Elder Self-Neglect and the Justice System: An Essay from an Interdisciplinary Perspective

Marie-Therese Connolly, JD

Elder self-neglect is a complex issue for the legal system—one not always easily distinguished from other types of elder abuse, neglect, and exploitation. The issue inherently implicates several disciplines, and although self-neglect is not prosecuted per se, prosecutions of other types of elder abuse, neglect, and exploitation may affect self-neglect as well. In addition, other types of legal intervention, such as guardianship actions, may serve to protect vulnerable older people, but it is critical to ensure that such interventions do not inappropriately infringe on the older person's civil liberties or result in exploitation or worse. There are daunting challenges to doing work in this field—death; ageism; medical, legal, and ethical complexities; and a chronic paucity of funding. It is nevertheless imperative that researchers expand their efforts to elucidate the nature and scope of elder self-neglect; its interplay with other forms of abuse, neglect, and exploitation; and the most effective mechanisms for intervention and prevention. Such efforts, and in particular interdisciplinary approaches to these common problems, are critical to improving care for the nation's older people and assisting millions of families and practitioners. **J Am Geriatr Soc 56:S244–S252, 2008.**

Key words: law; elder mistreatment; aging

This article (based on a presentation given at the first national conference on elder self-neglect) examines how concepts of neglect and self-neglect implicate the law and how self-neglect relates to the justice system's treatment of elder abuse and discusses some initiatives with the potential to improve prevention and detection of and intervention in elder self-neglect.

From the Woodrow Wilson International Center for Scholars, Washington, DC.

The presentation on which this essay is based was given while the author was Coordinator of the Elder Justice and Nursing Home Initiative, U.S. Department of Justice, Washington, DC.

Address correspondence to Marie-Therese Connolly, JD, Senior Scholar, Woodrow Wilson International Center for Scholars, One Woodrow Wilson Plaza, 1300 Pennsylvania Ave. NW, Washington, DC 20004.
E-mail: marie.connolly@wilsoncenter.org

DOI: 10.1111/j.1532-5415.2008.01976.x

ELDER SELF-NEGLECT AS A PHENOMENON THAT CROSSES MULTIPLE DISCIPLINES

The Words We Use

One can argue that those who work in the field of elder abuse, neglect, and exploitation (collectively referred to as "elder abuse" or "elder mistreatment") owe it to themselves and their work to cultivate a certain degree of role confusion. Said another way, working effectively for elder justice requires some familiarity with the tools available to the critical disciplines that make up the field: health care, social services, and the legal system. Neglect, and more specifically self-neglect, the subject of the conference, does not fit neatly into a single disciplinary column. Instead, the term "neglect" inherently combines medicine, law, and social services.

In contrast to such terms as "dehydrated," "malnourished," "pressure sore," and "bruise" (which may be sequelae of neglect), the term "neglect" does not solely describe a physical condition. The consequences of neglect range along a spectrum from no discernible harm to modest discomfort to serious deterioration in well-being to grave physical or psychological injury to death. The term "neglect" goes beyond simply describing a physical or psychological condition. It conveys information about the person who has been neglected—that he or she presumably could not properly care for himself or herself (for physical or cognitive reasons). It also conveys information about the person who did the neglecting—that he or she did not provide the care that the neglected person needed.

In addition to conveying information about the *neglected* and the *neglector*, the term "neglect" also conveys a relational information component, indicating some relationship between the neglector and the neglected in which the neglector has responsibility for the care of the neglected. This association suggests the next questions: Who neglected who? Did the neglected person neglect himself or herself? Did a third party neglect him or her? And perhaps even, Is the same person self-neglecting and neglecting someone else at the same time? These sound like simple questions, but this national conference was convened precisely because the answers are far from simple. Neglect is inherently relational and contextual, particularly when it involves adults who presumptively have capacity, whose capacity may although bewaning and differ depending on the situation.

0002-8614/08/$15.00

Imagine a graph representing the universe of neglect. On one axis is a continuum with clear self-neglect at one end and clear neglect by a third party at the other. In between, it is more difficult to ascertain when self-neglect ends and neglect by a caregiver begins. As autonomous adults (unless adjudicated to lack capacity), older people are presumptively responsible for their own care. One of the most difficult questions that a free society faces arises in attempting to define the point at which, if ever, the responsibility for care shifts from the once-autonomous and -competent self to another person or entity.

On the other axis are the various realms in which the term neglect has meaning. The point at which self-neglect ends and neglect by a third party begins may fall in different places and be defined differently under prevailing standards in law, ethics, medicine, and social services. For example, although the legal standard to declare someone incompetent may not have been met, family members, friends, or social workers may believe that the time has come for an older person to have assistance, even if that person does not want help.

Alternatively, although a medical professional may be concerned about whether an older person is adequately caring for himself or herself, Adult Protective Services (APS), in conjunction with the family, may decide it would be premature to intervene because the trauma of change (particularly if it involves moving) might do more harm than permitting the neglect to continue.

