Pain Evaluation and Management in Patients with Dementia: A Retrospective Study in a Medical Department of a Tertiary Hospital

Avaliação e Gestão da Dor em Doentes com Demência: Estudo Retrospetivo num Serviço de Medicina de um Hospital Terciário

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Abstract:

Introduction: Pain is common among elderly patients and poses specific challenges in dementia due to impaired communication and limited use of validated assessment tools.

Methods: To assess the prevalence, characteristics, and management of pain in hospitalized patients with dementia, compared with those without, we conducted a retrospective observational study including all patients admitted to an internal medicine ward between December 5–7, 2022. Cognitive status was determined by the assistant medical team. Patients were excluded if they did not have record of pain assessment, if they died or were discharged before the 72 hours-period evaluation. Pain was evaluated using the Numeric Rating Scale and the Pain Assessment in Advanced Dementia (PAINAD) scale. Demographic, clinical, and analgesic data were analysed according to the WHO analgesic ladder.

Results: A total of 114 patients were included, 54.4% with dementia, median age 81 (IQR 13.0). Overall pain prevalence was 45.6%, with no significant difference between groups (p=0.67). The Numeric Rating Scale was used in 24.6% of all cases and PAINAD in 9.6% of patients with dementia. No moderate or severe pain was documented in this group. Most patients (88.6%) with pain had at least one analgesic prescribed, with no differences in opioid use between the two groups. No non-pharmacological interventions were recorded.

Conclusion: Pain was frequent but often underrecognized and undertreated in patients with dementia. Structured assessment protocols and team training are essential to improve pain management in this population.

Keywords: Aged; Dementia; Hospitalization; Pain; Pain Management; Pain Measurement.

Resumo:

Introdução: A dor é um sintoma prevalente nos doentes idosos e a sua avaliação nos doentes com demência pode ser desafiante devido a limitações quer na comunicação, quer no uso adequado de instrumentos de avaliação validados.

Métodos: Com o intuito de avaliar a prevalência, caracterização e abordagem terapêutica da dor em doentes com demência internados num serviço de Medicina Interna, comparando-os com doentes sem demência, foi desenhado um estudo retrospetivo observacional, incluindo todos os doentes internados entre 5 e 7 de dezembro de 2022. O estado cognitivo dos doentes foi assumido de acordo com o determinado pela equipa médica assistente. Foram excluídos os doentes sem registo de avaliação da dor, em caso de alta ou óbito antes do término do período de avaliação. A dor foi avaliada através das escalas *Numeric Rating Scale* e *Pain Assessment in Advanced Dementia*. Foram analisadas características demográficas, comorbilidades e terapêutica analgésica prescrita segundo a escala analgésica da OMS.

Resultados: Foram incluídos 114 doentes, 54,4% com demência, com idade mediana de 81 (IIQ 13,0) anos. Foram excluídos os doentes que não tivessem avaliação da dor, com alta ou óbito antes das 72 horas do período de avaliação. A prevalência global da dor foi de 45,6%, sem diferenças significativas entre grupos (*p*=0,67). A *Numeric Rating Scale* foi usada em 24,6% do total dos casos e a *Pain Assessment in Advanced Dementia* em 9,6% dos doentes com demência. Não se registou dor moderada ou grave neste grupo. Do total dos doentes com dor, a maioria (88,6%) tinha pelo menos um analgésico prescrito, sem diferenças na utilização de opioides entre os grupos. Não foram documentadas medidas não farmacológicas.

Conclusão: A dor, ainda que frequente, foi subdiagnosticada e, possivelmente, subtratada em doentes com demência. São necessárias estratégias estruturadas de avaliação, gestão e formação das equipas para melhorar o controlo da dor nesta população.

Palavras-chave: Avaliação da Dor; Dor; Demência; Gestão da Dor; Hospitalização; Idoso.

