

# Geriatric Psychiatry

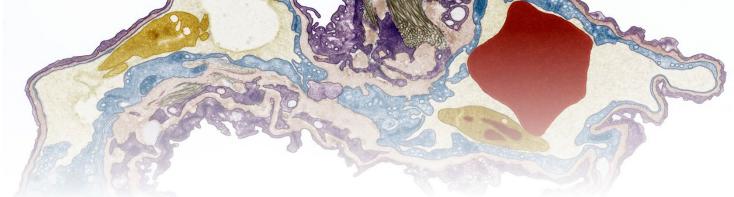
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# AMA Journal of Ethics<sup>®</sup>

October 2023, Volume 25, Number 10: E721-724

# **FROM THE EDITOR**

# **Why Should We Care About the Mental Health of Older Adults?** Badr Ratnakaran, MBBS

Older adults face various challenges that threaten their physical and mental health. Twenty-three percent of the total global burden of disease is associated with diseases related to older adults.<sup>1</sup> More than 20% of adults over age 60 suffer from a mental or neurological disorder, contributing to 6.6% of all disabilities in this age group.<sup>2</sup> Chronic diseases—such as cardiovascular diseases, cancer, musculoskeletal diseases, and chronic obstructive pulmonary disease—are prominent contributors to the disease burden of older adults.<sup>1</sup> The burden of chronic disease can negatively affect the psychological well-being of older adults and contribute to the risk of depressed mood.<sup>3</sup>

Due to physiological changes associated with aging, older adults experience muscle and bone loss; sensory deficits related to seeing, hearing, or speaking; and cognitive deficits related to senility and dementia.<sup>4</sup> These changes in older adults can result in a decline in mobility, frailty, and disability that can make them more reliant on their caregivers for their needs or require long-term care, thereby decreasing their autonomy in managing their affairs and making treatment-related decisions. A loss in autonomy can in turn impact the quality of life, well-being, and mental health of older adults.<sup>5</sup> Decline in functional and cognitive abilities and poor physical and mental health are also considered strong risk factors for elder abuse, including physical injury and mental illness.<sup>6</sup>

Life events related to aging, including bereavement, loneliness, social isolation, and decreased finances after retirement, can add to the psychological burden of older adults. Loneliness and social isolation in particular are associated with adverse mental health outcomes, including dementia, depression, and generalized anxiety disorder.<sup>7,8</sup> The decline in physical and mental health of older adults can reciprocally worsen social stressors, including social isolation and increased health expenditure, leading to further stress, difficulties in accessing care, and subsequent deterioration of health.

Meeting the mental health needs of older adults poses challenges, however, given that the population of older adults is growing at a fast pace. In 2020, there were 727 million people aged 65 years or older worldwide, and this number is expected to reach over 1.5 billion in 2050.<sup>9</sup> Twenty percent of the US population is expected to be 65 years or older by 2030.<sup>10</sup> In 2012, the Institute of Medicine released a report documenting the increasing prevalence of mental health and substance use disorders in older adults and

estimated that 10.1 to 14.4 million older adults will suffer from mental health and substance use disorders by 2030.<sup>11</sup> The report raised concerns about an impending crisis in the geriatric mental health workforce, with the pace of growth of the geriatric population exceeding that of trained geriatric psychiatric practitioners entering the workforce.<sup>11</sup> Psychiatric trainees entering geriatric psychiatry fellowships in the United States have also declined in the past 2 decades—from 106 geriatric psychiatric fellows in the 2002-2003 academic year to 58 in 2021-2022 academic year.<sup>12,13</sup> Long-standing ageism in mental health care on the part of clinicians, policy makers, and the public has created policy and financial constraints on equitable access to mental health care for older adults and made pursuing a career in geriatric mental health less lucrative.<sup>14</sup>

The current COVID-19 pandemic has taught us that older adults face significant adversity, including vulnerability to infection by the SARS-CoV-2 virus, and severe mental health symptoms, abuse, unemployment, poverty, neglect, and loneliness related to the pandemic.<sup>15</sup> Age-related mental health inequities were exposed during the pandemic as a result of ageism, financial and digital exclusion of older adults, discrimination against racial and ethnic minorities, and social isolation measures taken to protect older adults from the virus that resulted in social exclusion and lack of access to care and resources.<sup>15</sup>

In this issue of the AMA Journal of Ethics, the contributors focus on contemporary issues related to the mental health care of older adults. The topics covered related to geriatric mental health care pertain not only to geriatric mental health care practitioners, but also to the care of older adults by health care practitioners from other clinical specialties. The contributors have provided their expert opinions on ethical issues in mental health care of older adults related to antipsychotics, culturally appropriate care in long-term care facilities, telemental health, and cognitive-friendly policies in hospitals for preventing delirium in older adults. Various ethical concerns related to mental health care of older adults are addressed in this issue, including older adults' capacity for treatment decisions and clinicians' need to balance respect for autonomy, justice, beneficence, and nonmaleficence while ensuring the safety of older patients and their caregivers. The contributors also address broader issues of caring for older adults in our society, including aging in health care, ageism, approval of drugs for incurable diseases, and the geriatric mental health workforce crisis. We hope that, in reading this theme issue, readers will become mindful of the various ethical concerns related to the mental health care of older adults and work with our health care systems and organizations to provide appropriate standards of care for older adults.

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# CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

# Should Antipsychotics' Risks Be Accepted by Clinicians on Behalf of Patients to Achieve Benefits of Mitigating Older Adults' Behavioral Symptoms in Short-Staffed Units?

Alex Rollo, MD, Jeena Kar, DO, Uma Suryadevara, MD, and Mary Camp, MD

#### Abstract

This commentary on a case considers risks and benefits of pharmacological and nonpharmacological management of agitation in patients with dementia. Specifically, it considers beneficence and nonmaleficence in treatment decisions that affect both patients and staff as well as autonomy and surrogate decision making.

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#### Case

The Joint Commission audits—based on US Food and Drug Administration (FDA) and Substance Abuse and Mental Health Services Administration (SAMHSA) guidance antipsychotic use in inpatient geriatric mental health settings and will soon be reviewing, during an upcoming site visit, University Hospital's geriatric psychiatric unit's practices. Among older adults, antipsychotics can increase morbidity and mortality risk from falls and cerebrovascular events,<sup>1,2</sup> so their use is discouraged by the FDA<sup>3</sup> and SAMHSA.<sup>4</sup> Although antipsychotic use to manage delirium, dementia, and agitation helps decrease use of physical restraints and their risks of harm,<sup>5</sup> Dr A remains concerned about the unit's clinicians' escalating use of antipsychotics as behavior modification agents. Dr A asks unit staff to decrease use of antipsychotics on an "as-needed" basis and encourages more reliance on verbal redirection and other nonpharmacological techniques for managing patients' behavioral symptoms.

However, staff burnout and an insufficient number of staff members with time to implement nonpharmacological symptom management techniques with patients undermine the feasibility of Dr A's recommendations. Antipsychotics help overburdened unit staff respond with more efficiency and less disruption to patients' agitation. Dr A struggles to balance the benefits to staff of increased antipsychotic use against the risks to patients and wonders how to represent self-study documentation, especially about the unit's antipsychotics overuse, in preparation for the Joint Commission's upcoming site visit. Specifically, Dr A considers how to represent the reality that the unit's clinicians are aware of the risks to patients and accept those risks to their patients as

necessary to keeping patients on the unit as safe as possible, given the unit's labor, time, and management constraints.

#### Commentary

While there is no gold standard of care for managing agitation in the geriatric inpatient population, there is broad consensus that health care workers should first assess the patient on a case-by-case basis to identify and remove potential causes of the agitation, attempt to reduce agitation through nonpharmacological interventions, and reserve the use of pharmacotherapy for patients who do not respond to behavioral approaches.<sup>6,7</sup> This commentary considers the risks and benefits of antipsychotics and which cultural, regulatory, or other changes could facilitate clinicians' more appropriate and widespread use of nonpharmacological treatments to humanely manage older patients' agitation and other behavioral symptoms that compromise their quality of life.

#### **Possible Interventions**

Successful nonpharmacological interventions take a person-centered approach and can range from actions as simple as verbal redirection or reorientation to offering food or validation or even to specific evidence-based therapies, such as multisensory stimulation, aromatherapy, cognitive behavioral therapy, animal-assisted therapy, physical exercise,<sup>8</sup> massage and touch therapy, music therapy, and pet robot interventions.<sup>9</sup> A Delphi panel agreed that the DICE (describe, investigate, create, and evaluate) intervention, used for assessing root causes, planning care, and training and empowering caregivers, was one of the most promising nonpharmacologic methods, along with music therapy.<sup>10</sup>

The American, Canadian, and European Union associations of geriatric psychiatrists recommend that nonpharmacological interventions for agitation in people with dementia of any degree of severity be first-line treatments; however, their use in clinical practice remains limited.<sup>8,11</sup> This underutilization is due not only to inadequate funding and staffing, but also to the need for behavioral interventions to be individualized to the patient and setting, variability in implementation requirements, delays in onset of action, and negative perceptions of efficacy by patients, family, and health care practitioners.<sup>11</sup>

There is no FDA-approved agent for the neuropsychiatric symptoms (NPS) of dementia; in 2005, the FDA issued a black box warning based on a meta-analysis that showed that antipsychotic use in older patients with dementia was associated with a significantly higher risk of death.<sup>12,13</sup> Common side effects of antipsychotics include sedation, cognitive impairment, orthostasis, weight gain, dyslipidemia, diabetes mellitus, hypertension, and cardiovascular events, as well as urinary retention or incontinence.<sup>14</sup> Effects on movement and gait—such as dystonia, parkinsonism, and tardive dyskinesia—can also contribute to elderly patients' morbidity and mortality by increasing fall risk,<sup>2</sup> which raises the risk of broken hips or femurs.<sup>15</sup> The risk of side effects—ranging from dry mouth to death—is complicated further by older adults' increased sensitivity to antipsychotics resulting from changes in metabolism, fat distribution, dopaminergic pathways, and the blood-brain barrier.<sup>16</sup>

#### **Risks and Benefits to Patients**

Clinicians must carefully weigh the significant risks associated with antipsychotics against the potential benefits of their use. In 2016, the American Psychiatric Association advised that antipsychotic use in patients with dementia can be appropriate, as it can "minimize the risk of violence, reduce patient distress, improve patient's quality of life,

and reduce caregiver burden."<sup>17</sup> Accordingly, on this view of beneficence, exposing an agitated patient to the myriad risks of pharmacotherapy may at times be for the greater good. Beneficence in this case is most apparent in situations in which the need for action is urgent, such as when a patient's agitation jeopardizes the safety of self or others (eg, patients or staff in a hospital setting).<sup>18</sup> Even in the absence of impending physical harm to the patient or others, a patient's distress could be seen as emotional harm and suffering, which might also be treated ethically with medication.<sup>19</sup> This extension of the principle of beneficence is complicated by the confused patient's impaired capacity or lack of capacity to understand or consent to the treatment. Frequently, a discussion with the patient's family or primary caregivers is not feasible, and even when caregivers are available to comment, physicians must distinguish true patient distress from caregiver distress. In making a decision about antipsychotic use, the ethical physician should account for the benefit to the patient and to all involved in the care of the patient.

Physicians should seek input from all members of the treatment team while being vigilant for—and resistant to—any pressures to "medicate to make a person more manageable."<sup>19</sup> Following through on such requests would only be an attempt to mask the symptoms while ignoring underlying etiologies like short-staffed units. Patients should not be punished for the inefficiencies or failures of the hospital system they find themselves in. This dictum is underscored by the fact that members of this patient population often lack the capacity to choose their treatment or which health care ecosystem they will receive it in. They are in fact trapped through no fault of their own.