This, then, raises the most basic question of all: How do we define neglect? Answering this question also requires context. A person who lived untidily her entire life may not be thought of as self-neglecting when her house becomes even messier than usual, whereas someone who lived in pristine order, for whom such a mess is an extreme deviation from the norm, may be thought to be self-neglecting under the same circumstances.

Why is self-neglect of interest to those in the justice system (e.g., police, prosecutors, and courts) if it does not involve wrongdoing by a third person? Because it is inextricably linked to other types of elder mistreatment that involve wrongdoing, as demonstrated by the following four points. (1) The line between self-neglect and neglect by others can be murky in terms of when the duty to care and culpability for failing to care for someone else sets in. (2) Self-neglect is believed to be a risk factor for and a consequence of other types of elder abuse. (3) Fears about long-term care too often drive frail older people to stay in environments where they can no longer properly care for themselves or worse. (4) Improving how we identify and respond to elder abuse in many cases also will improve how we identify and respond to elder self-neglect, for example, through better interventions, training, research, and public awareness. Thus, most efforts relating to elder abuse have a direct bearing on self-neglect as well.

The reasons to take self-neglect seriously are many. Despite the dearth of research on the subject, most practitioners and experts, based on their experience, believe that self-neglect is more common than other forms of elder abuse and is a risk factor for other types of mistreatment. Stated another way, older people who self-neglect seem to announce their vulnerability, making them more likely to be abused, neglected, or exploited by others. The converse also appears to be true—that older persons who have been abused, neglected, or exploited by a third party are more likely to self-neglect in the wake of such an insult. This critical link between self-neglect and the other elements that constitute elder abuse requires holistic multidisciplinary treatment.

We urgently need research to expand what we know about elder self-neglect, including how it relates to other phenomena, and to discern the relationship between self-neglect on the one hand and abuse, neglect, and exploitation by others on the other. Topics at the complex intersection of self-neglect and the law are many. Those addressed in this article include examples of how legal actions brought by public entities can affect elder self-neglect; examples of some Department of Justice (DOJ) grants with a potential effect on self-neglect; and challenges and opportunities relating to elder self-neglect, for example, assessing the cost of and collecting data about the problem, and enacting legislation to address it. Each of these topics is reviewed below.

LEGAL ACTIONS WITH A POTENTIAL IMPACT ON ELDER SELF-NEGLECT

In the elder abuse context, legal action by government entities is pursued under one of two broad authorities: police power or parens patrie authority.

Police power involves the inherent authority of the government to use the force of law to restrain or regulate the conduct of its citizens, often through criminal or civil prosecutions (to punish, deter, recoup, or remediate some sort of wrongdoing). Governments use their parens patrie authority when they step into the role of a parent or guardian, using the law to protect vulnerable citizens who lack legal capacity for decision-making.[1]

Cases Brought Under Police Power Authority

Federal, state, and local government entities prosecute violations of the law under their inherent police power,[1] but this article will focus solely on federal cases enforcing federal laws brought by DOJ (including divisions in the department's headquarters (called "Main Justice") in Washington, D.C., and by the 93 U.S. Attorneys Offices throughout the country). Although there are no federal laws under which the department would pursue cases prosecuting self-neglect per se, there is still a relationship between federal prosecutions and elder self-neglect.

The relationship is as follows: DOJ pursues cases against healthcare providers under a "failure of care" theory. It has pursued such cases against individuals, nursing homes, nursing home chains, management companies, and other types of healthcare providers when they knowingly bill Medicare or Medicaid for goods or services never rendered or rendered in a worthless fashion. Examples include billing for care when the facility failed to feed, administer medication to, or turn and position a patient, resulting in suffering, injury, grievous harm, or even death.

In the absence of a federal abuse and neglect law, DOJ pursues most failure-of-care cases under the civil False Claims Act,[2] a financial fraud statute that provides for treble damages (three times the amount of the monies wrong-

fully obtained by the provider), plus penalties of up to $11,000 for every false claim submitted to the government. When DOJ began bringing such failure-of-care cases, some providers complained that it was meddling in medical judgment or essentially bringing malpractice cases. That is incorrect. These cases involve more than mere differences in medical judgment. Rather, they involve serious (and usually injurious or lethal) failures to provide the requisite care despite billing for it.

These cases are not so different from cases the government brings relating to other programs. For example, if the government buys an airplane and it arrives missing an engine or other critical part, the government got *something* for its money, but that product was worthless for the purpose for which it was purchased. So, too, with failure-of-care cases. The government pays healthcare providers under the Medicare and Medicaid programs to provide a bundle of services for older and infirm people. (Nursing homes receive approximately 60% of their revenue, more than $80 *billion* annually, from those programs.[3]) The core purpose of those programs is to provide care to beneficiaries, not to subsidize healthcare providers.

What is the nexus between failure-of-care cases and elder self-neglect? That nexus can perhaps best be articulated as follows: As long as people who need care stay in environments where they do not get it (because they neglect themselves or are abused or neglected by others) and believe that they cannot or will not receive adequate care in facilities, there is a nexus between self-neglect and failure of care by facilities. In other words, people are more likely to stay in situations (at home or elsewhere) where they neglect themselves or are abused or neglected by someone else because of their perceptions (whether accurate or not) about the state of long-term care.