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https://doi.org/10.24950/rspmi.2791

Introduction

Dementia has grown to be one of the major causes of morbidity and mortality worldwide, estimated to reach 131.5 million by 2050. In Portugal, it represents the third cause of morbidity and mortality, and its prevalence is increasing, with an expected prevalence of more than 64% above 80 years old.[1,2]

In aging populations, chronic pain is one of the most frequent symptoms, with an estimated prevalence of 25% to 84%.[3,4] The International Association for the Study of Pain defines pain as an *"unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage"*.[5] This reveals the subjectiveness of pain perception, there are no biomarkers, and the measurement of its intensity relies primarily on self-reporting by the patient. However, verbal description is only one of several behaviours to express pain, and patients with dementia are often unable to express it appropriately, recall a previous painful episode, request analgesics or manage their own medication. These are recognized barriers in pain evaluation and management, meaning that individuals with neurological disorders such as dementia are at increased risk of unrecognized and undertreated pain.[6,7] These barriers not only increase the risk of suffering and inappropriate treatments, but they may also increase stress for caregivers, worsening of cognitive impairment, functional loss, depression and anxiety, decrease of immune function, exacerbation of co-morbidities, and compromised sleep.[6] The General Healthcare Portuguese Committee has included pain as the fifth vital sign, establishing its management as a duty for healthcare providers, and a right of individuals who suffer, meaning an essential step towards humanization of healthcare facilities.[8] This data underscores the importance for health professionals to be aware and address pain in patients with dementia.

In this study, we aim to evaluate pain assessment and its management in patients with dementia admitted to an internal medicine ward and, secondarily, compare it with other hospitalized patients.

Methods

We carried out a retrospective longitudinal observational study. Based on the consultation of the electronic medical record, all patients over 18 years of age admitted to the internal medicine ward between December 5 and 7, 2022, were considered. Patients were excluded if they did not have a record of pain assessment, if they died or were discharged before the 72h hours-period evaluation. The study was approved by the Ethics Committee of the Unidade Local de Saúde de Santo António.

Demographic data on age and gender were collected. Clinical data regarding major comorbidities and dementia diagnosis were recorded. Cognitive status was determined by the assistant medical team. When not explicitly stated in the medical record, cognitive status was assumed based on the mental and functional states described. Mild cognitive impairment, when mentioned in medical records, was included. Staging of dementia was assessed by the *Functional Assessment Staging Tool* (FAST).[9] The main aetiology of pain was recorded.

Pain evaluation was assessed in the first day of the study (D0) and after 72 hours (D3) using the *Numeric Rating Scale* (NRS) and the *Pain Assessment in Advanced Dementia Scale* (PAINAD), when available. PAINAD is a well-recognized observational behavioural tool for pain assessment in people with dementia and was developed after an extensive review of the literature and available pain assessment tools, namely the Face, Legs, Activity, Cry, Consolability Scale, the Discomfort Scale-Dementia of Alzheimer Type and descriptions of pain by experienced dementia care clinicians. It consists of five items: breathing, facial expressions, vocalizations, body language, and consolability.[7] Each of these items scores from 0 to 2, and the total score ranges from 0, no pain, to 10. Between 1 and 3, the patient is considered to have mild pain; from 4 to 6 moderate pain; above 7, severe pain.

All clinical notes of physicians, nurses and therapists regarding pain were reviewed from charts. Records on non-pharmacological strategies and pharmacological/analgesic agents used for pain relief were daily reviewed. Medications were classified according to the World Health Organization analgesic ladder[10] as nonopioids (acetaminophen, aspirin, nonsteroidal anti-inflammatory drugs [NSAIDs]), "weak" opioids (tramadol, codeine), or "strong" opioids (morphine, fentanyl), and adjuvants (corticosteroids, antidepressants, anticonvulsants).

Categorical variables are presented as an absolute value and relative frequency, while continuous variables were expressed as mean and standard deviation (SD) or median and interquartile range (IQR), as appropriate. All statistical analyses were performed using Microsoft Excel (version 365). The statistical analysis aimed to compare demographic characteristics and analgesic prescription profiles between patients with and without dementia. The level of statistical significance was set at $\alpha = 0.05$ (5%), with results considered statistically significant when $p < 0.05$. Age was compared between groups using the Mann-Whitney U test, assuming a non-normal distribution. For comparing proportions between independent groups, Pearson's chi-square test was used when expected frequencies were equal or greater than 5, and Fisher's exact test was applied when cells had expected frequencies lower than 5. These tests were used to compare the prevalence of pain, comorbidities, and the use of analgesics between groups. To evaluate the distribution of pain severity measured by the Numeric Rating Scale (NRS) between groups, a 3x2 chi-square test was applied. The evolution of analgesic prescription between D0 and D3 was analysed using the McNemar test for paired data.

