were audio-recorded or recorded as field notes. Flexible topic guides ensured all aspects of pain related care were explored, including the detection and management of pain, how the process could be improved, how carers were involved and what an effective decision support tool might comprise.

A thematic analysis of the data from the four sites was undertaken through the lens of decision making theory. Data included transcripts of observation sessions, field notes of medical and nursing records, notes and interview transcripts. Both inductive and deductive approaches were used, and the strategy for analysis emerged from a series of interdisciplinary research team analysis meetings, ensuring consistency between sites. Emerging themes were compared, contrasted and discussed within the group and with the wider project team until consensus was reached.

Health economics

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In preparation for a health economics evaluation of the decision support intervention, data collection forms were developed during the observational study. Meetings with five project researchers elicited their views of relevant cost categories, including resource use, professionals' time, assessments, therapy/medication and reasons for admission.

Findings

No observational pain assessment tools were found in routine use on the wards. A range of information sources were consulted and/or used by different staff when detecting and managing pain in patients with dementia in acute hospital settings. Where possible, staff relied on patients' self-report of pain. For patients with dementia, however, communication difficulties experienced because of their condition, the organisational context, and brief time frames of staff interactions, hindered patient-staff communication about pain. A range of non-verbal communication cues were used, but their interpretation appeared to depend on the skills and experience of staff. Carers were often not present, being absent, unwell, or unable to visit, militating against the possibility of their providing expert interpretation of patients' pain cues and this information then being used by staff.

The multidisciplinary ward environment meant that patients' communication about their pain often involved several members of staff, each having to make sense of a patient's pain and create their own 'overall picture'. Information about patients' pain was elicited in different ways, at different times and by different health care staff and recording of information was fragmented. Frequently different aspects of pain were noted in profession-specific paper-based documentation. Responsibilities between wards varied, but often healthcare assistants undertook intensity assessments alongside routine observations; doctors undertook a full medical history including diagnoses pertinent to pain and relevant medications; pharmacists checked prescriptions and nurses provided medications and liaised between members of the multidisciplinary team staff as well as with patients and their family/friends. The only documentation routinely used by all staff, apart from healthcare assistants, was the medication chart. Analgesics were by far the most common intervention used for pain management and were frequently given using a trial and error approach, titrating the dose and assessing the patient's response.

In stark contrast with the generally accepted linear model of pain decision-making, decision-making processes in the acute environments studied here were far more complex. Staff identified and re-assembled the disparate items of pain related information to form their own

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'patient specific picture of the pain'. This required collective staff memory, 'mental computation' and time. This complexity potentially undermined the trials of medications used to provide pain relief to each patient and assessments of their responses.

The role of carers was difficult to assess. The majority of patients diagnosed with dementia either did not have a carer, or it was not possible for researchers to contact their carer, resulting in only four participating in formal interviews. Numerous brief informal conversations took place with carers (including those of patients not participating in the study), during observation periods, and input from the Lay Advisory Group informed interpretation of the findings. There appears to be untapped potential for carers to act as advocates and interpret pain behaviours on behalf of patients.

Three questionnaires were drafted; for patients, for friends or family and for staff, to be used in a future economic evaluation of a new decision support intervention (the PADDs). These were derived in part from the literature with input from researchers, health professionals and lay persons.

The main conclusions derived from the research reported here which could guide future work were:

- 1) There are no existing observational pain assessment tools which have been shown to have good validity, reliability, feasibility and clinical utility. No single tool can be recommended in preference to any other for general use in hospital settings.
- 2) Future assessment tools should:
 - a. Have a strong theoretical underpinning
 - b. Elicit self-reports and identify cues from the patient first, then from those who are familiar with them.
- 3) Clear opportunities for interactions between patients, carers and staff are needed, allowing time for the identification and understanding of pain.
- 4) The influence of the social context of wards should be recognized, incorporating assumptions about pain according to patients' medical conditions, etc.
- 5) The present reliance on medication provision to alleviate pain should be supplemented with non-pharmacological interventions.
- 6) Clear and effective communication between all the individuals involved in the care of the patient is needed.
- 7) Centralised records of all pain assessment and intervention information are needed.

- 8) Guidance on the use of assessment and/or decision support tools should be available.

Taken together, we conclude that a different approach to the assessment and management of pain for patients with dementia in hospital is needed. Rather than relying on the traditional linear concept of assessing pain, intervening and reassessing, a broader approach is needed. This requires staff to ensure that they spend sufficient time with patients to identify the presence of pain; that pain-related information elicited by different staff and informal carers is effectively communicated between all relevant colleagues; that records of such information are centralized and rapidly accessible by all staff; and that the almost exclusive use of medication to alleviate pain should be supplemented with other non-pharmacological approaches. The use of observational pain assessment tools, needs to be integrated into a complex, dynamic and multidisciplinary sense-making activity of hospital care.

Implications for practice

Self-report should remain the first line of pain assessment for patients with mild-moderate cognitive impairment. Where this is not possible, pragmatically, any of the seven best observational pain assessment tools identified may be a useful addition in settings where none are currently used. All incorporate facial expressions, verbalisations and vocalisations, body movements, changes in interpersonal interactions and activity patterns or routines, and mental status, each of which may indicate pain. Where possible, there is considerable scope for carers to act as interpreters of patients' pain cues.

Pain assessments need to be part of a much broader intervention which takes into account the range of staff, organisation of care and context within which pain assessment and management takes place, which are likely to differ between sites. A patient's pain may fluctuate and different members of staff may perceive (and document) different moments of a patient's pain. We hypothesise that the disparate communication, recording and treatment of pain may be ameliorated by centralising all pain related information. This information should be rapidly accessible to anyone involved in care, and presented in a way that is quick and easy to understand. Pain histories, intensity assessments, carer input, staff narratives, medication and other interventions should be presented in an integrated, easily accessible and chronological visual format.

Consequently, we have designed a specification for a preliminary electronic system which might achieve this, the PADDs (Pain And Dementia Decision Support) system. This comprises

key principles for wards which use electronic health records and is intended to complement rather than add to existing systems. PADDs requires further co-creation and refinement with users and its implementation would need to be part of a complex intervention, including staff education alongside streamlining of existing organisation of care and documentation practices. The economic questionnaires will require acceptability testing with patients and carers. The whole PADDs intervention would need feasibility testing and an economic evaluation prior to being tested in a clinical trial.

2,500 words (max 2500)

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