REPORT 7 OF THE COUNCIL ON SCIENCE AND PUBLIC HEALTH (A-08)

Elder Mistreatment (Resolution 429, A-07) (Reference Committee D)

EXECUTIVE SUMMARY

<u>Objective</u>: To provide a comprehensive overview of elder abuse and mistreatment in the community, as well as in institutions, and to discuss physician roles and responsibilities, and related educational, legal, and research issues.

Methods: An extensive search of the literature was conducted on the topics of elder abuse, elder neglect, elder mistreatment, and elder self-neglect. References from the 2003 National Academy of Science publication, "Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America," were selected based on the rigor of each research report, the accuracy and sources of statistics cited, the expertise of the authors, and the frequency with which a particular citation has been cited in peer-reviewed publications. Many of the articles chosen were featured at national meetings on elder mistreatment hosted by the Department of Justice, the National Institute of Justice, the Federal Bureau of Investigation, the American Geriatrics Society, and the Gerontological Society of America.

Results: Although elder mistreatment in both domestic and nursing home settings is widespread and regularly encountered by physicians, there is very little evidence-based data to guide physicians in recognition, diagnosis, and intervention of this ubiquitous public health problem. Addressing elder mistreatment in an aging America requires focus on increased awareness, interdisciplinary approaches, proactive physician involvement in clinical care, the education of medical students and residents, continuing education, research, and adoption of legislation, such as the Elder Justice Act (2007).

Conclusions: Elder mistreatment occurs in every US jurisdiction and our American Medical Association should adopt policy on the clinical, educational, and research issues surrounding this public health problem. Our AMA should advocate to federal and state governments, the National Institutes of Health and other funders, medical schools, and the public that abuse, neglect, and exploitation are major threats to safety and well being in old age. Physicians have the responsibility to help maintain patient safety in medical and community settings. Advocating for these most vulnerable persons in American society is the professional responsibility of physicians to our patients and society.

REPORT OF THE COUNCIL ON SCIENCE AND PUBLIC HEALTH

CSAPH Report 7 – A-08

Subject: Elder Mistreatment

(Resolution 429, A-07)

Presented by: Mary Anne McCaffree, MD, Chair

Referred to: Reference Committee D

(Robert T. M. Phillips, MD, PhD, Chair)

INTRODUCTION

Resolution 429 (A-07), introduced by the Illinois Delegation, asked:

That our American Medical Association (AMA) adopt policy that recognizes elder abuse and maltreatment in nursing homes as a continuing problem, and that further supports comprehensive steps to reduce its incidence; and

That our AMA support passage of appropriate legislation that would help prevent elder abuse in nursing homes and give consumers more information to guide nursing home placement.

After discussion, Reference Committee D recommended to the House of Delegates that this issue be referred to the Board of Trustees with a broader mandate, to provide a more comprehensive overview of elder abuse and mistreatment in the community as well as in institutions; it was referred.

Elder mistreatment cuts across class, race, and gender lines and occurs in both urban and rural areas, making it a pervasive, but often neglected public health problem. With coming demographic shifts in the US population, and corresponding increases in the occurrence of degenerative diseases, opportunities for elder mistreatment are increasing. The lack of clear definitions, population-based surveys, and outcome measures have prevented accurate studies of this phenomenon.

Almost every physician has encountered older patients whom they suspect may be mistreated, yet there is little guidance to help them in their care of these individuals. Policies are needed that call for increased awareness, education, research, and medical care for this sector of the population. This report describes the state of the field, including definitions, epidemiology, the role of physicians, and implications for medical education and research. It concludes with nine policy recommendations for better clinical care and increased education and research. The few existing methodologically sound studies are cited to support these recommendations.

METHODS

An extensive search of the literature was conducted on the topics of elder abuse, elder neglect, elder mistreatment, and elder self-neglect. References from the 2003 National Academy of Science publication, "Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America," were included based on the rigor of each research report, the accuracy and sources of statistics cited, the expertise of the authors, and the frequency with which a particular citation has been cited in peer-

reviewed publications. Many of the articles chosen were featured at national meetings on elder mistreatment hosted by the Department of Justice, the National Institute of Justice, the Federal Bureau of Investigation, the American Geriatrics Society, and the Gerontological Society of America.