#### **Risk to Staff and Other Patients**

Adding to the complexity of the decision to use antipsychotics in inpatient units is the need to consider staff members' and other patients' safety and well-being. Patients with advanced dementia have impaired judgment and a reduced capacity to understand consequences, which can result in unintended harm to others. Specifically, when patients with dementia and severe NPS are mixed with frail older patients in understaffed units, the potential for assaults and injuries increase significantly, as a ward's degree of overcrowding is a strong predictor of poor patient-patient interactions.<sup>20</sup>

Staff working in acute geriatric wards are also at higher risk of experiencing workplace violence,<sup>21</sup> burnout,<sup>22</sup> and poor professional quality of life.<sup>23</sup> A cross-sectional survey comparing staff caring for patients with dementia in long term-care facilities and hospital wards showed that hospital staff had higher scores on measures of emotional exhaustion and depersonalization and lower scores on measures of personal accomplishment in addition to reporting more frequent stressful events related to behavioral disorders.<sup>24</sup> Moreover, when staff members work in this extremely challenging and pressured environment, their ability to provide compassionate care is hindered and may lead to attrition and unplanned sick leave, worsening the issue of short-staffed units.<sup>25</sup>

When increasing resources is not a feasible option, employers often fall back on staff education and training to try to improve patient outcomes because they likely presume that behavioral changes would be easier to implement than tackling a larger system-wide issue. However, focal strategies to boost workforce compassion have not been enough to ensure adequate care in these challenging environments.<sup>25</sup>

#### **Cultural and Regulatory Changes**

Since the late 1980s, there have been policies and agencies that have focused on reducing the use of chemical restraints, including antipsychotics and sedatives. The Nursing Home Reform Act of 1987 was enacted to provide oversight and empowered regulators to identify and issue citations for excessive use of physical or chemical restraints.<sup>26</sup> Toward this end, the Minimum Data Set system enables public reporting of quality measures at the state and facility level using the Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare Data Set.<sup>27</sup> In 2012, CMS—along with state agencies, nursing homes, advocacy groups, and other stakeholders—started the National Partnership to Improve Dementia Care in Nursing Homes not only to decrease the use of psychotropics but also to improve quality of life for patients with dementia.<sup>28</sup> One of the issues highlighted by this program was that facilities that were relatively understaffed with respect to registered nurses had difficulty decreasing the use of psychotropics.<sup>28</sup>

The insufficiency of nursing staff to care for older patients has been observed for decades and remains a challenge without a clear single solution. One key factor in the nursing staff shortage is that the training of new nurses has not kept pace with demand due to the shortage of nursing educators.<sup>29,30</sup> Four strategic domains to address the nursing faculty shortage have been identified: advocacy, funding, educational partnerships between schools and health care organizations such as Project WINNER (Workforce Increases in Nursing and Nursing Education Excellence in Resources), and academic innovations such as recruiting retired nurses or educators without a nursing background.<sup>29,31</sup>

Advocacy by professional organizations can also lead to significant legislative and regulatory changes. For example, the American Medical Association recently voted in favor of a "Nursing Shortage D-360.991" directive that aims to better understand the extent of the shortage, what factors are impacting it, and how best to address those factors.<sup>32</sup> Advocacy on this issue has already led to increased public awareness and funding, including the passage of the Nurse Reinvestment Act of 2002, which authorized funds for education, training, and retention<sup>33</sup>; the Affordable Care Act of 2010<sup>34</sup>; and the American Rescue Plan Act of 2021, which authorized additional funds for nursing education and workforce development programs.<sup>35</sup>

As other evidence-based techniques to help patients with significant agitation or aggression are explored, regulatory agencies actively include them in their standard of care guidelines. The adoption of such guidelines can promote a culture of safety and guide responses to critical events. Additional facility-level options include providing staff with continuing education and training, maintaining a safe environment free of breakable hardware and sharp objects, and creating a designated "retreat" space if patients elect to be separate from others.<sup>36</sup>

To further promote patients' self-determination, advance directives (ADs) can include decisions related to the use of antipsychotic medications for symptoms related to dementia management.<sup>37</sup> Unfortunately, it is estimated that only 37% of American adults have completed an AD, and only approximately 70% of older adults complete ADs prior to their death.<sup>38,39</sup> Barriers to implementation include difficulty integrating a new practice into existing agency culture, legal misunderstandings, and limited access to ADs when needed.<sup>40</sup> Patients from minoritized populations generally have lower AD completion rates.<sup>41</sup> Moreover, that AD documents are not culturally acceptable to

certain minority populations,<sup>42</sup> including those that consider family and community to be the primary source of treatment decisions, further illustrates the complexity of antipsychotic use in dementia patients.<sup>43</sup>

#### Conclusion

Public policy, funding, and institutional choices may create unjust situations in which clinicians like Dr A are forced to pragmatically rebalance the risks of overmedicating with the potential harm of agitation and aggression in crowded, understaffed units. However, it is vital that this realism does not blind one to the truth of the situation—that the status quo has fallen short of the ethical ideal of beneficence. While there is no one simple answer, individual clinicians and health systems have opportunities to advocate for prevention of this all-too-common scenario in geriatric care.

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# CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Should Be the Scope of Long-Term Care Organizations' Obligations to Offer Culturally and Linguistically Appropriate Services to Patients?

Darlon Jan, MD, Azziza Bankole, MD, and Mamta Sapra, MBBS

#### Abstract

Limited access to health services, decreased quality of care, and worse health outcomes are well documented barriers people with limited English proficiency (LEP) face in US health care. Laws enacted since the 1964 Civil Rights Act recognize such barriers and have helped generate demand for culturally respectful health service provision, assessment of cross-cultural relations, and adaptation of services that fail to meet persons' needs and improve quality of life. Yet, as this commentary on a case considers, even with legal protections for language services for patients with LEP, long-term care facilities face limited resources and thus have limited capacity to offer such services.

#### Case

JK is an 85-year-old, widowed, native Bosnian speaker with limited English language proficiency (LEP), who is admitted to a nursing home. JK experiences chronic physical illness and cognitive dysfunction and can no longer live in her home since the death of her 69-year-old daughter, who was her caregiver. JK came from Bosnia-Herzegovina to the United States many years ago with her husband to live with her daughter and has no remaining family in the United States. JK briefly communicates via an online interpreter service daily with staff during rounds, but otherwise she interacts only minimally with others. JK has become socially withdrawn and depressed, has minimal appetite, and is losing weight.

When JK is visited by a Bosnian-speaking friend of her daughter, who brings Bosnian food, she eats and converses with ease and joy. JK's visitor informs the staff that JK is not comfortable talking about her body or how she is feeling with the interpreter offered by the online international language service, who is Serbian.

JK's caregivers' encounter with JK's visitor illuminated for them how profoundly the linguistic and food services they have been offering JK undermine her well-being and

their capacity to understand her needs. A case worker requests better services during her regular meeting with liaisons at the company that owns and operates the facility and several others in the region. The appeals are denied since they would be "too costly" and "impossible to provide to all patients." JK's caregivers are distressed about being unable to provide services that would offer such clear benefit and wonder what to do.

#### Commentary

JK's story highlights some of the ethical challenges faced by caregivers in providing linguistically and culturally appropriate care for patients with LEP, who have higher mortality due to sepsis, higher readmission rates, and greater social needs than Englishproficient (EP) patients.<sup>1,2,3,4</sup> Health care barriers for people with LEP are well known and have been documented for decades. Language barriers associated with LEP affect communication between health care professionals and patients, resulting in worse health outcomes.<sup>4,5,6,7,8</sup> For example, history-gathering difficulties or decreased use of screening services as a result of LEP can delay or prevent clinicians' identification of illnesses, 3,4,5,6,7 including cardiovascular disease, as patients with LEP are less likely to report cardiovascular symptoms than those without LEP.<sup>8</sup> Additionally, language barriers can limit the therapeutic alliance if patients have difficulty explaining illnesses or clinicians have difficulty explaining treatments. Patients with LEP are also less likely to be active in seeking medical treatment or to be aware of what services are available.<sup>3</sup> Even if they are able to access care, they may have difficulty in adhering to treatment due to challenges in understanding the health care plan and unmet social needs. Poor chronic disease management due to negative social determinants of health (eg, unmet social or medical-legal assistance needs, poor health literacy, or poor understanding of medical benefits) has also been associated with language barriers.<sup>3,7,8</sup>

Access to formal interpreters or bilingual staff improves health outcomes and quality of care (though ad hoc interpreters have not been shown to be effective in improving health outcomes).<sup>4,6,7</sup> However, interpreter use can also be limiting due to concerns about the accuracy of the interpretation.<sup>3</sup> (Is it verbatim? Does some word or expression translate appropriately? Does the interpreter explain directions with the appropriate amount of detail?). Given these overall barriers and worse medical outcomes for patients with LEP, patients with LEP in long-term care facilities (LTCFs) are a vulnerable population. As the US population ages, minority and LEP populations are projected to represent a larger proportion of the geriatric patient population.<sup>9</sup> While federal nondiscrimination regulations to protect the legal right of patients with LEP to receive health services in their preferred language exist,<sup>10</sup> concerns about noncompliance highlight the importance of identifying and addressing language and cultural resources in LTCFs.<sup>7,9</sup>

#### Legal Obligations

Beyond ethical obligations for language-concordant care, organizations have a legal obligation to provide linguistically appropriate services. Title VI of the 1964 Civil Rights Act prohibits discrimination on the basis of race, color, or national origin in any program or activity that receives federal funds or other federal financial assistance.<sup>11</sup> The law prohibits not only intentional discrimination, but also administrative procedures, criteria, or methods that are discriminatory without intent. These practices must be discontinued if any alternatives are available for achieving the same objectives with less discrimination. In 1974, *Lau v Nichols* established that discrimination based on national origin included discrimination based on language.<sup>10</sup> It was not until 2000 that an executive order and Office of Civil Rights (OCR) policy guidance were issued to ensure

providers' compliance with their Title VI obligations to provide equal access to language services.<sup>10,12</sup> Major federal laws affecting language access include, among others, Section 1557 of the Affordable Care Act of 2010, which requires that covered entities take reasonable steps to provide language services<sup>13</sup>; the Hill-Burton Act (also known as Titles VI and XVI of the Public Health Service Act), which requires that Hill-Burton-funded facilities provide language services for languages spoken by at least 10% of local households<sup>14</sup>: and the Emergency Medical Treatment and Labor Act (EMTALA), which requires that hospitals with emergency departments provide easy-to-read signage about patients' rights under the law in the languages of the population served.<sup>15</sup> The extent of providers' obligations is determined by 4 factors specified in OCR policy guidance: (1) the number or proportion of persons with LEP served, (2) the frequency of contact with a particular language group, (3) the nature and importance of a program or service, and (4) resources required and available.<sup>12</sup> These factors allow for differentiation of obligations between different facilities (eg, between larger, urban facilities serving a diverse population vs smaller, rural facilities serving a more homogenous population) that receive federal funds.<sup>12</sup> Several states have also established additional laws specifically addressing LTCFs and language availability.<sup>16</sup>

Interpreters, however, may also need to act as cultural brokers to facilitate communication and understanding since linguistic competency is intertwined with cultural competency.<sup>17</sup> The US Department of Health and Human Services developed cultural and linguistic competency guidelines for providers, the National Standards for Culturally and Linguistically Appropriate Services (CLAS),<sup>18</sup> although hospitals' application of and compliance with these standards is inconsistent.<sup>19</sup> CLAS standards focus on improving quality of care for patients through care and services that are respectful of and responsive to patients' cultural and linguistic needs.<sup>18</sup> CLAS standards also provide guidance for health care organizations on meeting federal regulations for language services for patients with LEP.<sup>18,19</sup>

#### **Geriatric LEP Inequity**

Studies have shown that in geriatric populations, as in the general population, individuals with LEP have worse access to care and health status than EP individuals.<sup>20,21,22</sup> Furthermore, minorities and patients with LEP are more likely to be in lower-quality LTCFs that have deficiencies, lower staff investment, poor financial viability, and worse health measurements of care.<sup>21,23,24,25</sup>