Several reports seem to support this hypothesis.[4,5]First, in a study of end-of-life decisions some years ago, 30% of seriously ill people surveyed told researchers that they would rather die than go to a nursing home.[6]

Second, reports issued by the Government Accountability Office, the Department of Health and Human Services, Office of Inspector General (OIG), and other entities conclude that serious quality problems continue to afflict many long-term care facilities and that, by some estimates, as many as one-third to one-fifth of all nursing homes provide care so deficient that the conditions put residents at risk for harm.[7,8] Chronic staffing issues compound the problem. Studies conducted for the Centers for Medicare and Medicaid Services (CMS) and presented to Congress in 2000 and 2002 report that 50% to 90% of all nursing homes are understaffed at levels placing residents at risk for harm.[9] Although the reports about nursing homes are less than encouraging, at least there are *some* nationwide data about that part of the long-term care system. Much less is known about non-nursing home facilities, such as board and care homes, assisted living facilities, residential care facilities, and the like, which house another 1 million Americans. For example:[10]

(1) Few data exist about non-nursing home long-term care, let alone any that correlate from state to state.
(2) Standards governing such long-term care are inconsistent at best.
(3) Oversight over non-nursing home care differs from state to state (in terms of existing laws and regulations and in terms of implementation).
(4) There is little clarity about what types of facilities provide what types of services from location to location.
(5) There is widespread confusion among consumers about what kinds of facilities exist, which ones provide which types of services, and what they (consumers) are entitled to, in which settings.
(6) Long-term care provided in home settings provides more challenges still, with even fewer standards and opportunities for scrutiny or oversight.

If people who need care would rather die than go to a facility to obtain that care, imagine what hardships they are willing to endure as an alternative to going to a facility.

Thus, as it pertains to the issue of self-neglect, it is likely that perceptions of quality problems in long-term care, whether real or imagined, cause countless older people to remain in environments where they neglect themselves (or are at risk for other reasons). If that is true, then prosecutions to redress bad care, remedies to improve long-term care facilities, and the perception that facilities will be held accountable for wrongdoing, could, in the long term, reduce the number of people who self-neglect.

Moreover, in a civilized and humane society, frail and vulnerable people should have access to the long-term care they need. They should not have to be terrified to seek out long-term care or about the prospect of aging. Many have paid into Social Security and Medicare their entire working lives, contributing premiums to cover what they need in old age. Having upheld their end of the bargain, they should be entitled to decent care in exchange. Federal and state government entities have the responsibility to exercise stewardship over the Medicare and Medicaid programs, among other things, to enforce fiscal and quality standards and, when necessary and appropriate, to recommend prosecution of those who defraud or otherwise violate those programs. Such accountability is critical not only to promoting quality standards (by drawing a line in the sand about what is legally unacceptable), but also to the public's confidence about the possibility of obtaining quality long-term care.

Some years ago, many nursing homes, including several of the nation's largest chains, fell into a financial crisis that resulted in several chains filing for bankruptcy (at the time, the largest healthcare providers ever to have filed for bankruptcy). DOJ was simultaneously pursuing cases against many of these entities for financial fraud and egregious failures of care. DOJ worked closely with the Department of Health and Human Services (HHS), including the OIG and CMS (then called the Health Care Financing Administration) to forge settlement agreements under which the government not only recouped monies it lost, but insisted on remedies designed to protect residents with ongoing monitoring. These monitoring agreements mean that defendants pay monetary damages and enter into agreements (usually with OIG) under which they pay monitors to oversee their quality and programmatic compliance.

The goal of such monitoring agreements is to track and improve systems, data collection, outcome measurement, staffing patterns, management and training practices, and ultimately and most importantly, to improve the care pro-

vided to residents. Unlike state surveyors, whose reviews focus on individual facilities, monitors focus on the entire operation, which in the case of a large nursing home chain may involve sites in multiple states or even countries. Monitors may review policies, infrastructure, and implementation of standards, and help to educate entities to leverage data to improve care.

OIG has entered into monitoring agreements with many of the nation's largest nursing home chains and several smaller entities as well, together representing well over a thousand facilities. It would be a fascinating and important contribution to the field to evaluate these monitoring agreements in a methodologically rigorous fashion. Such analysis could generate evidence-based data to help answer the questions: Do monitoring agreements improve care? How do they work? Which provisions work most effectively? Which provisions work less well? Which monitors' approaches are most successful? How are monitors most effective in translating their methods to the entities they monitor? And so forth.

Some of the monitors are themselves researchers and have approached their monitoring in a scholarly fashion. They collect data about the providers' outcomes, process, and culture and about the monitoring process and results as they go along, making mid-course corrections based on their observations and data collection. A review of such data could yield useful information about ways to improve nursing homes specifically and a broader range of providers in general.

