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Prioritizing Diversion and Decarceration of People With Dementia

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Abstract

An aging prison population means more people who are incarcerated will experience dementia and related symptoms (eg, cognitive impairment, behavioral outbursts, poor impulse control). This article canvasses clinical and ethical complexities of caring for people with dementia who are incarcerated and examines how to adapt carceral settings to better meet the needs of people with dementia. This article also recommends policy reforms, such as treatment-based diversion programs, early parole, and medical release, to decrease numbers of individuals with dementia who are incarcerated whenever possible.

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Dementia and Incarceration

Although the total number of people who are incarcerated in the United States at a given time has decreased in recent years,^{1,2} the number of people age 55 or older in state and federal prisons increased from 43 300 to 164 400 (280%) between 1999 and 2016.³ Caring for older adults who are incarcerated brings unique challenges, including management of a higher burden of chronic health conditions and the earlier onset of aging-related health concerns (often termed “accelerated aging”) that may occur in part from the experience of incarceration and past trauma.^{3,4,5,6,7,8}

Dementia is a common age-related condition that is particularly challenging for people to experience—and for health and custody staff to address—behind bars. There are different types of dementia, such as Alzheimer’s disease, vascular dementia, Lewy Body dementia, and others. This article uses the term *dementia* to broadly refer to the set of neurocognitive disorders associated with progressive cognitive and functional impairment beyond what is typically expected among the elderly.⁹ The main risk factor for the development of dementia is aging; other risk factors include limited education, cardiovascular disease, depression, history of substance use, and traumatic brain injury.^{10,11} Although comprehensive data on the prevalence of dementia in US prisons are lacking, individuals who are incarcerated may be at higher risk of developing dementia compared to those in the community, given the high prevalence of dementia-related risk factors among the incarcerated.^{3,4,5,12}

In this article, we examine the clinical and ethical challenges of supporting people with dementia in US prisons. Given these challenges, whenever possible we call for prioritizing diversion and decarceration strategies for elderly individuals at risk of developing—or who have already developed—dementia.

Clinical Considerations

Diagnostic challenges complicate the assessment of dementia in prisons.¹³ Assessing functional status through activities of daily living (ADLs) and instrumental ADLs (iADLs) is a key component in the diagnosis of dementia. However, many iADLs, such as cooking or driving, are not applicable in prisons. Health staff may use standard neuropsychological tests, such as the Mini-Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA), to screen patients for cognitive impairment in prisons, although these types of instruments have typically not been designed or intended to be used with incarcerated populations.^{14,15} These challenges may lead to underdiagnosis. For example, a 2020 study found that 70 of 869 people older than 50 and incarcerated in England and Wales screened positively for possible mild cognitive impairment or dementia, yet just two had dementia diagnoses in their clinical documentation.¹⁶

Dementia symptoms may also be misinterpreted both in the community and in prisons, which can lead to adverse health and legal outcomes for people with dementia. For instance, dementia may be associated with behavioral symptoms, such as impulsiveness, mood lability, and physical aggression,^{17,18} potentially leading elderly individuals to experience arrest and incarceration related to traffic violations, property theft, or trespassing in the community.^{19,20} Within prisons, these types of behaviors and difficulty fulfilling basic activities (eg, eating, clothing) can place people at risk of disciplinary infractions, placement in restrictive housing, and victimization from peers, which could exacerbate dementia symptoms.^{21,22}

Although curative therapies are not available for dementia at this time, early detection—including development of better screening tools and establishment of supportive protocols—can help address the health needs of people behind bars who are experiencing dementia. For example, standardization of prison-specific screening tools for dementia (ie, assessing ADLs or iADLs that mirror activities during incarceration) could help determine the prevalence of dementia in prisons and enable more rapid identification of individuals who are incarcerated and require additional supports.²³ Neuropsychological tests, such as the MMSE and MoCA, likely require a tailored threshold for what constitutes a positive screen for the incarcerated population, as has been proposed for other special community populations, which may enable more accurate prevalence estimates and support studies examining the utility of dementia-specific interventions in prisons.^{15,24,25,26}

Providing general training on aging-related health concerns to health and custody staff might help facilitate referrals of those with (or at risk of) dementia to health staff for further assessment. Clinical reminders to consider regular dementia-related screening for patients older than 60 years may be another way to enhance detection of cognitive impairment among elderly individuals behind bars.^{26,27,28} Some prisons offer additional accommodations to support the needs of elderly people with dementia, such as assigning a bottom bunk to prevent falls, having younger people who are incarcerated assist elders with activities of daily living, and providing routine follow-up visits and regular clinical monitoring and adjustment of care plans.²³

Ethics

Consent to treatment is a unique ethical challenge for people with dementia who are incarcerated, given the inherently liberty-restricted, coercive nature of prisons.^{29,30} Moreover, people with cognitive impairment who are incarcerated may have difficulty understanding their present circumstances, including the proposed risks and benefits of and alternatives to proposed treatments.

