

Forget Me Not: Dementia in Prison

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The number of older adults with dementia in U.S. prisons is rapidly rising. Yet, the vast majority of this marginalized subgroup of the aging population is left neglected behind bars without access to adequate medical and mental health care services. We assert that proactive, interdisciplinary collaborative efforts to improve practice, policy, and research and to develop a high-quality evidence-based continuum of care for this aging population are urgently needed. The overarching goals of this paper are to raise awareness of the life and experiences of persons with dementia in prison and to stimulate discussion, research, and advocacy efforts for this forgotten subgroup of older Americans. We describe the growing number of older adults with dementia in U.S. prisons, high-risk factors for dementia present in the prison population, and the life and experience of persons with dementia in the culture and environment of prison that is primarily not designed for them. We review the current state of services and programs for dementia in prison. We conclude by proposing practice, policy, and research-related priority areas and strategies for interdisciplinary gerontological responses.

Key Words: Alzheimer's disease, Prison, Older prisoners, Serious mental illness, Social justice, Human rights, Rights to health care

Dementia has been identified as a national public health priority with the projected growth in the number of Americans affected by this illness, including older adults in prison. As part of this priority of combatting dementia, older adults in prison must not be forgotten. Dementia is a “cruel and unusual” disease in that it often brings devastating consequences to the people afflicted with this disease, their families, as well as society (Haley et al., 2008; Judge, Menne, & Whitlatch, 2010). Similar to community population, persons with dementia in prison struggle with gradual, irreversible loss of memory, judgment, functional abilities, health, and eventually threats to one’s personhood. The individual and collective financial cost of caring for persons with dementia also is high, especially in prisons. The estimated public spending on caring for persons with dementia has reached upward of 202 billion dollars (Alzheimer’s Disease

International, 2010). In general, the estimated costs annually to house older adults in prison are \$70,000, almost 3 times estimated comparable costs for their younger counterparts (\$22,000; Falter, 1999, 2006). Although exact estimates are not available, given the nature of secure care environment, appropriate dementia treatment in prison is more than likely much more costly than in the community when the additional needs for security staff are factored in these costs (Wilson & Barboza, 2010).

Many important strides have been made to identify and treat dementia. This includes identifying the biological and psychosocial causes of dementia, understanding the impact on individuals and families, and the promotion of early detection, pharmacological, psychosocial, environmental interventions, and community services (Allen, Burgio, Fisher, Hardin, & Shuster, 2005; Gitlin et al., 2009; Haley et al., 2008; Mitrani et al., 2006). These efforts, however, have not been fully extended to an already large but rapidly growing population segment of older adults with dementia in prison. We assert that this special subgroup of older adults is the most vulnerable and neglected in our efforts to improve quality of life and care for dementia. Many older adults in prison present with multiple risk factors for dementia due to poor health and history of multiple environmentally induced traumas. The vast majority of prisons lacks any special geriatric or dementia special care unit or services, all too often creating conditions of neglect, pain, and suffering for older adults within confined prison settings (Stojkovic, 2007).

The primary goals of this paper are to raise awareness of the experience, the need for adequate care of older adults with dementia in prison, and to encourage discussion, research, and advocacy efforts for this vulnerable subgroup. We first describe the growing number of older adults with dementia in the United States, high-risk factors for dementia present among older adults in prison, and the experience of living with dementia in prison. Then, we review the current state of services and programs for dementia in prison. We conclude by proposing practice, policy, and research-related priority areas and strategies for interdisciplinary gerontological responses to improve early detection, treatment, and care throughout the continuum of care.

Older Adults With Dementia in U.S. Prisons

Demographic Projection

In 2007, there were over 180,000 adults aged 50 years and older in U.S. prisons, constituting

over 10% of the total prison population. The overwhelming majority of older adults in prison are men (93%) are mostly of Caucasian (50%), African American (32%), and Hispanic (14%) descent (Sabol & Couture, 2008). These “aging prisoners” constitute the fastest growing segment of the prisoner population, now twice as large as it was in 2001 and 5 times as large as it was in 1990 (Aday, 2003). This growth has largely been attributed to the 1980s conservative sentencing policies that resulted in longer sentences and necessitated many convicted offenders would grow old behind bars (Falter, 2006).

