How can we assess pain in people who have difficulty communicating? A practice development project identifying a pain assessment tools for acute care

Julie Gregory

University of Manchester, UK. Email: Julie.gregory@manchester.ac.uk

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Abstract

Background: A group of practitioners identified difficulties in identifying and assessing pain for people with communication problems. They felt there was a need for a behavioural pain assessment tool.

Aims and objectives: To identify a pain assessment tool for people with communication problems (including people with dementia) in acute care settings.

Method: This was a practice development project and was based on a participatory action research (PAR) methodology using cycles of planning, acting, evaluating, reflecting and re-planning. It included many stakeholders – this was to raise their awareness and to promote ownership and commitment to the project, leading to changes in practice.

Conclusions: A large number of behavioural pain assessment tools are available and three were used by staff in acute care but they did not always identify pain. There is a need to include members of the family or close carers in recognising and assessing pain in people with communication problems.

Implications for practice:

- There is a need to ensure that pain is recognised in acute care settings for people with communication problems and/or cognitive impairment
- Behavioural pain assessment tools can be used in acute care settings
- A holistic assessment of behaviour associated with pain includes the involvement of family members to identify and assess pain
- Actively involving members of the clinical team in all aspects of a project can result in changes to practice development

Keywords: Behavioural pain assessment, pain and cognitive impairment, acute care and dementia, participatory approaches, practice development, practice change, participatory action research, emancipatory action research.

Introduction

Pain is a common symptom associated with illness, injury and surgery for many people in hospital (Clinical Standards Advisory Group, 1999; Strong et al., 2002). It is associated with reduced quality of life, reduced mobility, impaired sleep, delayed healing, poor nutrition and reduced involvement in recreational activities (Clark et al., 2004). Unrelieved pain may lead to depression, agitation, sleep
disturbances and decline in function in the elderly population (Curvo et al., 2007). Good pain management therefore improves function, reduces complications and length of hospital stay (Murdock and Larsen, 2004; Helfand and Freeman, 2008). It is essential that pain is recognised, assessed and treated appropriately for everyone in hospital. A lack of pain detection and treatment is frequently reported (Warden et al., 2003; Helfand and Freeman, 2008) with older people’s pain often under-reported and frequently under-treated (Murdock and Larsen, 2004). For people with communication problems – for example, cognitive impairment – there is evidence of even more inadequate treatment (Warden et al., 2003; Murdock and Larsen, 2004). This could be because they cannot articulate and convey the way they feel (Curvo et al., 2007) and/or they may be perceived by healthcare staff as incapable of experiencing or recalling pain (McAucliffe et al., 2008).

This paper describes the process used by a team of healthcare staff based in an acute hospital setting to identify a suitable pain assessment tool to assist them in the identification and assessment of pain for people with communication problems, including dementia.

**Literature and background**

**Pain assessment**

Perception of pain is a complex experience because it is subjective and a multifaceted phenomenon, which is influenced by factors that include past experiences and culture (Fothergill-Bourbonnais et al., 2004). It can be physical, social, emotional or spiritual (Royal College of Physicians, British Geriatric Society and British Pain Society, 2007; Ruder, 2010). Recognising pain and the assessment of pain severity is important to initiate and evaluate the effectiveness of pain treatments (Bird, 2005; Coker et al., 2008; Kumar and Alcock, 2008; Ruder, 2010).

Assessment begins by asking an individual about their pain because only the individual can determine how much pain they are experiencing (McCaffery and Pasero, 1999). Unfortunately some healthcare staff assess pain intuitively as a result of observing behaviours associated with pain and discomfort. This is subjective, inaccurate and fails to measure the intensity of an individual’s pain (Ruder, 2010). This may have resulted in a failure by staff, and specifically nurses, to assess pain using self-report, despite the person’s ability to provide the information about their pain (Clark et al., 2004; Chang et al., 2011).

There is an increased interest in pain management in the older population, and specifically in older people with cognitive impairment (Schofield, 2008). Pain assessment is more complex in older people, where obtaining information can be difficult due to poor memory, depression and sensory impairment (Kumar and Alcock, 2008). Some of the problems may be as a result of their different attitude about pain. For example, the belief that it is a normal part of aging (Coker et al., 2008; Ruder, 2010), can result in a reluctance to report pain. Older people may use different words, initially denying pain, but they will acknowledge discomfort, hurting or aching (American Geriatric Society, 2002).

**Pain assessment tools**

Pain assessment tools attempt to quantify pain intensity. They provide a uniform standard assessment of pain and when used consistently they can improve communication, with the score obtained incorporated into a chart in the majority of acute care settings (Fothergill-Bourbonnais et al., 2004; Ruder, 2010). Self-report is the standard method for pain assessment in acute care, using simply worded tools and questions that are designed to assess pain intensity (Kumar and Alcock, 2008). There are many pain assessment tools available that can be used to identify the intensity and behaviours associated with pain. The tools include Visual Analogue Scale (VAS), Numerical Rating Scale (NRS), Verbal Descriptor Scale (VDS), the Wong Baker smiley faces and a Numerical Descriptor Scale (NDS). Table 1 describes the assessment tools. No single pain assessment tool can objectively...
rate pain or all the behaviours associated with pain. The scores or ratings obtained should be used alongside a thorough clinical assessment of the individual patient (Ruder, 2010).