The 1987 Omnibus Budget Reconciliation Act set forth quality of care mandates for nursing homes and rights for nursing home residents, including the right "to be fully informed in language that he or she can understand,"<sup>26</sup> be it orally or in writing.<sup>27</sup> The Centers for Medicare and Medicaid Services (CMS) State Operations Manual highlights this requirement, stating that "health information and services" must be provided in a manner that "makes sense" to the resident or their representative and that LTCFs must offer language assistance and provide qualified interpreters as needed.<sup>28</sup> Communication, including speech and language, is regarded as part of the activities of daily living that LTCFs must provide the resident "to maintain or improve his or her ability to carry out the activities of daily living."<sup>28</sup> Beyond these responsibilities, LTCFs are expected to "incorporate the resident's personal and cultural preferences" in goals of care and to provide "culturally-competent" comprehensive care plans and staff.<sup>28</sup> Cultural appropriateness extends to resident needs and preferences for nutrition (food and meals), although this responsibility to individual patients may be limited based on the "overall cultural and religious make-up of the facility's population."<sup>28</sup> Failure to

comply with cultural and linguistic requirements qualifies as noncompliance. For example, failure to accommodate cultural dietary needs or beliefs is a level 2 deficiency, with deficiencies being categorized according to severity of harm to patients on a scale of 1 to 4 (with 4 being the most severe).<sup>28</sup> Facilities are expected to exhibit "good faith" attempts to address noncompliance with regard to the severity and frequency of the infraction, with investigators determining "good faith" on the basis of evidence of the facility's actions as a whole.<sup>28</sup>

#### Conclusion

JK's case highlights ongoing health disparities and challenges on linguistic and cultural levels within LTCFs, despite legislated requirements for language services. While JK's LTCF has provided interpreter services, it has failed to account for the cultural suitability of the situation. JK demonstrates clear distress with her Serbian interpreter. Although JK's experiences with the Bosnian War and other Balkan conflicts are unclear, high levels of general psychological distress have been found in survivors and participants of the Bosnian War and other groups involved with armed conflicts.<sup>29,30</sup> The CMS manual specifically mentions that LTCFs need to address mental distress and possible posttraumatic stress disorder, including in "racial, political, or cultural groups" that have "witnessed or been subjected to intentional and systematic destruction."<sup>28</sup>

JK's improvement with visitors from members of her cultural group and with dietary changes highlights the impact on her well-being of the LCTF's failure to provide culturally competent care. LTCFs have a legislated obligation to provide language services "in a way that makes sense" to residents.<sup>28</sup> It is arguable, depending on JK's experiences, that her psychological distress due to the LCTF's noncompliance with cultural and linguistic requirements may constitute "actual harm that is not immediate jeopardy" (a level 3 deficiency) as opposed to "no actual harm with a potential for more than minimal harm" (a level 2 deficiency).<sup>28</sup> JK's ongoing depression and weight loss already suggest evidence of actual harm, depending on her medical condition. Further exacerbation of these symptoms could qualify as "immediate jeopardy to resident health or safety," the highest level of deficiency an LTCF can be charged with for individuals within their care.<sup>31</sup>

While LTCFs have both ethical and legal obligations to implement a linguistically and culturally competent system of care to improve residents' quality of life, inadequate resource availability continues to hamper its realization. JK's caregivers were motivated to improve her care, but, as in many other cases, their appeals for cultural appropriateness of linguistic and food services, though required by law, were deemed "too costly." Depending on the demographics of her area, JK's care may in fact exceed legally required language services per Title VI in the provision of an ethnically Serbian language interpreter instead of a Bosnian one. In this case, the LTCF could have written and translated questions with responses in the form of ratings regarding her experiences with the translation service so that she could give a general response as to whether she felt it was satisfactory or had concerns or experienced discomfort without the presence of the translator that could be investigated further. Given JK's cultural background and age, along with associated global events, the LTCF could have also checked to see whether available translators could have caused JK some psychological distress.

Health care professionals and LTCFs have a moral as well as a legal imperative to reduce the barriers to care faced by patients with LEP. It is perhaps a poignant reminder

that Neil Armstrong stepped on the moon just 8 years after President Kennedy's call, whereas one elderly widow continues to struggle to obtain services and rights legislated nearly 6 decades ago and reinforced routinely by numerous acts of Congress and actions of presidential administrations.

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### **CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

# According to Which Criteria Should Telemental Health Be Deemed Elder Inclusive?

Joseph O. Aderemi, MD and Esther Akinyemi, MD

#### Abstract

Telepsychiatry offers opportunities to provide better access to and higher quality of psychiatric care for some patients. This commentary on a case considers an analysis of clinical and ethical barriers to equitable telehealth for elders with mental health needs.

#### Case

Dr JM has just begun working in a telepsychiatry clinic that serves patients from regions with mental health service shortages via an online video conferencing platform. Dr JM is scheduled to evaluate a patient, TT, who is 88 years old and accompanied by her 65-year-old son, who struggles to maintain audio and video call quality from where they are seated in a car outside a restaurant that has wi-fi connectivity in their community. Their home internet access is unreliable, and the instruction they received for enabling the supported smartphone application was not helpful. Due to poor audio and video transmission quality, Dr JM is unable to observe the symptoms (eg, anxiety and irritability) that TT's son worries about. As the appointment time ends, Dr JM remains concerned about the standard of care she just provided and is not at all confident that she learned clinical and diagnostic information that will help her help TT. Dr JM wonders how to follow up. What should be the scope of the health care organization's obligations to ensure equitable access to mental health services? According to which criteria should remote services be deemed equivalent in accessibility and quality to health services delivered in person?

#### Commentary

The COVID-19 pandemic's influence and effects can be seen not only in the physical health, but also in the mental health of patients. South Korean patients with a history of severe mental health illness were found to be at a slightly higher risk for severe clinical outcomes of COVID-19 than those without such a history, and, in the United States, a recent diagnosis of mental disorder was found to be associated with increased risk of infection.<sup>1</sup> One population that is particularly vulnerable to the impact of the pandemic in its various forms is the older adult population. Older adults are at higher risk of suffering negative outcomes, with 80% of deaths in the United States during February to March 2020 being among adults 65 years and older.<sup>2,3</sup> Studies suggest that the mental and physical health of older adults was negatively affected by social isolation during the

COVID-19 pandemic, with anxiety, depression, poor sleep quality, and physical inactivity as the main outcomes.<sup>2</sup> Some factors besides social isolation contributing to these outcomes include the presence of life stressors and the lack of technological expertise, which limited the availability of remote socialization options.<sup>4</sup>

Telemedicine provides access for those who might otherwise be unable to obtain services or have to wait for a long time to access them.<sup>5,6,7,8</sup> Justice as a principle speaks to the fair and equitable distribution of resources among diverse groups of patients regardless of their age, gender, race, or socioeconomic factors. Upholding this principle entails that access to care for older adults be equitable to that for the younger population. Since telepsychiatry is available to younger patients, it therefore should be available to older adults. This commentary will explore challenges experienced by elderly persons in accessing telepsychiatry and offer potential strategies for addressing these challenges to ensure equitable care.

#### **Difficulties for Elderly Persons**

While some studies have argued that there are no significant differences between telepsychiatry and in person face-to-face care, others point out that certain aspects of telepsychiatry can be problematic,<sup>9,10,11</sup> including "the knowledge and capacity to get online ... [and to] operate and troubleshoot audiovisual equipment."<sup>12</sup> For telemental health care to be deemed elder inclusive, barriers need to be identified and addressed at various levels. These barriers include technology factors, patient factors, and clinician factors. Technology factors include availability of equipment, issues of connectivity, and technological know-how. Even if an older adult has the capacity to get online, there may be limited internet accessibility in rural areas. Patient factors include autonomy, comfort with and acceptability of the treatment modality, and concerns about safety, privacy, and confidentiality. Because patients may need others to assist with the technology, their ability to share freely what might be concerning to them may be limited, raising concerns about autonomy and confidentiality. Patients may also struggle with acceptance of the treatment modality and perceived limitations in the establishment of "trustworthy, authentic, and effective patient-clinician relationships."<sup>13</sup> Clinician factors include expertise with the older adult population and with the use of relevant technology, comfort with the treatment modality, and knowledge of the legal ramifications of the use of telepsychiatry. Clinicians also need to be aware of the limitations of telepsychiatry and to be open about these limitations with patients. The obligation to be transparent overlaps the principle of fidelity, which requires that clinicians provide accurate information to the patient about the care provided. Among older adults, especially in rural areas, barriers posed by technological, patient, and clinician factors may result in a drastic decline in quality of care, rendering care less equitable. It is therefore important to creatively look at options that make telemental health care for older adults more equitable to the care provided to the younger population.

#### Accommodating Elder Access to Telepsychiatry

For telemental health care to be deemed elder inclusive, accommodations need to be put in place. The elderly have been identified as a group that has difficulty using new telecommunication equipment.<sup>5</sup> Some authors have argued that training older adults to use telemedicine for mental health may have limited impact.<sup>14</sup> One way to address this concern on an individual level is to have another party assist with the operation of technical equipment. Although this kind of assistance from family and caregivers may be helpful, elderly patients may find it difficult to communicate sensitive concerns in the presence of their children or caregivers. A potential benefit of having a family member present can be seen in cases in which patients have dementia, hearing impairment, or visual impairment or need repeated setup of equipment or in which a family member is necessary to supply aid or collateral information.

Having a family member present foregrounds the ethical issues of autonomy and confidentiality. While patients are allowed to involve whomever they wish in their care, involvement of others limits their ability to take charge of all aspects of their care, as there is a third voice in the conversation that might influence the visit. A potential solution would be to have someone set up the appointment and exit the room. This approach would be particularly beneficial in cases in which there is concern about potential elder abuse. Keeping in mind the principle of nonmaleficence, the clinician has to be cognizant of the potential for harm if an abuser is present in the room, as studies have shown that elder abuse—including physical, verbal, and emotional harm; financial exploitation; and neglect or indignity—increased tenfold during the pandemic.<sup>15</sup>

Institutionally, strategies need to be put in place to improve the clinician's ability to gather sufficient information to make clinical decisions that will not harm the patient, hence satisfying the clinician's need to provide appropriate care to patients who would otherwise have no access to it. Such strategies include providing internet-connected tablets and internet connectivity for appointments, as well as having community partners who can help older adults navigate their virtual world and provide safe and private spaces for consultations when necessary. An argument can also be made for a hybrid model that would require periodic in-person visits after a certain number of virtual visits. Hence, if something were missed during the virtual visits, it could be picked up during the face-to-face visit. In addition, thorough training should be provided for telemedicine practitioners on how to optimize assessing patients and hopefully improve confidence in decisions made with a limited physical exam. Training should also include information on how telemedicine practitioners can protect themselves from legal repercussions that may arise from making decisions based on limited information. Lastly, patients need to have an opportunity to access emergency help if there is a crisis during the encounter and to access prescription management, labs, and the after-visit summary. There is also a need to standardize the platform for providing virtual care to create consistency and reduce the burden for patients and caregivers as applications are updated.

In the case of TT, virtual care was offered. However, due to other challenges, the care might not have been equitable to the care delivered in person due to poor transmission and problems with the technology, as well as possible concerns about TT's autonomy. It is also clear that the clinician did not feel comfortable with the information obtained and utilized in clinical decision making.

#### Conclusion

In summary, for telemental health care to be deemed elder inclusive, certain boxes need to be checked. First, there has to be adequate technology to fulfil the need; second, there needs to be appropriate infrastructure to foster autonomous decision making and safety; and lastly, there has to be adequate training for clinicians. Satisfying these conditions will ensure that older adults are able to access and utilize telemental health services appropriately.

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### CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

## How to Draw on Narrative to Mitigate Ageism

William Smith, MD, MBA, MPH, David Elkin, MD, MSL, and Art Walaszek, MD

#### Abstract

Ageism is so structurally integrated and normalized in US health care that it is generally unnoticed by clinicians, despite its effects on the medical care and lives of older adults. Clinicians often lack time, incentives, and opportunities to pause and fully consider the perspective of older adults, especially those with mental illness. As a result, clinicians might infantilize older adults and pathologize or dismiss their preferences, values, and capacity for growth. This commentary on a case proposes a narrative-based ethical approach to shift clinicians' perception of older adults as suffering from the inevitable and unsolvable problems of aging to experiencing a need for dignity and the possibility of continued personal growth.