It perhaps is not surprising that prosecuting neglect of older people (which may affect self-neglect), whether at the federal, state, or local level, poses numerous challenges. Chief among them is the dearth of forensic knowledge in the field. Experts agree that the forensic science relating to elder abuse and neglect is some 40 years behind the science relating to child abuse and 20 years behind domestic violence. We simply lack the data to help us distinguish when a particular condition results from wrongdoing from circumstances when it results from benign causes. For example, although it is sometimes abundantly obvious that a person was neglected, when there is a close call, we often lack the science to establish what type of fracture, laceration, pressure ulcer, burn, malnutrition, or dehydration is the result of wrongful neglect or abuse rather than from some other factor. Further complicating the inquiry, the signs of elder abuse and neglect often mask or mimic signs of aging and disease, making those distinctions not only legally, but also medically complex.

Moreover, numerous legal challenges attend such prosecutions. For example, proving neglect often requires proving a negative (that something was not done, that care was *not* provided). It often is more difficult to prove that something was not done than to prove that an affirmative act was committed (e.g., that one person struck another). In addition to forensic issues, other challenges that arise in elder abuse and neglect prosecutions include witnesses who may lack capacity and, even if they are able to testify, are not believed or require significant logistical and emotional support, and evidentiary rules and recent court decisions (such as the Supreme Court's Crawford v. Washington)[11] that have produced further challenges to obtaining testimony from older frail adults. In addition, although there is significant infrastructure to assist those who prosecute child abuse and domestic violence, there is little supportive infrastructure for those pursuing elder abuse cases.

Cases Brought to Protect Vulnerable Persons Under the Government's Parens Patrie Authority

Similar lack of support is evidenced in parens patrie cases, in which the state steps into the role of protector, another type of action with a nexus to elder self-neglect. In such cases, it is critical to apply the right standard in deciding when and under what circumstances a person can or should no longer make decisions on his or her own behalf. In America, citizens have the inalienable right to make really bad decisions (as long as they do so with the requisite degree of capacity). Therefore, it is critical that infringement on an individual's liberty (e.g., by creating a guardianship or conservatorship relationship), often triggered by self-neglect, does not occur unnecessarily, prematurely, or inappropriately. Moreover, it is important to remember that interventions to address self-neglect may be no panacea and can even precipitate unintended declines in the well-being of the very person the intervention is intended to help. Thus, guardianship and conservatorship arrangements must be pursued thoughtfully, cautiously, and only with ample justification.

Infringement on an older person's liberty should occur only to protect and not merely because he or she has offended society's sensibilities or become an irritant, nuisance, or inconvenience to family, friends, or community.

Guardianships, conservatorships, and under some circumstances, powers of attorney and other legal agency relationships are powerful tools that can expand the legal rights and protections of a vulnerable person (when handled properly) or trample them (when handled inappropriately, insensitively, or venally). Thus, such actions should be adequately documented and monitored to ensure that they do not become a vehicle to exploit or steal from the very people they are designed to protect.

EXPANDING THE KNOWLEDGE BASE: DOJ GRANTS WITH A POTENTIAL EFFECT ON SELF-NEGLECT

In addition to pursuing the failure-of-care cases discussed previously, DOJ also engages in activities that fall under the heading "Administration of Justice." Under this umbrella, DOJ has made grants and organized and participated in various interagency and interdisciplinary groups, such as an Elder Justice Work Group, a Nursing Home Steering Committee, interagency groups of various sorts, and a group focused on technologies for successful aging.

Under the rubric of "Administration of Justice" DOJ also planned the 2000 Elder Justice Roundtable that launched a national discussion about medical forensics in elder abuse and neglect. The participants, leading experts in the field, who also presented their conclusions to former Attorney General Janet Reno, and generally agreed that, although it would take many years to complete research on the big issues like incidence and prevalence, research on more discrete and manageable issues could and should proceed immediately. This, more or less, is what has occurred, fueled largely by those who participated in that roundtable

discussion. (Two years later, a panel of the National Research Council, National Academy of Sciences concluded that it was premature to set forth a national research agenda because not enough was known to do so.[12])

The National Institutes of Health, and specifically the National Institute on Aging (NIA) is the entity that first comes to mind when we think of federally funded research in elder abuse, but DOJ also has a grant-making component called the Office of Justice Programs (OJP). OJP receives several billion dollars annually, most of which is earmarked, but DOJ, through the Elder Justice and Nursing Home Initiative, the National Institute of Justice (NIJ is DOJ's research arm and part of OJP), the Office on Violence Against Women, the Office for Victims of Crime, and the Bureau of Justice Administration has devoted funds to various elder abuse–related efforts, including research, and evaluations developing training curricula, supporting programs and pilots, supporting law enforcement and prosecutions, and organizing special events designed to advance the field.

In 2005, NIJ, at the same time as NIA, issued the first-ever federal solicitation for applications for research grants relating to elder abuse, neglect, and exploitation. NIA has issued similar solicitations periodically and NIJ every year since. Cumulatively, the approximately 20 grants funded by NIA and NIJ pursuant to these solicitations are yielding some significant data to advance the field.

In addition to the research grants, NIJ also organized meetings of grantees in 2004 and 2008 to synthesize and focus the discussion of NIJ and NIA elder abuse grantees and other stakeholders. One issue consistently raised relates to the formidable challenges of doing research in the field.

