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Citation: Schofield, Patricia, Clarke, Amanda, Faulkner, Mark, Ryan, Tony, Dunham, Margaret and Howarth, Amanda (2005) Assessment of pain in adults with cognitive impairment: A review of the tools. *International Journal on Disability and Human Development*, 4 (2). pp. 59-66. ISSN 2191-1231

Published by: Walter de Gruyter

URL: <https://doi.org/10.1515/IJDHD.2005.4.2.59>
<<https://doi.org/10.1515/IJDHD.2005.4.2.59>>

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Assessment of Pain in adults with cognitive impairment: A review of the tools

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This study was funded by the University of Sheffield, School of Nursing & Midwifery, CARER departmental grant.

Abstract

The aim of this paper is to discuss the results of a review into the literature related to chronic pain and the older adult. Several themes within the review have been identified and reported elsewhere and the final report has been published by the University of Sheffield in the form of an annotated bibliography. This report focuses upon the findings of the in relation to the assessment of pain in the adult with cognitive impairment. Issues surrounding assessment in the non-cognitively impaired older adult have also been reported elsewhere. For this paper nine studies will be discussed which report the development and testing of pain assessment scales the focus of which is upon behavioural indicators of pain. Some scales have been omitted from the review and the rationale for this decision will be discussed. Each of the selected scales will be discussed and the authors will make recommendations for both clinical practice and for future research based upon the validity, reliability and user friendliness of the scales. From the paper it can be concluded that the Abbey, DOLOPLUS-2 and PACSLAC appear to be the most reliable and valid and in terms of the “user friendliness” would be appropriate to explore further. Recommendations are made for further multi-centre evaluation of these scales.

Introduction

Since the introduction of the Gate Control Theory (Melzack & Wall 1965), there have been great strides in the management of pain. The introduction of the recognised definitions of pain, acute pain services and the expansion of chronic pain services to encompass the multidimensional aspects of the problem and consequently pain management programmes have all been introduced. These are exciting times for pain management as it continues to evolve and develop whilst attempting to place pain on the government agenda. Despite this, there are groups of people within society who appear to be under-represented in this area. For example, pain services for individuals with learning disabilities, ethnic communities and older people. Literature surrounding pain management in these areas is sparse. It is only during the last decade that the issues pertaining to pain in the older adult have begun to be highlighted and primarily, much of this work has been carried out in the USA. However, there are some UK studies appearing and recent developments are making carers consider the older population and their needs in terms of pain. The recent National Service Frameworks (DoH) published in the UK does highlight the need to address chronic pain in the older adult and during the International Association for the Study of Pain (IASP) conference in San Diego (2002) it was suggested that it is time for clinicians to “grasp the nettle” and provide services tailored to meet the needs of the older person, as numbers are increasing and it is anticipated that there will be a population explosion of older people in pain by 2020. Some researchers have suggested that 50% of older people living in the community are experiencing chronic pain and this number increases to 80% in the nursing home population (American Geriatrics Society 1998).

Whilst research suggests that the prevalence of pain in the nursing home population is high in the USA, it also highlights that the issues of cognitive impairment are also very high with this group. Figures for the USA suggest between 37-47% (Ferrell et al 1990, Horgas & Tsai 1998, Parmalee et al 1993). Similar figures have been reported by investigators within the UK (Allcock et al 2002, Schofield 2005). As there appears to be around 50% of the care home population that are cognitively impaired it is quite worrying that they could be neglected within the literature as they are potentially unable to articulate their pain and this could suggest the potential for poor pain control, or pain control that is not tailored to their specific needs. The purpose of this paper is to present the findings of a review of the literature related to pain in the older adult. However a particular emphasis will be placed upon the use of assessment in adults with cognitive impairment as the results of the review are published elsewhere.