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#### Case

Mrs P is an 83-year-old widowed woman with ischemic heart disease, hypertension, type 2 diabetes, and generalized anxiety disorder who has been hospitalized for congestive heart failure (CHF) 4 times in the last 2 months. She has not been adherent to her medication regimen and to a low-sodium diet, contributing to CHF exacerbations. Due to uncontrolled anxiety, she has been afraid to leave her apartment to attend primary care appointments. After a recent fall, physical therapy was ordered, but Mrs P did not allow home health staff to enter her home.

Mrs P is now hospitalized for the fifth time. She was restarted on outpatient medications, and her condition improved. She was advised to move into an assisted living facility, an idea that her 2 adult children supported; she refused. Hospice was recommended in order to focus on quality of life; she refused. Due to concerns about her cognition, neurology consultation was requested. Bedside cognitive testing and neurological examination were normal; there was no evidence of delirium or dementia. Due to concerns about capacity to manage her medical problems and live independently, psychiatry consultation was requested. She was found to have decisional capacity for health care; she was very anxious, leading to the antidepressant dose being increased and a referral to a psychotherapist.

As Mrs P approaches discharge, members of her care team express frustration about her high utilization of scarce inpatient resources. They consider requesting ethics consultation about whether further inpatient care of her condition should be discontinued.

#### Commentary

The population of older adults is increasing each year. In 2019, there were an estimated 703 million people 65 years or older worldwide; this number is expected to double by 2050 to 1.5 billion.<sup>1,2</sup> For those working in health care, it is easy to recognize in this case the complicated dynamics involved in health care for older patients.

Ageism, an unfortunately pervasive feature of medicine, is defined as any form of negative attitude, stereotyping, or discrimination against individuals based on their older age.<sup>1,3</sup> Like racism and sexism, ageism operates through complex mechanisms at different levels of society, including individual, social, and structural levels.<sup>4</sup> In medicine, at the individual level, ageism can manifest as paternalistic and infantilizing approaches to medical decision making, including limiting patients' involvement despite their intact decision-making capacity and succumbing to the cognitive bias of attributing symptoms simply to old age.<sup>5,6,7</sup> At the structural level, ageism can include age-based discriminatory practices, such as exclusion from research or the unjust resource allocation recently observed on a global scale during the COVID pandemic.<sup>5,6,7</sup>

Ageism results in a significant burden on the health care system, contributing to higher costs and poor health outcomes for older adults. Levy et al estimated the costs of ageism to be \$11 billion per year based on analyses of the effects of ageism on—and comprehensive health care spending data on the 1-year costs of—the 8 most-expensive health conditions among older adults in America.<sup>8</sup> Conversely, mental illness and subsequent disability can lead to ageist stereotyping, negative attitudes, and discriminatory practices that contribute to poor health outcomes.<sup>9</sup> For older adults with mental illness, ageism and stigma constitute a double hit and can compound poor health outcomes. Another product of ageism is that we tend to think of adults as persons who age and of children as persons who grow. This article interrogates this idea in relation to the stories of older adults in our health care system.

#### Approaches to Understanding and Addressing Ageism

Behavioral scientists have developed a series of approaches to understanding ageism, including the stereotype embodiment theory, which proposes that stereotypes are embodied when their assimilation from the surrounding culture leads to self-definitions that in turn influence functioning and health.<sup>10</sup> Others have taken a human rights-based approach, examining the role of dignity in health care and its impact on ageism and the human rights of older persons.<sup>11</sup> A deontological approach prioritizes rules that individuals and societies should follow based on common values and agreed-upon social contracts<sup>12</sup>; on human rights-based and deontological approaches, ageist practices would be seen as unacceptable violations of autonomy or agency. On the other hand, a consequentialist approach, which may be invoked to justify rationing of health care resources based on age,<sup>13</sup> could promote ageist practices. Virtue ethics takes an entirely different tack, placing the experience of the people at the forefront of ethical decision making.<sup>14</sup> For example, by empowering older adults to make decisions about their health care even in the context of scarcity, clinicians will foster their own virtues by respecting the autonomy of persons of all ages.<sup>13</sup>

Here, we would like to consider narrative-based ethics as a way of understanding and addressing ageism, with a focus on incorporating older adults' capacity for growth as a means of countering ageism in health care. Narrative medicine refers to an approach first proposed by Rita Charon.<sup>15</sup> Charon, a professor of medicine who holds a doctorate in English literature, describes key elements or goals of the narrative approach: to use listening skills and the centrality of story to develop an understanding of patients' lives, to better understand patients' individual experiences of illness and their concerns, to strengthen the bond between physicians and patients, and to appreciate the common and important phenomena of guilt and shame in the experience of illness.<sup>16</sup>

The narrative medicine approach is built upon an appreciation of the medical humanities. Medical humanities is a relatively young field that considers the overlap between the humanities—the arts, literature, poetry, film, music, dance, and more—and medical concerns. We can, for example, apply the same principles involved in analyzing a story, novel, poem, film, or piece of art in describing our patients and their attendant clinical or ethical problems. Doing so can help us preserve a sense of ambiguity when approaching problems that demand careful consideration rather than premature decision making.

The medical humanities provide ample material for clinicians and trainees to explore the experience of aging. Reading, as well as viewing film and art, can build empathy and understanding of aging. The goal of considering and discussing such works is to enable us, as physicians, to use our moral imaginations to vicariously experience the phenomenon of aging in order to better understand our patients. For example, former US poet laureate Billy Collins mourns the loss of memory in his poem, "Forgetfulness."

No wonder you rise in the middle of the night to look up the date of a famous battle in a book on war. No wonder the moon in the window seems to have drifted out of a love poem that you used to know by heart.<sup>17</sup>

In the movie *The Father*, Anthony Hopkins depicts a man who does not realize he is developing dementia, much less the impact of his illness on his family. Two nonfiction works are especially relevant for understanding the experience of aging: *Elderhood* by Louise Aronson and *Being Mortal* by Atul Gawande.<sup>18,19</sup> Each of these books, written by a physician, explores aging, death, and dying in the context of the patient-physician relationship, with an emphasis on the narratives and values of patients as their doctors help them adapt to illnesses.

#### A Narrative Approach to Ageism

What does the narrative approach look like in clinical practice? Narrative medicine has various practical implications for clinicians interacting with their patients. These include a focus on the narrative arc of patients' understanding of their own lives.<sup>20,21</sup> Rather than asking, "What brings you to the clinic/hospital?," a clinician committed to the narrative approach might begin an interview with: "Before we explore your medical problems, could you tell me about yourself for 10 minutes?" Physicians and patients benefit from this approach, as even a brief exploration of patients' developmental history and their individual narrative often helps physicians more firmly ground their premorbid identities and may serve to help their "cases" stand out.

How patients organize their stories may yield information beyond content alone. For example, providing a history with few details may suggest that the person is cautious

about what they disclose to others or is mistrustful of health care professionals. Multiple or perhaps even repetitive questions might suggest worry about one's condition that a clinician should address. A patient with extensive or elaborate responses might be lonely or bored and appreciate the opportunity to talk to someone.

Returning to our case, we wonder what we might have learned had we asked Mrs P about her developmental history. For example, her parents may have instilled in her a strong respect for older adults and the expectation that children care for their parents. An expectation that her children will be more involved in her care may have contributed to her rejecting the recommendation to move to an assisted living facility.

The vignette notes that Mrs P is widowed. It may be helpful to explore what her relationship was like with her spouse, what the circumstances of her spouse's death were, and to what extent she may still be grieving. For example, if Mrs P was her spouse's caregiver, then this role may be influencing her views of illness and the health care system. If her spouse required assisted living or skilled nursing care, this circumstance may color her perception of herself moving into such a setting.

We also wonder about the nature of the interactions between Mrs P and her health care team. Consulting multiple specialists may have conveyed to Mrs P, who is cognitively intact, that they doubt her ability to care for herself and make her own decisions.

Finally, we can't tell from the vignette what matters most to Mrs P. "Matters Most to Me" is 1 of the "5 *M*'s" of geriatrics, which also include mind, mobility, medications, and multicomplexity, all of which are relevant in this case.<sup>22</sup> The What Matters Most-Structured Tool asks people to rate how important various values and goals are—the ability to take care of oneself, to have physical or sexual intimacy, to have relationships with family and friends, to avoid being a burden to others, to have privacy, and so on.<sup>23</sup> It would also be important to assess the influence of religious or spiritual beliefs on Mrs P's decision making and how much input she wants from family and from her doctors about her health care decisions.

It's clear that the case is missing many salient features of Mrs P's story, including what she hopes she will do in the next chapter of her life. Narrative approaches would have helped elicit her unique life course and experiences while highlighting her values and preferences.

#### Conclusion

The narrative approach can strengthen our appreciation of older adults' personhood and their continued capacity for growth by helping us center each patient's values as rooted in their lived experience. The humanities help us both to interrogate the values, attitudes, and stories that we, as clinicians, bring to our interactions with older adults and to challenge our preconceptions of aging as only a time of decline and loss.

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# POLICY FORUM: PEER-REVIEWED ARTICLE

## Why We Must Prevent and Appropriately Manage Delirium

Jennifer M. Connell, MD, Maria C. Duggan, MD, MPH, and Jo Ellen Wilson, MD, PhD, MPH

#### Abstract

Delirium is common and increases in prevalence with age and medical complexity. A form of acute brain dysfunction, its presence is associated with significant morbidity, such as cognitive impairment, decreased mobility, depression, and institutionalization, as well as mortality. Many organizations have developed clinical protocols to prevent and treat delirium and what are called "cognitive-friendly" policies to care for elderly patients.

The physician must be able to tell the antecedents, know the present, and foretell the future —must mediate these things, and have two special objects in view with regard to disease, namely, to do good or to do no harm. Hippocrates<sup>1</sup>

### Delirium as Acute Brain Dysfunction

Delirium, characterized by acute deficits in cognition and attention with specific alterations in ability to focus, sustain, or shift attention, is unfortunately a common and highly morbid condition that is often underrecognized. A 2020 meta-analysis of 33 studies of medical adult inpatients found an overall delirium prevalence of 23%.<sup>2</sup> This figure, however, underestimates the prevalence of delirium in critically ill and palliative care patients, which is estimated to be 32% and 75%, respectively.<sup>3,4</sup> Delirium is associated with poor outcomes, including worse cognition and increased postdischarge mortality and hospital length of stay.<sup>5,6</sup> In addition, delirium has been associated with new onset posttraumatic stress disorder, depression, and dementia.<sup>7,8,9,10</sup> Delirium affects more than 2.3 million older Americans annually, complicating 17.5 million inpatient days.<sup>11</sup> It was estimated in 2008 that delirium costs up to \$64 421 per inpatient and costs the health care system between \$38 billion and \$152 billion per year.<sup>12</sup> Delirium disproportionately affects older patients and will therefore become an even larger issue as the population continues to age.<sup>13</sup>

Although delirium is preventable in 30% to 40% of inpatient cases,<sup>13</sup> it is often underrecognized and undertreated in the hospital.<sup>13,14</sup> Delirium is a multifactorial condition resulting from a combination of neuroinflammation, brain vasculature dysfunction, altered brain metabolism, imbalance in neurotransmitters, and impaired neuronal network connectivity.<sup>15</sup> Other forms of acute organ dysfunction are routinely monitored for, such as pulse oximetry, telemetry, and creatinine for pulmonary, cardiac, and renal function, respectively. Not only do we monitor for these conditions, but we also actively prevent organ dysfunction through, for example, the national movement for prevention of hospital- or ventilator-acquired pneumonia, avoidance of multiple QT-prolonging medications, and fluid resuscitation in the setting of acute kidney injury. In contrast, although strategies exist to prevent and mitigate harms from delirium, their implementation and reach is lacking. In this paper, we discuss the ethical considerations of implementing "cognitive-friendly" policies to prevent delirium among hospitalized older adults.

