KANSAS JOURNAL of MEDICINE

Commentary

Ethical Obligation of Adequate Pain Management in Long Term Care Residents with Dementia

Donna F. Ewy, M.D., D.Be., MTS, M.A., FAAFP, CMD
University of Kansas School of Medicine-Wichita, Wichita, KS
Department of Family and Community Medicine

Received April 4, 2024; Accepted for publication June 6, 2024; Published online July 24, 2024
https://doi.org/10.17161/kjm.vol17.22135

Preserving personhood and its inherent dignity is a crucial challenge in dementia care. People living with dementia in long-term care facilities often experience many indignities and sufferings, some of which are beyond the control of caregivers, but some can be effectively mitigated. Pain always can be treated, and relieving suffering is a priority in any physician-patient relationship, particularly for this population. Adequate pain management is imperative for maintaining the dignity and quality of life for individuals with dementia.

People with dementia in long-term care settings are particularly vulnerable due to their inability to accurately and consistently express their experience of pain. To achieve optimal quality of life, individuals with dementia in nursing homes require special attention to appropriate pain assessment and treatment, which should include a full complement of non-pharmacologic and pharmacologic interventions. Careful monitoring and, when appropriate, reduction in the use of opioids is necessary, especially in the current health crisis marked by the widespread availability of opioids and increasing deaths due to opioid overuse. However, opioids remain an appropriate modality for pain control in many scenarios, including for nursing home residents with dementia. In this discussion, natural opiates and synthetic opioids are considered together as "opioids."

Population Issues

By the time people require placement in a long-term care facility, they are generally elderly and have multiple chronic diseases, many of which cause pain. Pain decreases quality of life and is associated with problems such as depression and insomnia.[1] It also increases functional impairment in elderly people, further impacting their quality of life. In a systematic review, Cole et al.[1] found that the prevalence of current pain in nursing home residents ranged from 22% to 85%, and persistent pain ranged from 55.9% to 58.1%. The prevalence of pain of any description is 72% in persons over the age of 85.[2] This represents a very large number of elderly people experiencing significant pain, which negatively impacts their quality of life.

Older age also is associated with dementia, which affects 5% of patients over the age of 65 and over 50% of those over 90 years old.[2] Persons suffering from dementia often have behavioral and psychological symptoms, including disturbed perceptions, impaired thought processing, and cognitive communication disabilities.[1] Due to memory and language deficits, the ability to express pain may be substantially impaired, especially as dementia progresses.[1] Neural pathways affected by dementing processes, such as the plaques and tangles of Alzheimer's disease or ischemic areas due to vascular dementia, also are important in the perception and expression of pain.[2] Dementia appears to dysregulate pain processing, and different subtypes of dementia may alter pain processing in different ways.[3]

There is a substantial risk that pain is unrecognized and undertreated in these individuals. Therefore, determining which persons exhibiting dementia symptoms have pain, and the nature and severity of that pain, is a challenge that demands careful evaluation and treatment by caregivers.

Expressions of Pain

Pain often underlies behavioral and psychological symptoms in people living with dementia, and agitated behavior or repetitive crying out may reflect pain.[2] If agitation or aggression is perceived as a mood or behavior problem, it may be treated with psychotropic medications. Tearful or anxious vocalizations of distress may be interpreted as depression or anxiety when they might represent expressions of pain. If physical comfort is adequately addressed through appropriate treatment of painful experiences, behaviors or mood disturbances may resolve, reducing the need for psychotropic medications such as benzodiazepines or antipsychotics.

The use of psychotropic medications increases the risk of sedation, falls, and other adverse effects, such as increased confusion and sedation.[4] Due to their high risk in elderly persons with dementia and their potential use as chemical restraints, they are tracked as quality measures in long-term care facilities. Opioids also carry risks of sedation, confusion, constipation, and falls, but appropriate treatment of pain is generally safer overall than the use of psychotropics.[5]

Long-term care facilities house concentrated populations of individuals who experience dementia and pain, and caregivers working in dementia care have access to tools and training to adequately assess and treat pain. Pain scales for people who are unable to verbally describe their pain, such as the Abbey Pain Scale[6] and the Pain Assessment in Advanced Dementia (PAINAD) scale,[7] use facial expressions, behaviors, vocalizations, and other physical changes to assess pain. Caregivers who routinely provide dementia care can be quite skilled at effectively assessing pain in people experiencing dementia, so expert attention to pain management can and should be expected in these settings.