**Table 1: Self-report pain assessment tools**

<table>
<thead>
<tr>
<th>ASSESSMENT TOOL</th>
<th>DESCRIPTION</th>
<th>ADVANTAGES</th>
<th>DISADVANTAGES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Visual Analogue Scale</strong></td>
<td>A 10cm line with anchor words at each end of the line from ‘no pain’ and ‘worst pain imaginable’. A mark on the line is made by the patient with a pen or pencil and is measured. (Schofield and Dunham, 2003)</td>
<td>Provides an accurate score and is appropriate in the research setting (Bird, 2005)</td>
<td>Twenty per cent of patients are unable to use a VAS scale or found it confusing. Complicated and requires cognitive skills (Wood, 2004). Difficult to use for people with visual impairment, with older people, and inappropriate for people with cognitive impairment (Wood, 2004)</td>
</tr>
<tr>
<td><strong>Numerical Rating Scale</strong></td>
<td>Individuals are asked to rate their pain as a number, with 0 indicating no pain and 10 the worse pain imaginable (Wood, 2004)</td>
<td>Quick and easy to use in patients who can communicate effectively (Ruder, 2010) and more reliable than the VAS according to Weiner et al. (1999). Can overcome problems of visual and physical impairment</td>
<td>Some people cannot conceptualise pain as a number and difficulties using the scale have been found regardless of age (Bird, 2005). Many older people find it difficult to use (American Geriatric Society, 2002). Inappropriate in the cognitively impaired patient (Wood, 2004)</td>
</tr>
<tr>
<td><strong>Verbal Descriptor Scale</strong></td>
<td>Use of words to represent pain (for example, mild, moderate or severe)</td>
<td>Quick and easy to use, is valid and fits with the WHO analgesic ladder. Often the preferred scale for older people; reliable and valid for this group of patients (Bird, 2005). Useful for patients with cognitive impairment (Wood, 2004; Ruder, 2010)</td>
<td>Ratings are subject to patients’ interpretation of the words and it lacks the sensitivity of other scales (Wood, 2004). Extra descriptors may be used that may confuse patients and there is an assumption that there is equal distance between the descriptors (Schofield and Dunham, 2003)</td>
</tr>
<tr>
<td><strong>Wong Baker smiley faces</strong></td>
<td>Consists of a range of faces from very smiley that scores 0 to very sad scoring 5, to indicate increasing intensity of pain (Sheffield and Dunham, 2003).</td>
<td>Patients identify which face represents their pain (Ruder, 2010). Have been used with the cognitively impaired (American Geriatric Society, 2002).</td>
<td>The faces could equally indicate increased distress for another reason. People with Alzheimer’s had difficulty comprehending the smiley faces (Chibnall and Tait, 2001).</td>
</tr>
</tbody>
</table>

The Joint Commission on Accreditation of Healthcare Organizations in the USA recommended that organisations adopt pain as the fifth vital sign, with temperature, pulse, respiratory rate and blood
pressure (American Geriatric Society, 2002). This monitoring and documentation of a pain score can improve pain control according to Bird (2003). Each hospital should have a consistent practical approach to pain measurement (Buffum et al., 2007). Within the hospital where this project occurred, a verbal descriptor score was combined with a numerical score (0=no pain, 1=mild pain, 2=moderate pain and 3=severe pain) to aid documentation with other observations of vital signs. It appears to have been accepted by the majority of staff, with the documentation of pain score increasing from 16% in 2004 to 93% in 2008 (Gregory, 2011). Before this project there was no alternative to a verbal self-report of pain available for people with communication difficulties.

**Problems associated with pain assessment tools**

To self-report pain there is a requirement to understand the request for a pain rating, to have a memory of painful events, to be able to rate the pain and to interpret the noxious stimuli (Buffum et al., 2007). Therefore the use of self-report is not always practical for some groups of patients – for example, young children, or people with communication difficulties, language barriers, an impaired conscious level or cognitive impairment (Rider, 2010). With increased cognitive impairment people are less likely to report pain and staff are less likely to identify and treat pain (Schofield, 2008). Clark et al. (2004) found that the majority of staff in nursing homes described a relationship-centred pain assessment (knowing the patient), acquiring crucial knowledge of pain cues for that individual. The staff interviewed in this study described how a change in behaviour triggered a pain assessment as a result of this knowledge. It can take between one week and three months to obtain this knowledge of an individual (Clark et al., 2004; McAuliffe et al., 2008). In acute care settings there is a lack of time and consistency of staff to develop this type of relationship (McAucliffe et al., 2008). Pain assessment in non-communicative people is challenging and requires data from sources not reliant on self-report, including proxy reports, health history and observation of behaviours (Ruder, 2010; Ersek et al., 2010).

Observing behaviour is an aspect of all pain assessment, but when patients are unable to communicate, observation of pain behaviours may be the only means of obtaining information (Ruder, 2010). The American Geriatric Society (2002) identified six behaviours that may indicate pain. These are: verbalisation (moaning); facial expression (grimacing); body movements (rigid, tense); changes in interaction (aggressive, withdrawn); changes in activities of living (increased wandering, refusal to eat); and mental status changes (crying, increased confusion). But there is an overlap between these behaviours and the indicators of other conditions such as hunger, thirst, over- or under-stimulation, anxiety or depression (Buffum et al., 2007), hence the need to incorporate the observed behaviour with other sources of information.

Behavioural pain assessment tools have been developed that include some or all of these components (Ruder, 2010). They may not be specific to pain behaviours but they are an important first step in pain assessment and should be used consistently (Buffum et al., 2007). A review of behavioural pain scales can be found at [http://prc.coh.org/PAIN-NOA.htm](http://prc.coh.org/PAIN-NOA.htm).

No one tool can be recommended across care settings and populations. There are two main types of behavioural assessment tools. The first one is where the caregiver is familiar with the person and can detect slight changes in behaviour; alternatively, a tool can be used that comprises fewer, more obvious pain behaviours observed over a short period of time, which are appropriate for frequent pain assessment and monitoring response to therapy in acute care settings (Ersek et al., 2010). Buffum et al. (2007) suggests that a behavioural assessment tool used with information from family members can help assess the presence of pain and to assess or evaluate a response to treatment when patients cannot report pain themselves.
Background to the project
A pain management course was held in-house for all members of the healthcare team, which encouraged participants to critically examine and reflect on pain management practice within their area of clinical practice. Clinicians (a group of physiotherapists and nurses) identified the absence of a behavioural pain assessment tool. They reflected that this was a problem for the increased number of older people admitted to the hospital with cognitive impairment and dementia. They did not measure this perceived increase, although there was an agreement that patients were older (over 80 years) and cognitive impairment appeared to have increased. This perception may be due to an increased awareness and diagnosis of dementia as a result of the Dementia Strategy (2009). Some of the observations made by the physiotherapists included problems in mobilising. For example, an individual may resist when the physiotherapist attempts to help them move; this may indicate pain, but without an assessment tool or confirmation from the patient it is difficult to verify this. Some of the nurses described how family members informed them when an individual was in pain, but they had not been able to identify and assess pain. A brief examination of behavioural assessment tools failed to identify a tool recommended for use in acute care. Clinicians on the psychiatric unit were contacted for advice about a behavioural pain assessment tool and reported that they did not use one for their client group. Instead an ‘instinctive feeling’ that relied on their knowledge of patients over a prolonged period was used, as described by Clark et al. (2004) and Chang et al. (2011).