In the United States, it is estimated that 13% of individuals, aged 65 years and older, have some degree of dementia. However, there is no national study to estimate the prevalence of dementia among the U.S. prison population (Maschi, 2011). However, based on the review of 10 published studies of dementia among older adults in prison, the estimated rate ranges from 1% to 44% depending on the nature and size of the correctional setting (author blinded for review). On a national level, the rate of dementia in the general population is expected to increase from 1.7% in 2009 to 1.9% in 2030 and 2.6% in 2050. Wilson and Barboza (2010) estimate that the number of prisoners with dementia in 2010, 125,220 prisoners, will double in 2030 ($n = 211,020$) and triple in 2050 ($n = 381,391$). This higher rate has been attributed to the process of accelerated aging in which the health status of offenders is hastened by approximately 15 years due to the health and environmental risk factors associated with prolonged imprisonment (Wilson & Barboza, 2010).

Older Adults in Prison: Especially Vulnerable to Dementia “Victimization”

The high proportion of older adults with dementia in prison may be attributable to several unique biological and environmental risk factors linked to the onset of dementia present among the prison population. Biological risk factors for dementia include neuron degeneration, frontal lobe or corticobasal degeneration, metabolic imbalances, such as thyroid, kidney, and liver disorders, and mental disorders (e.g., depression; Alzheimer’s Association [AA], 2011; Cox, 2007). Poor physical and mental health status of prisoners, especially older adults, puts them at much higher risk of dementia. Older adults in prison often experience a myriad of severe health and mental health problems. Seven out of 10 prisoners report some type of physical health problem, including lung and heart disease,

HIV, and AIDS (Maruschak, 2008). In fact, the official definition of the National Commission on Correctional Health care of “older adult” can be considered beginning at age 50 as opposed to the traditional retirement age of 65 (Falter, 1999). This is consistent with the general population recommendation that “old age” be considered to start at age 50, especially for African Americans (Administration on Aging, 2011). The rationale for aged 50 years may be because the average prisoner is often described as experience premature aging in disease, disability, and overall health. Their health condition also may approximate the health condition of nonincarcerated people who are 10–15 years older (Reimer, 2008).

Moreover, high prevalence rates of various mental health disorders among prisoners may add increased risk for developing dementia. About two out of three prisoners are reported to have mental health problems, including schizophrenia and dementia. National statistics reveal that 50% of prisoners aged 50–54 years and 36% of prisoners aged 55 years and older had mental health problems, and only one third will have access to treatment while in prison (James & Glaze, 2006).

The seriousness of mental health problems among prisoners has been a major concern and the subject of multiple class action suits. In 1999, a federal court ordered a settlement of a class action suit against the New Jersey Department of Corrections (DOC) and DOC’s private contractors mandating amendment of the DOC regulations and a mental health treatment plan requiring that all new prisoners receive a mental health assessment within 72 hours of their imprisonment (*D.M. v. Terhune*, 1999). Plaintiffs in this suit alleged denial of medical treatment for their mental disorders in violation of their constitutional rights against cruel and unusual punishment and their federal right against discrimination on the basis of their disabilities. Similar class action suits alleging violations of prisoners’ rights to adequate medical and mental health treatment have been brought in the State of Wisconsin on behalf of female prisoners who were treated differently from male prisoners (*Flynn v. Doyle*, 2010; *United States v. Doyle*, 2008) and in Mississippi challenging inhumane conditions on behalf of roughly 1,000 male prisoners with serious illness as well as serious mental illness that ultimately resulted in the shutting down of Unit 32 at Mississippi State Penitentiary (*Presley v. Epps*, 2010). Most recently, the United States Supreme Court in May 2011 handed down a decision uphold-

ing a lower federal court ruling that found egregious violations of prisoners’ constitutional rights to medical and mental health treatment in California prisons due to severe overcrowding and ordering release of over 30,000 or as high as 46,000 prisoners (*Brown v. Plata*, 2011a; 2011b). This Supreme Court decision was the result of two consolidated class action suits on behalf of prisoners with serious medical conditions and prisoners with serious mental disorders and ongoing violations of the Cruel and Unusual Punishments Clause of the United States Constitution over a period of years that escalated the number of suicides among the prisoners to nearly one a week, a rate that was 80% higher than the national average, and caused them serious harm.

