

# Consortium for Research in Elder Self-Neglect of Texas Research: Advancing the Field for Practitioners

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An external advisory board consisting of members from the fields of geriatric internal medicine, family practice geriatrics, criminal prosecution, civil law, police force, adult protective services, and victims advocacy was created to advise and guide the research conducted by the Consortium for Research in Elder Self-neglect of Texas (CREST). This panel of experts performed site visits and facilitated the research through responses to every-other-week fact sheets and quarterly conference calls. This paper provides the perspective of five of the board members regarding the research findings that were presented at the CREST National Conference in 2006. The discussions outline the successes of the CREST research, describe obstacles and the necessary next steps for continuance of the scientific exploration of this syndrome, and highlight the practice implications of the current and proposed research. *J Am Geriatr Soc* 56:S276–S280, 2008.

**Key words:** self-neglect; elder mistreatment; Adult Protective Services; criminal justice system

A number of professionals who work with self-neglect patients or clients were selected to serve as an external advisory board for the Consortium for Research in Elder Self-Neglect of Texas (CREST). A National Institutes of Health (NIH) Roadmap Initiative grant funded CREST to establish a case definition for self-neglect, to describe its phenotypes, and to develop and test models to explain the relationships between physical, cognitive, and socioeconomic factors in community living elderly people reported to Adult Protective Services (APS) for self-neglect. The pur-

pose of this board (Table 1) is to ensure that the research performed and the interventions that will result meet the needs of self-neglecters. Each member has worked in the field of elder mistreatment for many years and has consulted for entities such as the U.S. Senate, the National Academy of Sciences, the Department of Justice, the Federal Bureau of Investigation, and the Department of Health and Human Services.

The purpose of the External Advisory Board was to ensure that the interdisciplinary CREST approach would lead to real-world solutions to the public health problem of elder self-neglect. Below, five of the external advisory board members describe their views of the current state and potential utility of the research findings.

## MEDICAL PERSPECTIVE

Many of the research findings presented at the conference can be readily applied to practice. These preliminary results demonstrated a multiphenotypic manifestation of self-neglect; nutritional deficiencies, including vitamin D and homocysteine; impairments in the ability to perform instrumental activities of daily living; and the feasibility and interrater agreement of a self-neglect screening tool. All of these findings provide insight into the self-neglect syndrome. Encouragingly, once fully developed, the potential exists for the Self-neglect Severity Scale (SSS) to adequately identify caseness. The SSS can be completed in less than 10 minutes and contains three components. Section A assesses personal appearance and hygiene. Section B assesses functional status and its effect on health and safety. Section C assesses the environment, both the exterior and interior conditions of the individual's home. Items in Sections A and C are ranked from 0 to 4 and range from normal to severe self-neglect with higher rankings. Associated color pictures are placed above the rankings of 0 and 4 to aid the administrator in determining the level of neglect, if any.<sup>1</sup> The SSS is currently undergoing tool development and therefore cannot be published.

A critical problem with self-neglect and the various forms of elder mistreatment is the underrecognition of cases. Further refining the scale into a concise tool that can be used in the field could provide a common definition and

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**Table 1. Members of the Consortium for Research in Elder Self-Neglect of Texas (CREST) External Advisory Board**

CREST Advisory Board	Expertise
Mark Lachs, MD	Geriatrics, Internal Medicine
Laura Mosqueda, MD	Geriatrics, Family Practice
Candace Heisler, JD	Prosecution
Randy Thomas, MA	Law Enforcement
Lori Steigel, JD	Civil Law
Joanne Otto, MSW	Victims' Advocacy, Social Work
Bonnie Brandl, MSW	Protective Service, Social Work

language and effectively decrease the number of missed cases.

The CREST study will have to address an issue that clinical investigators in the field of geriatric medicine commonly face: the determination of whether self-neglect is a symptom, a diagnosis, or a full-blown geriatric syndrome. The model indicates that self-neglect is a syndrome.<sup>2</sup> The longitudinal cohort study planned by the CREST researchers should be able to address this question and further define predictors of poor outcomes in these unfortunate elderly people.

CREST researchers and others need to inform the public about the deplorable conditions in which these seniors live. The findings from the SSS must be translated into a language that nonclinicians can understand. As a geriatrician who makes house calls, I have seen elders living in inhumane circumstances. These findings must generate public outrage. Putting a face on self-neglect will stimulate more research in this area and hopefully result in policy changes that will markedly improve the quality of life of these seniors.