Use of Opioids for Pain

Some may argue that it is ethically preferable to avoid opioids in frail elderly nursing home residents due to the risks of side effects, addiction, overuse, and the potential diversion of opioids. Nonmaleficence calls for avoiding the potential for serious harm associated with opioid use. In recent years, much attention has been given to the "opioid epidemic," with opioid overdose becoming a leading cause of death, especially among young adults.[8] The 38% increase in opioid-involved deaths between 2019 and 2020[8] has sparked widespread conversation about the responsible use of opioid medications. Educational requirements have been added for opioid prescribers, and prescribing behaviors have been scrutinized.[9]

These efforts aim to reduce the supply of opioids and subsequent opioid-caused deaths, but they also create an environment where treating pain with opioids becomes more difficult, as less effective

medications are less controlled and have fewer barriers to prescribing. Death certificate data do not differentiate between opioid deaths caused by prescribed versus illicit opioids,[10] and complex prescribing rules do not account for the fact that the largest contributor to opioid-related deaths in the latest wave of increased overdoses is illicitly made fentanyl.[8] Opposition to opioid use is primarily based on concerns about misuse, addiction, and diversion. Nonmaleficence calls for prescribers to use measures that reduce these potential harms.[11] However, this renewed "war on drugs" has negatively impacted those who suffer from pain, whom health care professionals ethically are obligated to treat.[12] The negative impact especially is likely for patients who are less able to articulate their pain or advocate for relief from their suffering.

While outpatient settings are different from residential facilities, the availability of opioids in long-term care facilities comes with rational concern for abuse, addiction, and diversion. However, these concerns, although not eliminated, are substantially mitigated in long-term care settings due to strong policies and procedures dedicated to the accountability for the appropriate distribution of every dose of medication, especially controlled substances. Diversion of prescribed opioids, addiction, and abuse, though present in some nursing homes, are much less likely in this environment due to high levels of control and the ability to closely monitor patients for adverse events.[13] Long-term care facility leadership, especially medical directors, are tasked with participating in quality initiatives to avoid problems such as opioid diversion.[13]

Treatment of Pain in Adults Experiencing Dementia

Appropriately treating pain in people experiencing dementia is vital and ethically necessary to protect their human dignity and promote quality of life. This is relevant not only to the individual but also at the societal level, as chronic pain further increases the psychiatric vulnerability of affected people.[14] Society benefits when all people are treated with dignity. Despite their risks, opioids may often be the safest and most effective pharmacologic approach to treating pain in elderly persons with dementia, especially those with conditions that limit the use of other classes of medications. Opioids can reduce human suffering for those with legitimate need, including patients enduring chronic pain that is severe, inadequately responsive to other therapies, or pain that adversely affects their function or quality of life.[10]

Nonopioid pain medications, such as non-steroidal anti-inflammatory drugs, carry higher risks for nephrotoxicity, gastrointestinal bleeding, and cardiac toxicity.[15] Caregivers usually can manage the side effects of opioids effectively, especially constipation. Additionally, the prompt availability of naloxone for use in the case of accidental overdose increases safety. In some cases, opioids provide the best pain relief, quality of life, and functioning,[9] and caregivers can mitigate many of the risks that those who argue against opioid pain relief often raise. Therefore, opioids should not be ignored as an important tool in the care of elderly people who experience pain while also managing dementia. Pain control is important for these vulnerable people for their dignity and quality of life.

Long-term care residents who live with dementia already are vulnerable due to their cognitive and physical function losses, exacerbated by communication deficits.[3] Unrelieved pain can severely impact quality of life and "may leave patients extremely vulnerable, speechless, changed, and even destroyed."[11] Being particularly vulnerable, they deserve special attention for justice in the care they receive. There is an ethical responsibility to not leave in place pain and suffering beyond what is necessary.[11] Because cognitive impairment limits the ability to express one's narrative of pain, physicians and other caregivers must be especially attentive to carefully assessing the experiences of pain.[3]

Dementia robs people of much of their autonomy. Chronic pain also may decrease autonomy by reducing mobility and participation in activities. In appropriate cases, opioids can optimize whatever autonomy a person with dementia may continue to possess. Good pain management can improve functioning and mood, and treating pain may prevent behaviors that physicians might otherwise treat with psychotropic medications, which often present more and greater risks to elderly people. Quality care of those with dementia must appropriately consider pain, assess pain with tools effective for people unable to adequately verbalize their experience, and address pain using all necessary tools to maximize comfort and dignity.