Method

All of the major data-bases were searched between the years of 1994-2004 (AHMED, CINAHL, MEDLINE, EMBASE, Science Citation Index, Psychlit, ageinfo, anchor housing, index for thesis, steinberg). It was anticipated that literature prior to this date would be sparse and out of date. Cochrane was contacted and there were no systematic reviews of literature in this field or any plans to carry out a review in the near future. The process for collection of the literature involved the following aspects:

Population

- The population included older people and by definition this would include individuals between the ages of 60-100.

Interventions

- The whole range of interventions were examined including, pharmacological, non-pharmacological, assessment methods and complementary approaches.

Outcomes

- Studies were reviewed that highlighted the clinical outcomes of interventions such as quality of life or depression. Also socio-economic information was included.

Study Designs

- It was anticipated that there is limited experimental research in this area and as such all study designs were included.

The following search terms were used:

Older people, elderly, pain, chronic pain, assessment, assessment tools, dementia

Each of the studies were rated using an instrument that addresses the requirements of both qualitative and quantitative studies (Hawker et al 2002)

In total 214 articles were collected. A preliminary review by the team excluded articles that were not research based or related to chronic pain and/or older people. At this stage 78 articles were rejected. The literature obtained was organised into five main categories as follows:

Socio-economic /Prevalence (8 articles)

Attitudes (8 articles)

Assessment (42 articles)

Experiences (40 articles)

Management (40 articles)

From the forty-two articles reviewed in the pain assessment section ten papers particularly focused upon pain in residents with cognitive impairment and nine papers actually discuss the development of specific scales for this group. These scales will be reviewed within this paper. It is important however, to note that the larger review does suggest that for the majority of residents with mild to moderate cognitive impairment, verbal report of pain can be used as a reliable indicator as with the non-cognitively impaired older adult (Kaasalainen & Crook 2004). Thus, suggesting that specific behavioural tools are only necessary for use with the severely cognitively impaired adult.

One of the early and much quoted papers that demonstrates the development of a pain assessment tool is that of Hurley et al (1992). This American paper presents the results of a study developing a tool specifically for the patients with advanced dementia of the Alzheimer type (DS-DAT). The initial study generated the content domain for the DS-DAT by conducting semi-structured interviews with staff in Alzheimer centres. From this investigation, the investigators were able to produce a list of 26 behaviours that were believed to manifest discomfort in this group of patients. Raters were then asked to rate these items and this left the investigators with 18 items. The second study pilot tested the scale with the aim of reducing the items thus achieving measurement reliability. This investigation was conducted over a period of six months within nine long term care facilities. Finally the investigators conducted a longitudinal study to examine the internal consistency of the scale in 82 residents.

Two raters administered the nine item scale (Table 1) over a period of six months and inter-rater reliability was audited three times over the period. Inter-rater reliability, internal consistency and psychometric properties were all found to be good with the DS-DAT

scale but external validity was limited as the scale was only tested in males. But the authors concluded that the scale was useful for the evaluation of “*comfort promoting interventions*” (pg 375). Although a promising scale of its time, sadly, no further evidence of testing of this scale could be found in the literature. Furthermore, no rating scale was applied, the scale was merely a checklist of behaviours. Nevertheless, many other scale developers have used the DS-DAT as a basis for the development of their own scales.

A few years later Feldt (1996) published a paper which proposed the checklist of non-verbal pain indicators (CNPI). This tool was developed following an extensive review of the literature and adding to the University of Alabama Birmingham Pain Behaviour Scale (UAB-PBS) from which they eliminated four pain behaviours. Thus confirming face validity, but no expert panel was invited to comment upon the behaviours. The instrument designed to measure pain behaviours in cognitively impaired older adults and was tested in a pilot study of 88 cognitively impaired and cognitively intact hip fracture patients, the majority of which were female (86%). Behaviours were correlated with self report of pain and of the six behaviours identified, facial grimaces/winces occurred in 44% of the patients tested. The investigators acknowledge that this was a very small part of a larger study and planned to evaluate further. Also, this study was conducted in an acute pain setting and further study would be required to validate the tool in a chronic pain setting.

