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## Elder Abuse And Dementia: A Review Of The Research And Health Policy

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ABSTRACT Older adults with dementia may be at high risk for abuse, but the topic has not been well studied. We conducted a literature review to examine the relationships between elder abuse and dementia. We found that psychological abuse was the most common form of abuse among older adults, with estimates of its prevalence ranging from 27.9 percent to 62.3 percent. Physical abuse was estimated to affect 3.5-23.1 percent of older adults with dementia. We also found that many older adults experienced multiple forms of abuse simultaneously, and the risk of mortality from abuse and self-neglect may be higher in older adults with greater levels of cognitive impairment. We summarize programs and policies related to the abuse of older adults with dementia, including adult protective services, mandatory elder abuse reporting, and the Long-Term Care Ombudsman Program. We also summarize aspects of the National Alzheimer's Project Act, the Older Americans Act, and the Elder Justice Act. In spite of a recent increase in research and policy developments on elder abuse, challenges such as insufficient funding, limited knowledge about elder abuse, a lack of funding for the implementation of federal and state programs relevant to elder abuse and dementia, and a lack of dementia-specific training for front-line health care staff persist. Stronger programs targeting the well-being of older adults with dementia are needed.

lder abuse is the physical, psychological, and sexual abuse; caregiver neglect and self-neglect; and financial exploitation of people ages sixty and older. It is an alarming public health and human rights issue. An estimated 11.4 percent of adults in this age group in the United States experienced some form of elder abuse in 2008.<sup>1</sup>

Elder abuse may lead to adverse health outcomes such as physical disability and psychological distress, and it has been linked to increased risks of morbidity and mortality.<sup>2</sup> Elder abuse also imposes a great social and economic burden on society.<sup>3</sup> The direct cost of elder financial

exploitation—defined as the improper use of an older adult's resources for someone else's profit or advantage—in the United States was estimated to be \$2.9 billion in 2009, up 12 percent from 2008.<sup>4</sup>

Older adults with dementia are particularly vulnerable to abuse. Dementia is ranked as the twentieth-leading cause of the global disease burden.<sup>5</sup> As the world's population ages, the number of people with dementia is predicted to increase from 35.6 million in 2010 to 115.4 million by 2050.<sup>6</sup> Dementia may have enormous social and economic impacts and impose physical, psychological, and financial stress on patients and their caregivers and family members.

Estimates of the prevalence of abusive behavior toward older adults with dementia who live in the community range from 5.4 percent to 62.3 percent.<sup>7,8</sup> Different definitions, recruitment techniques, and other study factors account for this large variation. In long-term care settings, where adults with dementia constitute a significant proportion of the residents, elder abuse is also a critical issue.<sup>9</sup>

Abuse of older adults with dementia is underreported because the detection of abuse is often complicated by various biological, pathological, ethnic, and cultural factors. For example, dementia is associated with a high level of dependence. Thus, older adults may be reluctant to disclose abuse because they fear retaliation or losing support. In addition, common physical signs of and reactions to abuse, such as withdrawal from communication or increased dependence, may be difficult to distinguish from dementia symptoms. In

Ethical issues such as challenges in obtaining informed consent from patients with dementia may impede research on elder abuse. 12 Moreover, cultural nuances increase the difficulty of understanding abuse of older adults with dementia. Typically, Asian cultures consider cognitive impairment to be a type of mental illness, while African and Hispanic cultures tend to perceive the decline of cognitive function as a normal part of the aging process. 13,14 In Asian cultures, families are often the primary caregivers for older adults with dementia, and long-term care facilities are often the last resort. 15 Thus, cultural perceptions may also affect the reporting of elder abuse.

In April 2013 one of the authors of this article, XinQi Dong, led a global Elder Abuse Prevention Workshop at the Institute of Medicine and gathered a group of experts to discuss the incidence and prevention of elder abuse. The experts stressed the need to distinguish among the levels of cognitive impairment when studying and treating elder abuse. This emphasis highlights the importance of better understanding elder abuse among adults with dementia.

For this article we conducted a literature review to examine the relationships between elder abuse and dementia. We summarize the challenges and opportunities for health policies and programs concerning elder abuse in older adults with dementia in both community and institutional settings, in the United States and elsewhere.