### Application for Front-Line Workers

Front-line workers such as victim advocates and police officers will benefit from a standardized screening tool. It should be possible for case aides from APS or court investigators with various levels of education to use the tool, especially because these individuals could be instrumental in the detection of neglect in the field or through their interactions with seniors in their homes.

The SSS is a tool that relies largely on subjective observations made by a trained rater and focuses on evaluating the client's personal hygiene, functional abilities, and the status of the home's physical environment. Although this approach is necessary for some cognitively impaired individuals, many seniors could respond verbally, and with accuracy, to an instrument that uses focused or even open-ended queries. The research team should give consideration to adding some questions that require a subjective evaluation by the clients. This addition will help implementation of interventions that incorporate older individuals' preferences, within the bounds of safety and reason.

The preliminary findings presented at the conference have been exciting. Dissemination to a wider audience outside the field of medicine would benefit from the data and

the accompanying interpretation. Perhaps some of the findings can be published in social service–based journals, some of which are available on Medline. Well-placed monographs and other articles on the World Wide Web will help inform persons in related fields of elder self-neglect and its associated factors. In addition, disseminating this information may help to accomplish the NIH Roadmap goals of bringing new researchers to the field. Strategic planning for the dissemination of the research will help to achieve this goal.

### Protective Service Perspective

Work on self-neglect is critical to the work of protective service agencies in the country. Programs like the Texas Elder Abuse and Mistreatment Institute (TEAM), the University of California at Irvine's Vulnerable Adult Specialist Team (VAST), and other medical–APS collaborations have confirmed that self-neglect is the most prevalent and challenging form of reported mistreatment that workers must address. In complicated cases in which the most-egregious manifestations of self-neglect are encountered, the addition of specialized teams such as TEAM and VAST to usual APS care have helped guide and facilitate the treatment plans and interventions to remediate the self-neglecting behavior. Despite the 10-year collaboration between medical groups and APS, there have not been outcome studies needed to evaluate these teams.

As CREST researchers and others study self-neglect and consider interventions, these professionals will find that human contact will be the key to success with this population of seniors. This is a population that does not readily accept and even fears intervention or interference from the medical profession. Although telehealth and other electronic means will be helpful, personal rapport with medical providers, APS workers, and others will lead to more successful outcomes.

Further work on the definition of self-neglect is paramount. Health professionals, members of the justice system, and others are truly unaware of the severity of the self-neglect that APS and TEAM members see. Video representation, case histories,<sup>3</sup> and case series are still needed to assist other clinicians and researchers in understanding self-neglect.

### THE EFFECT OF CAPACITY STUDIES ON CIVIL LAW PROCEEDINGS

The CREST research, particularly in the areas of decision-making capacity and executive dysfunction, has the potential to significantly affect four complex areas of civil law:

- (1) The appointment of surrogate decision-makers by individuals and by the court system. New, improved tools for assessing decision-making capacity and a better understanding of the relationship between executive dysfunction and capacity may enable individuals to do a better job of proactively planning for the possibility of decision-making incapacity through the execution of legal tools such as durable powers of attorney or trusts. Lawyers and judges who handle guardianship and conservatorship cases are even more likely to benefit from the CREST research findings. Enhanced knowl-

edge about decision-making capacity and executive dysfunction could affect matters such as whether a court should determine (a) that an individual lacks capacity and appoint a surrogate decision maker, (b) whether the authority of the surrogate should be plenary (full) or limited, (c) the level of monitoring of the court-appointed guardian or conservator, and (d) whether an individual has regained some or all capacity and the court should reduce or terminate the authority of the surrogate.

- (2) Civil (as well as criminal) cases related to financial exploitation and other matters in which capacity to make a financial transaction is at issue. These areas include probate of wills and cases in which fraud, misrepresentation, or undue influence is alleged.
- (3) End-of-life care cases in which the capacity of an individual to consent to, reject, or terminate medical treatment, nutrition, or hydration is questioned.
- (4) Deciding housing matters, such as landlord-tenant relationships, code enforcement, nuisance cases, and animal control cases, is dependent upon understanding self-neglect. The rights of an individual who may lack decision-making capacity or lack the functional capacity to care for self and property must be considered along with the rights of cohabitants, neighbors, property owners, and the general public.