Results

One hundred and fourteen patients were included in this study, 54.4% (n=62) with dementia and 45.6% (n=52) without this diagnosis. The median age of participants was 81 years old and patients with dementia were significantly older. Although females predominate overall, most patients with dementia were female, 64.5% (IC 95%: 52.6% - 76.4%). Ninety-three patients presented with comorbidities, most commonly chronic pulmonary disease 48.2% (n=55) and heart failure 54.3% (n=62), similar in both groups, with a significant difference only in oncological disease and osteoarticular pathology ($p<0.05$). With oncological disease being more prevalent in the group of patients without dementia, 40.4% (IC: 27.4% - 53.8% without dementia vs 16.1% (IC: 8.5% - 25.7%)) and osteoarticular pathology in patients with dementia, 56.5% ($p=0.0252$; IC 95%: 44.1% - 68.8% *vs* 25.2% - 51.7%)

Of the group of patients with dementia, 75.8% (n=47) presented with severe dementia (FAST ≥ 6).

Most patients' records on pain assessment used NRS (53.8%, n=28), even in patients with dementia, in which PAINAD was used in 9.6% (n=5). There was no registry of moderate pain by PAINAD in the group of patients with dementia, while in the group of patients without dementia, they scored a mean value of 4.2 in NRS, with 39.1% (n=9) presenting moderate-to-severe pain. Osteoarticular pathology and oncologic disease were the most common pain-associated disorders considered. Osteoarticular and pressure ulcers were more prevalent in patients with dementia, and oncologic disease in those without.

Nineteen patients, ten with dementia, and 9 without, although had documented pain, had no pain stratification with any of the considered scales (36.5%; n=19). No difference in pain recording regardless of cognitive status.

Analysis of prescriptions revealed that 88.6% (n=101) of patients had at least one analgesic prescribed, 32.5% (n=37) if paracetamol was not considered. More than a third (38.4%; n=20) had analgesic prescription exclusively in SOS. In only two patients, paracetamol was explicitly prescribed as an antipyretic rather than for analgesic purposes. Regarding pharmacological intervention at baseline (D0), patients without dementia showed a significantly higher frequency of minor opioid prescriptions compared to those with dementia (47.8% *vs* 13.8%, respectively; $p=0.030$), representing the only analgesic class with a statistically significant difference between the two cohorts. At D3 75% (n=39) of patients with pain had their analgesic prescription maintained and only in 23.1% (n=12) of the patients it was titrated. No statistically significant differences in prescriptions were observed between the groups, either at baseline, suggesting a similar distribution of analgesia types in patients with and without dementia. No registry of non-pharmacological pain control strategy was recorded.

Table 1: Sample characterization regarding demographic and clinical features of patients.

	Total (N=114)	Dementia (N=62; 54.4%)	Without dementia (N=52; 45.2%)	*p*-value
Median age (IIQ)	81 (13.0)	83 (12.0)	77 (15.5)	0.005
Female gender, n (%)	59 (51.8)	40 (64.5)	19 (36.5)	0.001
Comorbidities, n (%)				
OAD	55 (48.2)	35 (56.4)	20 (38.4)	0.025
HF	62 (54.3)	33 (53.2)	29 (55.7)	1.000
CPD	55 (48.2)	25 (40.3)	30 (57.7)	0.180
CVD	21 (18.4)	6 (9.7)	15 (28.8)	0.094
DM T2	43 (37.7)	24 (38.7)	19 (36.5)	0.565
CKD	18 (15.8)	10 (16.1)	8 (15.4)	0.612
Oncologic disease	31 (27.2)	10 (16.1)	21 (40.4)	0.006
CHD	10 (8.8)	4 (6.5)	6 (11.5)	0.508

OAD- osteoarticular disease; HF- heart failure; CPD- chronic pulmonary disease; CVD- cerebrovascular disease; DM T2- diabetes mellitus type 2; CKD- chronic kidney disease; CHD- chronic hepatic disease.

Table 2: Staging in patients with dementia using Functional Assessment Staging Tool (FAST).

Dementia stage	No. (%)
FAST	
Stage 4	11 (17.7)
Stage 5	4 (6.4)
Stage 6	35 (56.4)
Stage 7	12 (19.4)
Total	**62 (54.4)**

Pain was recorded in 45.6% (52) of the patients, with no significant difference between patients with dementia and without ($p=0.67$; IC 95% 34.4%-59.2% *vs* 30.7%-57.7%).