Ironically, although research is urgently needed, the field is a peculiarly difficult one in which to do that needed research. Challenges cited by researchers include the paucity of funding; human subjects protection rules and other concerns of researchers and institutional review boards (of which there may be more than one when more than one institution is involved); lengthy periods to obtain approvals; concerns regarding and difficulties obtaining consent when the subject is incapacitated; proxies who may be reluctant to provide consent; concern that the proxy may also be an abuser; challenges to securing the cooperation of public and private agencies; potential ethical dilemmas, for example, concerning how and when to intervene when abuse is suspected and whether the research itself might pose a risk to the subjects; difficulties determining whether, and at what point, and what type of reporting is required when abuse or neglect is suspected; difficulties identifying and recruiting subjects, both individuals and entities, to mention just a few of the epic challenges that confound the field. The time has come to convene a group of stakeholders and experts to promulgate guidance on these vexing issues so that they become less of an impediment to urgently needed research.

At those NIJ grantee meetings, participants not only took stock of the work completed and under way, but also explored potential future directions, shared information about how they have addressed challenges, and identified opportunities for collaboration. With the increase in the number of grants funded on this topic, the 2008 meeting was approximately double the size of the 2004 meeting. So there is reason to be hopeful.

Although the last decade has produced real progress, with several researchers quietly working to fill the gaps in knowledge in the field, building a body of literature of critical importance to practitioners and policy makers alike, we still have a long way to go.

Forensics

The NIJ elder justice grant portfolio includes several studies intended to advance knowledge about elder abuse, neglect, and exploitation forensics—a subject woven through and integral to the research, education, and practice of the field, if not always identified as such. The term "forensics" literally means "pertaining to or employed in a legal proceeding." Popular television shows such as CSI (the acronym for Crime Scene Investigation) have given Americans a detailed (if not always accurate) image of what "forensics" means. But the definition is broader than what we might take from television. Relevant to this discussion, "forensic markers" are signs that elder abuse, neglect, or exploitation have occurred. The forensic marker could be a bruise, a knife wound, a filthy room, a check, or gas left running on the kitchen stove. There is a pressing need to expand on what is currently known about forensic markers to allow for better detection, investigation, prosecution, and prevention, and so that all entities (physicians, nurses, social workers, police, and prosecutors) can do a better job of distinguishing wrongdoing (e.g., neglect by others) from conduct where there may be no identifiable culprit (e.g., self-neglect).

Research and the Law of Unintended Lessons

The grants funded in this area are rife with "the law of unintended lessons": the unintentional discovery of something that researchers did not set out to study and the funders did not expect to learn. The collaboration between the Texas Elder Abuse and Mistreatment (TEAM) Institute, led by Dr. Carmel Dyer, and the Houston Medical Examiners Office, funded by NIJ, illustrates this principle. Initially, this grant was intended to begin researching forensic markers that might be found in death investigations or autopsies of older people. But as the project proceeded, it taught more-important lessons not only about substance (what physical markers to look for), but also about process (what procedures are more likely lead to the detection of wrongdoing).

When a medical examiner sees the body of a disheveled older person come in to the morgue with huge pressure ulcers, and other signs of neglect, how does he or she go about determining whether that person was neglected by someone else or suffered from self-neglect. These determinations can be difficult to make, even in the living. As the collaboration progressed, the team tried to identify suspicious indicators that would assist them in identifying wrongful deaths in older people and identify what process helped them best ascertain the truth.

They began to ask: How often do personnel in a medical examiner's office ask whether elder abuse, neglect, or exploitation has occurred? Are personnel in medical examiners' offices trained to identify issues in the cause of death of older people? How often does self-neglect or abuse or

neglect by others contribute to death? How often is there a scene investigation in the death of an older person, and what information does it yield? What is the correlation between the people the medical examiner's office sees and those who are clients of APS? Does anyone really ask the right questions when an older person dies? And what questions should be asked?

They learned that such questions are rarely asked, but in the context of this study, the research teams began to ask them. The geriatricians and forensic pathologists and the teams in the geriatric healthcare practice and in the medical examiner's office, learned to exchange information about what triggered suspicion for the other discipline. They learned that geriatricians are not trained to look for forensic markers (about which forensic pathologists have expertise) and medical examiners are not trained to identify normal versus non-normal conditions of aging. They all learned that a surprisingly high proportion of the older people who came to the medical examiner's office in death had been APS clients in life. They learned that when questions about elder abuse or self-neglect were not asked, those factors went undetected and were not cited as contributing factors to a death.

The research also demonstrated that people who work in the medical examiner's office are generally not trained to ask questions about elder abuse or neglect or self-neglect. Additionally, they found that the participation of a geriatrician in the case review of the death of an older person helps to elucidate the right questions about the medical and geriatric issues and about the circumstances and forensic factors relevant to the death. The research also taught that visiting the home of the deceased can be a critical step in assessing the circumstances of death of an older person. These visits help raise questions (some of which are relevant to a self-neglect versus neglect by another determination) such as: Was the deceased's home overflowing with trash, or was it spotless? Did the deceased have enough money to care for her- or himself, or was someone else cashing the deceased's Social Security check for drug money? Was the deceased caring for him- or herself, or was someone else supposedly or actually providing assistance? All of these questions have a potential bearing on an inquiry when a medical examiner might be trying to determine the circumstances of death.