In addition to an adverse environment, older adults in prison also may have a history of other environmental risk factors. These include brain injury among veterans, chronic substance abuse, medication side effects, and poor dietary histories resulting in vitamin deficiencies that add increased risk for dementia. Additionally, as detailed earlier the stressful prison environment, which often includes exposure to violence and inadequate service provision, also is a risk (Maschi, Dennis, et al., 2011; Maschi, Morgen, Zgoba, Courtney, & Ristow, 2011).

Disentangling the complex web of the interactions among the biological and environmental factors is no doubt a daunting task. There is an array of physical, mental, and environmental risk factors present among prisoners. Therefore, because older adults are at high risk for developing dementia in prison, there is a need for them to have substantial resources and support throughout the continuum of care. In the next section, we discuss in depth how the current prison environment can have detrimental affects on well-being and deprive older adults with dementia of quality of life and place them at increased risk of victimization.

An Inside Look at Dementia in the Context of Prison Culture

Punishment and Confinement.—U.S. prisons were not designed for short-term placement of adults with criminal offenses. Rather, prisons were designed to deter those that committed offenses from committing future crimes. The early architects of U.S. criminal justice policy targeted mostly punishment, deterrence, and incapacitation as the primary underpinnings for prisons (Maschi et al., 2009). This philosophy was codified in law, and prisons were built as a concrete reminder.

Historically, the purpose of prison has been punishment. People sentenced to prison for crimes were expected to use the prison experience to reflect upon and then change their criminogenic ways. This primary concern appears to have overshadowed concerns for the quality of life, personal safety, and well-being of people with dementia in prison. For example, most prisoners live in four-by-four-foot prison cells often without windows. In congregate setting, they eat in public mess halls and courtyards where violence may erupt (Kinsella, 2004). As evidence suggests that when people are sentenced to prison, they lose not only their freedom but also all too often lose their health and quality of life (Haney, 2001). Hence, promoting quality of life by providing quality health and mental health care for older adults, such as those with dementia, has not been a priority for corrections and has been mostly neglected.

Order and Obedience.—One of the most important and basic rules of survival in prison is to follow directions to avoid disciplinary infractions and remain as physically independent as possible. Therefore, being obedient is essential for survival and to avoid institutional charges that may result in secure confinement.

Even the healthiest of individuals must be vigilant to rapidly respond to authority in the prison environment and responding to prisoner leaders (Haney, 2001). However, this task is too complex for some of those with dementia who suffer loss of short- and long-term memory along with impairment in other areas such as reasoning, personality, language, visual processes, executive functions, behaviors, and relationships. As these impairments affect people's level of independence such as their ability to perform activities of daily living (e.g., eating) and social relationships (e.g., interpersonal communications), older adults with dementia may not be able to follow prison rules and run the risk of receiving institutional charges that may result in placement in secure confinement, which in turn may significantly compromise their physical and mental well-being (Haney, 2001).

Culture of Violence.—Prison also is often characterized as a frightening and traumatizing environment as aggression, violence, and bullying are part of the culture. Older adults, who have increasing symptoms of dementia are at an increased vulnerability to victimization by other prisoners or they

may become aggressive to staff or other prisoners resulting institutional reprimands or charges (Dawes, 2009). Older adults with dementia are often targets of other inmates including bullying, such as being made fun of often in an attempt to provoke them to respond in self-defense (Wilson & Barboza, 2010). If that self-defense response is violent, it may result in a disciplinary action. They are also vulnerable to sexual victimization by other prisoners because they are less able to defend themselves (Stojkovic, 2007; Struckman-Johnson, Struckman-Johnson, Rucker, Bumby, & Donaldson, 1996).