#### **Evidence-Based Mitigation Strategies**

Cognitive-friendly policies, or evidence-based strategies to prevent and mitigate harm from delirium, have been known for over 20 years.<sup>16</sup> Consensus guidelines recommend general prevention interventions, such as orientation, normalization of the environment (eg, diet, utilization of hearing aids, music), promotion of sleep/wake cycle, treatment of pain, mobilization, and avoidance of deliriogenic medications such as benzodiazepines.<sup>17,18</sup> Many of these recommendations have been combined into protocols or bundles. The Clinical Practice Guidelines for the Management of Pain, Agitation, and Delirium (PAD) in Adult Patients in the Intensive Care Unit (ICU) of the Society of Critical Care Medicine provide guidance for prevention of delirium.<sup>19</sup> The ABCDEF (Assess and manage pain; Both spontaneous awakening and breathing trials; Choice of analgesia and sedation; Delirium: assess, prevent and manage; Early mobility and Exercise; and Family empowerment) bundle is a way to operationalize the PAD guidelines through ICU delirium prevention strategies.<sup>20</sup> Adherence to this bundle is associated with a 40% reduction in likelihood of delirium on the day following exposure to the bundle.<sup>21</sup> Additionally, implementation of this bundle has resulted in other clinically meaningful outcomes, such as reduced time on mechanical ventilation, time in a coma, and use of restraints. Finally, the Hospital Elder Life Program (HELP) is a targeted, multicomponent strategy to prevent functional and cognitive decline in hospitalized older persons.<sup>16</sup> This bundle involves many members of the care team, as well as patients, and creates a personalized program using targeted interventions, such as daily visits, orientation, therapeutic activities, and more. The program has been shown to reduce the odds of delirium by 53%.22

Despite providers' best efforts, delirium is not yet fully preventable; efforts must still be undertaken to mitigate its harm because the duration of delirium increases the risk of long-term cognitive impairment and mortality up to 2 years posthospitalization.<sup>23</sup> While many risk factors for delirium—such as advanced age, baseline cognitive function, and frailty—are not modifiable, some are amenable to targeted risk reduction. For example, in the critical care setting, early physical and occupational therapy led to shorter delirium duration for adults who had been ventilated for less than 72 hours.<sup>24</sup>

As many interventions for risk factor modification are resource and labor intensive, interventions should be targeted to best utilize available resources. The PRE-DELIRIC model is an effective method to predict delirium in patients within 24 hours of admission to the ICU.<sup>25</sup> This and similar models can and should be used for targeted risk factor modification for all–but especially for high-risk–patients.

#### Lack of Implementation

Despite the evidence pointing to the high prevalence of delirium, its associated morbidity, and opportunities to intervene, many institutions lack rigorous delirium

prevention and mitigation strategies. Lack of recognition of delirium is one of the biggest barriers to its mitigation. Moreover, despite a clear recommendation to regularly assess for delirium in the PAD guidelines, 30% of ICUs in a worldwide survey conducted in 2016 never assessed for the presence of delirium.<sup>26</sup> In those that did, only 42% used validated tools.<sup>26</sup> Among all ICUs, only 31% to 67% implemented recommended nonpharmacologic practices, such as early mobilization, sleep promotion, and family participation,<sup>26</sup> with the trend continuing in the inpatient setting, where up to 38% of patients in one study experienced delayed mobilization.<sup>27</sup>

A possible cause of the incomplete implementation of the PAD guidelines are institutional barriers. Commonly cited barriers to implementation of delirium prevention and mitigation strategies include strict visitation policies, lack of delirium training among nurses, and light and noise disturbances.<sup>28</sup> Both presence of family at the bedside and environmental optimization to maintain sleep/wake cycles are part of the evidence-based bundle for delirium prevention.<sup>18</sup> As a result of the COVID-19 pandemic, many hospitals significantly limited the presence of family at the bedside, potentially undermining the hospital's ability to adhere to delirium prevention bundles.<sup>28</sup> The evidence-practice gap may also be attributed to a lack of prioritization of the needs of older adults with cognitive impairment and a low organizational strategic and financial investment in delirium, as well as to the fact that delirium is a condition that falls between specialties.<sup>29</sup> It is crucial that health care workers collaborate to ensure that evidence-based practices are implemented and executed in a consistent manner.

Delirium is often an iatrogenic complication of hospitalization, yet implementation of delirium prevention strategies lags behind other iatrogenic complications, such as falls, nosocomial infections like catheter associated urinary tract infections (CAUTIs), and pressure injuries. Similar to delirium, these other iatrogenic complications are recognized as major sources of morbidity and mortality. Yet these examples are more easily recognizable and lead to immediately visible ramifications, whereas delirium is a more recently recognized phenomenon that has less obvious-but no less prevalentdirect, negative effects. Moreover, in contrast to delirium, systemic, widely implemented practices to monitor, prevent, and mitigate harm from other iatrogenic complications have been broadly implemented. For example, in response to the problem of catheterassociated urinary tract infections (CAUTIs), both the Centers for Disease Control and Prevention (CDC) and the Institute for Healthcare Improvement (IHI) put out guidelines on best practices for prevention.<sup>30,31</sup> To incentivize enforcement, the Centers for Medicare and Medicaid Services stopped reimbursing costs associated with hospitalacquired CAUTIs. Since then, over 90% of US hospitals have implemented CAUTIprevention bundles, resulting in an over 80% reduction in CAUTI rates at one medical center.<sup>32,33,34</sup> Institutions should learn from this example and give both attention and funding to implementation of delirium prevention and mitigation strategies.

#### latrogenic Harm Avoidance

Reducing the prevalence of delirium and falls associated with delirium could result in an estimated \$16 billion in savings annually.<sup>35</sup> In addition to cost savings, reducing delirium would increase patient autonomy, as there is a higher likelihood that patients who are delirious would lose decision-making capacity and that a surrogate or legally authorized representative would have to make important medical decisions for them. By not implementing the nonpharmacologic best practices outlined above, we are thus allowing the health care system to potentially do harm to our patients.<sup>36</sup>

We could prevent significant morbidity and mortality associated with delirium if only hospitals, clinicians, and nursing staff would buy into the value of prevention and harm reduction. This buy-in, however, would require national-level policies from organizations like the CDC and IHI that push for bundles of delirium care. In addition, payers should also have to incentivize delirium-reduction bundles.

Despite the evidence in support of HELP and the ABCDEF bundle, there is a profound lack of policies to accelerate their implementation. Experts in this field have termed this lack the "know-do" gap.<sup>37</sup> While we know what programs work, hospitals are not implementing them properly. It is an ethical imperative for hospitals and policy makers to address underlying challenges, such as excess burden on nursing, financial incentives, and other system-level problems. Only when this is done can a multicomponent program on delirium succeed.

#### **Priorities**

As alluded to above, perhaps delirium does not receive the attention it deserves because the patients it most significantly affects are older adults, frail or complex patients, and the cognitively impaired.<sup>38</sup> These populations have been historically neglected in societal policies. Because they are less likely to have access to resources and to advocate for themselves, issues affecting them are not at the forefront of hospital policies. However, older adults make up the largest proportion of hospitalized patients in the American health care system.<sup>39</sup> If we are to provide equitable care for all patients,<sup>36,40</sup> we must make delirium care a priority in policy and practice. As we are lacking in prevention of delirium in hospitalized patients, we are inequitably doing harm to the most vulnerable populations.

There are policies we can and should implement to mitigate delirium's prevalence and resulting mortality in hospitalized older adults. Hospital administration must emphasize programs such as the ABCDEF bundle and HELP. But policies are not enough; we must stay true to their intent by practicing in accordance with these policies, as we have an ethical responsibility to our patients to avoid the largely iatrogenic harms of delirium and to treat delirium as a pressing issue deserving of our attention and action. Finally, to truly practice with justice, we must prioritize the most vulnerable patients, as this issue most affects them.

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# **POLICY FORUM: PEER-REVIEWED ARTICLE**

# How Should We Address Warehousing Persons With Serious Mental Illness in Nursing Homes?

Ari Ne'eman

#### Abstract

Despite long-standing efforts to keep patients with serious mental illness (SMI) out of nursing homes, many persons with schizophrenia, bipolar disorder, or psychoses become long-stay nursing home residents. This article discusses why this trend is inappropriate clinically and ethically and suggests how to reform federal review requirements to accomplish 2 goals: to better identify people with SMI at risk of nursing home placement and to support them to live in the community.

#### Patients With Serious Mental Illness in Nursing Homes

The proportion of nursing home residents with a serious mental illness (SMI) has risen dramatically over the last 2 decades.<sup>1,2</sup> In 2019, 1 in 5 long-stay nursing home residents had a diagnosis of bipolar disorder, schizophrenia, or another psychotic disorder.<sup>3</sup> Although hospital discharges to nursing homes are usually intended for short-term post-acute care, they frequently turn into long-stay placements.<sup>4</sup> Much like the criminal justice system, nursing homes have become an unwitting mental health provider—and not a very good one. This article examines factors that result in nursing home placement of persons with SMI and offers policy change recommendations.

#### **Preadmission Screening**

In 1987, widespread concern over the warehousing of people with SMI and people with intellectual disability (ID) in nursing homes prompted Congress to establish the Preadmission Screening and Resident Review (PASRR) process. As part of this process, facilities and hospital discharge planners are required to screen for both SMI and ID, then refer those so identified to a state agency. The state must then assess the appropriateness of nursing home placement and, when necessary, provide specialized services for diversion to a different setting.<sup>5</sup>

Nevertheless, the proportion of nursing home residents with SMI continues to grow.<sup>1,2</sup> Although the Centers for Medicare and Medicaid Services (CMS) has recently indicated that a portion of nursing home schizophrenia diagnoses are potentially erroneous,<sup>6</sup> prior work relying on preadmission schizophrenia diagnoses shows that middle-aged persons with SMI are still significantly more likely to enter nursing homes than their peers without mental illness.<sup>7</sup> State PASRR programs have struggled to fulfill their obligations owing to unclear expectations, inconsistent enforcement, and insufficient community services.<sup>8,9</sup> According to the Bazelon Center for Mental Health Law, "the PASRR process in most states diverts a very small number of people from nursing home placement and instead functions to screen them *in* rather than *out* of nursing facilities."<sup>10</sup>

The PASRR requirement also suffers from a serious loophole: admissions for post-acute care that are anticipated to take less than 30 days are exempted.<sup>11</sup> Although evaluation is required if residents are later found to require a longer stay, return-to-community efforts are less likely to be successful the longer a resident has been institutionalized,<sup>12</sup> owing to disruptions in housing, natural supports, and community-based services. Prior research suggests that this exemption plays a role in the nursing home placement of many long-stay residents with SMI.<sup>13</sup> Concerningly, a February 2020 CMS proposal would expand PASRR exemptions to permit emergency, respite, and convalescent new admissions and all readmissions to enter a nursing home without receiving an evaluation as to the suitability of such placement.<sup>14</sup>

Although new admissions with SMI are less likely to have significant physical support needs, they are at greater risk of long-stay conversion than other new residents. One study found that approximately half (51%) of new admissions with SMI convert to long-stay status as compared to only 35% of persons without SMI.<sup>4</sup> Nursing homes have become a new way for people with SMI to be warehoused, serving as a setting to which hospitals can discharge individuals who no longer need acute care but who lack adequate supports in the community.

#### **Ethical Obligations**

Given the high risk that patients with SMI will experience long-term institutionalization if they enter a nursing home for post-acute care purposes, physicians and hospital systems should do everything in their power to avoid such discharges, as nursing home placement is generally inappropriate for persons with SMI. Nursing homes are ill equipped to provide mental health services.<sup>15</sup> Moreover, facilities with lower-quality rankings, which struggle to attract residents with greater ability to "shop around,"<sup>16</sup> have significant financial incentives to retain persons with SMI longer than they might strictly require, leading to greater risk of long-term institutionalization.