Many behavioural assessment tools have been developed with variable numbers and different client groups. A review of such tools by clinicians to identify the one that is most appropriate for their specific context was recommended by Herr et al. (2006). The healthcare team had identified the need for a behavioural pain assessment tool in the acute care setting because they have insufficient previous knowledge of individual patients with cognitive impairment and dementia to be able to conduct the intuitive assessment.

The aim of this project was to identify a pain assessment tool for non-communicative patients that is sensitive to the cognitively impaired patient (including dementia patients) in acute care settings, to ensure good pain control and improved outcomes.

The objectives:
- To develop individual skills in collecting and analysing data from a number of sources, examining evidence and changing practice
- To examine current pain assessment practice for this specific group by observation, discussion groups and examining documented care
- To carry out a review of the literature and obtain established tools to assess pain in people with communication problems, including dementia
- Clinical staff will review and choose the assessment tools to try in clinical practice
- To analyse the range of assessment tools to evaluate their usefulness in clinical practice
- To disseminate the findings and decide which pain assessment tool to use in everyday practice

Method
This project involved the examination of the evidence for behavioural pain assessment tools and using them in everyday acute care practice. The method and approaches used were based on a participatory action research (PAR) methodology and emancipatory practice development. Both these approaches are influenced by critical social science, where the aim, for example, is to empower and emancipate those who are the focus of the project so that they can be freed from the social, political and cultural influences that restrain both them and the opportunity for change (Fontana, 2004). As such, the study or project can become a resource for people to change their lives (Green and Thorogood, 2004; Fox et al., 2007). The intention is to alter people’s perceptions (Fox et
Practice development is a continuous process that enables evidence based practice and change, along with the development of healthcare teams’ knowledge and skills. The focus is not on just changing one particular aspect of practice but rather on transforming the culture and context of the care setting (Garbett and McCormack, 2002; Dewing et al., 2010). Emancipatory practice development focuses on understanding the social systems of practice as well as empowering the individual and teams to understand their practice and take actions to change rather than being directed or led (Manley and McCormack, 2003). A practice development project ensures that all participants have an opportunity to participate in discussions about practice, and to challenge it and the environment where it takes place in order to change the practice culture and improve patient care (Coiffi et al., 2007). There is a deliberate intention to enable staff to feel empowerment, to develop both as individuals and as a team (Manley and McCormack, 2003). For this project, this was achieved by involving the staff in the activities and decisions. This active participation and sharing of experiences is integral to the process and aims to develop practice and ensure credibility (Ross et al., 2004). The staff needed to see the relevance, have commitment and own the changes to practice (Manley and McCormack, 2003). A sense of ownership can be acquired through participation that produces a feeling of autonomy and a sense of control for change to occur (Waterman et al., 1998).

This democratic participatory process has an emancipatory function because people have the right to influence processes that may directly affect them (Snoeren and Frost, 2011). Key and influential clinicians responsible for pain assessment practice were involved in the project. They were the decision makers in relation to the project and this group ownership enhanced the change process due to the support within the group to sustain the change (Glasson et al., 2006). Changing pain assessment practice required accessibility and support from the medical and clinical team (Ross et al., 2004). Members of the ward based clinical team were also involved in the decisions; they were represented on the steering group and involved in decisions during workshops.

No issue that is studied within a hospital is context free (Coughlin and Casey, 2001). The unique contexts, priorities and choices individual clinicians face dominate the decisions and actions about patient care (Plesk and Greenhalgh, 2001). Each ward has its own context that is socially constructed, with specific meaning attached by individuals within the organisation (Plesk and Greenhalgh, 2001). This can be seen as a collection of force fields, (multiple clusters and multiple systems) constantly changing and moving, and influenced by cultural, historical, economic, political and psychological factors, which give the environment a character and a feel (McCormack et al., 2002). There is a need to understand the culture or other attributes of an organisation as well as the individuals within it. It is also important to acknowledge the complexity of change, especially when cultural changes are required to enable new ways of working that may be at odds with traditional professional beliefs, assumptions or roles (Powell et al., 2009).

The success of practice development is dependent on effective facilitation to develop individuals, teams and organisational attributes identified as essential for an effective workplace culture (Manley, 2004). Facilitation requires critical thinking, shared decision making, leadership, equity and helping (Simmons, 2004). The facilitation process has multiple dimensions, different levels and intensity that involves helping, enabling and support for development (Harvey et al., 2001).
clinical nurse specialist for acute pain was the project lead and acted as a process facilitator to help participants (Fox et al., 2007). The facilitator created conditions for reflection, critique, collaboration and high challenge, with high support and active learning (Dewing, 2009) to bring about changes. Discussions were encouraged by the facilitator throughout the project at steering group meetings and as part of the workshops. The groups reflected on practice and were encouraged to contribute ideas, which were discussed, and this enabled the groups to act and collectively question aspects of their everyday practice to bring about changes (Manley and McCormack, 2002; Shaw et al., 2008).