### **Study Data And Methods**

We searched the literature in the PubMed, MEDLINE, and PsycINFO databases. Informa-

tion about US federal policies, state regulations, and programs targeting abuse in older adults with dementia was retrieved online. We limited our search to studies published in English. The search terms were elder abuse, elder mistreatment, elder self-neglect, financial exploitation, dementia, Alzheimer's disease, cognitive impairment, cognitive decline, and public policy.

Because most state adult protective services agencies define *self-neglect* as a form of elder abuse, we included studies that examined elder self-neglect among adults with dementia. We excluded studies that existed only as abstracts and case reports published before 1990. Two investigators on our research team independently reviewed the findings identified by the search methods and selected studies that were relevant according to our criteria and the studies' content and construct validity. For additional details on the studies included in this analysis, see the online Appendix.<sup>17</sup>

### **Study Results**

**PREVALENCE** Our search identified twenty-eight studies from the United States and elsewhere related to the prevalence of abuse among older adults with dementia, risk factors for abuse, and data on abuse outcomes. Psychological abuse was the most common form of abuse among older adults, with estimates of its prevalence ranging from 27.9 percent to 62.3 percent. <sup>8,18</sup> In contrast, physical abuse has been estimated to affect 3.5–23.1 percent of older adults with dementia. <sup>18,19</sup>

A study of 284 sexual abuse cases reported that 60 percent of the elderly victims suffered from cognitive impairment or dementia. <sup>10</sup> In a study of 481 primary family caregivers for older adults with dementia, as many as 20.2 percent of caregivers admitted that they had neglected the person they were caring for. <sup>20</sup> A study of 4,627 community-dwelling older adults with cognitive impairments found rates of self-neglect of 18.8 percent and 13.6 percent among men and women, respectively. <sup>21</sup> In a survey of 101 caregivers for people with Alzheimer's disease, 15 percent of the care recipients reported experiencing financial exploitation. <sup>22</sup>

In community settings, older adults with dementia appear to experience different types of abuse simultaneously. In a study of 129 older adults with dementia, 31 percent of the abused older adults had experienced multiple forms of abuse.<sup>23</sup> Some studies have reported mutual abuse, in which the victim of abuse directs abusive behaviors toward the perpetrator. In one study, 35 percent of eighty-two caregivers of patients with dementia reported experiencing mu-

tual verbal abuse with the care recipients, and 6 percent reported experiencing mutual physical abuse with them.<sup>24</sup>

As noted above, abuse is also prevalent in longterm care settings. In a study of 816 US households with care recipients who received longterm care services, 12.6 percent of people with cognitive problems had experienced elder abuse.<sup>25</sup> Resident-to-resident abuse in long-term care settings is especially common.<sup>26</sup> A study of 294 resident-to-resident elder abuse cases found that 95.6 percent of the cases involved people with cognitive impairment.<sup>27</sup>

**RISK FACTORS** Given the complex nature of dementia care, the risk factors of elder abuse can be categorized into victim factors and perpetrator factors.

►VICTIM FACTORS: Older adults with dementia often have psychological or behavioral symptoms such as agitation and aggression, which may intensify caregiver-recipient conflicts and result in elder abuse. 8,24 Lower levels of cognitive function were associated with increased risk for elder abuse 28,29,30 and self-neglect 31 in both cross-sectional and prospective studies. 32

In addition, older adults with dementia may experience a higher burden of chronic illness and physical impairment, which further increases their risk of abuse, compared to older adults without dementia.<sup>33</sup> Older adults who spent more days residing with the perpetrators also were at higher risk for abuse.<sup>8</sup>

▶ PERPETRATOR FACTORS: Abusers of older adults with dementia include family members, paid caregivers, friends, and providers of health care services. Caregiver burden and stress are among the most common risk factors associated with elder abuse.<sup>8</sup>

Depression,<sup>7</sup> anxiety,<sup>34</sup> alcohol abuse,<sup>34</sup> social isolation,<sup>35</sup> and poor relationships with the victim<sup>35</sup> prior to the occurrence of dementia are also associated with higher risk of abuse by caregivers. In long-term care facilities, a lower level of job satisfaction and a higher level of burnout rate may lead to increased risks for abuse.<sup>25</sup>

