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Cochrane Corner

Is algorithm-based pain management for people with dementia in nursing homes possible? A Cochrane Review summary with commentary

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The purpose of this commentary is to explore pain management strategies for individuals with dementia, with a particular focus on the Cochrane Review titled "Algorithm-based pain management for people with dementia in nursing homes".[1] The review, authored by Manietta et al.[1] and published by Cochrane Dementia and Cognitive Improvement Group, provides valuable insights into how best to address pain in this population. This Cochrane Corner is being presented in collaboration with the *Turkish Journal of Physical Medicine and Rehabilitation*, with input from the review summary authors in the "implications for practice" section.

As our world continues to age, the number of people over the age of 65 has reached 728 million in 2020, and is predicted to double by 2050.[2] Unfortunately, expensive housing and inadequate pay have made it nearly impossible for older adults to maintain the traditional community norms of living with multiple generations under one roof and relying on their children for support. As a result, a growing number of older adults are choosing to live in nursing homes.[2]

Meeting the physical, mental, social, and environmental needs of elderly individuals living in nursing homes can be challenging, particularly for those with dementia. In fact, it is difficult to identify and address these needs in a timely and effective manner. Moreover, the proportion of people living with dementia in low- and middle-income countries is expected to increase dramatically, with a projected reach of 71% by 2050.[3]

Chronic pain is a significant global health issue for older individuals, not only as a negative subjective experience, but also as a social and economic factor.[4] Studies have found that the prevalence of chronic pain among older individuals living in the community ranges from 25 to 75%, while up to 83% of those in long-term care facilities are affected by chronic pain.[4]

A study of over 350,000 UK Biobank participants aged 39 to 73 years found that chronic pain, particularly when present in multiple sites in the body, was associated with a higher risk of dementia. Researchers found that after adjusting for potential confounders, participants who reported a single site of pain had a 15% higher risk of developing dementia compared to those without pain. However, this risk increased to 36% for those with pain in multiple sites.

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The findings were reported in the Proceedings of the National Academy of Sciences.[5]

Pain assessment and management for individuals with dementia living in nursing homes is complex, and remains an area where improvements are needed. Despite efforts to improve the provision of care, an optimal way to support frontline staff in pain assessment and management for these individuals has not been identified.[6] Research shows that 60-80% of nursing home residents with dementia experience pain on a regular basis. However, they may be unable to communicate their pain to caregivers, making it difficult to recognize and treat. As a result, nursing home residents with dementia receive less pain medication than those without dementia. This lack of treatment can negatively impact their well-being and health, and may also contribute to challenging behaviors, such as aggression.[1,6]

In this Cochrane Systematic Review, studies on the evaluation of the treatment algorithms and pain of the elderly living in nursing homes are compiled.

Algorithm-based pain management for people with dementia in nursing homes (Manietta et al., 2022)[1]

What is the aim of this Cochrane review?

The primary objective of this Cochrane review was to identify the effects of pain management interventions based on an algorithm for reducing pain and challenging behavior in individuals with dementia living in nursing homes. The secondary objective was to describe the components of the interventions and the content of the algorithms.

What was studied in the Cochrane review?

In this review, the description of the interventions' characteristics was guided by the Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare 2 (CReDECI 2) and the Template for Intervention Description and Replication (TiDieR) guideline.

As described in the review protocol, the authors included randomized controlled trials, individually or cluster-randomized, investigating the effects of algorithm-based pain management interventions for reducing pain and challenging behavior in people with dementia.

The population included in this review consisted of individuals with dementia or cognitive impairment living in long-term care facilities, with no restrictions based on the stage of dementia or cognitive impairment. They included all interventions offering pain treatment based on an algorithm.

The study utilized lists of recommendations that were initially evaluated for pain and included pharmacological and non-pharmacological treatments in an algorithmic format. These lists included specifications for the number of repetitions of treatment doses and defined response parameters. A particular emphasis was made to utilize control groups receiving usual care (standard pain assessment and treatment in the participants' care setting) or an active control intervention (i.e. other nonpharmacological or pharmacological treatments for reducing pain or challenging behavior not based on an algorithm).

Phrases that meet these criteria such as "algorithm", "decision tree" or "clinical pathway" were also evaluated.

Studies evaluating a single specific pharmacological or non-pharmacological approach were not included in the review.