During the course of this much-needed work, CREST researchers will face three key challenges in relation to the civil justice system:

- (1) Although the preliminary hypotheses about the relationship between self-neglect and decision-making incapacity and executive dysfunction seem logical and may well prove valid, the CREST researchers should act proactively and reactively to ensure that others do not misinterpret or misuse their work to equate self-neglect with incapacity.
- (2) The dearth of information and lack of appropriate tools for assessing or screening decision-making capacity and executive dysfunction is challenging for professionals in the civil justice system and related fields, including APS. This difficulty may result in inadvertent or unintentional misinterpretation or misapplication of information by these professionals. CREST researchers need to recognize that such misinterpretation, misapplication, or misuse may occur and take the appropriate proactive and reactive steps to ensure that these problems do not occur or are at least minimized.
- (3) CREST researchers will need to collaborate with practitioners to translate the research findings for use by civil lawyers and judges. Physicians deem incapacity (or incompetency, which is an outmoded term) be a legal determination, but lawyers depend, at least in part, on medical evidence to demonstrate incapacity. Judges, whose role is to apply the law to the facts, depend on the evidence compiled by lawyers or litigants who represent themselves.

The development of assessment and screening tools and the correct use of new information will benefit older individuals whose questionable capacity or self-neglecting

behaviors have brought them to the attention of civil lawyers and judges.

### Helping Law Enforcement to Identify Cases of Self-Neglect

Although medical personnel and protective service workers are key in identifying cases of self-neglect, the case is often severe by the time the person is reported to APS or admitted to the hospital. In many instances, the situation is identified when it is already too late. A whole host of first responders may be better positioned to detect cases early. These responders include police officers, animal control officers, emergency medical personnel, and mailmen. Although self-neglect is not criminal conduct, it should be recognized that law enforcement is often the only public service agency with 24-hour response capability. However, self-neglect may be the product of earlier or ongoing abuse or exploitation. If so, this becomes a possible criminal incident requiring an appropriate response from law enforcement.

The data presented at the CREST national conference and the proposed tool development and validation will be helpful to police officers and other law enforcement personnel. Few places are like Houston and Orange County, where medical teams are available to assess capacity or evaluate the homes of those who self-neglect. Rural communities with limited law enforcement personnel have even less access to medical professionals. These law enforcement personnel would benefit greatly from tools to help them identify cases, fashion appropriate interventions, and even lead to prevention in their locales.

The SSS is too cumbersome for use by many front-line workers. The training requirement is also limiting. A simple tool that can be administered quickly and that can be placed on a 3" × 5" card would be ideal. The concept of environmental assessment that TEAM and CREST introduced is vital for the identification of self-neglect cases. Because self-neglect affects elderly people from every ethnic and socioeconomic group, a tool that is as objective as possible would help all who come in contact with these self-neglecting elderly people.

### The Effect of Self-Neglect Data on Criminal Prosecution

Generally, self-neglect is not criminal conduct. As a result, prosecutors rarely see these cases. Rare exceptions arise when a person's living situation becomes a public nuisance; a gang or individuals takes over their living space and uses it for criminal acts; or when animals are mistreated through hoarding, starvation, dehydration, and inattention to their medical or health needs. Because the actions of self-neglecters are so difficult to understand, prosecutors and other members of the criminal justice system have often assumed that self-neglecters are mentally ill or demented and therefore not criminally responsible for their actions. Because most self-neglect is not criminal conduct, prosecutors traditionally have referred cases to local programs for social services and protective services interventions.

New unpublished data from CREST now shows that approximately 29% of self-neglecters do not screen positive for dementia or depression. In states where APS programs serve only persons with significant disabilities, prosecutors

need to reconsider whether APS referral is appropriate and useful.

Over the last decade, the traditional role of the prosecutor as the courtroom attorney has evolved to that of the “community prosecutor.” Although prosecutors will always handle court cases, community prosecution focuses on problem solving and prevention. The prosecutor works in partnership with appropriate professionals and community members to identify and remedy problems. These community prosecutors may address problems such as public nuisances caused by gang and narcotics activity and derelict homes occupied by self-neglecters and infested with pests, in advanced decay, or posing public health and safety hazards. Typically, prosecutors have worked with code enforcement, the fire department, city attorneys, county counsels, the health department, the humane society, and law enforcement officials in attempts to obtain compliance with local ordinances and state laws and to enforce voluntary cleanup and repair of unsafe and unsanitary homes. When voluntary efforts have failed, citations have been issued, and civil actions have been threatened and occasionally pursued. In some instances, arrest and prosecution for maintaining public nuisances or for animal mistreatment have been required. Inevitably, courts have ordered that the premises be cleaned and improved only to find that the problems begin again after only a short time. Resolution of such cases has been extremely difficult and frustrating.