**THE IMPACT OF ABUSE** The risk of mortality associated with abuse and self-neglect may be higher in older adults with cognitive impairment. In a prospective study of 9,318 community-dwelling older adults in Chicago, older adults with the lowest levels of cognitive function who had been self-neglected or abused had a much higher risk of mortality, compared to those who did not report self-neglect or abuse. Specifically, the study found that self-neglect was associated with increased risk for neuropsychiatric-related mortality.<sup>2</sup>

**ABUSE AMONG MINORITY GROUPS** We found little information on racial or ethnic differences

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in abuse of older adults with dementia. However, one study suggests that the prevalence of financial exploitation is almost three times higher, and the prevalence of psychological abuse is two times higher, in African American than in white older adults. According to another study, 35 percent of Chinese older adults have self-reported elder abuse, despite the high cultural expectations of filial piety toward elders.

Although elder abuse is prevalent among minority older adults, the scope of the problem among those with dementia remains unclear. Understanding culturally specific issues related to the definitions, perceptions, and other factors associated with elder abuse will be critical to the future design of prevention and intervention strategies in various cultures.

### The Health Policy Landscape

The growing awareness of both dementia and elder abuse has led to policy responses. We highlight important US federal and state health policies to illustrate the problems with existing policies and potential opportunities for new policy development.

### STATE POLICIES

►ADULT PROTECTIVE SERVICES: Adult protective services (APS) programs, typically run by local or state health departments, provide protections for adults against abuse—including neglect and financial exploitation—and investigate reports of abuse. In most states APS is often the first responder in cases of elder abuse. Selfneglect is the most common form of abuse referred to these programs.<sup>38</sup>

One ethical issue involved in reporting and investigating elder abuse is the lack of decision-making capacity among older adults with dementia. Without victims' comprehension and identification of abuse, it is hard for APS staff to substantiate claims of abuse. In addition, older adults with dementia may refuse to co-

operate with an investigation for fear of losing a caretaker on whom they depend.<sup>39</sup>

Furthermore, APS staff often have insufficient knowledge and mental health training. Findings from a survey of 175 APS staff in Georgia suggest that areas such as cross-training with other disciplines in the aging field and serving clients with mental health disabilities have the greatest knowledge gaps.<sup>40</sup> Efforts to improve APS staff's knowledge of interventions to use in cases of dementia-related elder abuse are needed.<sup>39</sup>

As the population of older adults with dementia continues to grow, the investigation of elder abuse by APS has become increasingly complex. Yet the resources of APS programs have not kept pace with the growing challenge. In 2009–11 the Government Accountability Office conducted a survey of APS programs in all fifty states and the District of Columbia. <sup>41</sup> The survey found that the greatest challenges confronting these programs were insufficient financial resources, insufficient access to information needed to resolve elder abuse cases, and inadequate administrative systems.

APS data collection varies across the states. A unified national data collection system for APS and enhanced collaboration between APS and partners in the field of elder abuse—such as cross-training APS staff and Alzheimer's Association staff—are needed to address issues such as insufficient knowledge about dementia on the part of APS staff.<sup>42</sup>

MANDATORY REPORTING: In most states mandatory reporting statutes require people to report injuries or cases of abuse or neglect to law enforcement officials, social services, or a regulatory agency. These policies vary across the states. For instance, some states say that all involved parties must report elder abuse, whereas other states require only professionals to report it.

These policies may help correct the underreporting of abuse of older adults with dementia, but they are controversial. Opponents note possible disadvantages such as diminished physician-patient rapport and the potential for retaliation by abusers.<sup>43</sup> The effectiveness of mandatory reporting policies in addressing abuse of older adults with dementia needs further evaluation.

►LONG-TERM CARE OMBUDSMAN PROGRAM: The Long-Term Care Ombudsman Program was authorized in 1975 under title VII (Vulnerable Elder Rights Protection Activity) of the Older Americans Act. Each state has a long-term care ombudsman's office that is federally funded but that may also receive state and local funding.

The ombudsman's offices are charged with investigating and resolving complaints filed by or

on behalf of residents of long-term care facilities, such as nursing homes and assisted living facilities. Among other activities, the ombudsman's offices are also charged with advocating for long-term care system changes on behalf of the residents and protecting their legal rights. Given that the majority of residents in long-term care facilities are older adults with dementia, the ombudsman program should help reduce abuse among this population.