Another tool introduced in 1999 was that developed by Kovach et al (1999). This tool developed in the USA and consists of a protocol that was designed to assess several factors a) discomfort in people who can no longer describe their pain b) accurately and thoroughly treat physical discomfort and c) decrease inappropriate use of psychotropic medication. The project described by Kovach et al (1999) was one aspect of a larger

educational study designed to improve pain management practice. Fifty-seven long term care facilities were recruited into the study and an education strategy was introduced over a period of 12 months which included the addition of the ADD protocol (Assessment of Discomfort in Dementia). Thirty-two volunteer nurses from twenty-five of the facilities agreed to participate in a pilot assessment of the utility of the ADD which had been developed following a review of the literature and an adaptation of the DS-Dat scale.

Internal consistency and test-retest reliability were not established with the study. But inter-rater reliability and predictive validity were demonstrated. Evaluation of the protocol identified a number of problems associated with its use, including time, resistance to change and lack of education regarding the use of the protocol. Positive comments included an increased staff awareness of resident's discomfort and 44% commented that they found it helpful. The authors concluded that the protocol was useful and recommended further evaluation using randomized controlled trials. However, further studies have not been identified within the literature as yet.

In 1995 a group was formed to evaluate a scale developed from work with children which was designed to measure pain in the non-communicative elderly, this group was known as DOLOPLUS (Wary 2001). The group refined the scale which was later released as DOLOPLUS-2 and consists of ten items organised into three sub-groups; somatic, psychomotor and psychosocial. Each are rated according to levels of intensity (0-3) thus providing an overall score of 0-30.

Test-retest validity, concurrent validity and inter-rater reliability were evaluated in a series of studies in France and Switzerland in which the authors report positive outcomes (Lefebvre-Chapiro 2001). But further validation testing will need to be carried

out on an International scale before the tool can be accepted and reliability will also need to be further assessed. On a pragmatic level, the DOLOPLUS-2 has been reported within the UK as being rather complex for staff within the care home setting to complete. Further investigation would be required to confirm this anecdotal evidence.

The NOPAIN scale (non-communicative patients pain assessment instrument) Snow et al (2001) was developed following observation of behaviours whilst carrying out activities of living such as bathing and dressing. The tool is divided into four main sections, section one asks the caregiver to provide information regarding the care being delivered at the time of assessment. The next section provides the carer with six pain behaviours (words, noises, faces, rubbing, bracing, restlessness) and the carer is asked to state if these behaviours were identified and score them on a scale of 1-5 depicting intensity. Finally the carer is asked to rate the overall pain intensity for the day using a pain thermometer. The tool was evaluated in two studies with trained and untrained staff in care homes in the USA and there is evidence of moderate validity and reliability testing but content validation will be required. The items identified within this scale do not appear to be generated conceptually but they do reflect those identified by Feldt (1998).

Villaneuva et al (2003) later developed the Pain Assessment Scale for Dementing Elderly (PADE). Again this scale was developed in the USA and was designed to help carers determine the presence of pain in residents of care homes. Twenty-four items were identified in three parts and these items were based upon a literature review, and interviews and observations with care home staff. The items were categorized into three main themes and validated in three clinical settings. Reliability and validity was assessed by evaluation of the scale in a number of long term care settings with residents suffering from dementia but much further investigation is needed before this tool could be

accepted. There is little evidence to support the credibility of the behaviours as determined by the unqualified carers and the validation panels were not clearly identified as being separate from the study.

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The PAINAD (Warden et al 2003) is a scale developed in the USA to assess pain in people with advanced dementia. The scale was developed using a combination of expert clinicians and observational methods. The literature review by the authors recognized the DS-DAT scale but commented that this scale was too complicated. Therefore they based their scale upon the FLACC (The Face, Legs, Activity, Cry & Consolability) scale which is used with children (Merkel et al 2002). Initially, the scale was rated by the investigator, three trained nurses and two untrained carers. Later the psychometric properties of the scale were examined using an expert panel of nurses and a social worker from the dementia special care unit where the study was carried out. Observations of the residents were then carried out and the scale used and compared against the DS-DAT scale. The investigators reported adequate evidence of inter-rater reliability and construct validity but the sample size was very small, with only nineteen residents used and six staff, so further work will need to be done on this scale. Nevertheless the scale is less complex than the DS-DAT scale and therefore easier for staff to administer, although, the authors commented that training for use of this scale required a few hours which is an important consideration in practical settings.