The new data give insight into the reasons self-neglecters may be resistant to remedial efforts. Self-neglecters may be unaware of their living situations and unable to extricate themselves. These elderly people may be unable to develop and implement remedial plans. If the preliminary data are further confirmed, then relying on the self-neglector to resolve such situations is unrealistic and unproductive. The traditional approaches used to resolve nuisances for the short and long term will need to be reexamined. Innovative responses led by a professional who is able to gain the trust and cooperation of the self-neglector should be considered from the initial contact with the person. The use of protective and legal interventions, including some that are involuntary, may be necessary to protect the self-neglector and the community and to address the broader problem.

These data also suggest that community responses may benefit from expansion to include a broader interdisciplinary team of protective services workers, clinicians, aging services, systems-based advocates, and social workers. These new team members will assist by fully assessing the self-neglector and providing additional professionals who may be better able to develop a personal relationship with the person. CREST data indicated that many self-neglecters will cooperate when approached consistently by medical personnel perceived as helping professionals. Thus, this approach is promising for resolving such problems.

Assessment may also identify self-neglecters who have vitamin and micronutritional deficiencies. With relatively simple treatment, these self-neglecters may be better able to appreciate the need to maintain a safe and wholesome residence and to attend to personal and medical care needs. The treatments may improve their executive functioning, which, in turn, will allow them to develop and execute remedial plans. With improved health, some self-neglecting

elderly people who were crime victims may recover memory and be better able to describe their victimization.

Data strongly suggest that a new understanding of capacity for self-neglecters is needed. Current assessments of verbal skills and comprehension may be inadequate to test executive functioning. Instead, tools that test the ability to develop and execute a plan and perform activities of daily living may be used. Prosecutors have relied on professionals to address issues of capacity, including the ability to consent, understand legal transactions and documents, make gifts, and resist undue influence. Assessment has been heavily focused on verbal skills rather than executive functioning. The new data may require reconsideration of how capacity should be evaluated. Current legal standards and tests may need to be changed. The new data should also lead to consideration of the minimum qualifications for persons administering assessments. Furthermore, training of attorneys, protective service workers, other social workers, and law enforcement professionals who currently may request or administer capacity assessments in a variety of contexts should be updated.

The new data may have long-term consequences for the criminal justice system in another area. The self-neglect behavior that CREST studied began at an unknown point in time. The earlier arrest records of these subjects may provide important information. Was their conduct serious enough to require court or correctional supervision? How did these persons perform while on probation or parole? Were they able to follow through with counseling, treatment, or other orders that required planning and execution of a plan? If not, could their self-neglect and deficits of executive functioning explain this inability? Currently, few courts and probation authorities assess self-neglect in younger offenders. If this idea proves valid, a different kind of assessment and approach to sentencing terms and monitoring may be required for certain offenders.

In addition, prior data indicated that 28% of referred self-neglecters had also been victims of elder mistreatment at the hands of a perpetrator. Whether these elderly people were crime victims before or after the self-neglect began remains unknown. Did their living and personal situation, including social isolation, make them “attractive targets” for abusers? Was the self-neglect an outcome of the victimization? In either case, the self-neglecting behavior may have hidden the crimes committed against them. Prosecutors, like law enforcement professionals, need to determine whether an elderly person who self-neglects is also a crime victim.

## CONCLUSION

Since the inception of CREST, investigators have approached the problem of self-neglect from the perspective that all outcomes generated by their work should be applicable to real-life experiences of patients suffering from this condition. CREST investigators believed that a group of national experts from fields relevant to elder self-neglect would be best to guide and oversee the project. The interdisciplinary External Advisory Board reviews the work of the Consortium to ensure that pertinent problems in the field remain the focus. The Board members have broadly disseminated the findings to a variety of professions

involved with the self-neglecting population. Furthermore, this dissemination of data allows the refinement of other systems' approaches to self-neglect. The External Advisory Board will continue to serve in this capacity in the future endeavors of CREST.

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