The primary outcomes of the included studies were pain-related, including the number of participants experiencing pain, mean change in pain intensity the number of participants experiencing at least a 50% improvement in pain intensity, behavior change (measured with the Cohen-Mansfield Agitation Inventory (CMAI) or the Neuropsychiatric Inventory (NPI)), and the number of individuals experiencing major side effects.

The secondary outcomes included quality of life, as assessed by tools such as EuroQol (EQ-5D) or Dementia Related Quality of Life (DEMQOL), performance of activities of daily living (including mobility, assessed by appropriate validated instruments), depression (assessed by validated instruments such as the Cornell Scale for Depression in Dementia [CSDD]), number of people experiencing adverse events (such as sedation, constipation, and nausea), mortality, effect on caregivers, intervention costs, and implementation-related outcomes.

Search methodology and up-to-dateness of the Cochrane review?

The review authors searched for studies that were published up to 30 June 2021 in electronic databases including; ALOIS (alois.medsci.ox.ac.uk), which is the Cochrane Dementia and Cognitive Improvement Group's (CDCIG) specialized register, Cochrane Library's Central Register of Controlled Trials (CENTRAL), MEDLINE, Embase, CINAHL

(Cumulative Index to Nursing and Allied Health Literature), PsycINFO, ClinicalTrials.gov, LILACS (Latin American and Caribbean Health Science Information database) and the World Health Organization's International Clinical Trials Registry Platform (ICTRP) which covers ISRCTN; the Chinese Clinical Trials Register; the German Clinical Trials Register; the Iranian Registry of Clinical Trials; and the Netherlands National Trials Register, plus others and ISI Web of Science Core Collection. They also conducted backward and forward citation tracking for all included studies.

What are the main results of the Cochrane review?

A total of 5542 records were evaluated in this review. After deduplication and an initial assessment by Screen4Me and the review authors, 44 records were potentially eligible and were screened in full-text. According to the authors, three studies (reported in seven publications) met the inclusion criteria and were included in the review. One of the three studies was conducted in the United States, one in Hong Kong, and one in Taiwan, and included a total of 808 people. The studies were completed with 673 participants.

The authors established a link with all the study authors to clarify the methodological details that were not mentioned in the text, and additional information was obtained from all of them. All studies were cluster-randomized controlled trials and were conducted in nursing homes in two studies and special care units in one study. The follow-up period ranged between 3-6 months, and the number of nursing homes per study was 17 and 27 and the number of special dementia care units was 6. The mean age of the participants ranged between 82 and 89 years, and most of them were female (56.6 to 83.6%).

The three studies included patients with varying levels of dementia and pain severity. One study included all nursing home residents, regardless of whether they had pain, and followed them up for pain. In the other two studies, only those with mild to moderate pain were included. Additionally, the level of dementia was mild to moderate in one study, while it was advanced in the other two studies. The level of pain at the beginning of the study also varied: in one study less than half of the participants experienced pain and therefore, the mean pain score in the study groups was very low and in two studies the participants had mild to moderate pain. All studies reported proxy-rated pain assessments, two studies also relied on patient self-report for pain assessment.

The algorithms were developed based on various recommendations, including clinical guidelines from organizations such as the American Medical Directors Association, American Geriatric Society, British Pain Society, and British Geriatric Society, as well as an Interdisciplinary Expert Consensus Statement.

In three studies, different protocols were used for the evaluation of pain and treatment algorithm.

One study trained registered nurses using the Pain Recognition and Treatment Protocol (PRT), which consists of four steps;

First step includes that a self-report of pain from the residents, the observation of residents' nonverbal expressions of pain (according to the recommendations of the American Geriatrics Society panel), a physical examination to identify potential causes of pain and information from other healthcare providers or family members.

Second step of the protocol includes assessment of the characteristics of pain (presence, location, type, intensity and frequency of pain, frequency of unusual behaviors, "things" that improve pain), psychosocial comorbidities (e.g. psychological well-being, interpersonal interaction) and a summary of the characteristics and causes of the residents' pain and its impact on their lives. The other two steps include non-pharmacological and pharmacological treatment and re-evaluation of the patients (related to effects and side effects).

One study used the Pain Management Algorithm (ALG) in their study, which consists of 11 evidence-based decision trees, some of which are linked with other decision trees. These steps are grouped under the headings of general (initial) pain assessment, managing pain in nonverbal residents, pain treatment, and management of medication side effects.