Moreover, prisons most often are congregate living environments. Behavior typical of early to late stages of dementia, such as not being able to follow directions, pacing about a cell or aggressive behavior may cause disruptions in the general population prison movement or in congregate living quarters (Wilson & Barboza, 2010). These behaviors related to dementia coupled with a highly volatile prison environment may place persons at risk of becoming victims or perpetrators of violence (Stojkovic, 2007).

The Response to Older Adults and Dementia in Prison

There is a lack of data at the federal prison level, and at the state prison level, there are minimal services or programs specifically designed for older adults with dementia in prisons. Whereas there is a legal mandate that all correctional facilities should provide general medical services (*Estelle v. Gamble*, 1976), there is no such policy for geriatric specific services (Kinsella, 2004). According to the most recent publicly available data from the 2000 Bureau of Justice Statistics Survey of State and Federal Correctional Facilities, only 4% ($n = 38$) of state institutions provided any type of geriatric specific health care services. One percent of state institutions offered services in geriatric care facilities, 2% had segregated geriatric units, and 1% had mixed (younger-older) unit models (Thivierge & Thompson, 2007). There were no available data found on dementia in federal correctional facilities.

Although so few state institutions offer any geriatric or dementia-specific services or programs, there are some programs that focus on geriatric and dementia prisoners that warrant discussion. Program characteristics include one or more of the following: dementia-sensitive environmental modifications, interdisciplinary staff and volunteers, services specifically designed for persons with dementia,

or cognitive impairment from early to late stages, including hospice care. Some program exemplars are outlined subsequently.

The Unit for the cognitively impaired (UCI) in Fishkill, New York, opened is a 30-bed unit of prison's medical center. It is known for having good lighting including windows, and access to an outdoor patio, and common social space. It has a specially trained interdisciplinary staff consisting of psychologists, nurses, doctors, social workers, pastors who treat UCI patients and provide prison reentry services (Hill, 2007).

The "True Grit" program housed in the Nevada Department of Corrections and includes a combination of physical activity, therapy, the arts, and other activities. Outcome evaluation results show that the number of doctor visits and medications taken by elderly inmates has decreased, and social support and well-being have been enhanced (Harrison, 2006).

The California Men's Colony in San Luis Obispo, California has a dementia unit that can be described as a "peer support." The program aides consist of six volunteer inmates or "social aides" who have records of 10 years of exemplary behavior and receive training in dementia caregiving. Their responsibilities include making sure they receive medical care, provide social support, and protect them. Because prison is an often-dangerous prison environment in which older adults with cognitive disorders are vulnerable to victimization, the use of peer support can be a source of protection (Ubelacker, 2011). Similarly, the Angola State Prison Hospice Program in Louisiana uses peer support. Prisoners who volunteer for the program are taught basic hospice practices and how to counsel and provide assistance with activities of daily living (Jervis, 2009).

Policy and cultural level responses include the Project for Older Prisoners (POPS) and human rights arts and social media advocacy. POPS was established in 1989 at Tulane Law School and has expanded across the United States. In 2003, the POPS program suggested the expansion of its programs across the United States to the growing aging prisoner population as an advocacy issues. The POPS program is a risk-based approach to addressing the aging prisoner problem. It involves law student volunteers who assist individual low-risk prisoners older than 55 years to help them obtain paroles, pardons, or alternative forms of incarceration. If an assessment for risk of recidivism is low, the student helps to locate housing

and support for the prisoner and help prepare the case for a parole hearing (Turley, 2007).

Social media advocacy and public awareness campaigns are another macrolevel cultural strategy that addresses the issue of aging prisoners as a human rights and social justice issue. The use of social media and the arts, such as documentary films, can increase awareness of aging prisoners and hospice care. Policy initiatives mean next to nothing unless the public supports their passage and implementation (Chui, 2010).