BACKGROUND

 <u>History</u>: Physicians began writing about elder mistreatment in the late 1950s. ^{1,2,3,4} In a 1975 letter to the *British Medical Journal*, Burston was the first to describe physical abuse of an elder, which he referred to as "granny battering." ⁵ Despite such reports, elder mistreatment was thought to be largely a social problem. In 1974, the passage of Title XX of the Social Security Act mandated that states develop protective service agencies for senior citizens. ⁶ By 1981, every state had an agency whose role was to protect vulnerable older people. Many if not most of these agencies were housed in state or county social service entities.

In the 1990s, physicians and nurses began to systematically study the phenomenon of elder mistreatment. There have been two National Research Council reports, one in 2002 ("Confronting Chronic Neglect: The Education and Training of Health Professionals on Family Violence") and one in 2003 ("Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America"). ^{7,8} The National Institute on Aging is currently funding several grants on the subject; however, prior to 2004, there were fewer than 15 funded national grants that addressed elder mistreatment. ⁸ The literature on this problem is scant and includes mostly case series and reviews, although more primary data is starting to emerge.

<u>Definitions</u>: The specific definitions of the types of elder mistreatment vary from state to state, as defined by state laws. The lack of widely accepted definitions precludes comparisons as well as assessment of the extent of the problem. The National Center on Elder Abuse uses specific definitions, which are listed in Figure 1 (see Appendix). Often referred to generally as "elder abuse," the term "elder mistreatment" is used by those in the field to encompass, broadly, physical abuse, neglect, and financial exploitation, and often includes self-neglect. The establishment of standard definitions would facilitate research, especially population-based studies.

Although sometimes subdivided, there are generally considered to be three broad types of elder mistreatment: abuse, neglect, and exploitation. Elder abuse is defined as the infliction of physical harm on a senior and includes sexual assault. Neglect is the failure to provide the goods or services needed to meet basic needs (food, shelter, medical care) and can be perpetrated by a caregiver or by the vulnerable individual on him- or herself (self-neglect). Exploitation is use of an older adult's money or resources by caregivers for their own purposes. Common examples of community abuse (see below) are noted in Figure 2 (see Appendix).

The unifying feature of elder mistreatment is that those who suffer mistreatment are vulnerable and unable to protect themselves. Moreover, when elder mistreatment is committed by others, the perpetrator is known to the elder. As opposed to frank crimes against the elderly, in elder mistreatment, a trust relationship exists between the elder and family members or paid caregivers. In these ways, elder mistreatment is similar to child mistreatment. Children are vulnerable because their brains are developing and they cannot act autonomously; elders lose the ability to act autonomously because they develop cognitive and functional impairments.

 <u>The Special Case of Self-neglect</u>: Although recognized by 35 states as a reportable form of elder mistreatment, self-neglect (which can be voluntarily reported) is the most common type of case received by state and county APS agencies. ^{10,11} Seniors who neglect themselves often live in squalor and dangerous environments such as homes with gas leaks, vermin, and animal and human feces. ¹²

Self-neglect almost always involves medical issues, such as comorbid diseases that affect cognition and function. ¹³ Perhaps the most obvious role for physicians and the greatest need for medical care lie in identifying and intervening in cases of elder self-neglect.

Self-neglect is often viewed as a benign condition that is the result of poor choices by cognitively intact elders. However, in a study of persons with self-neglecting behaviors, Tierney and colleagues measured harm in 131 persons. ¹⁴ They defined harm as physical injury, property loss or damage, or an incident requiring emergency community intervention. The risk for experiencing harm was 21%. Dyer and colleagues reported on serious consequences of self-neglect, which included the absence of utilities, the presence of spoiled or rotting food, living with untreated advanced medical disease, or laying in excrement. ¹³

Epidemiology

The National Association of Protective Service Administrators conducted two national surveys, funded by the Administration on Aging, on the number of reports of elder mistreatment received by states in 2000 and 2004. All 50 states and the District of Columbia and Guam responded. Although the best of its kind, this data set is incomplete because of the definitional variations from state to state and the variation in the ways that states organize their protective service agencies. Some states (e.g., California) organize protective service agencies by county, while in Texas there is central organization through the state office. As a result very few states could provide answers to all 21 questions; for many of the questions only 50% or less of the states could respond to specific questions.