Initially a diagnosis of the need for change was made by assessing the situation (Ross et al., 2004). This was made by the group of staff who identified the need for a behavioural pain assessment tool, as described above. An advisory or steering group representing stakeholders was formed to establish partnerships and engage managers (Ross et al., 2004). This was multiprofessional and included: the project lead (acute pain nurse specialist); the clinical nurse specialist from the mental health liaison team for older people; matrons; medical staff (geriatricians); nurses; and physiotherapists from the complex care and trauma wards. This support was required to ensure patient-centred care in practice (Glasson et al., 2006). This group had an understanding of the contexts and culture of the individual wards and was credible. The group members were also in a position to influence other staff through leading by example and reminding staff to use the pain assessment tools. The purpose of the group was to provide expert advice, set milestones and meet regularly to ensure the project kept to its targets.

Ethical considerations
This study did not fall under the criteria of research requirements for the local ethics committee because it involved healthcare professionals and was using research evidence in practice. It was therefore not reviewed by this body. An outline of the project including its aims and objectives was presented to the director of nursing, who agreed and supported this study. However, it is important that the people involved in the project followed ethical principles throughout. As healthcare professionals, members of the project team were required to follow professional codes of practice to ensure that participants were not harmed by taking part. Principles of confidentiality and anonymity were maintained throughout the project, and all participants were kept informed of the progress of the project. Everyone involved volunteered to take part and were not coerced at any point.

The action cycles used during the project will be described as phases below.

Phase 1: Audit of practice and examination of literature about behavioural pain assessment tools

Audit of current practice
The steering group identified six wards that frequently cared for people with communication problems and dementia; four complex care or medical wards and two trauma wards. The matrons and ward managers were enthusiastic and supported the project. Each ward has its own unique context and culture, which is accepted by the people working there, but the contexts had not been examined to assess their readiness for change. An attempt to undertake an assessment of the context was made using the Context Assessment Index (McCormack et al., 2009) but just a few nurses completed the assessment. The feedback obtained to explain this poor response from the nursing staff was that the questionnaire appeared too long and complex. The physiotherapists who attempted the questions found it difficult because they work on a number of wards. The Context Assessment Index examines elements of a context to ensure there is person-centred practice, and it can help identify areas of strength and weakness to develop practice towards person-centred care (McCormack et al., 2009).
An audit of current practice was undertaken using a variety of approaches. This involved observing practice using audit tools produced by the steering group and was conducted by nurses and therapists on each of the wards. Practice relating to pain assessment was observed for up to ten patients on each ward during the administration of medication, measuring of vital signs and the medical consultants ward round. The observer recorded if each patient was asked about pain during these activities. The data obtained from five wards compared cognitively intact patients with those who appeared to have a communication problem, such as cognitive impairment. A total of forty-five patients were observed, see Table 2 for results. The observations suggest that cognitively impaired patients were less likely to be asked about pain and there were issues about recording a pain score for both groups of patients.

**Table 2: Results of the observational audit**

<table>
<thead>
<tr>
<th></th>
<th>35 COGNITIVELY INTACT PATIENTS</th>
<th>19 COGNITIVELY IMPAIRED PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asked about pain</td>
<td>30 (86%)</td>
<td>15 (79%)</td>
</tr>
<tr>
<td>Pain recorded</td>
<td>23 (66%)</td>
<td>9 (47%)</td>
</tr>
</tbody>
</table>

**Examination of literature**

An examination of the literature relating to pain assessment tools and cognitive impairment and dementia was conducted by one of the geriatricians, a physiotherapist and nursing staff, with the help of the hospital librarian. A total of 17 behavioural pain assessment tools were identified. The abstracts for many of the assessment tools were examined and inclusion/exclusion criteria agreed before examining the specific assessment tools. See Table 3 for inclusion and exclusion criteria.

**Table 3: Inclusion and exclusion criteria for the literature review**

<table>
<thead>
<tr>
<th>INCLUSION</th>
<th>EXCLUSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tool needs to have been validated</td>
<td>Not validated or used on real patients</td>
</tr>
<tr>
<td>Used on patients</td>
<td>Used in long-term care facilities only</td>
</tr>
<tr>
<td>Used in the acute care setting</td>
<td>Appears complex and difficult to use</td>
</tr>
<tr>
<td>Easy to use (subjective)</td>
<td>Requires a lot of instruction/education</td>
</tr>
<tr>
<td>Clear appearance</td>
<td></td>
</tr>
</tbody>
</table>

**Evaluation**

As a result of the audit of practice and examination of literature, we confirmed that assessment of pain was a problem on the complex care and trauma wards and a large number of behavioural assessment tools have been produced. An assessment tool for cognitively impaired patients was not used in the six wards involved in the project. This may be because there is no one tool that has strong reliability and validity and can be recommended for adoption in clinical practice (Herr et al., 2006).

The results of the audit and examination of literature were presented and discussed at a meeting of the steering group. The literature search by staff had identified and obtained seven assessment tools that they felt could be used in practice. The steering group examined the seven tools and subjectively rated their appropriateness for use in practice. Three assessment tools obtained a high rating and these are highlighted in Table 4.
Table 4: Summary of literature examined for pain assessment tool

<table>
<thead>
<tr>
<th>SCALE</th>
<th>REFERENCE</th>
<th>COMMENTS</th>
<th>INITIAL RATING</th>
</tr>
</thead>
</table>
- Long-term care and relies on previous knowledge of patient  
- Easy to use                                                | 5-6/10               |
- Not pain specific, no grading of pain  
- Scores on movement and on rest but scoring system is confusing | 7/10               |
- Long-term care and extended time required  
- Lots of questions (23) and over two pages | 1/10               |
- Long-term care and relies on knowledge of patients  
- Not validated - relied on caregivers giving list of pain-related behaviours | 3/10               |
- Tested in nursing homes and specialist dementia care units  
- Complicated to use and misleading but we liked some aspects of the tool | 5/10               |
- Statistically analysed results  
- 22 behaviours identified by tool  
- Looked complicated for use | 2/10               |
- Suitable for long-term care, chronic pain and musculoskeletal pain  
- Identifies three pain behaviours and difficult to elicit an intensity score | 2/10               |
Phase 2: Decision of which assessment tools to trial

Workshops

Two workshops were held, with participants including registered nurses, physiotherapists, healthcare assistants and student nurses. Information about cognitive impairment, delirium and dementia, pain assessment and the management of pain for older people was presented. The workshop groups then carried out a ‘claims, concerns and issues’ exercise in relation to assessing pain in patients with cognitive impairment. This exercise is based on fourth generation evaluation to enable a focus on different stakeholders, and leads to mutual understanding between stakeholders (Guba and Lincoln, 1989). See Table 5.