When planning the post-acute care needs of persons with SMI, clinicians and organizations should be frank about the risks of nursing home care. They should clearly state that admissions intended to be short-term frequently extend indefinitely and highlight other risks, including chemical restraint,<sup>17,18</sup> infectious disease (including COVID-19),<sup>19</sup> lack of expertise,<sup>15</sup> and the absence of meaningful treatment options. These risks are present across nursing home settings but may be exacerbated for persons with SMI, who are more likely to enter lower-quality facilities (as are Black Americans, people with low incomes, people with disabilities under age 65, and higher-acuity admissions).<sup>3,20,21</sup>

When patients with SMI have stable housing or family support, a suitable home health agency option for post-acute care services should be identified. Even when patients are homeless, other options may exist. Hospital discharge staff should build relationships with providers of intensive community mental health services and Medicaid home- and community-based services (HCBS). Such provider networks are often unfamiliar to clinicians and hospital personnel, as they usually do not provide post-acute care but

instead focus on the long-term services and support needs of persons with SMI. For persons with SMI, however, nursing home placement rather than discharge to the community often results from such ongoing support requirements.

Given that 81.6% of long-stay nursing home residents under age 65 are between the ages of 50 and 64,<sup>3</sup> clinicians might also give serious consideration to the Program of All-Inclusive Care for the Elderly (PACE), which receives capitated payments from Medicare and Medicaid to provide comprehensive services to persons over age 55 eligible for nursing home placement but living in the community.<sup>22</sup> According to the National Program of All-Inclusive Care for the Elderly (PACE) Association, an industry group, over 40% of PACE participants have a mental illness.<sup>22</sup> However, some caution is warranted. While more integrated than a nursing facility, PACE programs have historically relied on a center-based model for the delivery of day services and are not under the same requirements as Medicaid HCBS providers to facilitate service-recipients' integration into the broader community.<sup>23</sup>

Hospital systems should also seek to incorporate the needs of persons with SMI in alternative payment models. Recent work has found that accountable care organization participation is associated with significant reductions in both hospitalization and post-acute care utilization for persons with SMI without reducing mental health spending.<sup>24</sup>

#### Reform

Given persons with SMI's high risk of converting from post-acute to long-stay nursing home placement, Congress should repeal the present PASRR exemption for post-acute admissions. Rather than weaken PASRR through additional exemptions, federal regulators should look for opportunities to strengthen the program, including through auditing state practices.

In addition, reform is necessary to expand the availability of community-based alternatives to nursing home placement to enhance efforts at diversion. States should expand funding for community-based services, such as assertive community treatment and caregiver respite. One of the primary financing vehicles available to states is the Medicaid HCBS waiver, authorized by Section 1915(c) of the Social Security Act, which supports community services in lieu of institutionalization.<sup>25</sup> However, such waivers include a cost-neutrality requirement, indicating that states may not spend more on average for community services than they would have on institutional care for the same population.<sup>3,25,26</sup> Moreover, under the Medicaid Institutions for Mental Diseases (IMD) exclusion, states are usually not permitted to use Medicaid dollars to pay for placing working-age adults in an institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of people with mental diseases.<sup>27</sup> To be clear, clinicians and policy makers should not look to IMD as an alternative to nursing home placement for people with SMI. But the requirements of the 1915(c) waiver and the IMD exclusion interact to create a serious challenge for funding community-based mental health supports, as states may not count avoided IMD expenses as cost savings that can be reinvested in 1915(c) waiver services.<sup>3,25,26</sup> This practice is particularly unfortunate, given evidence that HCBS can successfully divert people with SMI from institutionalization.28

Although some have proposed repealing the IMD exclusion altogether,<sup>29</sup> doing so would be ill-advised, as it would open the door to warehousing of persons with SMI in mental institutions and consume resources that could be invested in more appropriate

community supports.<sup>27</sup> Instead, Congress and CMS should clarify Section 1915(c) costneutrality rules to make it easier for states to fund HCBS for people with SMI.

CMS also possesses substantial authority to issue demonstration waivers to states, thereby allowing them to experiment with services that would typically violate Medicaid law. The agency should indicate its willingness to issue such waivers to permit states to pay for rental assistance for targeted populations at risk of institutionalization, such as persons with SMI. Although typically not permitted under Medicaid, funding housing could substantially reduce nursing home placement, offsetting its costs.<sup>30</sup> Such housing investments should follow the well-validated Housing First model by prioritizing the placement of persons with SMI in independent housing without requiring them to adhere to therapeutic or service requirements to maintain their residence.<sup>31,32,33,34,35</sup>

#### Conclusion

People with SMI have significant ongoing support needs that are best met with community support. The growing role of the nursing home industry as a mental health provider should concern both clinicians and policy makers. Both individual clinicians and hospital systems have an ethical obligation to work to divert persons with SMI from nursing home placement, including via discharges for post-acute care. At the same time, hospital systems and policy makers should work collaboratively to build more effective infrastructure for supporting persons with SMI in community-based settings.

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# MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Ageism as a Source of Global Mental Health Inequity

Pamela B. Teaster, PhD, MA, MS and Al O. Giwa, LLB, MD, MBA, MBE

#### Abstract

Ageism manifests as stereotyping of or discrimination against people usually older adults—because of their age. Since ageism contributes to global mental health inequity among older people, responding to their needs should be a clinical, ethical, and policy priority. This article suggests how relatively simple, low-cost, high-yield interventions can be implemented globally and domestically to improve the well-being and quality of life of older individuals.

#### **Origins of Ageism**

More than 50 years ago, psychiatrist Robert Butler coined the term *ageism*, which he defined as a process of "systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin color and gender."<sup>1</sup> The term arose during his 1969 interview with novice *Washington Post* reporter, Carl Bernstein,<sup>1</sup> which concerned younger adults' objections to turning an apartment complex in a posh neighborhood in Chevy Chase, Maryland, into a high-rise to house older individuals of various races and ethnicities. Instead of attributing their objection to community racism, Butler attributed it to ageism, a prejudice against older people based on age. Furthermore, Butler confessed that, in his own field, many psychotherapists harbored a disdain for older patients. Characterized as "therapeutic nihilism," these attitudes, he suggested, impeded clinicians' efforts related to patient care.<sup>2</sup>

Studies conducted during the 1980s concerning mental health clinicians' attitudes toward older adult patients revealed that they gave older patients consistently poor therapeutic prognoses.<sup>3,4</sup> The view was that older adults were essentially beyond treatment, reflecting a reluctance to care for them. Such attitudes have persisted, as evident by their being reported in the 1990s in studies from Israel,<sup>5</sup> Great Britain,<sup>6</sup> Australia,<sup>7</sup> and Portugal.<sup>8</sup> These attitudes led to a general belief on the part of many clinicians that depression is a normal part of aging. Although few recognized the term *ageism* or its implications at the time, the insidious attitudes and effects of ageism have since been documented worldwide, and we argue that it is a source of global mental health inequity among older adults. Adding to our assertion, the 2016 standards of the Council for Accreditation of Counseling and Related Educational Programs fail to mention ageism or older people.<sup>9</sup>

#### Ageism as a Source of Inequity

Health inequity involves the unfair allocation of resources or treatment options based on a person's race, sex, sexual identity or orientation, or age, whereas health equity is the fair allocation of health care resources to all members of society.<sup>10</sup> The World Health Organization (WHO) stresses that health inequities are clear "systematic differences in … health status."<sup>11</sup>

McClung et al define health equity as "when every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances. Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment."<sup>12</sup>

Asada identified health inequity as a moral concern due to the value that most people place on their health and the general consensus that access to health care is viewed as a necessity; limitations of that right represent an ethical, if not a legal, wrong.<sup>13</sup> To measure health inequity, Asada proposed operationalizing a concept of equity and a measurement strategy that includes measures of health (eg, life expectancy), unit of time (eg, life stage or life course), and unit of analysis (eg, individuals or groups). Moreover, she argued that it is critical to compare health status using methods that take into account population size.

We recognize that measuring health outcomes to determine the consequences of ageism has proven challenging, given that older people generally have more advanced disease than younger members of society. However, it is possible to measure access to care, attitudes of health care professionals toward older individuals, quality of life, and various other measures to determine health care inequities. Furthermore, we must stress that equity is not the moral equivalent of equality, and we reject the use of these terms interchangeably. We emphasize that no 2 people are the same, although there are general treatment options that apply globally to classes of individuals (eg, COVID vaccination). Equality entails the exact same access to treatment for all. Equity, however, acknowledges that individuals' needs may differ but that they should be afforded rights and access to treatment, as exemplified by policies and laws mandating access to public services by persons with disabilities. Not all follow the same path, but they are afforded fair opportunity based on need.

#### **Health Outcomes**

Although the effects of ageism on mental health are generally understudied, notable examinations exist. For example, Herrick et al emphasize that mental health problems of older adults can exacerbate physical symptoms and that early detection of mental health problems has the potential to prevent some physical problems related to untreated mental illness.<sup>14</sup> In addition, loneliness and ageism holistically affect mental health, specifically by contributing to anxiety and depressive symptomology.<sup>15,16,17</sup>

With a particular emphasis on the influence of individual and systemic factors that lead to health inequities, a meta-analysis conducted by Chang et al revealed that, in 10 studies, ageist attitudes predicted a shorter lifespan in adults aged 50 and older in Australia, China, Germany, and the United States.<sup>18</sup> In relation to mental health, 95.5% of 44 studies found that ageism affected psychiatric conditions—in particular, the onset and continuance of depressive symptoms over the lifespan. Finally, "a greater prevalence of significant ageist-health findings was found in less-developed countries

than more-developed countries," and less educated older people were more likely to experience adverse health effects of ageism.<sup>18</sup> A systematic review by Hu et al<sup>19</sup> included a subset of observational studies from the United States, Britain, and Canada on ageism and its relation to health, which demonstrated that the prevalence of perceived age discrimination was higher than the prevalence of perceived sexual and racial discrimination.<sup>20,21,22</sup> The authors found a range of health outcomes associated with ageism and stressed that it should be regarded as a public health risk.<sup>19</sup> Using data from 5083 diverse women in the National Longitudinal Survey of Mature Women, Shippee et al explored long-term effects of age discrimination in the US workplace on mental health.<sup>23</sup> They found age discrimination to be a "significant predictor of women's depressive symptoms and life satisfaction over the life course, even controlling for other forms of discrimination and other factors."<sup>23</sup>

#### Effects of COVID-19

This article would be incomplete without mentioning the global effects of COVID-19, which most profoundly affected the physical and mental health of the aging population. The virus highlighted and widened existing gaps in physical and mental health care. Not only were older adults particularly susceptible to dying from the disease, but they were also susceptible to the effects of loneliness due to prolonged social isolation, which reinforced the ageist perception of society and of older adults themselves that they were expendable and an incumbrance. Kessler and Bowen emphasized that a "thwarted sense of belonging and perceived burdensomeness are risk factors for suicidality" and that prevailing attitudes of politicians and the public served to reduce older adults' attention to their own mental health, thus affecting their longevity and physical and mental health.<sup>24</sup>

Other authors have identified issues related to ageism and health inequities during the height of the pandemic. Banerjee pointed out that older adults were not necessarily comfortable with the mechanisms of communication (eg, smart phones, social media) and so were unaware of evolving situations related to the pandemic, making them easy targets of misinformation and inadequate precautionary measures and increasing incidences of depressive disorders, complex posttraumatic stress, and adjustment reactions.<sup>25</sup> Flett and Heisel found that, during the COVID-19 pandemic, fear, loneliness, and isolation combined to undermine the mental health of the population of older adults.<sup>26</sup>

#### **Mitigating Ageism and Inequity**

Action strategies. Results from the 2021 Global Report on Ageism confirmed that ageism is a social determinant of age-based health inequities and poor health outcomes.<sup>27</sup> Globally, ageism affects billions of people, with at least 1 in 2 adults ages 16 through 99 holding ageist attitudes, with even higher rates reported in countries with lower incomes.<sup>28</sup> Combating ageism has been listed in the *Global Report* as 1 of 4 action areas of the Decade of Healthy Ageing (2021-2030).<sup>27</sup> In 2021, the WHO released a plan for the Decade of Healthy Ageing (2021-2030), which it described as "10 years of concerted, catalytic, sustained collaboration."<sup>29</sup> Embracing a human rights approach, the plan stresses 4 areas for action, one of which, Area 3.1, endeavors to "change how we think, feel and act towards age and ageing."<sup>29</sup> Proposed action strategies are to develop communities that foster older people's abilities, to deliver person-centered integrated and primary health services that respond to the needs of older people, and to provide long-term care for those older people in need of it.