The research is teaching us what we might have suspected intuitively—that home visits and caregiver interviews, for example, may provide important information about the circumstances under which an older person died.

As we have learned from the field of forensic pediatrics, and the long-standing collaboration between forensic pathologists and pediatricians, on the other end of the age spectrum, the cross-pollination of different fields (in this case geriatrics and forensic pathology)—and the modified process—make a valuable contributions to the substantive outcomes. Introducing new procedures can, as in the example of home visits by an investigator from the medical examiner's office, provide synergistic opportunities; catalyze new questions, new methods, and development of a shared knowledge base that expands both fields; and in the end, provide geriatricians, medical examiners, and others on the front lines with important information that will assist them in determining when a situation involves wrongdoing and when it does not.

Another important piece of forensic research funded by NIJ relates to bruising in older people. When looking at the parameters of accidental bruising, the research team at the University of California, Irvine, was able to identify one type of forensic marker through their study of *unintentional* bruising. The principal investigator reported that the results of this study echoed the mantra of what most real estate agents say is a prime factor in their line of work: "location, location, location." The researchers found that approximately 90% of accidental bruises occur on the extremities and about 10% on the torso. Typically, few people remembered how they got bruises on their extremities. *None* of the accidental bruises were found on the genitalia, neck, ears, or inner thigh. From this deceptively simple study, practitioners learn that, if they see a bruise on the genitalia, inner thigh, head, or neck of an older person, they should, at the very least, ask questions and take the matter to the next level. This study also debunked a misconception commonly held by some, that a bruise cannot be dated according to its color. Part II of the bruising study, examining *inflicted* as opposed to accidental bruising, is currently under way. Although the bruising study will primarily be of assistance in analyzing abuse cases, it might be applicable to a possible self-neglect situation in which someone is trying to ascertain whether an accidental fall caused certain bruises, or whether they were caused some other way.

Another DOJ grant examines death reviews in nursing homes. In 1999, Arkansas passed a law requiring that the county coroner investigate every nursing home death. This law has generated no small amount of controversy and a significant body of information. The question is what can be learned from those data. One of the first projects that the multidisciplinary research team on this grant undertook was to conduct focus groups with coroners and medical examiners. The results were revealing if sometimes daunting. Some focus group participants said that the funds would be better used on younger people.

In addition to exploring forensic markers, DOJ had hoped that the research team could also determine whether the law, as claimed, had a sentinel effect. In other words, do nursing homes provide better care after such a death investigation law goes into effect, because they know that every resident who dies in their home will be scrutinized? If so, the law becomes much more interesting to policy makers as a possible vehicle to improve nursing home care.

DOJ is interested in research that is methodologically sound, will advance the field, and will forge new ways to meet the many unmet needs of practitioners. Descriptions of the various elder justice research projects are available on NIJ's Web site.

Why does this matter to self-neglect? Because the dramatic dearth of knowledge in the field means not only that we do not have all the tools we need to recognize elder mistreatment, but also that we know little about the relationship between elder self-neglect, elder mistreatment and which tools are most effective in preventing both. Additional research would help to build that knowledge base, allowing practitioners to respond more effectively to self-neglect, as well as other types of mistreatment.

Programmatic and Education Grants

DOJ also has been active in grant-making for purposes other than research, including, for example, funding an Elder Fatality Review Team project. For years, fatality (or death) review teams have analyzed deaths of children and younger people. Usually these teams focus on what went wrong and whether a systemic breakdown contributed to the death. Until a few years ago, there was not a single fatality review team in the country to examine elder deaths. Now there are a handful—including in Maine, Texas, Arkansas, southern California, New York, Indiana, and Illinois. DOJ's Office for Victims of Crime funded a grant to the American Bar Association Commission on Law and Aging to seed such teams, examine them, and produce a replication guide, which is now available through the Office for Victims of Crime. Again, self-neglect is a difficult issue that the existing fatality review teams face, and drawing up guidance to address the issue could be of significant assistance to practitioners.

In addition, DOJ has funded curricula to be used in training various types of professionals about elder abuse, neglect, and exploitation. The TEAM Institute in Texas developed a curriculum on the Medical Management of Elder Abuse. The International Association for Forensic Nurses is working on a curriculum for forensic nurses. The Police Education Research Foundation worked with consultants to develop a curriculum for law enforcement. In addition, DOJ has made grants to produce curricula and training videos for judges and court personnel, community corrections personnel (e.g., parole officers), and law enforcement officers (among other things, providing guidance about how to investigate these types of cases), and a series of videos to train frontline professionals on issues relating to domestic violence in later life.