However, evaluations of the program found that issues such as insufficient funding, an absence of clear lines of authority and accountability for ombudsmen at all levels, inappropriate staffing, and a lack of common standards for responding to and resolving complaints have eroded the overall capability of the ombudsman program.<sup>44</sup> An investigation by the National Association of State Long-Term Care Ombudsman Programs in 2003 found that ombudsmen had insufficient knowledge about how to care for and communicate with older adults with dementia, and, as a result, ombudsmen may have difficulties in resolving dementia-related cases.<sup>45</sup>

### FEDERAL POLICIES

The National Alzheimer's Project Act of 2011 was designed to coordinate governmental efforts for preventing and treating Alzheimer's disease. The act directed the Department of Health and Human Services (HHS) to release a national plan to address Alzheimer's disease and revise it annually. The plan was released in 2012<sup>46</sup> and updated in 2013.<sup>47</sup> One of the most critical goals of the plan is to protect the dignity, safety, and rights of people with Alzheimer's disease.

To address elder abuse, the original plan required HHS to provide guidance on training specifically related to Alzheimer's disease for legal service professionals and to develop a multifaceted approach to monitor, report, and reduce the inappropriate use of antipsychotics in nursing homes. <sup>46</sup> The updated plan expanded efforts to address abuse in older adults with Alzheimer's disease. <sup>47</sup>

For example, the updated plan required HHS to enhance training for professionals serving in the Long-Term Care Ombudsman Program. It also required the Administration for Community Living/Administration on Aging to improve elder care and aging networks and to increase awareness of elder abuse. In addition, the plan called for the dissemination of educational materials to raise caregivers' awareness of elder abuse. <sup>47</sup>

The 2013 plan also recommended funding for programs that promote legal service delivery systems that people with dementia can use and programs that train diverse professionals who work

with older adults to identify abuse and make referrals to APS. In an effort to prevent financial exploitation, the plan required the Consumer Financial Protection Bureau to create guidelines to help nonprofessional financial advisers (such as family members and agencies that assist elders) manage the finances of people with Alzheimer's disease.

▶THE OLDER AMERICANS ACT: The Older Americans Act of 1965 was designed to improve the independence of older adults. It included many specific provisions to address abuse of older adults with dementia.

Title II of the act created the Administration on Aging (now the Administration for Community Living) as the agency responsible for federal elder abuse prevention and services. That agency's duties included developing objectives, priorities, policies, and a long-term plan for carrying these activities out. Its duties also included assisting states and other entities improve their coordination of activities, research, and training related to elder justice. In title III, the act required the Administration for Community Living to fund state services intended to support adult protective services.

Title IV of the act authorized the Administration for Community Living to fund a national legal assistance support system for elder abuse projects in local communities. It also mandated the creation of outreach programs to assist victims of elder abuse; extend older individuals' access to family violence and sexual assault programs, including mental health services, safety planning, and legal advocacy; and encourage the use of senior housing, hotels, or other services when appropriate as emergency short-term shelters for victims of elder abuse.

In addition, title IV required the Administration for Community Living to provide funding to establish and operate resource centers on Native American elders and to evaluate projects involving collaboration among the states' long-term care ombudsman offices, legal assistance agencies, and state protection and advocacy systems for people with developmental disabilities or mental illnesses.<sup>48</sup>

Title VII of the act also authorized the Administration for Community Living to establish the Long-Term Care Ombudsman Program (discussed above) and other programs to combat elder abuse. 49

Since its passage, the Older Americans Act has played an important role in protecting the rights of older adults. However, the act has not been reauthorized since 2011. Its reauthorization should be a policy priority to ensure the health, security, and well-being of older adults with dementia.

# Policies at the federal and state levels were designed to reduce abuse and improve the quality of care for older adults with dementia.

▶THE ELDER JUSTICE ACT: The Elder Justice Act is the most comprehensive piece of federal legislation to address elder abuse. Enacted as a part of the Affordable Care Act in 2010, the Elder Justice Act established two advisory bodies: the Elder Justice Coordinating Council and the Advisory Board on Elder Abuse, Neglect, and Exploitation. The two bodies recommend to HHS strategies to reduce elder abuse.

The Elder Justice Act also authorized \$100 million per year for state and local adult protective services programs and \$25 million per year for state demonstration activities to test methods to improve those programs. In addition, the act authorized funding for HHS to enhance data collection and dissemination, develop and disseminate information regarding practices related to adult protective services, and conduct research related to those services.

