TESTIMONY OF

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Good morning. I am Constantine Lyketsos, Professor of Psychiatry and Behavioral Sciences and Co-Director, Division of Geriatric Psychiatry and Neuropsychiatry, at the Johns Hopkins University and Hospital. I also serve as the Academic Director of The Copper Ridge Institute and chair the Medical and Scientific Advisory Board of the Maryland Chapter of the Alzheimer's Association.

Let me begin by thanking the Senate Committee on Aging for holding this very important hearing and for inviting me to testify. I am thankful that the Senate continues to rise to the occasion in our ongoing fight to conquer Alzheimer's disease. I am delighted to be here with my friends from the Alzheimer's Association and want to acknowledge their staunch advocacy on behalf of people with Alzheimer's disease and their families. I also want to acknowledge the central role of the NIH, esp. the National Institute on Aging (NIA), the National Institute of Mental Health (NIMH), and the National Institute of Neurological Disorders and Stroke (NINDS) in our effort to find the answers to Alzheimer's disease.

I speak to you today as a research scientist, as a physician who has cared for thousands of patients with Alzheimer's disease and their families, but also as the husband of a woman whose grandmother suffered greatly before dying from this horrible illness. Alzheimer's has touched me personally, as it has so many here in this room today.

The topic that brings us here today has to do with a very common but inadequately recognized aspect of Alzheimer's disease and related dementias: the psychiatric and other behavioral features of the disease, including verbal or physical aggression, and violence. The public usually thinks of Alzheimer's disease as a condition that affects memory. Since this is such a widespread disease of the brain, it should be no surprise that upwards of 90% of people with dementia develop one or more of these psychiatric and related behavioral features over the typical decade-long clinical course of the disease. Professor Cohen and the others testifying before you today have very eloquently brought to life through examples the sorts of issues that we are talking about.

My testimony will focus on the following questions: (1) How common are the psychiatric and behavioral symptoms of dementia and what is their cause? (2) How do we treat them, and how good are our treatments? (3) How does our health system fall short in treating these aspects of the disease? (4) What research is needed to improve treatments? (5) What are some of the community responses to this issue? As you can imaging large volumes have been written on each of these questions, but I will be brief and hit the main points.

1. How common are the psychiatric and behavioral symptoms of dementia and what is their cause?

Our work from two population-based studies, coupled with that of many others, has found that over the course dementia over 90% of patients develop one or more psychiatric and related behavioral features. Among the most troubling to patients and caregivers are depression, delusions, hallucinations, and otherwise unexplained agitation. Physical violence is not uncommon, being exhibited by about 15-18% of patients per year. When you multiply this by the number of people with dementia alive today, you will appreciate how big the numbers are. The vast majority of such violence occurs against caregivers, both at home and in assisted living or nursing facilities, is short lived and does not result in significant injury. In fact, most of the time we never hear about it, sometimes because the caregivers feel embarrassed or ashamed to report it, or may blame themselves. Occasionally, violence gets out of hand and we hear about cases like the ones presented today. In my experience, typically violence gets out of hand when treatments are ineffectively applied, although we should be clear that even the most effective treatments cannot prevent all cases of violence.

What is the cause of these symptoms and of violence in particular? The primary cause is the brain damage brought about by Alzheimer's disease. The disease, as it spreads in the brain, damages centers that regulate mood, perceptions, or the patient's ability to control his impulses. As a result, we see moodiness, depression, irritability, delusions, hallucinations, and loss of inhibitory control.

With regard to violence specifically, as with any behavior, it is affected by many factors, sometimes many contributing at once. The best way to think of this is that both patient and environmental factors play a role. With regard to patient factors, the brain damage brings loss of inhibitory control that may limit the patients' ability to stop themselves once provoked. Specific symptoms such as depression, delusions, and hallucinations may drive patients to respond or act in aggressive ways to provocations that to others are rather minor. Many times depression, delusions, and hallucinations are the primary cause of big outbursts, such as the ones we heard about today. The cognitive loss may make patients less able to "read" what is going on around them. Men are more likely to be violent than women. When patients get sick, such as with colds or bladder infections, they are more likely to act out.

With regard to environmental factors, lack of structure, boredom, change in routine, even changes in room temperature may serve to provoke violence. In some cases, caregivers who are not sophisticated may rush patients too much during care, or may respond inappropriately to the symptoms patients are exhibiting resulting in physical aggression from the patient who is unable to communicate her needs well. Some caregivers do not quite know how to deal with delusional ideas or suspicions and may feed in to them making matters worse. Caregivers who are tired and overwhelmed may lose their patience and become angry leading to fear and agitation in the patient.