A further scale developed in Canada is the PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate) (Fuchs-Lacelle & Hadjistavropoulis 2004). This study was conducted in three phases, phase 1 involved the investigators conducting interviews with experienced nurses and care assistants to generate a list of

behaviours, in phase 2 the nurses were asked to complete the checklist whilst carrying out potentially pain provoking procedures and phase 3 involved an evaluation of the scale in terms of determining pain events. Twenty-eight staff were involved in the first phase of the study, with forty registered nurses taking part in phase two. Residents were not actively involved in the study but they were assessed by staff using the scale in both phase 2 & 3. Upon completion of the three phases, the authors concluded that the scale was easy to complete and could be completed within five minutes thus concluding that there is a potential for use of this scale within long terms care facilities. However, the caregivers were asked to provide retrospective reports of the pain which could be influenced by memory bias and whilst the psychometric properties of the scale were deemed to be good, further multi-centre studies would need to be carried out and the scale does appear to be fairly complicated on face value so again important training issues occur.

The final scale within this review is that of Abbey et al (2004) which was reported in an Australian study conducted in two stages. The study was designed to develop a highly reliable pain scale for people with end stage dementia and was carried out in 24 residential care facilities across four states. Initially twelve pain measures were identified which were then refined to leave the scale with six. Each of the six items were given a potential score of three grades (0-2, 3-7, 8-13) thus 18 being very severe pain. Staff were then asked to complete the scale independently for each resident thus confirming inter-rater reliability. Within this stage facilities that were included in stage one were asked to participate but also new facilities were added. Unique to this study, qualitative evidence was also collected from staff related to their views of the scale. The authors conclude that they have demonstrated evidence of reliability and validity but they do acknowledge that depression, fatigue and agitation can confound their behaviours. In

spite of this the scale is easy to administer which is an important issue when working in busy care setting. However, further reliability and validity testing will need to be carried out.

Conclusion

The review of the literature carried out for this paper was not a systematic review in terms of a Cochrane type review; it was conducted as part of a larger project to develop an annotated bibliography. The bibliography itself will be published elsewhere and other themes identified within the review have also been published elsewhere. As such this could be perceived as a limitation. A number of papers were identified that relate to the assessment of pain per se and those have been reported separately, however, from these papers we are able to conclude that assessment tools such as NRS and VRS are the preferred methods for the older adults by which to self-report their pain intensity (Schofield et al 2005). Furthermore, Kaasalainen & Crook (2004) demonstrated with their study that only adults with severe cognitive impairment were unable to complete the self report scales and as such there is only a need to adopt behavioural scales when severe cognitive impairment is present.

The purpose of this paper was to review the pain assessment tools that have been designed and tested specifically to measure the experience and to be able to make recommendations regarding both practice and further research. Nine scales have been reviewed in total and it is acknowledged that there are other scales which have been excluded. For example, the Facial Action Coding System (FACS) (Ekman & Frieson 1978) and the PBM (Pain Behaviour Measurement approach) (Keefe & Block 1982).

Both of these measures have been reported as having good validity (Hadjistavropoulos 2001) but they are far too complicated and require training to apply, and it is important that any recommendations for practice are tools that can be easily applied. As experience highlights that any complex measures or charts do not get completed. A further scale omitted is that of Simons & Malabar (1995) which is one of the few UK studies. However, this was omitted as statistical analysis of the scale was not performed. Finally, "Amy's guide" was also omitted as the authors do not report any psychometric properties of the scale (Galloway & Turner 1999).