How does all of this relate to self-neglect? Because the several phenomena that constitute elder abuse, neglect, and exploitation are inextricably linked to elder self-neglect. To show how the phenomena are often linked, it is worth examining a hypothetical case that illustrates the point. A not-uncommon scenario might involve a young police officer being called to a house where he finds garbage and filth piled high, numerous pets, and an elderly woman unable to get up off the floor where she has been lying for days but apparently with someone bringing her food and water. Where should the police officer begin? How should he or she go about ascertaining whether the woman was responsible for her own care or whether there might be a third party with responsibility? What should the emergency department physicians and nurses do to care for the woman? What should APS do to investigate her situation and ensure her safety, especially if she is adamant about wanting to stay in her home? What type of investigation or inquiries, if any, should the police officer (or a detective) make, and under what circumstances should he present the case to a prosecutor? What factors would cause a prosecutor to open a case? And if a case is opened and presented to a court, how can the court most effectively mete out justice? At each step, the many different entities will have to address how to weigh the possibility of self-neglect, and if it is self-neglect, how to intervene most properly.

DOJ also has made grants that focus on "promising programs." One exciting aspect of working in this field is that, where there recently was a vacuum, there are now new and fascinating programs emerging. The TEAM Institute is a good example. DOJ provided a grant to develop a replication guide to help determine whether the TEAM model can be replicated in other communities. Similarly, the University of California, Irvine, has several promising programs funded by NIA, the Archstone Foundation and other funders, including the first Elder Forensic Center in the country, a Vulnerable Adult Specialist Team, and the emerging Center of Excellence. These programs all are well worth watching and studying.

CHALLENGES AND OPPORTUNITIES

It is no secret to practitioners in this field that many daunting challenges lie in the path of progress, among them death in high numbers, ageism, and medical, legal, and ethical complexities.

Death is an independent challenge, because so many people die in old age that researchers have not yet found a way to ask the right questions to identify suspicious deaths. The morbid success of such mass murderers as Dr. Harold Shipman, the English doctor who killed approximately 250 of his patients, and Charles Cullen, the nurse in Pennsylvania and New Jersey who killed approximately 37 of his patients over 15 years illustrates that deaths of older people, even unexplained ones, are rarely scrutinized and that even when they are, we rarely know what to look for. In each of these cases, had the majority of victims been children, the murderer would have been caught much sooner.

Why does this matter to self-neglect? Because there is an insidious apathy, often borne of ageism, that hinders us from ascertaining when someone is suffering or has died as the result of self-neglect rather than by other means. Few practitioners working on the front lines of medicine or law enforcement are familiar with what characteristics should raise suspicions. Because of the reluctance to ask questions about the circumstances of older people's lives and deaths and the paucity of knowledge regarding forensic markers of abuse and neglect, not only do murders go unidentified, but a much greater number of cases of abuse, neglect, exploitation, and self-neglect (regardless of death) remain invisible as well. We urgently need more research into the entire spectrum of phenomena, training for those in a position to detect problems, and more resources for intervention and prevention. Until we begin to ask questions, measure what we are finding, and learn more about what interventions and prevention mechanisms work, the field will lack critical information about the real scope of self-neglect, its tremendous human and economic cost, and how to prevent or ameliorate it.

A third factor that complicates work in this field is its complexity; the symptoms and signs of old age mask and mimic those of elder abuse. Thus, distinguishing factors that indicate wrongdoing from those that do not is often easier said than done. This complexity affects practice not only for those on the front lines, but also for researchers and policy makers.

Capacity is also a complicating issue legally and from a research perspective. Capacity is particularly relevant to self-neglect. For example, when should a family member "just leave Dad alone" as he has instructed them to do and

let him live a life of squalor and apparent low-level risk? When should people accede to an older person's wishes not to take him to see the doctor despite declining health and medical problems? And when is there an obligation to disregard the older person's stated wishes and intervene?

Those on the front lines who must make these decisions every day have dauntingly little guidance, let alone evidence-based research, to guide their work. We have unlocked more-complex mysteries of science and humanity. It is time (particularly given the looming demographic imperative) that we turn our attention to and put real resources into better understanding these ubiquitous issues.

Assessing the Cost

Among the many gaps in our knowledge is the critical absence of information regarding the cost of elder abuse, neglect (by self and others), and exploitation. Child abuse is estimated to cost more than $90 billion a year in direct and indirect costs,[13] intimate partner violence is estimated to cost approximately $6 billion a year,[14] and domestic violence (not limited to just intimate partners) is estimated to cost more than $60 *billion* a year.[14]

Gathering more information about the human and economic costs of various aspects of elder abuse should allow policy makers to make better-informed decisions about how to shape and guide policy, legislation, allocation of resources, and practice.