The authors of the last study conducted their study using the "Observational Pain Management Protocol" consisting of five steps: pain assessment, verification of the score, interpretation of the Chinese version of Pain Assessment in Advanced Dementia Scale (PAINAD-C) scores, pain treatment based on the PAINAD-C score, and evaluation and monitoring to assess the effectiveness of pain treatment using the PAINAD-C. This study tested the intervention in a pilot study, whereas the other studies did not provide information on feasibility or pilot testing.

All studies provided theoretical training and practical exercises (both virtual and real cases) on pain diagnosis and treatment to registered nurses.

Additionally, the research team and pain team held meetings or interviews to discuss challenging cases. While the control group received pain education training in two studies, one study did not train their control group and instead recommended they continue with their usual care.

The primary outcome assessment was conducted using different pain assessment tools in the included studies. One study used the Verbal Descriptor Scale (VDS) to assess pain (scored 0-3, with higher scores indicating more severe pain), another study used the Iowa Pain Thermometer (IPT) (scored 0-12, with higher scores indicating more severe pain), while all three studies used the PAINAD-C to assess pain.

Only one study evaluated challenging behavior and measured it using the Chinese version of the Cohen-Mansfield Agitation Inventory (CMAI-C).

For the secondary outcome evaluation, all studies assessed the implementation of the interventions, but none of them evaluated other secondary outcomes. The evaluation focused on the assessment of pain and the application of treatments based on the pain evaluation. Furthermore, the ability of nurses to sustain the program and apply what they had learned was also examined.

In two studies, the accomplishment of the training was evaluated. In one of these two studies, all nurses completed the program and 90% consistency was requested between the researcher and the nurse in terms of applying the information. Those who were not able to comply with the program received additional training. In the other study, algorithm compliance was monitored using a checklist.

In the third study, decision tree compliance was monitored using a 30-day "self-developed Pain Management Chart Audit Tool". Additionally, focus group meetings were held with the research group in four out of the 13 nursing homes where difficulties in adapting to the algorithm were discussed.

None of the studies reported any serious side effects.

In all studies, pain was assessed by other people than the participants themselves. In one of the two studies, which included participants with mild to moderate pain, pain was reduced in the group that performed an algorithm-based pain management in comparison with the control group receiving usual care after 12 weeks (MD: -1.49, 95% CI: -2.11 to -0.87; range 0 to 10; 128 participants, certainty of the evidence is low). In the other study, the algorithm-based pain management did not lead to a reduction of pain in comparison with the control group that received pain education (MD: -0.2, 95% CI: -0.79 to 0.39; range 0 to 12; 383 participants, certainty of the evidence is low). For the third study, where the participants had no or nearly no pain, it was uncertain whether an algorithm-based pain management had an effect on pain.

Staff and leadership turnover, high resident-to-staff ratio, government regulations, lack of time, physicians' negative attitudes about nurses' pain management skills, and fears of addiction and over-sedation from staff, family and residents were identified as barriers to the implementation of the intervention.

In summary, there is no clear evidence to support the use of an algorithm-based pain management intervention compared to pain education for reducing pain intensity in people with dementia in nursing homes, although the intervention may reduce proxy-rated pain compared with usual care. The number of studies and participants per study were small, and the certainty of evidence was low. Implementation fidelity also appears to be limited.

How did the authors conclude?

Pain-free living is a fundamental human right. However, as demonstrated in this review, there is currently no algorithm that has been proven to be effective in diagnosing and treating pain in patients with dementia living in nursing homes. Nevertheless, the intervention may reduce proxy-rated pain compared to usual care. Ethically, effective pain treatment should be a standard. Therefore, further studies are needed to investigate the effectiveness of different approaches implementing comprehensive pain management, including the use of appropriate methods for assessing pain in people with dementia, and providing adequate pain treatment with non-pharmacological interventions or pain medication if necessary, and overcoming common implementation barriers.

Furthermore, there is a need for well-designed, prospectively registered, and adequately powered randomized controlled trials that adhere to established methodological standard such as the use of concealed allocation, appropriate blinding of participants and outcome assessors, and active control groups to ensure the reliability and validity of findings.

What are the implications of the Cochrane evidence for practice in rehabilitation?

In an increasingly aging world, pain is an important problem that limits functions and contributes to the development of physical and mental illnesses. The difficulty in accurately assessing pain, particularly in patients with dementia, leads to functional impairment. Therefore, developing guidelines to help caregivers identify pain in people with dementia will facilitate the creation of pharmacological and non-pharmacological treatment algorithms.

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