More than 560,000 cases of mistreatment in community dwellers were reported to state agencies in 2004, which represented nearly a 20% increase from the earlier survey. In the second survey the types of mistreatment as reported by 19 states were: self-neglect 37.2%, caregiver neglect 20.4%, financial exploitation 14.7%, emotional abuse 14.8%, and physical abuse 0.7%. The most common sources of reports were family members (17%), social services workers (10.6%), and friends and neighbors (8%) – these data were derived from only 11 states. Sixty-six percent of the elder mistreatment victims were white, 18.7% were African American, and 10.4% were Hispanic. The fact that so many states did not collect the data and could not respond to the survey questions is a strong example of why better research, uniform language and definitions, and data collection are so essential. The state agencies are funded to provide services and are not equipped to conduct valid research.

 Despite the incomplete nature of the studies, these data on total numbers of reports are felt to represent only one-fifth of the cases that actually occur, and the true number is likely from two to five million cases per year. ¹⁶ In an in-home survey in Israel, 18% of seniors reported physical abuse or neglect. ¹⁷ Fear, cognitive impairment, and unwillingness to implicate family members may prevent seniors from reporting the majority of cases.

<u>Facility versus Community Mistreatment</u>: Elder mistreatment can occur in nursing facilities. In the United States, some 1.6 million people live in approximately 17,000 licensed nursing homes, and another 1 million in an estimated 45,000 residential care facilities, such as personal care homes, adult congregate living facilities, domiciliary care homes, adult care homes, homes for the aged, and assisted living facilities. ^{18,19,20} In California an estimated 20% to 30% of institutions have been cited annually for abusive events that resulted in actual harm. ²¹ In 2003, state long-term care ombudsman programs nationally investigated 20,673 complaints of abuse, neglect, and exploitation. Physical abuse was the most common type reported. ²² Individuals in these settings are felt to be at much higher risk for abuse and neglect than older persons who live at home, since they are often more

cognitively and functionally impaired and less able to protect themselves. Furthermore, nursing home patients and others in long-term care facilities are often too impaired to report or prevent acts of mistreatment. In fact, most adult protective services (APS) agencies receive reports of mistreatment in community dwellers, and do not always receive reports on nursing home residents; separate agencies undertake the investigation of mistreatment in facilities. Depending on the state, these may include departments of health and human services, departments of aging, and ombudsmen programs, which are present in every state. The investigations vary widely depending on funding and training of those involved.

Outcomes

Very few studies have examined outcomes for self-neglect and the types of elder mistreatment that involve perpetrators. There have been no longitudinal studies on elder mistreatment to determine trajectory, recurrence rate, effects of interventions, and health outcomes. In a landmark study, Lachs and colleagues crossed the Established Populations for Epidemiologic Studies in the Elderly (EPESE) database with the Connecticut Ombudsmen program. This New Haven EPESE was one of four studies on cohorts of aging individuals funded by the National Institutes of Health (NIH). This study demonstrated that physical abuse and caregiver neglect increased the risk of death threefold, while self-neglect increased it twofold. None of the subjects in either group died from injury and the authors posited that death was due to malnutrition, multiple comorbidities, or frailty.

THE ROLE OF PHYSICIANS IN ELDER MISTREATMENT

Recognition

Elder mistreatment is a complex issue involving medical disease complicated by social issues. The difficulty is rooted in the inability to consistently arrive at a firm diagnosis of elder mistreatment. How does one distinguish among physiological changes associated with aging, degenerative and other diseases, and elder mistreatment? In the case of bruising, for example, are ecchymoses due to thinning, aged skin, a blood dyscrasia, or physical abuse? The same is true of many other "red flags" of mistreatment such as weight loss, fractures, pressure ulcers, and over-medication. Common red flags of elder mistreatment are described in Figure 3 (see Appendix). Distinguishing among the effects of aging versus disease versus mistreatment requires a clear understanding of the living situation and environment, as well as medical judgment.

Joint Commission standard PC.2.05.0 requires that "the [organization] have criteria to identify [patients] who may be victims of ... elder or child abuse and neglect." This policy also requires reporting to the appropriate agency. Identification and assessment of elder mistreatment is a sophisticated evaluation and requires time, medical knowledge, and an appropriate level of suspicion. There is a need to sensitize physicians to look for elder mistreatment earlier so that intervention is possible.