Table 3: Pain prevalence in absolute frequency in dementia and without dementia patients and overview of use of both tools, Numerical Rating Scale (NRS), Pain Assessment in Advanced Dementia (PAINAD) on pain evaluation in cognitively preserved and cognitively impaired individuals, admitted on internal medicine (IM) ward during the period of study.

Category	Dementia (n, %)	Without dementia (n, %)	Total (n, %)	*p*-value
Pain	29 (46.8)	23 (44.2)	52 (45.6)	0.670
No Pain	33 (53.2)	29 (55.6)	62(54.4)	
Pain associated disorders				
Pressure ulcers	12 (19.4)	1 (1.9)	13 (11.4)	0.003
Oncologic disease	10 (16.1)	21 (40.4)	31 (27.2)	0.006
OAD	35 (56.4)	20 (38.4)	55 (48.2)	0.025
Tool				
NRS				0.038
Mild (1-3)	7 (24.1)	5 (21.7)	12 (23.1)	
Moderate (4-6)	7 (24.1)	5 (21.7)	12 (23.1)	
Severe (7-10)	-	4 (17.4)	4 (7.7)	
PAINAD				N/A
Mild (1-3)	4 (13.7)	-	4 (13.7)	
Moderate (4-6)	-	-	-	
Severe (7-10)	1 (3.4)	-	1 (3.4)	
NON-STRATIFIED	10 (34.5)	9 (39.1)	19 (36.5)	0.726

OAD- osteoarticular disease; N/A – not applicable; NS- non-specified.

Table 4: Pain prevalence and pharmacological prescription on day 1 (D0) and after 72h (D3) in absolute and relative frequency in dementia and without dementia patients.

Category	Dementia			Without dementia			*p*-value
	No pain 33 (53.2%)	Pain 29 (46.8%)		No pain 29 (55.8%)	Pain 23 (44.2%)		
Prescription		**D0** No. (%)	**D3** No. (%)		**D0** No. (%)	**D3** No. (%)	
NSAID		0	0		2 (8.7)	2 (8.7)	0.191
Acetaminophen		15 (51.7)	18 (62)		14 (60.9)	14 (60.9)	0.582
Minor opioid		4 (13.8)	7 (24.1)		11 (47.8)	12 (52.2)	0.030
Major opioid		6 (20.7)	8 (27.5)		5 (21.7)	5 (21.7)	1.000
Adjuvant		2 (6.9)	2 (6.9)		1 (4.3)	1 (4.3)	1.000
No analgesia prescribed		6 (20.7)	4 (13.8)		2 (8.7)	1 (4.3)	0.443

Discussion

The prevalence of dementia observed in the study sample was considerable, reflecting the high burden of this condition in the hospitalized elderly population. This finding is consistent with the literature, which points to a growing prevalence of dementia syndromes associated with population aging and increased life expectancy. Elderly patients comprise a large proportion of admissions to Internal Medicine wards and some Portuguese cohorts refer almost a third of acute hospital beds occupied by patients above the age of eighty years old.[11]

Pain prevalence in our cohort is according to what is described in the literature, without a statistical difference between patients with and without dementia.[12,13] This result suggests that, despite the recognized difficulty in communicating pain in individuals with dementia, its identification was not negligible. However, in patients with dementia, correctly evaluated, there was no registry of moderate-to-severe pain. Nevertheless, PAINAD was only properly used in one-third of the subjects. The most used tool for pain assessment in these individuals was, probably inappropriately, NRS in 2/3 of the cases, which is not validated for this population. Furthermore,

considering the severity of dementia (75.8% presented with severe dementia), the NRS was probably misused, since it should be the person themselves who assesses their pain, provided they have the capacity to do so.

This misapplication may explain why moderate-to-severe pain was rarely documented in the cognitively impaired group, raising concerns about underdiagnosis. Moreover, it is not feasible to consider that pain was correctly assessed in these individuals. The tendency toward underassessment and undertreatment of pain in patients with dementia is often related to difficulties in verbal expression, less use of appropriate scales, and misperception of reduced pain sensitivity.[14] Such underdiagnosis inevitably leads to a conditioned clinical progression, with a negative impact on comfort, mobility, and functional prognosis.[15] In comparison to patients without dementia, this group showed a broader distribution of recorded data; however, this difference did not reach significance. Consequently, while a direct association between cognitive status and pain severity cannot be statistically confirmed, the findings suggest that pain in cognitively impaired patients may be underestimated due to their reduced ability to self-report. This is particularly noteworthy given that both groups were comparable regarding clinical conditions likely to elicit pain. Although the pharmacological intervention was no different between the two groups, less than a quarter had analgesic therapy optimized. Furthermore, we cannot guarantee that paracetamol was prescribed primarily as an analgesic and not as an antipyretic. The lack of therapeutic adjustments may be due to limited pain monitoring throughout hospitalization, the absence of formal reassessment protocols, and limited multidisciplinary involvement.[16]