2. How do we treat behavioral symptoms, and how good are our treatments?

Current treatments consist of prevention, removal of causes and provocations, psychiatric hospitalization, and/or use of certain medications. The use of these is articulated in great detail in our book <u>Practical Dementia Care</u> (Oxford University Press, 1999). Prevention focuses on putting in place good "Dementia Care" practices for all patients, such as:

- meticulous medical care
- removal of unnecessary medications
- implementation of a structured day to day schedule, sometime adult day care
- early detection of psychiatric symptoms
- de-escalation of agitation in its early phases

- caregiver education
- caregiver skill instruction
- and many other activities.

Medications have been shown in some cases to reduce delusions, hallucinations, depression, or non-specific agitation. Medications can carry significant risks especially in frail older people.

Overall, our treatments in the hands of seasoned clinicians are successful in reducing or eliminating psychiatric and other behavioral symptoms to a manageable level well over 80% of the time. However, in many cases success is not complete and patients and caregivers are troubled for years with these symptoms. Little scientific is known about how well treatments available today are able to prevent violence, even though common sense would tell us that they do. These treatments have been shown to delay nursing home placement that is often driven by behavioral issues. Much more needs to be learned about how to treat the psychiatric and behavioral symptoms of dementia. Despite this, these are some of the most treatable symptoms of Alzheimer's disease.

3. How does our health system fall short in treating these aspects of the disease?

The health and long-term care systems falls short in several ways. Detection rates for ***dementia itself*** in primary care, assisted living homes, and nursing homes remains unacceptably low. Only about 30% of people with dementia are given this diagnosis by their primary care doctor, only about half to two-thirds in long-term care. Detection rates for behavioral problems before they escalate and get out of hand, such as in the recent Florida case, are probably much lower. This is a major missed opportunity on the part of our healthcare system to intervene early to prevent severe behavior problems among Alzheimer sufferers.

While the know-how for preventing and managing these symptoms is rather good, this knowledge has not been transferred to the vast majority of care settings. Most primary care doctors have very little background or training on how to treat these symptoms. The same is true for staffs at nursing and assisted living homes that are confronted with these symptoms many times a day. Part of the problem is that the costs associated with treating these symptoms are high, and Medicare fee and reimbursement structures are not conducive to clinicians getting paid for managing theses symptoms. Doctors working in this area—such as those on my team—and their staff, often nurses or social workers, may spend many hours a day on a single patient and only get paid for part of that. The fees paid by Medicare are so low that our ablest doctors are not interested in learning how to care for these symptoms. Alternative treatment models, using telemedicine, and physician extenders would probably be very successful but are currently either not reimbursable or reimbursement is very cumbersome.

A third problem has to do with the setting in which patients with the more severe forms of these symptoms are to be treated. Nursing and assisted living homes are unable to care for the more serious case for many reasons. We could do better on this by raising the level of expertise of assisted living and nursing home staff in managing these symptoms. Hospitals are usually not well equipped with specialty units and end up managing these patients on typical medical surgical wards or emergency departments often through restraint or sedation. Staffs here usually do not know what to do or how to approach and manage the symptoms. Specialty units are slowly springing up around the country but are faced with reimbursement pressures due to the long lengths of stay and complexities of caring for some of these very ill Alzheimer’s patients. On our specialty unit at Johns Hopkins, length of stay is on the order of 18-20 days, and it is not unusual for some patients to end up staying with us for several months until their violent behaviors get better after complicated treatment efforts.

4. What research is needed to improve treatments?

Research is an essential part of the battle to conquer Alzheimer's. The ultimate goal must be to find treatments that will cure, prevent, or delay this illness. At the same time, we must focus our energies on research to ***improve the care*** of the 4.5 million people with Alzheimer’s currently alive in the United States, and of their caregivers, who are just as affected by the disease. It is critical that we as a nation dedicate adequate resources to this effort.

We at Johns Hopkins are proud to be at the forefront of both research and care of Alzheimer's and related disorders. Our memory disorders clinical program, one of the first ever established in the United States, spanning the several Johns Hopkins Medical Institutions and our affiliated long-term care facility, Copper Ridge, provides diagnostic evaluations and ongoing care "from diagnosis to the end of life" for thousands of patients with Alzheimer's every year. As well, much of the Alzheimer’s related research going on at Johns Hopkins exemplifies the sort of work that is going on around the country.