Risk Factors

There are a number of recognized risk factors for elder mistreatment. Dementia and depression, alcohol use or other substance abuse, and dependence on others are recognized risk factors for mistreatment. Other substance abuse, and dependence on others are recognized risk factors for mistreatment. The Indian Distriction of the In

themselves.^{26,28} Although poverty and ethnic or racial background are associated with an increased incidence of reports to protective service agencies, elder mistreatment is observed in all sectors of society.¹⁰

Screening

 APS agencies do not use reliable and validated screening tools; most state or county agencies do not have the resources to develop, test, and study instruments for the identification of elder mistreatment. Researchers have developed and studied a few tools, but few have undergone the rigorous repeated studies that are necessary for validation (i.e., multiple settings, multiple administrators). One exception is the Elder Assessment Instrument, developed by Fulmer and colleagues, which has been utilized to detect caregiver neglect in emergency center patients. This tool requires 20 minutes to administer and training prior to administration and thus is not suitable for the physician in practice. The Brief Abuse Screen of the Elderly is five-item instrument suitable in a clinical setting, but this tool requires training, does not screen for self-neglect, and has not been widely used. Some recommend that physicians can probe using three questions: Do you feel safe at home? Who prepares your meals? Who handles your finances? Insufficient answers to any of these questions should prompt further investigation.

A widely accepted, validated, and reliable screening tool, which is also practical and can be applied quickly, is needed to enable physicians to detect mistreatment. The ideal tool would help physicians and other health care and social service professionals in every setting quickly apply a standardized screen for mistreatment and recommend the appropriate medical and social interventions. It would also create a common language for communication to agencies, such as APS; other disciplines; and even across state lines. Since elder mistreatment is known to be an independent risk factor for death, data on the risk factors and markers for death could identify those at greatest risk of dying as a result of elder mistreatment. A tool based on these data could help physicians and others to triage the more critical cases, as well as help medical examiners determine if death was due to elder mistreatment or natural causes.

Reporting

In 44 states physicians are considered mandated reporters to the state or local protective service agencies. In a national survey by the National Association of Protective Service Administrators, physicians were noted to report fewer than 3% of cases.³³ Nurses and social service agency personnel are also mandated reporters in other states and report at much higher rates than physicians. There must be a suspicion of mistreatment and iron-clad evidence is not required. Physicians and other reporters are often granted immunity from civil and criminal liability if the report is made in good faith. The decision to report is easy in obvious cases; however, in more subtle cases it may take several visits and discussions with collateral sources before a physician is convinced that there is a suspicion of mistreatment. Failure to report in most states is a punishable offense; incarceration and or fines can be imposed, although few cases are ever prosecuted. Published reports have identified the major barriers to physician reporting. These include time pressures and lack of awareness of the extent of the problem. Sometimes, other medical professionals, such as nurses or hospital social workers, report the cases referred by physicians or the medical team. Many physicians fear that they will endanger the patient-physician relationship, lose control of case outcomes, be drawn into court, and decrease quality of life for the patient. 34,35 Some others do not believe that state agencies will help, are not aware of the specific laws in their states, or cannot recognize the key risk factors for elder mistreatment.³⁶

APS agencies are known by a variety of names across the United States, but they are most commonly social service agencies that perform investigations and provide social interventions. These include:

• Home clean up;

- Arranging for provider services; transportation services;
- Linking patients with health care providers and services;
 - Paying utility bills; food and other basic needs; and
 - Obtaining legal services such as representative payees and guardians.

The National Association of Protective Service Administrators survey determined that from 2000 to 2004 expenditures by protective service agencies increased 20%. ¹⁵ There are high recidivism rates among reported cases; i.e., cases that were reported multiple times. Recidivism can be explained by the reluctance of victims to accept services, or inappropriate reporting by family members or others (examples of such inappropriate reports might be those seeking social services or responding to conflicts among family members). In some cases, recidivism can be explained by undiagnosed and untreated medical disease and the need for sophisticated medical judgment that APS workers cannot provide. Many physicians are frustrated by the inability of APS agencies to resolve more cases of elder mistreatment; ³⁷ however, there are likely multiple reasons for this. APS interventions may not be accepted by clients and since these workers are representatives of the state they cannot force interventions on unwilling elders with adequate mental capacity. Furthermore, although APS workers may have social work training, few have any medical training. 38 As an example, APS workers may not recognize the more subtle cases of mental incapacity and can leave their clients in dangerous situations, believing that the elder is making a lifestyle choice. Self-determination is a major tenet of APS casework. Due to their lack of medical training, APS workers may not always recognize occult or undiagnosed or even life-threatening diseases. This underscores the need to apply medical judgment to complicated cases. No study of the effectiveness of APS intervention has been conducted since the passage of Title XX, despite the nearly half billion dollars spent annually on these agencies nationally.