This exercise was very useful and assisted in the identification of the workshop participants’ desire to recognise and assess pain. It also acknowledged the need for an assessment tool to provide consistent assessments in patients with cognitive impairment and dementia, which would identify pain and assist in overcoming the problem of prescribing analgesia.

Table 5: Summary of claims, concerns and issues

<table>
<thead>
<tr>
<th>CLAIMS</th>
<th>CONCERNS</th>
<th>ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ That we do recognise pain in patients with cognitive</td>
<td>▪ That pain in dementia patients is ignored or not recognised</td>
<td>▪ Why do patients with cognitive impairment not get appropriate</td>
</tr>
<tr>
<td>impairment</td>
<td></td>
<td>assessment in regards to pain?</td>
</tr>
<tr>
<td>▪ Recognise that dementia patients do feel pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Talking and discussing pain assessment for dementia</td>
<td>▪ Pre-judgement by health professionals that people with dementia do</td>
<td>▪ How to get doctors to recognize patients are in pain</td>
</tr>
<tr>
<td>patients</td>
<td>do not experience pain and so do not address this</td>
<td>▪ How to make sure the pain does not get ignored</td>
</tr>
<tr>
<td>▪ Pain is recognised in dementia patients by visual</td>
<td>▪ That we cannot get doctors to recognise this and to prescribe regular</td>
<td>▪ How to improve pain management in the elderly</td>
</tr>
<tr>
<td>rather than by asking them</td>
<td>regular analgesia</td>
<td></td>
</tr>
<tr>
<td>▪ Recording if in any pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Discuss how we can improve the management of pain for</td>
<td>▪ Doctors not willing to prescribe opiates for elderly confused patients</td>
<td>▪ Recognising pain in people with dementia and cognitive impairment</td>
</tr>
<tr>
<td>individuals with cognitive impairment with their families/</td>
<td></td>
<td>▪ Tools for dementia patients to assess pain needed</td>
</tr>
<tr>
<td>carers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The seven behavioural pain assessment tools selected following the literature review were examined by workshop participants to identify a suitable tool for use in clinical practice. They identified the same three tools as suitable for trial within the clinical area that were identified by the steering group. The assessment tools chosen for the trial were: The Abbey Scale, Pain Assessment in Advanced Dementia (PAINAD) and Checklist for Non Verbal Pain Indicators (CNPI). Table 6 presents the main features of the assessment tools.
Phases 3 and 4: Trial and evaluation of the assessment tool

Table 6: The main features of the pain assessment tools

<table>
<thead>
<tr>
<th>FEATURE</th>
<th>ABBEY</th>
<th>CNVI</th>
<th>PAINAD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocalisation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Facial grimace</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Body language</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Behavioural changes</td>
<td>✓</td>
<td>Restless/rubbing</td>
<td>✓</td>
</tr>
<tr>
<td>Physiological changes</td>
<td>✓</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Physical changes</td>
<td>✓</td>
<td>Breathing</td>
<td>X (Consolability)</td>
</tr>
</tbody>
</table>

Phase 3: Trial and evaluations of the assessment scale

Six wards were involved in the project, four from complex care within the medical division and the two trauma surgical wards. It was agreed at the workshops that all six wards would be involved, with two wards each trying one of the three assessment tools – for example, the trauma wards used the Abbey scale, two complex care wards used PAINAD and two used the CNPI.

A practitioner or ‘champion’ from each ward, who had attended the workshop or was a member of the steering group and had demonstrated an interest in the project, volunteered to explain how to use the behavioural pain assessment tool to staff and to promote its use within their ward.

Evaluation of the initial trial

An evaluation sheet was produced by the steering group. Six weeks after introducing the behavioural pain assessment tools, the staff on each ward were invited to evaluate the tool they had used. They were asked to provide basic demographic data, their professional group, ward type and the assessment tool they had used. The questions asked if they had understood how to use the assessment tool, if it was easy to use, how long it had taken to administer and if any action was needed as a result of their assessment. They were asked to rate the assessment tool with a score from one to ten. Finally, the respondents were invited to add any comments they wished about the assessment of pain for people with communication problems/dementia.

A variety of staff groups (healthcare assistants, assistant practitioners, registered nurses, student nurses and physiotherapists) from four of the six wards completed and returned the evaluations. All three scales were evaluated as understandable and easy to use, and took between one and five minutes to administer. The overall mean rating for each scale from a possible score of ten was produced and is presented in Table 7 with some of the comments made by the clinicians.

Table 7: Initial evaluation of three pain assessment tools

<table>
<thead>
<tr>
<th>MEAN SCORE</th>
<th>PAINAD</th>
<th>ABBEY</th>
<th>CNVI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6/10</td>
<td>6.5/10</td>
<td>7/10</td>
</tr>
<tr>
<td>COMMENTS</td>
<td>Easy to follow and completed fast</td>
<td>Gives prompts</td>
<td>Useful if analgesia insufficient</td>
</tr>
<tr>
<td></td>
<td>Good to use especially in those who cannot communicate</td>
<td>Effective and helps justify analgesia</td>
<td></td>
</tr>
</tbody>
</table>
Other general comments included:

‘Difficult to assess if patient has pain or dementia’
‘Pain assessment in dementia is hard because they are shouting; it doesn’t mean they are in pain’
‘Find it hard to read body language’
‘I would like more education’
‘Assessment tool is not to be relied on, only as a guidance tool’

The results of these evaluations were discussed by the steering group. The behavioural pain assessment tools appeared to have been positively accepted by those completing the evaluation. Two wards had not used the scales in practice; clinical workload was the main reason provided on one ward and a lack of knowledge and awareness on the second ward.