If we consider table 1, we can see that the behaviours highlighted by each of the authors are fairly consistent with facial expression, voacalisation and body language being identified by most. The scales tend to vary in the number of indicators with the maximum being twelve indicators Kovach et al (2003) and the least being four (Warden et al, Villeneuve et al (2003) and some of the scales are too complicated for every-day use. But in terms of user friendliness, the scales that are reported best are that of Abbey (2004) & Fuchs-Lacelle (2004) which is an important consideration for practice. Clearly, there is a need to acknowledge that certain behaviours can indicate pain and as such for practice, doctors, nurses and carers should be prepared to acknowledge these behaviours and act on them as potentially being linked to pain.

Each of the studies do report evidence of reliability and validity and acknowledge limitations of their work. Collectively they do corroborate the behavioural indicators, but individually, they do not demonstrate sufficient evidence to support the use of the scale. The DOLOPLUS-2 is the only scale to demonstrate an International perspective within two countries. But all of the studies are consistent in that they recommend further testing. Interestingly, some of the scales have been around for a number of years but

there is limited evidence of further evaluation within the published literature. The only exception to this is the DS-DAT scale (Hurley et al 1992), although, some of the scales are adapted from the others, such as the PAINAD which has combined the DS-DAT and FLACC scale. It is important that we embrace the scales that already exist and stop developing further scales but spend more time validating the most promising scales.

In conclusion, the most promising scales for both practice and research appear to be PACSLAC, Abbey and DOLOPLUS-2. In terms of research, all of the authors have attempted to address many of the requirements of validity and reliability to a lesser or greater degree and they do appear to be incorporated into a chart format that could be adopted in practice with a fairly easy scoring system. The CNPI, DS-DAT and ADD have been around for a number of years without any further investigation. PADE needs more work to support the credibility of the behaviours identified and PAINAD was introduced with a very small sample size, whilst NOPAIN does not appear to stem from concepts within a literature base. A way forward with this would be to carry out a multi-centre study that compares the three main scales.

On a final note however, whichever pain assessment tool is selected for practice, it is important to remember that the management of pain is not just about assessment, it is a much more complex process and staff cannot afford to ignore the responses that they are identifying by using pain assessment scales, the next and very crucial part of the process is to act upon the results and manage pain in the older cognitively impaired adult more effectively. An important part of this whole process is to involve family and carers who may be able to provide very relevant information.

4079 words

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Table 1

Hurley et al	Feldt	Kovach et al	Wary & DOLOPLUS group	Snow et al	Villaneuva et al	Warden et al	Fuchs-Lacelle & Hadjistavropoulis	Abbey et al
DS-DAT	CHPI	ADD	DOLOPLUS	NOPAIN	PADE	PAINAD	PACSLAC	Abbey
Noisy breathing	Non verbal vocalisations	Tense body language & repetitive movement	Somatic complaints	Words	Facial expression	Breathing	Activity/body movement	Vocalization
Negative vocalization	Facial grimacing	Fidgeting	Body posture	Noises	Breathing pattern	Negative vocalization	Facial expression	Facial expression
Content facial expression	Bracing	Physical aggression	Protection of sore areas	Faces	Posture	Facial expression	Vocal behaviours	Body language
Sad facial expression	Rubbing	Tearfulness	Expression	Rubbing	Proxy evaluation of pain	Body language	Social personality mood	Behavioural changes
Frightened facial expression	Restlessness	Delusions	Sleep patterns	Bracing	Dressing	consolability	Eating sleeping	Physiological changes
Frown	Vocal complaints	Withdrawal behaviour	Washing/dressing	restlessness	Feeding			Physical changes
Relaxed body language		Sad of frightened facial expression	Mobility		Transfer			
Tense body language		Verbal outburst	Communication					
fidgeting		Repetitive waking at night	Social life					
		Phobias of fears	Behaviour problems					
		Hallucinations						
		Noisy breathing						