MEDICAL CARE IN CASES REPORTED TO APS

Primary Care Physician Role

Once a case is reported to APS, an investigation ensues. In some states feedback is provided to the physician; in other instances the investigation continues without any notification to the reporter. Physicians may be asked to provide medical records to APS workers, but this differs by state. The physician is often tasked with providing ongoing care to the patient. Occasionally, a physician may be called on to testify on behalf of the patient; however, excellent documentation of the findings and explicitly identifying the suspected mistreatment in the medical record can often preclude the need for a court appearance. Once APS has completed its intervention (for example, placing a provider in the home, and closing the case), it is the ethical duty of the primary care physician to provide ongoing monitoring of the patient. This may be particularly important for elderly patients with early neurodegenerative diseases that may worsen over time.

The Physician as Member of the Care Management Team

Some physicians are opting for involvement with APS clients beyond traditional office care, and are participating in medical case management teams. Indeed, numerous disciplines and agencies are often simultaneously involved in elder mistreatment cases. Often efforts are duplicated, incurring more costs and not achieving resolution. Medical case management teams, such as the Texas Elder Abuse

and Mistreatment Institute and the Vulnerable Adult Specialist teams, have been formed to increase the efficiency and effectiveness of public and private groups that treat vulnerable mistreated elders. Since APS agencies do not employ physicians or other health care personnel, they must refer clients for medical care. Physicians may work directly with APS on case management teams and participate directly in investigations and interventions. They generally provide comprehensive geriatric assessment, which includes evaluation of cognition, mood, medications, and function in addition to history and physical examination.

Physicians who serve on medical case management teams often make home visits with APS workers. A major role for the physician is the diagnosis of unrecognized diseases, such as vitamin B12 deficiency or depression, and evaluating unusual physical signs and presentations. Physicians can adjust or simplify medication regimens and order home health and other services to curtail neglect; at times they serve as consultants to the primary care physician or assume the care of the patient. They advise APS workers about the severity and prognosis of the condition as well as the time course so that APS agencies can plan and carry out the appropriate interventions. Often the most pressing need is a capacity assessment of the patient, which determines if a social-legal intervention is needed or if the APS worker can intervene at all against patient wishes. Physicians provide the needed medical interventions that complement the social service interventions of APS agencies.

Work on a case management team is very different from traditional medical practice. Unlike patients who come willingly to a medical clinic or emergency center, medical examinations of APS clients may be compelled by the state and patients often undergo them begrudgingly.⁴³ The type of capacity assessment is different from that with which most physicians are familiar. Unlike capacity assessments performed in the clinic or hospital setting where the physician is assessing the person's ability to consent to a medical procedure, APS clients require an assessment of their decision-making and executive capacities to perform self-care and self-protection.⁴⁴ Those deemed incapacitated often require guardians or conservators to remain safe in the community.

A book entitled *Elder Abuse Detection and Intervention: A Collaborative Approach*, co-authored by individuals from medicine, social work, protective services, criminal and civil law, and law enforcement, details best practices for interdisciplinary teams across the United States and the processes for elder mistreatment team development. Although generally felt to be very useful by health care and other professionals, outcomes of these teams have not been formally evaluated. There is no agreed upon methodology for evaluation, generally accepted definitions, or outcomes or other measures by which to study the effectiveness of APS services. There has also been little to no funding for demonstration projects or program evaluation.

Expert Witness and Other Physician Roles

A handful of physicians across the United States have the necessary experience and interest to serve as expert witnesses in elder mistreatment cases. Prosecutors often lack enthusiasm for trying elder mistreatment cases due to the dearth of suitable expert witnesses. Attorneys often ask forensic nurses to assist with these cases because they have the necessary forensic training. 46,47

Physicians in approximately eight states participate in elder abuse fatality review teams. Like child fatality review teams, these teams are forming in numerous sites across the United States to explore ways to improve state agency, law enforcement, criminal justice, and medical care processes. Some child protective service agencies have medical directors who advise the staff on care of children. A similar position for physicians or perhaps a medical advisory board may also be appropriate for APS agencies.