To what extent can someone give informed consent for health care services when that person is both developing cognitive impairment and confined against their will? This question does not have a straightforward answer, and, as a result, the decision-making process will vary on a case-by-case basis. When caring for patients at risk of developing—or who have already developed—dementia, prison health staff should conduct assessments to gauge patients' decision-making capacity regarding proposed treatments.³¹ Doing so may be complicated when patients who are incarcerated cannot understand why they are incarcerated, where they are, or how long they might be confined.³² Pursuing advance care planning when patients are still able to fully participate in decision making may help avoid some of the ethical challenges that can arise with future cognitive impairment.³³ Nevertheless, if patients lack decision-making capacity for specific health care decisions and lack advance care planning, health staff should identify **surrogate decision makers** using local legal standards and, if necessary, involve custody staff leadership to assist with locating surrogate decision makers.³³

Amid these ethical complexities, some prison systems have turned to dedicated, dementia-specific programs. In 2006, New York State established a unit specifically for cognitively impaired individuals incarcerated at Fishkill Correctional Facility.^{34,35} Similarly, a federal correctional facility in Massachusetts opened a unit dedicated to those with dementia in 2019.³⁶ These units are similar to a skilled nursing facility and apply established geriatric care principles. For instance, the unit at Fishkill has white walls instead of a concrete finish, maximizes lighting to elevate mood, and allows patients to walk freely around the unit to reduce anxiety.³⁵ By comparison, a California prison established a different model of care using individuals who are incarcerated to provide peer support for those with dementia.³⁷

Although well intentioned, these types of specialized dementia units still have drawbacks. For one thing, they raise ethical concerns about the ability of patients who are incarcerated to consent to such care. In addition, designing and maintaining such dedicated programs may entail considerable financial costs; estimates indicate that incarceration of older individuals costs approximately 2 to 9 times more than younger individuals, primarily due to health care costs, although estimates can vary based on age cutoffs, services provided, and how health care costs are defined.^{38,39} Furthermore, whether these specialized units and care programs adequately support people with dementia remains largely unknown, given limited formal outcome studies.

Prioritizing Diversion and Decarceration

Diversion and decarceration strategies that focus on people at risk of developing dementia or who have already developed dementia, particularly elderly individuals, can decrease the number of incarcerated people with dementia and connect them with more appropriate environments for care.⁴⁰ Diverting elderly people early on from incarceration, whether through community-based crisis services instead of arrest or through treatment-based courts instead of traditional criminal courts, might offer upstream solutions that prevent people with dementia from being incarcerated.^{41,42,43}

Once these individuals have been incarcerated, decarceration strategies, such as early parole and compassionate release,⁴⁴ should be used to expedite assessment of dementia, the severity of dementia if present, and appropriateness for release. Although underutilized, compassionate release is a public health measure that could be applied to those with dementia.⁴⁴ Moreover, existing data indicate that recidivism rates significantly decrease with older age, which should encourage authorities to look favorably upon requests for elder release or parole.^{45,46} It is important to recognize that people with dementia face continued challenges even after release, such as the stigma of criminal conviction, limited availability of senior living facilities in the community, and difficulties navigating community reentry.⁴⁰ Dedicated discharge planning for elderly individuals leaving prison should be prioritized to facilitate these individuals' community reentry and connections with supportive services upon release.⁴⁰

Conclusion

As practices of **mass incarceration** have come under increased scrutiny in recent years, policy makers must face the realities of what it means to keep people with dementia behind bars. People with dementia who are incarcerated present some of the most complex clinical and ethical challenges for the US prison system. Prisons are not designed to care for elderly people with cognitive impairment and, even when redesigned to meet these goals, raise considerable ethical concerns. Amid many potential solutions to these problems, keeping people with dementia out of prisons whenever possible is likely the most effective approach of all.

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