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#### SPECIAL ARTICLE

### Advanced dementia pain management protocols\*

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#### **KEYWORDS**

Pain; Dementia; Pain management **Abstract** Pain management in advanced dementia is complex because of neurological deficits present in these patients, and nurses are directly responsible for providing interventions for the evaluation, management and relief of pain for people suffering from this health problem. In order to facilitate and help decision-makers, pain experts recommend the use of standardised protocols to guide pain management, but in Spain, comprehensive pain management protocols have not yet been developed for advanced dementia.

This article reflects the need for an integrated management of pain in advanced dementia. From the review and analysis of the most current and relevant studies in the literature, we performed an approximation of the scales for the determination of pain in these patients, with the observational scale PAINAD being the most recommended for the hospital setting. In addition, we provide an overview for comprehensive management of pain in advanced dementia through the conceptual framework "a hierarchy of pain assessment techniques by McCaffery and Pasero" for the development and implementation of standardised protocols, including a four-phase cyclical process (evaluation, planning/performance, revaluation and recording), which can facilitate the correct management of pain in these patients.

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#### PALABRAS CLAVE

Dolor; Demencia; Manejo del dolor

#### Protocolos de gestión del dolor en demencia avanzada

**Resumen** La gestión del dolor en demencia avanzada es compleja debido a los déficits neurológicos presentes en este tipo de pacientes, siendo las enfermeras directamente responsables de proporcionar intervenciones para la evaluación, manejo y alivio del dolor a las personas que

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sufren este problema de salud. Para facilitar y ayudar a la toma de decisiones, los expertos en dolor recomiendan la utilización de protocolos estandarizados que guíen en el manejo del dolor, pero en España no se han desarrollado protocolos integrales de gestión de dolor en demencia ayanzada.

El presente artículo reflexiona sobre la necesidad de que exista una gestión integral del dolor en demencia avanzada. De la revisión y análisis de los estudios más actuales y relevantes de la literatura, realizamos una aproximación a las escalas para la determinación del dolor en estos pacientes, siendo la escala observacional PAINAD la más recomendada para ámbito hospitalario. Además, proporcionamos una visión general para la gestión integral del dolor en la demencia avanzada, a través del marco conceptual «la jerarquía de evaluación del dolor de McCaffery y Pasero», para el desarrollo e implementación de protocolos estandarizados, que incluye un proceso cíclico formado por cuatro fases (evaluación, planificación/actuación, revaloración y registro), lo que puede facilitar el correcto manejo del dolor en estos pacientes. © 2017 Elsevier España, S.L.U. Todos los derechos reservados.

#### Introduction

Dementia is a progressive debilitating disease characterised by serious cognitive decline, loss of language and the ability to carry out everyday activities. 1 The loss of superior cognitive functions is the main cause of the difficulty in quantifying pain, leading to a lack of its detection and treatment.<sup>2</sup> Pain management is a critical factor in the treatment and effective care of this patient group.3 Pain is the principal symptom of many diseases which affect this population group. The estimated prevalence of pain at a national level is 25-40% within the community, and this figure rises to 50-80% in the institutionalised population. The main causes of the persistence of pain are muscular and skeletal conditions, upper airway infections, urinary infections, pressure ulcers, injuries from falls and the worsening of chronic illnesses.<sup>6,7</sup> They are also the main reasons for this patient group to be admitted into hospital. Ineffective pain management may lead to greater suffering, discomfort and the use of healthcare resources. 9,10 Prognosis affects wellbeing and leads to a reduction in the life expectancy of this group. In contrast, pain which is properly treated is associated with a reduction in risk or delay in the development of delirium and a shorter hospital stay. 11

Defining pain for advanced dementia is an unpleasant subjective experience, which may be communicated through self-reports whenever possible or a combination of behaviours relating to pain. Behaviours relating to pain which these advanced dementia patients present with may be difficult to interpret and this complicates its management. It is thus useful to use observational tools to improve management. Pain experts suggest that any observational tool may be used as part of an integral management protocol for pain, which includes interpretation of scores and verification of appropriate suggested treatments. 13

Over recent years, research has focused on the development of observational tools and their systematic reviews. In one previous review of the literature<sup>14</sup> the need for guidance was detected regarding the best possible available evidence on the development of supportive interventions when taking decisions to aid pain assessment and management in patients suffering from advanced dementia in an acute care

setting. As a result of this need we initiated this literature searching project so that a future pain management protocol could be established, based on the best scientific evidence and later implemented in standard care of people with dementia in our hospital environment.

## Observational scales for advanced dementia pain assessment

The first step towards correct pain management is to detect the presence or suspicion of pain. The most reliable and precise indicator for this is a description from the person concerned aided by validated and reliable tools. The tool selected by the nurse will depend on the patient's characteristics. The gold standard for expressing pain is the self-report. However the communication challenges presented by people with advanced dementia, with cognitive and verbal impairments make it impossible to use this resource.

Instead, these patients may communicate they have pain or discomfort through different behaviours, including restless physical movements and verbal message of difficulty such as groaning and shouting. Pain behaviours presented by elderly patients with advanced dementia may be complex to interpret. As a result of this, in 2002 the American Geriatric Society organised an integral framework of guidelines indicating behaviour patterns of persistent pain in elderly people with advanced dementia. 16 Many observational scales are based on these indicators for people suffering from advanced dementia, with these pain behaviour observations replacing that of self-reporting. Choosing the most appropriate observational tool has to include consideration of the clinical context. In a hospital setting they must be guick and easy to complete because they must be more frequently used due to acute treatment. In residential environments that are larger and more multidimensional a more complete list of behaviours may be assessed, less commonly related to pain but more to changes in activities, interaction and the patient's mental state. Due to their complexity they are useful for monthly or quarterly assessment (Table 1).

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