EDUCATIONAL ISSUES

In the 2002 National Academy of Science report "Confronting Chronic Neglect: The Education and Training of Health Professionals on Family Violence" the authors equate family violence, including elder mistreatment, with the most serious public health issues such as cancer and heart disease, and call for better education of physicians and other health professionals in this area. Specific recommendations are summarized below:

- 1. Creation of family violence centers to conduct research on the impact of family violence on the health care system and evaluate and test training and education programs for health professionals. The centers should be established by the Department of Health and Human Services and modeled after similar multidisciplinary centers in fields such as injury control, Alzheimer's disease, and geriatric education.
- 2. Health professional organizations and educators--including academic health center faculty—should address the essential skills to be included in health professional curricula on family violence; effective teaching strategies; and approaches to overcoming barriers and promoting and sustaining behavior changes by health professionals in dealing with family violence.
- 3. Health care delivery systems and training settings, particularly academic health care centers and federally qualified health clinics and community health centers, should assume greater responsibility for developing, testing, and evaluating innovative training models or programs.
- 4. Federal agencies and other funders of education programs should create expectations and provide support and incentives for evaluating curricula on family violence for health professionals. Evaluations should focus on the impact of training on the practices of health professionals and the effects on family violence victims.

The report asserted that health professionals alone cannot solve this complex problem and encouraged society to pay greater attention to the tragedy of family violence.

<u>Medical Students</u>: Almost all medical students in the United States are trained to recognize child abuse, but in an Association of American Medical Colleges survey published in 1998, only 38% recalled receiving training on elder mistreatment. In a study in Virginia, only 19% of medical school and residency programs included curricular content on elder mistreatment. This may reflect a low priority accorded geriatric medicine in most curricula. Medical school faculty should train students to recognize and intervene in cases of elder mistreatment. Several medical schools where faculty are interested in this topic have worked with APS agencies in their specific states to organize "ride-alongs" with APS workers. Students report that these sessions are enlightening and informative and are likely to make a lifelong impact on these trainees.

Residents: Residents, especially in internal medicine, emergency medicine, psychiatry, and family medicine, will likely begin to care for mistreated elders during residency training. They must be able to recognize, diagnose, properly document, and intervene in these cases. Residency is an ideal time for trainees to begin to form relationships with state agencies and realize the public health responsibilities of physicians. Teaching the multifaceted aspects of elder mistreatment addresses each of the core competencies, especially patient care, professionalism, and systems-based practice. Residents practicing in the hospital also come under The Joint Commission umbrella and are expected to recognize and report elder mistreatment.

Continuing Medical Education: In some states, such as Texas, physicians are required to have one hour of ethics or family violence training each year in order to maintain their licenses. Practicing physicians in the community may see many cases of elder mistreatment in their practices, but without training to recognize, intervene, and report, they may miss cases and leave elders in jeopardy. Training physicians to identify older patients who are at high risk of elder mistreatment could lead to broader use of preventive measures to reduce this risk. In the early 1990s, our AMA convened an expert panel to develop a consensus document entitled "Diagnostic and Treatment Guidelines on Elder Abuse and Neglect," which described a practical approach for physicians in elder mistreatment cases.51

RESEARCH ISSUES

State of the Science

A 2002 *JAMA* editorial described the lack of research in elder mistreatment and called elder abuse and neglect a "new research topic." Only a limited number of small or state-based studies on elder mistreatment have been conducted, and the full breadth and depth of the issue is unknown. These studies were retrospective and used inconsistent definitions as noted above. What is needed are data derived from prospective cross-sectional studies that are population based. Only a small number of federally funded studies of elder mistreatment have been conducted. Recently, the Department of Justice (Office on Violence Against Women and the National Institute of Justice) has funded seed grants for researchers in elder mistreatment. In 2004, the National Center for Research Resources funded an exploratory center called the Consortium for Research in Self-Neglect of Texas. In 2006, the National Institute on Aging began funding epidemiological studies to quantify the prevalence and incidence of elder mistreatment through methodologically rigorous research.

Challenges in Elder Mistreatment Research

Lack of funding has hampered research, but there are also significant methodological challenges to the study of this phenomenon. The major barriers to research on elder mistreatment are the varying definitions, difficulties associated with studying vulnerable populations, the lack of a "gold standard" or definitive diagnostic test, and selection of appropriate outcome measures.

Problems with Studying a Vulnerable Population

Mistreated elders are by definition a vulnerable population and are thus protected under the code of conduct for investigations. Many institutions with faculty who want to study elder mistreatment have faced difficulty in obtaining institutional review board (IRB) approval for elder mistreatment studies, even when the studies involved only interviews. Mistreated individuals may shun research studies, as they do medical care, wanting no involvement from others because of fear of being removed from the home or that perpetrators, known to the victims, may be prosecuted. Vulnerable groups can be studied by obtaining consent by proxy; however, in a given mistreatment case the available proxy may be the one who is exploiting or neglecting the elder and may not consent for fear of being exposed. IRB processes and protocols for studying this special population are needed, including guidelines on research subject surrogates.