Considering the ethical principle of beneficence, people dealing with dementia benefit from an improved quality of life when pain is managed. Nonmaleficence is addressed by closely monitoring potential risks and adverse effects of these medications. The application of justice calls for fair and equitable treatment for all patients.[9] People living with dementia require additional effort to ensure they are treated fairly with their pain appropriately managed. Modalities to address pain will include non-pharmacologic and pharmacologic interventions and should include opioids when clinically appropriate, rather than dismissing them due to the complicated nature of pain expression in this patient population. Quality care does not mean taking the path of least resistance due to a sociopolitical context that exists outside the individual patient or facility.

CONCLUSIONS

While it is important to reduce opioid overdose deaths, it also is ethically imperative to appropriately treat pain in the vulnerable population of those experiencing dementia. People living with dementia suffer many losses in their sense of dignity due to their cognitive and physical debilities. Effectively treating their pain can restore an element of that dignity. Amid the opioid epidemic, there is a growing sense that our ethics of pain care have shifted from compassionate, rational use of opioids to a swift restriction of access for patients who genuinely need them.[6]

Failure to relieve the suffering of people in a position of vulnerability through effective pain management should be considered cruel, inhuman, and degrading,[6] and it flirts with violating the human right to realize a full life. Relief of pain is vital for quality of life and dignity. People experiencing dementia deserve dignity and respect, which includes adept attention to chronic pain. The use of opioids as valid tools in pain management is especially important for those made particularly vulnerable by their dementing illness.

REFERENCES

[1] Cole CS, Carpenter JS, Chen CX, Blackburn J, Hickman SE. Prevalence and factors associated with pain in nursing home residents: A systematic review of the literature. J Am Med Dir Assoc 2022; 23(12):1916-1925.e1. PMID: 36162443.
[2] Achterberg WP, Pieper MJ, van Dalen-Kok AH, et al. Pain management in patients with dementia. Clin Interv Aging 2013; 8:1471-1482. PMID: 24204133.
[3] Pergolizzi JV, Raffa RB, Paladini A, Varrasi G, LeQuang JA. Treating pain in patients with dementia and the possible concomitant relief of symptoms of agitation. Pain Manag 2019; 9(6):569-582. PMID: 31755371.
[4] Oya N, Ayani N, Kuwahara A, et al. Over half of falls were associated with psychotropic medication use in four nursing homes in Japan: A retrospective cohort study. Int J Environ Res Public Health 2022; 19(5). PMID: 35270813.
[5] Virnes RE, Tiihonen M, Karttunen N, van Poelgeest EP, van der Velde N, Hartikainen S. Opioids and falls risk in older adults: A narrative review. Drugs Aging 2022; 39(3):199-207. PMID: 35288864.
[6] Nowak T, Neumann-Podczaska A, Deskur-Śmielecka E, Styszyński A, Wieczorowska-Tobis K. Pain as a challenge in nursing home residents with behavioral and psychological symptoms of dementia. Clin Interv Aging 2018; 13:1045-1051. PMID: 29872283.
[7] Lichtner V, Dowding D, Esterhuizen P, et al. Pain assessment for people with dementia: A systematic review of systematic reviews of pain assessment tools. BMC Geriatr 2014; 14:138. PMID: 25519741.
[8] Spencer MR, Minino AM, Warner M. Drug overdose deaths in the United States, 2001-2021. NCHS Data Brief 2022; (457):1-8. PMID: 36598401.
[9] D'Souza RS, Lang M, Eldrige JS. Prescription drug monitoring program. StatPearls. Treasure Island (FL) 2024.
[10] Christo PJ. Opioids may be appropriate for chronic pain. J Law Med Ethics 2020; 48(2):241-248. PMID: 32631179.
[11] Carvalho AS, Martins Pereira S, Jacomo A, et al. Ethical decision making in pain management: A conceptual framework. J Pain Res 2018; 11:967-976. PMID: 29844699.
[12] Bockhold CR, Hughes AK. The ethics of opioids for chronic noncancer pain. Nursing 2016; 46(10):63-67. PMID: 27654445.
[13] Edelman LS, Hemmert R. Opioid use in long-term care: Guidelines and policy recommendations. J Gerontol Nurs 2019; 45(9):5-10. PMID: 31437286.
[14] Kaufmann L, Moeller K, Marksteiner J. Pain and associated neuropsychiatric symptoms in patients suffering from dementia: Challenges at different levels and proposal of a conceptual framework. J Alzheimers Dis 2021; 83(3):1003-1009. PMID: 34366340.
[15] Marcum ZA, Hanlon JT. Recognizing the risks of chronic nonsteroidal anti-inflammatory drug use in older adults. Ann Longterm Care 2010; 18(9):24-27. PMID: 21857795.

Keywords: dementia, opioids, quality-of-life, dignity, long term care