Medical education. Burnes et al conducted a systematic review and meta-analysis examining the effectiveness of 3 intervention strategies designed to change students' attitudes toward aging: education, intergenerational contact, and a combination of education and intergenerational contact.<sup>30</sup> One controlled, prospective, longitudinal trial included in the meta-analysis that combined intergenerational contact (via biannual structured interviews with a senior community-dwelling mentor during the first 2 preclinical years) and education (via small-group discussion of interviews mediated by geriatrics faculty) found that this low-intensity intervention to introduce entering medical students to healthy older people positively affected attitudes toward aging.<sup>31</sup> Furthermore, Meshel and McGlynn found that middle-school students randomly assigned to a 6-week intervention involving cross-age contact developed more positive attitudes toward older people, whereas those assigned to the didactic condition did not.<sup>32</sup> In sum, although Meshel and McGlynn did not find that the interventions translated into any reductions in health inequity for older populations, Burnes et al found that interventions using a combination of education and intergenerational contact produced the most significant improvements in the attitudes of females and of adolescents and young adults towards older adults.<sup>30</sup> The authors stressed that low-cost interventions resulted in substantial reductions of ageism and should be part of an international, public health effort to reduce this pernicious problem. Similarly, Mikton et al<sup>16</sup> emphasized the need for global investments in effective strategies for prevention and intervention, research, and the construction of a movement to alter the present global playbook about aging.

We emphasize that the scourge of ageism contributes to global mental health inequities among older adults. We stress that a moral imperative exists to address mental health inequities extant in the rising worldwide population of older adults. The global institution of relatively simple interventions would be both low-cost and exceptionally high yield and would have the potential to demonstrably reduce real and opportunity costs of health care as well as to improve the well-being and quality of life of present and future cohorts of older individuals.

The clear and demonstrable health inequity of ageism and its negative effects on older persons' mental health violates one of the key tenets of medical ethics—namely, justice and fairness. Respecting older persons means acknowledging that they are deserving of mental health care. It is past time to reconcile this inequity on both a local and a global scale.

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## **MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

# Why Does the US Overly Rely on International Medical Graduates in Its Geriatric Psychiatric Workforce?

Rajesh R. Tampi, MBBS, MS, Aarti Gupta, MBBS, and Iqbal Ahmed, MBBS

#### Abstract

International medical graduates (IMGs) tend to choose careers in geriatric psychiatry likely because high-quality training and robust mentorship opportunities from other IMGs are available. Geriatric psychiatry offers stable career prospects and opportunities to express humanitarian impulses by working closely with elders. IMGs currently constitute almost a quarter of the psychiatry workforce and approximately 53% of the geriatric psychiatry work force in the United States. However, the number of IMGs entering psychiatry residencies—and, subsequently, geriatric psychiatry fellowships—has recently declined. Overreliance on IMGs in the US geriatric psychiatric workforce means these shortages will further burden an already-limited geriatric mental health care workforce and further compromise US health system capacity to meet its elders' needs.

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#### A Subspecialty Since 1989

Although there are different definitions of a geriatric or older adult, in the United States, the traditional definition is someone who is at least 65 years of age (ie, Medicare eligible).<sup>1</sup> In 2019, there were 54.1 million older adults in the United States, representing 16% of the total population.<sup>2</sup> The population of older adults in the United States is expected to grow to 80.8 million, or 21.6% of the total population, by 2040.<sup>2</sup>

Psychiatric disorders are not uncommon among older adults in the United States, with 1 in 5 individuals over age 55 having a diagnosable disorder.<sup>3,4</sup> Based on a 2004-2005 survey, the most common psychiatric disorders in adults age 55 and older were personality disorders (14.5%), anxiety disorders (11.4%), mood disorders (6.8%), and substance use disorders (3.8%).<sup>5</sup> In 2016, approximately one-third of older adults were reported to suffer from mild cognitive impairment or dementia and resulting neuropsychiatric symptoms.<sup>6</sup> The number of older adults in the United States with Alzheimer's disease is expected to rise from 4.7 million in 2010 to 13.8 million by 2050.<sup>7</sup>

Geriatric psychiatry is a subspeciality of psychiatry involved in the practice of caring for older adults with psychiatric disorders.<sup>1</sup> The American Association for Geriatric Psychiatry (AAGP), the national association for geriatric psychiatry, was established in 1978.<sup>3</sup> The American Board of Psychiatry and Neurology constituted a committee in November 1989 to officially establish the field of geriatric psychiatry as a subspecialization in psychiatry and to identify properly trained and experienced geriatric psychiatrists.<sup>8</sup> This article examines the participation of international medical graduates (IMGs) in the US geriatric psychiatric workforce and argues that their declining numbers will further burden an already-limited geriatric mental health care workforce and further compromise US health system capacity to meet its elders' needs.

International Medical Graduates and the Psychiatry Workforce in the United States

An IMG in the United States is any physician who has obtained their primary medical degree outside the United States or Canada.<sup>9</sup> Presently, IMGs represent 23.3% of the total active US physician workforce and 29.2% of the psychiatry workforce.<sup>10</sup> The largest group of active IMGs in psychiatry comprises US citizens (22.7%), also referred to as US-IMGs at the time of their entry into medical school. Approximately 20.6% of residents in US psychiatry residency programs are IMGs.<sup>11</sup> IMGs in psychiatry are nearly 2 years older than their US counterparts and are more likely to work in the public sector and receive a larger proportion of their income from Medicare and Medicaid.<sup>10</sup> IMGs in psychiatry are less likely to work as administrators or medical teachers and more likely to work as full-time hospital staff or locum tenens physicians than their US counterparts.<sup>10</sup> Those who choose an academic career are less likely to obtain leadership positions.<sup>12</sup> Occupying positions of lower prestige, IMGs "encounter biases and microaggressions and lack support groups and mentors."<sup>12</sup>

Recently, significant changes have occurred in the number of IMG physicians entering the US psychiatry workforce.<sup>13</sup> Among all major medical specialties, psychiatry has had the largest relative decrease in the number of IMG physicians matched from 2014 to 2020 (46.3%),<sup>13</sup> which has subsequently reduced the pool of IMGs who can enter psychiatry subspecialties, including geriatric psychiatry. An important reason for this decline is increased interest in psychiatry among American medical graduates (AMGs), as reflected in growing numbers of AMGs entering psychiatry residency programs between 2015 and 2019.<sup>14</sup>

#### Why IMGs Choose Geriatric Psychiatry

IMGs represent 52% of the geriatric psychiatry workforce in the United States.<sup>10</sup> This number is significantly greater than what has been noted in other subspecialities of psychiatry, including forensic psychiatry (21%), child and adolescent psychiatry (29.6%), psychosomatic medicine (31%), and addiction psychiatry (41.1%).<sup>10</sup>

Although there is no empirical data on why IMGs preferentially choose a career in geriatric psychiatry, factors associated with psychiatric residents' interest in geriatric psychiatry as a field of specialization could offer some insight. One cross-sectional online survey of Canadian psychiatry residents found that the variables that were robustly associated with an interest in geriatric psychiatry were "completion of geriatric psychiatry rotation(s) before the third year of residency," "comfort working with geriatric patients and their families," "positive experiences caring for older adults prior to medical school," and "the presence of annual conferences in the resident's field of interest."<sup>15</sup> Moreover, geriatric psychiatry fellowships with more geriatric psychiatry faculty can provide role models and mentors.<sup>16</sup> Furthermore, access to a robust pipeline

scholarship program that provides greater understanding of the field of geriatric psychiatry in addition to offering excellent mentorship during psychiatry residency (eg, the AAGP Scholars Program) possibly attracts IMGs to geriatric psychiatry.<sup>16,17</sup>

In addition, non-US IMGs often come from countries and cultures where older adults are an important part of the extended and multigenerational family structure and therefore may experience greater comfort and confidence in working with older adults, even those with psychiatric disorders. Surveys of IMGs indicate that they may harbor more favorable cultural and societal attitudes toward elderly patients. Geriatric psychiatry fellows with a career interest in geriatric psychiatry have reported that personal relationships and experiences with seniors, as well as cultural attitudes, influenced their interest.<sup>18</sup> They also identified respect for elders, enjoying their life stories, and believing it is society's responsibility to care for the elderly as inherent in their choice of career.<sup>18</sup>

#### Need for IMGs

Currently, there are approximately 64 Accreditation Council for Graduate Medical Education (ACGME)-approved geriatric psychiatry fellowship programs in the United States.<sup>19</sup> However, the proportion of IMGs in geriatric psychiatry fellowships has declined from the decade 2000 to 2010, when more than 50% of the geriatric psychiatry fellowship slots were taken by IMGs, to 37% in 2021.<sup>18,19</sup> This decline is most likely a reflection of the decreasing number of IMGs matching into psychiatry residencies and therefore a lower number of them available to apply for fellowships. While AMGs have a higher match rate into psychiatry residencies than IMGs, the number of geriatric psychiatry fellows declined between 2015 and 2019,<sup>14</sup> the reasons for which are not clear. Specifically, the number of trainees entering geriatric psychiatry fellowships fell by 27.6% between 2015 and 2019, as compared to a 2.5% decline in addiction psychiatry fellows and a growth of 11.1% in forensic psychiatry fellows, 7.6% in child and adolescent fellows, and 8.9% in consultation-liaison fellows during the same period.<sup>14</sup> The 2019 fill rate for the geriatric psychiatry fellowship programs was 29.5%, down 8.6% from 2017.14 In 2021-2022, there were only 55 geriatric psychiatry fellows in the United States.<sup>18</sup> If the current trend of decreasing numbers of AMGs and IMGs going into geriatric psychiatry continues, the geriatric psychiatry workforce is bound to decrease.

As the population of older adults in the United States becomes increasingly racially diverse,<sup>20</sup> another important benefit of the significant presence of IMGs, especially non-US IMGs, is that they often provide services to minority and socioeconomically challenged older adults. Assuming that non-US IMGs contribute to the diversity of the workforce, given that IMGs still compose the majority of the geriatric psychiatry workforce,<sup>10</sup> the trend of decreasing numbers of IMGs entering psychiatry and subsequently geriatric psychiatry could present challenges with respect to the long-term concordance of patient-clinician characteristics (eg, race, ethnicity, language).<sup>12</sup> Creating a more diverse physician workforce has been the goal of many organizations, with much greater attention to race, ethnicity, gender, and sexual identity than to country of origin. IMGs add to that diversity, often providing medical services to patients of the same racial/ethnic background. It could be stated that the overreliance on IMGs has actually led to a more diverse geriatric psychiatry workforce, which has benefitted the increasingly diverse population of older adults in the United States.

#### Conclusion

The field of geriatric psychiatry in the United States is at a crossroads at the present time.<sup>15</sup> On the one hand, the need for geriatric psychiatrists has continued to grow

significantly, but despite this growing demand, the number of geriatric fellows in the United States has shown a remarkable decline since 2001-2002.<sup>14,21</sup> The reasons for this decline are numerous, including a lack of financial incentives to embark on a career in geriatric psychiatry.<sup>22</sup> Other reasons may include lack of exposure to geriatric psychiatry or geriatric psychiatrists during medical school and the early part of residency.<sup>16</sup> As the number of IMGs matched into US psychiatry residencies continues to decline, the number of these trainees choosing a career in geriatric psychiatry will also decline. The result will be a substantial shrinkage in the pool of practicing IMG geriatric psychiatrists in the United States, which will worsen the burden of care of older adults with psychiatric disorders and reduce the diversity of the geriatric psychiatry workforce.