Lack of a Gold Standard

Rigorous investigation of any public health problem is more easily achieved with a gold standard--a widely accepted method to distinguish cases from non-cases--but there is no biopsy or imaging study that can detect elder mistreatment. Elder mistreatment is a complex medical diagnosis that may touch

the core values of the examiner. APS agency evaluation may be the closest to a standard, but untested screening tools and variations in worker training and experience make APS assessment unreliable. Although there may never be a true gold standard for a problem as complex as elder mistreatment, researchers must develop rigorous measurements to reliably evaluate interventions by APS agencies and medical or legal professionals.

LEGISLATION

The Elder Justice Act (S. 1070 and H.R. 1783): This comprehensive act, first introduced in 2003 and reintroduced to both houses of Congress in March 2007, seeks to accomplish many things. To elevate elder justice issues to the national level the act proposes creation of: (1) Offices of Elder Justice at the departments of Health and Human Services and Justice to serve programmatic, grant-making, policy, and technical assistance functions relating to elder justice; (2) a public-private partnership and a Coordinating Council to coordinate activities of all relevant federal agencies, states, communities, and private and not-for-profit entities; and (3) a consistent funding stream and national coordination for APS.

Under this proposed legislation, an Elder Justice Resource Center and library would provide information for consumers, advocates, researchers, policy makers, health providers, clinicians, regulators, and law enforcement personnel. The center and library would both increase knowledge and support/fund promising projects. Centers of excellence would be funded to develop forensic capacity. Victim assistance, "safe havens," and support for at-risk elders are to be provided. The bill also describes measures for enhancing prosecution. Technical, investigative, coordination, and victim assistance resources would be made available, as well as increased training for medical, legal, and social service professionals. The bill calls for special programs to support underserved populations, including rural, minority, and Native American seniors. Lastly, model state laws and practices would be studied, along with ways to increase security and improve consumer information on long-term care.

A concerted national effort is needed to bring together all of the interested parties (from federal and state governments, medical societies, medical schools, and research institutions) to address the serious public health problem of elder mistreatment in the fastest growing segment of society.

CONCLUSIONS

Elder mistreatment occurs in every US jurisdiction and our AMA should adopt policy on the clinical, educational, and research issues surrounding this public health problem. Our AMA should advocate to federal and state governments, the NIH and other funders, medical schools, and the public that abuse, neglect, and exploitation are major threats to safety and well being in old age. Physicians have the responsibility to help maintain patient safety in medical and community settings. Advocating for these most vulnerable persons in American society is the professional responsibility of physicians to our patients and society.

RECOMMENDATIONS

The Council on Science and Public Health recommends that the following statements be adopted in lieu of Resolution 429 (A-07) and that the remainder of this report be filed:

That our American Medical Association:

- 1 1. Recognize elder mistreatment as a serious and pervasive public health problem that requires an 2 organized effort from physicians and all medical professionals to improve the timely recognition 3 and provision of clinical care in vulnerable elders who experience mistreatment. (New HOD 4 Policy)
- 2. Recognize the importance of an interdisciplinary and collaborative approach to this issue, and 6 encourage states to bring together teams with representatives from medicine, nursing, social work, adult protective services (APS), criminal and civil law, and law enforcement to develop 8 appropriate interventions and evaluate their effectiveness. (New HOD Policy)
- 10 3. Encourage all physicians caring for the elderly to become more proactive in recognizing and 11 treating vulnerable elders who may be victims of mistreatment through prevention and early 12 identification of risk factors in all care settings. Encourage physicians to participate in medical 13 case management and APS teams and assume greater roles as medical advisors to APS services. 14 (New HOD Policy)
 - 4. Promote collaboration with the Liaison Committee on Medical Education and the Association of American Medical Colleges, as well as the Commission on Osteopathic College Accreditation and American Association of Colleges of Osteopathic Medicine in establishing training in elder mistreatment for all medical students; such training could be accomplished by local arrangements with the state APS teams to provide student rotations on their teams. Physician responsibility in cases of elder mistreatment could be part of the educational curriculum on professionalism and incorporated into questions on the US Medical Licensing Examination and Comprehensive Osteopathic Medical Licensing Examination. (Directive to Take Action)
 - 5. Encourage the development of curricula at the residency level and collaboration with residency review committees, the Accreditation Council for Graduate Medical Education, specialty boards, and Maintenance of Certification programs on the recognition of elder mistreatment and appropriate referrals and treatment. (Directive to Take Action)
- 30 6. Encourage substantially more research in the area of elder mistreatment. (Directive to Take 31 Action)
 - 7. Encourage the US Department of Health and Human Services, Office of Human Research Protections, which provides oversight for institutional review boards, and the Association for the Accreditation of Human Research Protection Programs to collaborate on establishing guidelines and protocols to address the issue of vulnerable subjects and research subject surrogates, so that research in the area of elder mistreatment can proceed. (Directive to Take Action)
- 39 8. Encourage a national effort to reach consensus on elder mistreatment definitions and rigorous 40 objective measurements so that interventions and outcomes of treatment can be evaluated. 41 (Directive to Take Action)
- 43 9. Encourage adoption of legislation, such as the Elder Justice Act, that promotes clinical, research, 44 and educational programs in the prevention, detection, treatment, and intervention of elder abuse, neglect, and exploitation. (Directive to Take Action) 45