The Universal Declaration of Human Rights, Article 1, guarantees that individuals should be treated with dignity and respect. Although there is no constitutional right to health care in the United States, there is a well-recognized human right to adequate health care. The United States Supreme Court has held that deliberate indifference to a prisoner's serious illness constitutes cruel and unusual punishment in violation of the Eighth Amendment (*Estelle v. Gamble*, 1976). The Court states in its opinion: "denial of medical care may result in pain and suffering which no one suggests would serve any penological purpose" (429 US 97) Health care justice demands that the intrinsic worth of each human person be accounted for in the allocation of scarce resources (Sulmasy, 2003). This is clearly not the case, when older adults are dying the slow death of dementia in prison often without access to appropriate treatment and services.

Social media and advocacy therefore on the part of a number of nongovernmental organizations and advocacy groups with Internet blogs that address aging prisoners. Topics such as compassionate release almost always result in diverse public opinions from punitive ("they did the crime so they should do the time") to rehabilitative responses ("let them die with dignity"; e.g., Too, 2011) Human rights philosophy argues that all individuals should be treated with dignity and respect. This includes older adults, individuals with mental disorders, and criminal offense histories (Wronka, 2008).

Furthermore, the result of doing nothing is what Engels (1895) refers to as social murder and will result in countless deaths of older adults with dementia in prison. French Jewish philosopher Levinas (1969) has also helped us understand the inalienable moral claims of vulnerable others who are suffering and call upon us to not murder them but to hold and nurture them in our maternal embrace (Morrissey, 2011a). A national strategy with practice, policy, and research components in response to the growing crisis among aging prisoners in the U.S. prison

system is needed to prevent heightening of the illness burden and social suffering imposed upon and experienced by the nation's older adult prison population.

Practice, Policy, and Research Priorities for Interdisciplinary Gerontological Response

Next, we propose priority areas for clinical practice and policy to improve early detection, treatment, and care throughout the continuum of care and research and evaluation strategies. The main challenges ahead include how to infuse high-quality health, mental health, and end-of-life care to these elders, including development and implementation of compassionate release policies (Chui, 2010). Because of the complex nature of dementia in corrections, efforts to improve practice must entail a multifaceted response. However, there is very little information available on dementia management in correctional settings. Therefore, what follows is a compilation of best practice recommendations that may be useful strategies for practice, policy, research, and dementia management in corrections (Schoenly, 2010; Turley, 2007; Wilson & Barbazzo, 2010).

Practice Priorities

Continuum of Care.—Dementia is progressive and affects functioning in multiple domains, such as physical, mental health, and social well-being. The continuum of care of services includes early detection from the point of entry into the criminal justice system to graduated services that include forensic hospitals in prisons and in the communities. Even within prisons, the complexity of the dementia necessitates a comprehensive response of formal and informal caregiving. A best practice interdisciplinary response in institutional and community corrections would involve diverse professionals, such as doctors, nurses, social workers, psychologists, physical therapists, and dieticians. Additionally, the use of nonprofessional caregivers, including in prison, would involve peer and family and community supports.

Early Detection.—Most scholars and practitioners agree that although dementia cannot be stopped, early detection can help individuals, families, and service systems plan ahead. Accurate and timely assessment would enable appropriate intervention strategies that involve individuals and families. For

example, prison medical departments can provide physical examinations, laboratory tests, and cognitive assessments. Because the self-report information of persons with dementia may be impeded, obtaining information from other sources such as family and staff would be needed. Fellow prisoners also could be educated and trained to observe and identify subtle changes occurring among inmates. In addition, a focus on advance care planning for older adult prisoners and improved communication as part of the early detection assessment and response process is critical.

These combined efforts and reports can identify and corroborate changes in appearance (e.g., disheveled), functioning (e.g., incontinence), personality and mood changes, and prepare older adults adequately for living through the experience of dementia in congregate prison settings (Schoenly, 2010). If these changes are regularly observed and monitored by staff and/or peer supports with appropriate communication with older adult prisoners, appropriate referrals for mental health evaluations for dementia could be made if any of these changes become regular observations (Wilson & Barboza, 2010).