Evaluation and reflections of the evaluation
The overall rating was similar for all three behavioural scales. The steering group discussed the findings and reflected that ‘something was better than nothing’. The scales appeared to have been accepted but we reflected that there was a lack of critical appraisal of their use at this point. We agreed that there was a need to evaluate the tools further to establish if any one tool was appropriate. A second trial was suggested, using the same pain assessment tools but on different wards to enable a comparison between the tools. For example, the two trauma wards that had initially used the Abbey scale used the CNPI during the second trial. The clinical staff and the champions on each ward agreed to the second trial.

Second evaluation
The same evaluation sheet was used and completed by staff six weeks after trialling the tools for a second time. The Abbey and PAINAD were again rated as understandable and easy to use by 100% of respondents. The CNPI was found to be understandable by 100%, but just 44% found it easy to use. See Table 8 for a summary of the evaluation following the second trial of the pain assessment tools. Many practitioners asked for Cheyne-Stokes to be removed from the PAINAD because it is a term used when an individual's breathing is very slow and irregular with temporary cessation, and is not associated with pain.

Table 8: Initial evaluation of three pain assessment tools

<table>
<thead>
<tr>
<th></th>
<th>PAINAD</th>
<th>ABBEY</th>
<th>CNVI</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEAN SCORE</td>
<td>7.75/10</td>
<td>7.4/10</td>
<td>4.2/10</td>
</tr>
</tbody>
</table>
| COMMENTS      | ▪ A very good pain assessment tool
▪ Easy to use
▪ Remove the ‘Cheyne-Stokes’
▪ Like the documentation
▪ Effective and justifies analgesia
▪ It is not clear what the numerical scores should action….would need several sheets per day if patient on regular observations
▪ No clear guidance as when to action giving pain relief
▪ Nowhere to document findings |
During both the trial periods relatives of people with communication problems/dementia/cognitive impairment identified pain that had not been found using the assessment tool. The individual patient did not appear to be in pain and the assessment tools did not identify the specific pain behaviour for a small number of patients. This indicated that pain behaviour can be very individual and the literature describes this issue when attempting to categorise behaviours that may indicate pain. For example Fuchs-Lacelle and Hadjistavropolous (2004) identified 60 behaviours. The assessment tool therefore helps to indicate pain but is not to be relied on entirely.

Evaluation and reflections
The findings of this second evaluation were discussed by the steering group. The Abbey pain scale and the PAINAD had similar ratings from the staff using them. The PAINAD layout was popular, with clear descriptions of the behaviours to observe. The Abbey contained all the six observational factors suggested by the American Geriatrics Society’s pain management guidelines (2002). The lack of involvement from family members or close carers was an area that the group reflected on and discussed. It was strongly felt that their knowledge of the patient meant they should be involved in the recognition and assessment of those with communication difficulties. The physiotherapists also wanted an area to record any specific observations made during mobilising the individual.

As a result of this discussion, an initial draft of a composite assessment tool that combined the layout and some of the content of PAINAD (omitting Cheyne-Stokes respiration) with the content and scoring system of the Abbey assessment tool. A section for the family or close carer of the patient to describe specific behaviours that indicate pain was added and a section for the physiotherapist was also included. In addition, a chart was produced to record a sequence of assessments to observe any changes in behaviours following interventions. This initial draft was distributed to everyone involved in the project; copies were sent to the six wards for consultation. The draft tool was discussed at a meeting of senior healthcare staff from across the Royal Bolton Hospital NHS Foundation Trust. The suggestions resulted in slight changes to produce the Bolton Pain Assessment Tool (BPAT), see Figure 1.

Discussion
Greater use of a pain assessment tool depends on the existence of an adequate tool specifically designed for pain assessment for people with communication problems and/or dementia. There is some evidence that the tools available are deficient (McAucliffe et al., 2008). This project demonstrated that three pain assessment tools for people with communication problems could be used in acute care but the clinicians identified problems with each one. The Abbey pain scale includes all six dimensions recommended by the American Geriatric Society (2002), but staff found it to be subjective, requiring knowledge of the person. PAINAD was found to have a user friendly layout, but lacked the detail of the Abbey scale, and CNPI was not found to be acceptable when compared to the other two assessment tools.

The project leader, the acute pain nurse specialist, could have examined the literature and decided to use a pain assessment tool from this literature and then expect practitioners to use it in practice. This would have been a conventional way of introducing a change to practice, using a linear or technical practice development approach, where the outcomes of the project are decided in advance by the facilitator and the staff are the instrument through which practice is changed (Manley and McCormack, 2004). When using this approach, the focus is usually to apply new knowledge, skills, behaviour and attitudes to improve performance or productivity. There is an assumption that the change will be unproblematic, linear and rational (Parkin, 2009). This approach has been found to produce limited change in practice.
This project used an emancipatory practice development approach, where collaboration and participation with as many stakeholders as possible was encouraged and the practitioners themselves shared the responsibility of introducing the pain assessment tools (Manley and McCormack, 2004). Staff members examined the literature and decided themselves which pain assessment tools to trial. This was more successful than traditional models of change because the responsibility for the change lay with the workplace team rather than policy makers, who tend to be far removed from the situation (Hall, 2006). In this project the group itself defined the issues, instigated, implemented and assessed actions for change in a collaborative manner (Parkin, 2009). Staff usually want to improve their own service – they tend to feel more confident to say something about their own situation and own the changes (Fox et al., 2009). In this case the behavioural pain assessment tool was selected by the steering group and participants during the workshops. Each pain assessment tool was evaluated by the staff based on their experiences of using them in practice. This emancipatory approach ensured that their involvement led to raised awareness and action, resulting in changes in pain assessment practice. It also increased their awareness of the importance of including a member of the patient’s family or close carer in the process.