Fiscal Note: \$5,000

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APPENDIX

Figure 1: National Center on Elder Abuse Definitions of Elder Mistreatment

Physical abuse is defined as any act of violence that causes pain, injury, impairment, or disease, including striking, pushing, force-feeding, and improper use of physical restraints or medication.

Psychological or emotional abuse is conduct that causes mental anguish. Examples include threats, verbal or nonverbal insults, isolation, and humiliation. Some legal definitions require identification of at least 10 episodes of this type of behavior within a single year to constitute abuse.

Financial abuse is misuse of an elderly person's money or assets for personal gain. Acts such as stealing (eg, money, social security checks, possessions) or coercion (eg, changing a will, assuming power of attorney) constitute financial abuse.

Neglect is the failure of a caretaker to provide for the patient's basic needs. As in the previous examples of abuse, neglect can be physical, emotional, or financial. Physical neglect is failure to provide eyeglasses or dentures, preventive health care, safety precautions, or hygiene. **Emotional neglect** includes failure to provide social stimulation (eg, leaving an older person alone for extended periods). **Financial neglect** involves failure to use the resources available to restore or maintain the well-being of the aging adult.

Sexual abuse is defined as nonconsensual intimate contact or exposure or any similar activity when the patient is incapable of giving consent. Family members, friends, institutional employees, and fellow patients can commit sexual abuse.

Self-neglect is behavior in which seniors compromise their own health and safety, as when an aging adult refuses needed help with various daily activities. When the patient is deemed competent, many ethical questions arise regarding the patient's right of autonomy and the physician's oath of beneficence.

The **miscellaneous category** includes all other types of abuse, including violation of personal rights (eg, failing to respect the aging person's dignity and autonomy), medical abuse, and abandonment.

Figure 2: Examples of Elder Mistreatment

- *Physical abuse*. A 72-year-old woman with deforming rheumatoid arthritis is pinched and beaten by her schizophrenic daughter because the elder can no longer help clean the house.
- Caregiver neglect. A 77-year-old woman status post multiple strokes, is found dead at a nursing facility due to undiagnosed sepsis from multiple deep pressure ulcers on her back, vagina and scalp.
- Financial exploitation. A 68-year-old former CIA agent with early Alzheimer's disease is threatened by his paid caregiver who steals \$100,000 of his retirement funds. With markedly diminished funds he now presents to the public hospital with pneumonia and an albumin of 1.5 g/dL.

• Self-Neglect. A 80 year old man with diabetes and severe depression that blunts his judgment, fails to accept care for his gangrenous foot, becomes immobile and burns to death in a house fire.

Figure 3: Red Flags in Elder Mistreatment

General: medical noncompliance in vulnerable elders; dysfunctional family relationships; history inconsistent with physical examination

Physical abuse: bruising - especially trunk, neck, head, genitalia ^{53,54}; fractures – especially in areas not usually affected by osteoporosis; lacerations, skin tears on trunk, neck, head, genitalia

Neglect (caregiver or self): malnutrition; contractures; over- or under-medicated; pressure ulcers⁵⁵, contractures; lice or scabies; multiple ill-cared for pets

Financial exploitation: failure to obtain medications; multiple evictions; patient unaware of their income, costs

For more complete descriptions see National Academy of Science report on the medical forensics of elder mistreatment.⁵⁵