Postdetection Disclosure.—Most training protocols recommend that the topic of diagnosis is disclosed, it should be treated sensitively, and allow the individual to experience the process of understanding and accepting the illness (Carpenter & Dave, 2004). Lecouturier and colleagues (2008) identify the following key areas for postdetection disclosure: preparing for disclosure, integrating family members, exploring the patient's perspective, disclosing the diagnosis, responding to patient reactions, addressing quality of life and well-being, planning for the future, and communicating effectively. Preparing for disclosure involves prediagnostic counseling that alerts the individual that dementia is a possible diagnosis and determining their preferences for disclosure. Integrating family members, including in correctional settings, involves sharing appropriate information with family members to understand and provide support.

Exploring the patient's perspective includes understanding the individuals' perceptions and expectations and the degree to which it is congruent with factual information about dementia. Disclosing the diagnosis involves not only providing information on the prognosis and diagnosis but also checking the individual's understanding and meaning of dementia. Responding to patient reactions

involves first allowing the patient space to process the information and then exploring the range of emotional reactions that may follow disclosure and responding empathically to their questions. Addressing quality of life and well-being includes coping strategies, including fostering a hopeful realism, that focus on abilities and maintaining agency. Planning for the future includes use of a liaison, referral, and follow-up. Communicating effectively includes rapport building, listening skills, use of appropriate language, structuring and signposting, and a number of behaviors relating to antidiscriminatory practice (Lecouturier et al., 2008).

Tailored Treatment.—Once a prisoner is diagnosed with dementia, therapeutic pharmacological and nonpharmacological interventions should be implemented, monitored, and adjusted as the disease progresses. In the mild or early stages, programming that keeps individuals physically, mentally, and emotionally involved is warranted. Prisoner companions should be made available if needed.

In the moderate or middle stage of dementia progression, a person with dementia may become emotionally volatile and exhibit behavioral problems such as emotional overreactions, becoming easily angry or frustrated, social withdrawal, incontinence, and a shuffling walk. Although these behaviors are easily detectable, they also may easily be misinterpreted actions that have intentional disruptive or criminal intent as opposed to a behavioral consequence of this brain disease (AA, 2011). For older adults placed on general population units, this behavior can cause problems in an already highly stressful environment. Therefore, staff training is essential to accurately detect these signs. Some strategies to address this stage are to provide protective housing that is designed as a dementia friendly environment and can reduce confusion and agitation among prisoners. In general, this would enhance public safety for all prisoners and decrease the risk of aggression and violence or being harassed or victimized (Schoenly, 2010; Wilson & Barboza, 2010).

For prisoners at the severe or late stages of dementia with severe impairment in physical and cognitive functioning, interdisciplinary teams should consider creating nursing care facilities or secure care community facilities (Schoenly, 2010). For older adults with end-stage dementia, information about timely palliative and hospice care services should be offered (Imhof & Kaskie, 2008). The provision of such information about palliative and end-of-life options may now be mandated by

state law as it is in New York under the Palliative Care Information Act (New York Public Health Law, 2010) and should not be withheld from older adult prisoners.

Activities of Daily Living.—To accommodate difficulties in carrying out activities of daily living among prisoners with dementia, several practical solutions are available. They include providing uniforms that are easy to take on and off, such as the use of Velcro clothes or slip on shoes, and hearing aids and eyeglasses to reduce eye strain that may increase agitation. Carefully screening for prisoner companions to assist older adults with dementia may provide the needed assistance (Wilson & Barboza, 2010).

Alternative Interventions.—Alternative modalities that appeal to different senses and use nonverbal communication can be used to supplement medication. Some promising practices include: physical or health promotion activities (i.e., exercise, massage, and diet) and artistic or group activities (i.e., music, art, exercise and pet therapies, and peer support). Enhancing coping resources in the form of cognitive, emotional, social, spiritual, and social coping that can assist with mental and physical well-being (Wilson & Barboza, 2010).