Data Collection

Except in the nursing home context, there are few data relating to elder abuse, neglect, and exploitation, let alone to elder self-neglect. Yet APS reports that self-neglect makes up a significant portion of its caseload. It is thus imperative that we begin to collect data about this bedeviling phenomenon and develop the necessary tools to begin collecting such data.[15]

Legislation

This brings the discussion to another form of legal intervention: a legislative intervention, or the drafting, passing, and enacting of laws. Although comprehensive federal legislation to address child abuse was enacted in 1974[15] and to address violence against women in 1994,[16] a comprehensive piece of elder abuse legislation has yet to be enacted. The Elder Justice Act (EJA), which in its initial iteration would have comprehensively addressed elder abuse, neglect, and exploitation, including self-neglect, has been introduced in four consecutive congresses but has yet to pass either house of Congress, let alone be enacted and funded.

Although the initial version of the EJA included a provision calling for data collection, the EJA's current version does not, because HHS urged Congress to instead first conduct a "feasibility study," which is what has occurred. Other provisions, still part of the EJA, with a bearing on self-neglect include measures to provide APS with much-needed resources, a centralized office, and the capacity to develop greater consistency and nationwide standards. Because so many APS cases involve self-neglect, such a provision could significantly affect self-neglect.

In addition, the EJA (and some of its prior provisions that were moved to the Older Americans Act) would strengthen elder forensics, provide for additional geriatricians, provide for additional geriatric training for nonphysician healthcare workers, and provide resources for educating families. Unfortunately, the provision calling for coordinated Centers of Excellence to develop the knowledge base is no longer in the current version of the EJA, although there is some possibility that such a provision could be revived in another format. Those are just a few of parts of the EJA with a potential bearing on addressing the complex issues related to amelioration of self-neglect.

At this writing, the EJA has yet to pass and elder abuse, neglect (of self and others), and exploitation remain largely invisible. Yet countless scores of older people and their loved ones suffer because of the problem daily. The EJA's long languishing in Congress along with many factors cited at this conference provide ample evidence of the urgent need for improved advocacy and additional research to promote and inform the efforts of policy markers, funders, and those on the front lines. There is much to be done.

ACKNOWLEDGMENTS

Conflict of Interest: MT Connolly worked for the Department of Justice at the time she gave the presentation that was the basis for this essay. She has since moved to the Woodrow Wilson International Center for Scholars. In neither position did she receive any funds for giving the speech or writing this essay.

Author Contributions: M.T. Connolly wrote her speech and paper.

Sponsor's Role: The NIH had no role in the design, methods, subject recruitment, data collections, analysis, and preparation of this article.

REFERENCES

1. Connolly MT. Where elder abuse and the justice system collide: Police power, parens patrie and twelve. J Elder Abuse Negl, in press.
2. 31 U.S.C. 3729 et. seq. See general discussion in Connolly MT. Federal law enforcement in Long Term Care. J. Health Care L & Pol'y 2002;230:15–18.
3. Medicaid facts, Medicaid and long-term care services and supports. Kaiser Commission on Medicaid and the Uninsured [on-line]. Available at http://www.kff.org/medicaid/upload/2186_05.pdf Accessed September 15, 2008.
4. Lachs MS, Williams CS, Williams S et al. Adult protective service use and nursing home placement. Gerontologist 2002;42:734–739.
5. Seema J, Flaherty JH. Elder abuse and neglect in long-term care. Clin Geriatr Med 2005;21:333–354.
6. Mattimore TJ, Wenger NS, Desbiens NA. Elder abuse and neglect in long-term care. Clin Geriatr Med 1997;45:818–824.
7. Nursing home quality: Prevalence of serious problems, while decreasing, reinforces importance of enhanced oversight. United States Government Accounting Office [on-line]. Available at: http://www.gao.gov/new.items/d03561.pdf Accessed September 15, 2008.
8. Despite increased oversight, challenges remain in ensuring high quality care and resident safety. United States Government Accounting Office [on-line]. Available at: http://www.gao.gov/new.items/d06117.pdf Accessed September 15, 2008.
9. Department of Health and Human Services, Office of the Inspector General. Trends in Nursing Home Deficiencies and Complaints [on-line]. Available at http://www.oig.hhs.gov/oei/reports/oei-02-08-00140.pdf Accessed October 9, 2008.
10. Health Care Financing Administration (HCFA). Reports to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes, 2000.
11. U.S. Centers for Medicare and Medical Services. Appropriateness of minimum nurse staffing ratios in nursing homes: Part II final report. Cambridge, MA: Abt Associates, 2001.
12. About assisted living. Assisted Living Federation of America [on-line]. Available at: http://www.alfa.org/i4a/pages/index.cfm?pageid=3285residents accessed September 15, 2008.

13. Crawford v. Washington, 541 US 36, 147 Wash.2d 424, 54 P.3d 656 [on-line]). Available at: http://www.law.cornell.edu/supct/html/02-9410.ZS.html Accessed September 15, 2008.
14. Bonnie RJ, Wallace RB., eds. Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America. Washington, DC: National Research Council of the National Academies, 2002.
15. Fromm S. Total Estimated Cost of Child Abuse and Neglect in the United States: Statistical Evidence. Chicago, IL: Child Abuse America, 2001.
16. Costs of intimate partner violence against women in the United States. Centers for Disease Control and Prevention [on-line]. Available at: http://www.cdc.gov/ncipc/pub-res/ipv_cost/index.htm. Accessed September 15, 2008.