Furthermore, the act authorized funding to support the Long-Term Care Ombudsman Program and the recruitment and training of long-term care workers. The act also added provisions to the ombudsman program, such as mandatory reporting of elder abuse that occurs in federally funded long-term care facilities.

For example, the act required such facilities to report within two hours any suspected elder abuse that caused severe bodily injury. The facilities were also mandated to report all other suspected elder abuse within twenty-four hours. Facilities that fail to report suspected abuse within the required time period can face monetary and programmatic penalties. Civil fines of up to \$200,000 and exclusion from further participation in federal health care programs are possible. These provisions together have the potential to improve the safety of older adults with dementia in long-term facilities.

However, the promise of the Elderly Justice Act has not been realized, primarily because

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no federal funds have been appropriated for programs authorized by the act. Increased federal leadership and resources are needed to fulfill the promise of the law.<sup>50</sup>

Taken together, policies at the federal and state levels were designed to reduce abuse and improve the quality of care for older adults with dementia. Yet there have been many implementation challenges, such as insufficient funding and inadequate training for people working with older adults who have dementia. More important, very few studies have investigated the extent to which these policies may reduce the rate of abuse among older adults with dementia. Health policies related to elder abuse among older adults with dementia should be subjected to more rigorous evaluation.

### Discussion

Our review highlights the need for an improved understanding of abuse of older adults with dementia. Estimates of the prevalence of abuse in this population vary substantially across studies because of different definitions, sampling techniques, and methodologies. Nationally representative, longitudinal studies are needed to better examine the extent of abuse as well as the risk factors and outcomes associated with abuse.

Many studies have investigated abuse among older adults with dementia. However, very few have exclusively focused on selected types of elder abuse, such as financial exploitation and self-neglect. Such focused analyses would be valuable because they would increase knowledge about the association between different subtypes of elder abuse as well as their joint effect on adverse health outcomes.

There is also a shortage of evidence-based intervention studies that could assist the victims of elder abuse and their families. Numerous caregiver factors are associated with abuse of older adults with dementia. Thus, we suspect that

caregiver support groups may be effective approaches for reducing abuse. Future research is needed to develop and evaluate such interventions.

Our review also identifies major gaps in understanding of the cultural complexities of abuse among minority older adults with dementia. With the increasingly diverse aging populations in the United States and other countries around the world, studies are needed to explore these complexities. Interdisciplinary efforts should be made to promote the awareness of elder abuse in a culturally appropriate way at the community, state, and national levels.<sup>51</sup> A community-based participatory research approach that involved academic institutions, community organizations, and key stakeholders could be implemented to help researchers explore culturally sensitive issues such as dementia and abuse among minority older adults.52

Our review of state and federal level policies demonstrates the need to improve dementiarelated education and training for people working with older adults. It also suggests the importance of collaboration between stakeholders at the community, state, and federal levels.

For example, to improve the detection and management of suspected abuse of people with dementia, Georgia Anetzberger and coauthors developed an interdisciplinary program to crosstrain adult protective services staff and Alzheimer's Association staff and volunteers and to use community resources to help identify cognitive impairment and elder abuse.<sup>53</sup> Anetzberger and coauthors found that the program led to an increase in understanding and communication between the Alzheimer's Association and adult protective services about how to address elder abuse among people with dementia. This program could be a model for addressing the challenges that front-line staff face.

In addition, communities should work to form multidisciplinary teams that bring together patients, families, other community members, clinicians, nurses, mental health experts, ombudsmen, law enforcement agencies, and other key stakeholders should be established to improve the safety of older adults with dementia.

### **Conclusion**

Elder abuse is common in people with dementia. As the population ages, it is likely to be of increasing concern to people with dementia, caregivers, health care professionals, and policy makers. Vast gaps remain in knowledge about elder abuse.

The presence of state and federal policies signals a growing awareness of elder abuse. How-

ever, challenges that still need to be overcome include insufficient knowledge of the relationships between elder abuse and dementia; a lack of funding for the implementation of federal and state programs related to elder abuse and dementia; and inadequate education and training for,

and collaboration among, people who work with older adults who have dementia. Stakeholders at the federal, state, and local levels should be involved in developing collaborative strategies to improve the well-being of older adults with dementia. <sup>54</sup>

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