Dementia-Sensitive Physical Environment.—Because individuals with dementia are highly sensitive to their environment, modifying the prison environment is important. Possible recommendations include: attention to proper lighting, use of different colors for walls, such as the bathrooms, use of large lettered signs and pictures, handrails, wheelchairs, and accessible showers. Pending the setting, separate and locked settings may be appropriate for older adults in advanced stages of dementia whose safety cannot be assured in a less restrictive environment (Wilson & Barboza, 2010). The most important aspect of the environmental change process, however, is creating a socially responsive system of supports that is experienced by the prisoner as empathic and providing comfort and security in the midst of stressful environment.

Education, Training, and Support.—To effectively implement many of these recommended practices, it is imperative to educate, train, and provide support to staff. Comprehensive clinical training should be offered to staff to accurately identify early symptoms of dementia as well as to detect changes in symptoms

as the disease progresses. Because interpersonal skills training may vary widely across interdisciplinary staff, it should not be assumed that all prison staff had prior training in or mastered the use of communication skills, including the use of empathy and respectful language. These communication skills, especially empathy, are essential in dementia management. It is a balancing act for correctional staff to maintain prison management while also attending to prisoners with dementia special needs.

Dementia training for staff can increase awareness that a prisoners' disobedient behavior may be a mental health and not behavioral issue (Carpenter & Dave, 2004). Staff also must understand the subjective experiences of individuals with dementia who may need additional time for mental processing and comprehension of their experiences. Communicating respectfully to individuals with dementia also is critical. For example, stating "here is your medication" may get a more positive response as opposed to more infantilizing statement, such as "it is time to take your medication" that may get a more negative or agitated response.

When in prison, individuals with dementia will be underserved without proper supports in place to provide the level of care needed that is often provided by family caregivers in community settings. Hence, if they are not released on compassionate release, they will be denied the family caregiver's support. The role of social support as an important aspect of mental health maintenance is almost severed when family members are separated by institutional walls (AA, 2011). Additionally, although dementia behind bars seems "out-of-sight" and "out-of-mind," it is not. Therefore, regular debriefing of staff and prisoner volunteer caring for prisoners with dementia, would be a helpful strategy to foster well-being. Additionally, addressing stress and burden among family members who are in regular contact with loved ones in prison also may be warranted.

Policy Priorities

The absence of any clear and comprehensive public policies addressing the urgent health and mental health care needs of older adults in prison may heighten their suffering and increase their risk for developing dementia. This policy failure disproportionately affects minority older adults in the prison system. National deliberations among policymakers and public discourse about what to do with the aging prisoner population, including those

with dementia, are driving a new social agenda for care for older adults in prison. Older adults released from prison have lower recidivism rates than their younger counterparts, and they are considered less of a public safety threat (Snyder, van Wormer, Chada, & Jagers, 2009). Therefore, as a cost-shifting and cost-saving measure, several states are using discretionary parole, inmate furloughs, or medical or compassionate release to address the aging prisoner population (Chui, 2010).

The financial burdens to provide medical and mental health services for older adults in prison are costly and on the increase. For example, in a large state, such as Texas, in 1999 providing health care costs were projected to be \$56 million in 2008 and double the 1999 figure of \$27 million (Abner, 2006). Specialized geriatric units also are projected to be more expensive than housing older adults in the general prison population. For example, in an Ohio-based geriatric facility, it costs 17% higher (\$81 vs. \$69) in a special facility. Although exact cost-saving figures for community reentry programs for infirm elder adults are not available, early release home detention programs are promising cost-saving option (Chui, 2010). Other promising considerations include a seamless system of care that includes joint collaborations and pooled funding with public health departments, hospitals, and universities. Similarly, the need for a common database management system would also increase the efficiency of collaborative efforts. It is too costly not to consider a rational response to the growing crisis of older adults with dementia in prison. Drawing from various sources, we identify several policy reform priorities that include training and psycho-education, advocacy, and systemic reform.