Using this collaborative approach to change resulted in it being viewed as less specialised or threatening for the staff involved (Fox et al., 2009). Members of the ward teams introduced and explained the assessment tool to their colleagues and demonstrated that the proposed assessment tools did not require specialised training by the nurse specialist. They were members of the individual wards involved and understood the specific context. They were responsible for and owned the change of introducing the use of a behavioural pain assessment tool locally (Manley, 2004), see Figure 1.
**Figure 1**

**BOLTON PAIN ASSESSMENT SCALE**  
(For patients with communication problems)

<table>
<thead>
<tr>
<th>SCORE</th>
<th>ABSENT</th>
<th>MILD 1</th>
<th>MODERATE 2</th>
<th>SEVERE 3</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>VOCALISATION</strong></td>
<td>None</td>
<td>Occasional moan or groan</td>
<td>Low level speech with a negative or disapproving quality</td>
<td>Repeatedly crying out, loud moaning or crying</td>
<td></td>
</tr>
<tr>
<td><strong>FACIAL EXPRESSION</strong></td>
<td>Smiling or relaxed</td>
<td>Looking tense</td>
<td>Sad Frowning</td>
<td>Grimacing and looks frightened</td>
<td></td>
</tr>
<tr>
<td><strong>CHANGE IN BODY LANGUAGE</strong></td>
<td>None</td>
<td>Tense, fidgeting</td>
<td>Guarding part of the body</td>
<td>Withdrawn, rigid, fists clenched. Knees pulled up</td>
<td></td>
</tr>
<tr>
<td><strong>BEHAVIOURAL CHANGE</strong></td>
<td>None</td>
<td>Increased confusion</td>
<td>Refusing to eat, alterations in usual pattern</td>
<td>Pulling or pushing away, striking out</td>
<td></td>
</tr>
<tr>
<td><strong>PHYSIOLOGICAL CHANGE</strong></td>
<td>Normal</td>
<td>Occasional laboured breath, increased heart rate</td>
<td>Hyperventilation, increased heart rate and BP</td>
<td>Change in pulse BP, respiratory rate and perspiring, flushed or pallor</td>
<td></td>
</tr>
<tr>
<td><strong>PHYSICAL CHANGES</strong></td>
<td>None</td>
<td>Skin tears</td>
<td>Pressure sores, arthritis</td>
<td>Post surgery, trauma</td>
<td></td>
</tr>
</tbody>
</table>

Comments by family or usual care givers

Pain on movement/ physiotherapy

| TOTAL SCORE: |

0-2 = NO PAIN  
3-7 MILD PAIN  
9-13 MODERATE PAIN  
14+ SEVERE PAIN

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However, this understanding was not explored to identify the values and beliefs of each ward or to recognize the contradictions of espoused or spoken values and beliefs compared to reality of their practice (Manley and McCormack, 2003). This lack of examination of the contexts was demonstrated by the lack of engagement and ownership on two of the six wards. The Context Assessment Index could have provided information about the individual wards to identify the contextual issues that explain this, but we failed to obtain this information during the first phase of the project.

An important element of practice development is to use and develop the knowledge and skills of the staff involved to provide good quality patient-centred care (Manley and McCormack, 2003). As a result of working through each phase, evaluating and reflecting on activities, members of the steering group and ward staff developed a variety of skills including: literature searching; and analysis of the information obtained from the audit, the literature review and the production of an evaluation sheet. Involvement of the clinical teams led to an understanding of pain assessment and its difficulty, as indicated by some of the comments made during the workshops and the evaluation of the tools. The practitioners involved also increased their knowledge of behavioural pain assessment tools and their critical skills as a result of examining and comparing the various tools.

The CNPI assessment tool was originally devised for use in acute care whereas the majority of tools were introduced to long-term care. Simply examining the literature could have identified the CNPI tool as suitable for use in acute care, but by conducting the trials in clinical practice the project demonstrated how this tool was not as easy to use as the others. As a result of conducting trials within practice and comparing the assessment tools, the rating for the CNPI was low. This tool fails to identify the severity of pain and evaluation of its sensitivity in detecting a response to treatment is required (Ersek et al., 2010).

The PAINAD tool was described as reliable and a useful measure by Schofield (2008). The tool was compared to other pain ratings during its development and PAINAD was able to detect differences in pain associated with different medical conditions and analgesic administration. Internal consistency of PAINAD was lower than expected and this was considered to be because there were only five items. It was validated on a very small number of limited subjects, all white and male in the USA (Warden et al., 2003). One of the items found to lack utility in a study by Jordan et al. (2011) was the ‘breathing’ item that suggests that severe pain is indicated by Cheyne-Stokes respiration; none of the steering group or clinicians agreed with the suggestion that Cheyne-Stokes indicates pain.

A study by Ersek et al. (2010) compared the psychometric properties of the CNPI and the PAINAD tools. They concluded that both possess limited reliability and validity, with neither demonstrating clearly the properties required to become a preferred tool. They suggested further evaluation with clinical staff for both tools, which this project has accomplished within a specific context and on a small scale, finding that PAINAD was easier to use in practice on the four wards that used it compared to CNPI.

The assessment of pain using the Abbey pain scale was not compared to another assessment rating during its development; instead it was rated by nurses familiar with the nursing home resident. It is the only scale trialled in this project that includes all six components suggested by the American Geriatric Society guidelines (2002). The Abbey pain scale is advocated for use by the Royal College of Physicians, British Geriatric Society and British Pain Society (2007) but it has not been formally studied in acute care settings. The practitioners using the Abbey scale in practice found it very useful but subjective and dependent on prior knowledge of the individual. It does provide a scoring system that is compatible with the pain score used within the hospital.
During the project there were some patients in whom the assessment tools failed to identify pain, but their relatives did describe pain problems to nursing staff. The family or carers have not been included in previous pain assessment scales and it was felt by everyone involved in the project that this was an important factor. The association between the patient report and surrogate reports has been described as strong for the presence of pain, but not for intensity (Scherder et al., 2009). Surrogate reports frequently include healthcare staff rating pain, not a family member or usual carer; this is an area that requires further investigation.