To avert this looming health care crisis, the federal government must act promptly to incentivize the choice of geriatric psychiatry as a specialty among psychiatric trainees and additionally encourage the recruitment of IMGs into psychiatry residency programs, which would increase the number of graduates entering geriatric psychiatry fellowships and subsequently the number entering the US geriatric psychiatry workforce. To address the issue of diversity of the geriatric psychiatry workforce, active efforts should be made to recruit underrepresented minorities into medical schools and psychiatric residencies, in addition to continued recruitment of IMGs.<sup>23</sup> To increase the number of trainees going into geriatric psychiatry fellowships, efforts would need to be made by residency programs to recruit and retain geriatric psychiatric faculty to help develop geriatric psychiatry curricula, provide early exposure to geriatric psychiatry, and provide mentorship in the field to medical students and residents.<sup>16,18,21</sup> Other strategies to enhance recruitment could include desensitizing trainees to ageist biases, identifying those trainees with favorable attitudes and experiences, and educating them about geriatric psychiatric practice and opportunities. The potential barrier of student debt to subspecialty training for general and academic career tracks also needs to be addressed. Loan forgiveness programs may help in this regard. In addition, measures such as increased reimbursement for patient care services, improved pay packages, improvement in workplace environment, and optimal working hours may be needed not only to bridge the diversity gap in the geriatric psychiatry workforce but also to proportionally increase the overall workforce.

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## **MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

What Might Aducanumab Teach Us About Clinicians' Judgment About Whether to Recommend Emerging Alzheimer's Interventions?

Adam W. Burroughs, MD and Lewis P. Krain, MD

#### Abstract

Alzheimer's disease (AD) is an incurable, progressive deterioration that ends, eventually, in death. For many years, AD's hallmark etiological feature was beta-amyloid plaque accumulation in the brain, but, to date, costly drugs designed to reduce beta-amyloid levels offer only marginal clinical benefit and pose significant risk of harm. Thus, there is strong interest in finding alternative AD-modifying interventions, and, despite controversy, aducanumab—an antibody—recently received approval by the US Food and Drug Administration. This article considers how ethical issues in the care of patients with AD could influence, for better or worse, clinicians' judgment about whether and when to recommend aducanumab.

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#### Aducanumab Controversy

Dementia (also known as major neurocognitive disorder in the fifth edition, text revision of the *Diagnostic and Statistical Manual of Mental Disorders*<sup>1</sup>) remains an incurable illness, with Alzheimer's disease (AD) accounting for 60% to 80% of dementia cases.<sup>2</sup> AD entails heavy caregiver and financial burden, as it causes progressive deterioration and eventual death of the patients suffering from it. This impact, magnified by an ageing population, has vastly accelerated efforts to effectively treat this disorder. Until recently, there were only 5 US Food and Drug Administration (FDA)-approved treatments for neurocognitive symptoms of AD<sup>3</sup>; however, there are no agents that alter the disease course of AD.

Two clinical trials conducted by the manufacturer of aducanumab showed reduction of brain beta-amyloid (A $\beta$ ) levels in patients with early-stage AD.<sup>4</sup> In 2021, aducanumab was granted accelerated approval by the FDA as the first potentially disease-modifying treatment for AD and the first FDA-approved AD therapy since memantine in 2003.<sup>5</sup> Although researchers believe that A $\beta$  clearance by aducanumab is a rational mechanism to slow cognitive decline in AD, there has been significant controversy surrounding the FDA's approval of this drug. First, there is no correlation between the reduction of A $\beta$ 

plaques and clinical improvements in trials to date.<sup>6,7,8,9</sup> Additionally, the price of aducanumab was initially 56 000 USD per person annually.<sup>10</sup> In January of 2022, the price was cut to 28 200 USD per year for a person of average body weight (74 kg)<sup>11</sup>; however, the full cost extends beyond the drug itself, as patients will require close monitoring with brain scans.<sup>11</sup> Although Medicare announced a national coverage determination process,<sup>12</sup> there are likely to be substantial out-of-pocket costs for many patients. Many have commented on the FDA's approval of aducanumab,<sup>6,10,13,14,15,16</sup> and a postapproval confirmatory trial will not be completed until 2030.<sup>17</sup> Meanwhile, the toll of dementia on individuals and families continues to grow.<sup>18</sup> In this article, we canvass ethical considerations that can arise in the care of patients with AD and apply them to the case of aducanumab.

#### **Quality of Life**

Given the absence of disease-modifying treatments for AD and AD being an incurable illness with deterioration that ends in death, clinicians' focus appropriately turns to quality of life. In aiming to maintain or enhance the patient's quality of life, clinicians must uphold the ethical principles of beneficence, nonmaleficence, and respect for patients' autonomy—and, in the case of neurocognitive disorders, protection of those with diminished autonomy.<sup>19</sup> One approach to supporting quality of life consists in helping patients obtain as much freedom from their disease as possible, while maximizing their functioning and engagement in their world.<sup>20</sup> At its core, maximizing quality of life represents a clinician's obligation of beneficence. In cases of incurable illness, beneficence must be weighed against the autonomy of the patient (and family) to decline or stop treatments that may have become onerous (eg, cholinesterase inhibitors might cause side effects that outweigh their benefits<sup>21</sup>).

With any treatment in cases of incurable illness, important considerations pertaining to quality of life include the following<sup>19</sup>: Are we, as clinicians, offering the patient a net benefit? What are the prospects, with or without treatment? It is important to understand that in seeking to "do no harm" and acting in the patient's best interest, we are not ethically obligated to keep the patient with incurable or chronic illness from being affected by it—that is often impossible. Jennings et al eloquently noted that the primary obligation is rather "to assist the person in keeping the transformative power of illness (needs) into a coherent and satisfying life."<sup>22</sup> This aim will look different depending on the disease and the individual in question, making it crucial to understand the individual and how the individual experiences the disease throughout its course.

In the case of aducanumab, the lack of clinical improvements in trials to date and risk of side effects such as brain edema,<sup>4,6</sup> combined with the considerable cost, does not suggest a population-level justification on the basis of quality-of-life arguments for widespread use of this medication, at least at the present time. In fact, the significant financial burden<sup>23,24</sup> could reduce quality of life by creating financial stress or limiting a family's ability to provide other necessities, such as food, shelter, amenities, or ancillary care. One could argue that lack of any other disease-impacting treatment justifies the use of a medication with limited proof of efficacy. A counterargument, however, would be that lack of alternatives does not justify the application of a questionable or ineffective treatment. Put another way, prescription of an ineffective medication just for the sake of having an intervention is a very expensive placebo, and in general, placebo use is not regarded as ethical standard of care.

#### **Resource Allocation**

Resource allocation is a significant concern in the care of patients with AD. The financial burden of dementia care is high, and few families are able to handle these costs entirely out of pocket. This burden (ie, unreimbursed care) is spread among patients, their families, insurance providers, federal and state programs, and health care facilities. In the case of aducanumab, an ethical tension exists between beneficence (providing a potentially useful treatment) and justice (fair distribution of a limited resource). Jennings et al have noted: "Justice does not require that individuals should receive any and all health care they might conceivably want. Equitable access does not mean unlimited access, either for acute or chronic care."<sup>22</sup>

In decisions about allocation of a high-cost medication such as aducanumab, it is important to note who is paying for the treatment. When individuals pay for their own treatment, they allocate their own resources according to their own values and objectives. However, when tax payers or third parties fund treatments, important ethical questions about resource allocation arise.<sup>25</sup> The decision to give financial and research priority to a particular condition requires careful consideration of the effectiveness of alternative interventions, the cost of treatment, and the impact of that condition on the physical and mental health of patients, families, and caregivers. As mentioned, the cost of aducanumab was initially 56 000 USD per person annually, a price tag that was estimated to exceed Medicare spending in 2019 on all other infused drugs combined and to entail cumbersome out-of-pocket payments for patients.<sup>23,24</sup> Whittington and colleagues noted that aducanumab would need to be priced at a discount of 85% to 95% from the launch price of 56 000 USD to meet commonly cited value thresholds.<sup>23</sup>

#### **Public Trust**

An impartial and scientifically rigorous review process promotes public confidence and trust in the medication approval process, which is highly important—and not just for aducanumab. Both clinicians and consumers might not have the time—or the expertise in some cases—to review the efficacy and safety data themselves. If an approval process is abbreviated for any single medication, the public and clinicians might not only view that medication with skepticism, but also lose confidence in review processes in general, compromising introduction of other treatments.

The approval of aducanumab proceeded after the FDA's independent advisory committee recommended against it.<sup>6,12,26</sup> Here, an argument could be made that lack of any other available treatments could justify an individualized and accelerated review. However, few other medications are allowed to continue undergoing review with the same level of evidence of clinical efficacy and high cost as aducanumab-and against the recommendations of the advisory committee, as did aducanumab. Maintaining transparency and uniformity in the process by which medications are reviewed and approved is pivotal to and safeguards the trust of patients and clinicians. Since the FDA's approval of aducanumab, the US House of Representatives and the US Department of Health and Human Services have opened investigations into the aducanumab approval process and accelerated approvals, respectively.17,27 In December 2022, results of a congressional investigation into aducanumab's regulatory review and approval, pricing, and marketing were published.<sup>28</sup> This report noted that the FDA's review and approval of aducanumab consisted of atypical procedures and that the drug manufacturer had aggressive launch plans despite concerns about the drug's efficacy, safety, and affordability.<sup>28</sup> Controversy surrounding aducanumab-a medication

that might have received approval that would not have been granted for other medications—seems to have impaired trust in the review process.

#### Conclusion

Clinicians are bound to face ethical challenges in the treatment of AD, given the scope and severity of the disease, with the introduction of novel treatments making the discussion even more complex. Adding further complexity, the approval of aducanumab by the FDA represented an unprecedented move on the part of the agency. Aducanumab was approved against the recommendations of the advisory committee premised on its ability to clear beta-amyloid from the brain rather than on evidence of clinical benefit to the patient—a requirement for all previously approved AD therapies. We hold that, in approaching the care of patients in AD, clinicians are on their most sound ethical footing when quality of life is considered a primary imperative.

There is little to support the notion that this medication will directly improve quality of life for the majority of patients or for their families. In the absence of proven quality-of-life benefits of aducanumab, combined with its considerable financial burden and unusual FDA approval process, we find it difficult to justify the widespread use of aducanumab for the average AD patient at the present time. This calculus might change with additional data, changes in cost-benefit ratio, or other factors.

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# MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

**Prioritizing Diversion and Decarceration of People With Dementia** 

Lay Kodama, MD, PhD, Brie Williams, MD, MS, and Nathaniel P. Morris, MD

#### 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,<sup>1,2</sup> 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.<sup>3</sup> 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.<sup>3,4,5,6,7,8</sup>

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.<sup>9</sup> 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.<sup>10,11</sup> 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.<sup>3,4,5,12</sup>

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.<sup>13</sup> 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.<sup>14,15</sup> 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.<sup>16</sup>

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,<sup>17,18</sup> potentially leading elderly individuals to experience arrest and incarceration related to traffic violations, property theft, or trespassing in the community.<sup>19,20</sup> 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.<sup>21,22</sup>

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.<sup>23</sup> 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 dementiaspecific interventions in prisons.<sup>15,24,25,26</sup>

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.<sup>26,27,28</sup> 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.<sup>23</sup>

#### 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.<sup>29,30</sup> 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.<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup> 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.<sup>33</sup>

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.<sup>34,35</sup> Similarly, a federal correctional facility in Massachusetts opened a unit dedicated to those with dementia in 2019.<sup>36</sup> 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.<sup>35</sup> By comparison, a California prison established a different model of care using individuals who are incarcerated to provide peer support for those with dementia.<sup>37</sup>

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.<sup>38,39</sup> 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.<sup>40</sup> 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.<sup>41,42,43</sup>

Once these individuals have been incarcerated, decarceration strategies, such as early parole and compassionate release,<sup>44</sup> 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.<sup>44</sup> 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.<sup>45,46</sup> 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.<sup>40</sup> Dedicated discharge planning for elderly individuals leaving prison should be prioritized to facilitate these individuals' community reentry and connections with supportive services upon release.<sup>40</sup>

#### 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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