There are at least three public policy responses that would need to be considered carefully to address the complexities of this important public health problem. They all target education for prisoners and prison staff and professionals who may be providing services to prisoners and include: (a) providing education to prisoners as early as possible in their prison careers about their rights to make health care decisions, make advance directives and engage in advance care planning, and exercise their constitutional right to refuse medical treatment subject to certain limitations (*Cruzan v. Director, Missouri Department of Health*, 1990; Patient Self-Determination Act, 1990); (b) providing professional education to prison staff and other professionals who are providing critical services to older adults in prison about the fluid nature of

decision-making capacity for older adult prisoners who have dementia and the clinical assessment of capacity that is task specific; and (c) providing education about person-centered care that will engage older adult prisoners with dementia in a process of making choices, fostering the constitution of personal agency or recovery of lost agency, and improving their quality of life (Jennings, 2009; Morrissey, 2009b).

Priorities for system reform are currently being deliberated at the legislative level, and main areas for consideration are best expressed by recommendations made by Jonathan Turley, Esquire, a champion of older prisoner rights. In his 2007 Testimony on Prisoner Reform and Older Prisoners before the House Judiciary Committee Turley recommended: (a) the establishment of POPS programs throughout law schools to identify and evaluate low-risk prisoners within the system for parole release; (b) the creation of a system for the supervised release of low-risk, high-cost prisoners; (c) the creation of alternative forms of incarceration for mid-risk prisoners to reduce costs; and (d) the establishment of geriatric units for high-risk, older prisoners to reduce costs.

Research and Evaluation Priorities

There is a dearth of research on the older adults in the criminal justice from arrest, courts, prison, and community reintegration. There are even fewer research studies regarding mental health care needs of prisoners, especially those with dementia (Fazel, McMillan, & O'Donnell, 2002). Gaining accurate information on how dementia is assessed and treated at each stage of the process would be an essential step toward developing effective clinical interventions. Hence, future research is needed using longitudinal and cross-sectional designs that include large and representative samples to accurately estimate current and projected prevalence, incidence, and severity of psychiatric, mental health, or other chronic health conditions including dementia. More research is also needed to examine diagnoses of these conditions and access to and use of health, mental health, palliative care, and other prison services among older adults in different stages of dementia in prison and after their release to community. Furthermore, studies to examine barriers to and facilitation of access to these services among prisoners while they are in prison and after they are released back to communities are needed.

Several recommendations for care of older adults with dementia in prison are put forth in this piece and they also need to be evaluated. Research is needed to develop assessment and intervention protocols to address physical, mental, and emotional needs and behavioral symptoms of prisoners with dementia at different stages of dementia. Developing and testing the efficacy of models such as simple environmental modification, psychosocial and behavioral interventions, interdisciplinary approaches to care, and companion programming programs are all needed. Of particular interest is the effect of the peer (e.g., prison volunteers) programming on outcomes given the advantage in cost savings and potential positive effects on not only the person with dementia but also volunteer inmates. Attention is also needed to examine knowledge, attitudes, and skills of prison staff in working with older prisoners, those with dementia in particular. Given the current lack of emphasis on quality of life and care for older prisoners, it would be important to assess and identify areas of education and training for staff.

Conducting research and evaluation studies on older adults in prison in correctional settings is plausible as evidenced in the small, but growing number of studies in this area. There are also guides on how to conduct such research to address ethical issues of working with older adults, persons with mental illness, and prisoners (Maschi, Bradley, & Ward, 2009).

Closing Reminder: Forget Me Not—Dementia in Prison

In conclusion, it is too costly and inhumane to do nothing about this social problem. The good news is that the gerontological community of diverse disciplines and professionals can provide a needed collective biopsychosocial perspective in this national debate and provide practical strategies for practice, policy, and research on the ground. In the aftermath of this mental health service and policy shortfall, this is an aging, mental health, and criminal justice crisis that is too large to ignore. Therefore, we need to make sure that we take care of all of its "victims," wherever they reside, including in prison. The goals are clear: improved practice, policy, and research to develop a high-quality, evidence-based continuum of care. With a humanitarian vision fueled by ingenuity, careful planning, and collaboration, we can achieve a just world in which all people can live and die

with dignity and respect. Perhaps the first step toward this goal is to remember these words: forget me not—dementia in prison.

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