It is also important to emphasize that, according to the records analysed, no non-pharmacological pain management strategies were documented. This gap may reflect a bias inherent in the retrospective nature of the study, since these interventions (such as physical therapy, positioning, comfort measures, or relaxation techniques) are rarely recorded in detail in medical records. Nevertheless, the lack of mention of such measures may also suggest a clinical practice focused almost exclusively on pharmacological therapy. Overall, these findings suggest therapeutic inertia.

LIMITATIONS

This study is a real-world analysis of pain assessment and its management in patients with dementia, which enhances the findings. However, its retrospective nature limits the quality and completeness of the available data, as the information was obtained exclusively from medical records. Interventions performed were likely omitted or underreported, especially regarding non-pharmacological strategies or clinical decisions that were not formally documented. These aspects may have influenced the overall interpretation of the results and underestimated the true complexity of pain treatment in this population.

Conclusion

Pain was highly prevalent in both patients with and without dementia. Although cognitive status did not significantly condition the therapeutic choice, pain was substantially underrecognized, underestimated or undertreated.

Patients with advanced dementia will increase substantially and urgent steps are needed to address valid pain assessment techniques and to explore possibilities of pain perception across the spectrum of dementia:

- Implement formal protocols for systematic pain assessment and reassessment in patients with dementia;
- Train multidisciplinary teams in the use of appropriate scales and in adapting therapy to individual needs;
- Encourage dynamic treatment adjustments and structured recording of interventions.

Future prospective investigations with larger samples may clarify whether the observed lack of differences in prescriptions is due to equitable practice or to limitations in pain recognition and therapy adaptation. Locally, we aim to divulge, educate and establish protocols for improving pain assessment and control. ■

Acknowledgments/Agradecimentos

This project was mentored by Sara Vieira Silva, member of the Palliative Care Unit, in *Unidade Local de Saúde de Santo António*, which helps taking Palliative care to all patients, both medical and surgical patients, aiming and contributing for improving care, comfort and dignity to these patients.

Awards and Previous Presentations/Prémios e Apresentações Anteriores

We declare the preliminary data were presented at a scientific meeting: *29.º Congresso Nacional de Medicina Interna — Pontes para o Futuro in 2023*. This was in oral presentation form only.

Contributorship Statement

MVM, ACB – Data collection and analysis
MT – Statistical analysis and data processing
SVS – Study supervision and revision
All authors approved the final version to be published.

Declaração de Contribuição

MVM, ACB – Recolha e análise de dados
MT – Análise estatística e tratamento de dados
SVS – Revisão e orientação do estudo
Todos os autores aprovaram a versão final a ser publicada.

Ethical Disclosures

Conflicts of Interest: The authors have no conflicts of interest to declare.
Financing Support: This work has not received any contribution, grant or scholarship
Confidentiality of Data: The authors declare that they have followed the protocols of their work center on the publication of patient data.
Protection of Human and Animal Subjects: The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and those of the Code of Ethics of

the World Medical Association (Declaration of Helsinki as revised in 2024).
Provenance and Peer Review: Not commissioned; externally peer-reviewed.

Responsabilidades Éticas

Conflitos de Interesse: Os autores declaram a inexistência de conflitos de interesse na realização do presente trabalho.
Fontes de Financiamento: Não existiram fontes externas de financiamento para a realização deste artigo.
Confidencialidade dos Dados: Os autores declaram ter seguido os protocolos da sua instituição acerca da publicação dos dados de doentes.
Proteção de Pessoas e Animais: Os autores declaram que os procedimentos seguidos estavam de acordo com os regulamentos estabelecidos pela Comissão de Ética responsável e de acordo com a Declaração de Helsínquia revista em 2024 e da Associação Médica Mundial.
Proveniência e Revisão por Pares: Não comissionado; revisão externa por pares.

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Received / Recebido: 16/10/2025
Accepted / Aceite: 19/02/2026
Published Online / Publicado Online: 30/10/2026
Published / Publicado: 30/10/2026

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