The ‘Bolton Pain Assessment Tool’ is now under trial on the six wards involved in the project. A research proposal is currently under development to test its usefulness in a variety of acute care settings. The research will also explore the experience of pain assessment of the families of people with dementia and their involvement in the recognition and assessment of pain.

**Conclusion**

There are several behavioural pain assessment tools available, but they are not used in everyday practice. Using a participatory and emancipatory approach involving clinical staff led to three pain tools actually being used in practice. The staff were involved in decisions relating to the project. They evaluated and became critical of the scales and provided suggestions for improvement.

From the literature, the CNPI assessment tool appeared to be suitable for acute care (devised in acute trauma specialties) but in practice and when compared to other tools it was not useful. None of the established tools were ideal and at times failed to identify pain. The need to produce an assessment tool specifically for acute care was identified by the people involved in the project. Ideally, the pain assessment should involve relatives and/or established carers.

An assessment tool that combines two established scales has been produced. Behavioural pain assessment should always be used with other information and ideally with someone who knows the individual well. This tool now needs to be used in practice and requires further investigation by both healthcare staff and family members of the patients.

**Implications for practice**

Nurses and other healthcare professionals have a responsibility to recognise and assess pain in all client groups. When an individual is unable to describe and express pain, staff should attempt to identify pain through observing behaviour and by obtaining a surrogate measure from someone close to the person.

This project demonstrates that busy clinical staff can be actively involved in a practice development project. They identified the problem initially, examined the literature about behavioural pain assessment tools, and collaboratively made decisions about which tools to trial. Using a participatory and emancipatory approach, active participation and changes were made by the staff themselves as a result of raised awareness and ownership of the change, not because they were told to do it. Behavioural pain assessment tools can be used in practice to help identify pain in people with communication problems, but there is a need for input from someone close to patients.

**References**


Acknowledgements
This project involved a multi-professional group and a large number of clinical staff at Royal Bolton Hospital and I would like to thank each of them for their valuable contributions. The outcomes of the project are as a result of their participation and contribution.
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Julie Gregory (PhD, MSc Pain Management, BA Hons Health Management, RGN), Nurse Lecturer, University of Manchester, Manchester, UK.

A commentary by Loretta Bellman follows on the next page.
COMMENTARY

How can we assess pain in people who have difficulty communicating? A practice development project identifying a pain assessment tool for acute care

Loretta Bellman

Anticipating pain, recognising pain cues, and providing effective relief from pain are essential nursing skills that reflect compassionate practice. This is a very worthwhile project, addressing as it does current gaps in nursing knowledge regarding pain assessment in acute care settings for people who have difficulty communicating. My interest in this topic is threefold: a background in surgical nursing and action research, a recent postoperative experience regarding inadequate pain relief (even though I could communicate), and an appreciation of the changing demographic in society.

The classic quotation by McCaffery (1968): ‘Pain is what the patient says it is and exists whenever the patient says it does’ is still considered by many to be the gold standard. However, increasingly, there are many more people being nursed within the acute care sector who are unable to articulate their need for analgesia or describe the frequency and severity of their pain. Indeed, the number of people aged 65 and over is projected to increase by 23 per cent from 10.3 million in 2010 to 12.7 million in 2018 (Rutherford, 2012), and people with dementia will rise to more than 1 million by 2021 (Alzheimer’s Society, 2012). There is, therefore, a great need for the development, implementation, evaluation, and auditing of the relevance and use of a pain assessment tool for people with communication problems, cognitive impairment and dementia.

In this nurse-led emancipatory practice development project, encompassing a participatory action research approach, there is clear engagement with, and participation of, the multidisciplinary team to change practice. Within the word allowance, the research approach is clearly demonstrated and appears to meet the criteria for judging action research projects (Williamson et al., 2012). The descriptions also provide insight and understanding for colleagues in other healthcare settings to improve their practice (transferability).

The authors are to be praised for gathering different sources of evidence to underpin the need for tool development and the critical review of a growing literature on the topic. Yet, I wonder why family/carer involvement was not included in the project. There is increasing evidence in the literature (for example Falls et al., 2004; Smith, 2007) and the authors specifically quote Buffum et al. (2007) who identified family involvement as helping to assess the presence of pain and response to treatment when patients cannot report pain themselves. It is good to see that a follow-up research proposal will address this issue.
Ethical approval was not sought and this is justified by the authors. I am well aware of the challenges of presenting an action research project to over-cautious ethics committees. However, it is good practice to contact the chair of the local research ethics committee to review a proposal. The chair can then decide if there are any ethical issues to be addressed in the project and whether it needs to be submitted formally for approval (Bellman, 2012).

Whenever I read that confidentiality and anonymity were maintained throughout a participatory action research project, I wonder how is this always possible? No doubt others in the same organisation will know who participated. Can you always disguise the data or individuals in specific roles? Also, while the guarantee of anonymity may protect participants (from negative consequences), it also excludes them from public ownership of the data and recognition of their input into its use. Participants may therefore choose to forego anonymity.

It is good to see the development of the Bolton Pain Assessment Tool and the inclusion of ‘comments by family or usual care givers’. Excellent that ‘pain on movement’ is also included. As a surgical patient I was only ever asked to score my pain when resting in a chair or on the bed. I was never asked if the score was different when moving around! Levels of pain on resting and on movement should both be incorporated into all pain assessment tools.

This study is to be commended for raising awareness of the need to anticipate, recognise, and take action to address pain in people who have difficulty in communicating. The contemporary research approach – although challenging to implement, particularly in dynamic healthcare contexts – has enabled staff to participate in the integration of continuous quality improvement, compassionate care, clinical change and innovation. Key objectives now include continuing to use and evaluate the new charts in the way intended. Also, the knowledge, continuous learning and practice development from this project reflects the NHS Institute for Innovation and Improvement’s call to action to improve care for people with dementia in acute hospitals by March 2013.

References

Loretta Bellman (PhD, BSc Hons, RGN, RCNT, RNT, Cert Ed), Independent Consultant, Nursing and Healthcare.