We are here today to discuss the research needs for the future. In the interest of time I will only make a few remarks about treatment research.

We must substantially and immediately increase research into the treatments of Alzheimer's disease. The most exciting possibility comes from recent knowledge of the pre-clinical phase of Alzheimer's disease. It turns out that the disease is damaging the brain for many years before the onset of any symptoms. This offers an opportunity to intervene and stop or slow it before symptoms occur. That is the key to preventing Alzheimer’s. One estimate indicates that if the disease could be delayed by five years, the number of people suffering from the disease would be reduced by half. To this end the National Institute of Aging has initiated prevention studies to find out whether certain medications can prevent the onset of Alzheimer's symptoms and other Institutes are now joining NIA in that effort.

At Johns Hopkins we are proud to have a leadership role in such prevention studies. By way of example, I mention the Alzheimer's Disease Anti-inflammatory Prevention Trial or ADAPT in which I have a leadership role. ADAPT is designed to find out whether healthy people 70 and older without memory symptoms are less likely to develop the disease if treated with non-steroidal anti-inflammatory medications. This study has already enrolled 2200 people at six sites nation-wide, about 400 here in the Baltimore-Washington area. We eventually plan to enroll a total of about 4,000 participants over the next few years. These sorts of studies are very expensive, costing tens of millions, but they are the only way we will find safe and effective ways to stop Alzheimer’s. Each study takes several years and involves scores of clinicians and thousands of participants. The most promising studies involve healthy seniors who must be enrolled in sufficient numbers over long enough periods of time. These studies also require substantial investment in outreach efforts to recruit and retain enough study participants, including those from the diverse ethnic and cultural backgrounds affected by Alzheimer's disease.

We must also pay special attention to understanding better the causes and treatments of the behavioral symptoms of Alzheimer's. Both medication and non-medication treatments and their combinations must be studied. Similarly we must study treatment benefits on a wide range of outcomes, including quality of life, and functional decline. For example, we are conducting a study of treating depression in Alzheimer's Disease (DIADS-2) with support from NIMH where we are looking to see not only if depression can be treated but also if treatment can benefit caregivers, patient quality of life, and possibly delay the functional decline of Alzheimer's. Many more studies of this sort are needed. I want to emphasize that we must not limit ourselves to medication treatments since a variety of other interventions greatly benefit patients. With our affiliate, the Copper Ridge Institute, we are investigating the benefits of several non-medication treatments for Alzheimer's patients and their caregivers. Increased funding in this area, thus far primarily supported by the Alzheimer's Association, will also be necessary. I encourage the NIH to place special emphasis on developing better treatments in the area of psychiatric and behavioral symptoms of Alzheimer's.

Finally, we need to be sure that we can deliver treatments where they are needed. I specifically want to mention the primary care and long-term care environments. Most people with Alzheimer's disease are seen in primary care in the early stages of the disease. This is a great opportunity to detect and intervene early with behavioral symptoms. We must educate primary care doctors in detection and treatment of these symptoms, and make available to them methods of implementing the necessary care regimens. We must also create the necessary incentives for doctors to do this without losing money.

Currently, millions of people with Alzheimer's disease live in residential care facilities. We have known for many years that a very large portion of the nursing home population has Alzheimer's or another dementia. We are only now finding this out about assisted living. In our Maryland Assisted Living Study (funded by the National Institute of Mental Health), our findings indicate that as many as 75% of residents suffer from memory disorders and that the detection and treatment of these disorders in that environment is sorely lacking. It is critical that we understand better the presence and course of Alzheimer's in assisted living, and that we deliver the most effective available treatments to these patients as well.

With my deep appreciation for your invitation for me to speak at this hearing, I would like to strongly emphasize that Alzheimer's is a disease that affects us all at a personal, an economic, and a societal level. Research is the key that will allow us as a society to manage this scourge. Redoubling research efforts in the laboratory, looking for risk factors and protective factors, improving diagnosis, understanding of the course of the disease, and developing a wide range of preventive and other treatments, with a special emphasis on drug discovery, and improving care for psychiatric and behavioral symptoms must be our mission for the future.

5. What are some of the community responses to this issue?

Through its nation-wide chapter network, the Alzheimer's Association is engaged in a wide range of efforts to develop community responses to these complex issues.

- Its national Safe Return program, supported with funds from the U.S. Department of Justice, links communities across the country to a single emergency alert network. Designed specifically to locate and return people with Alzheimer's who get lost, the program has had a much wider impact as it has trained law enforcement and emergency personnel to recognize and understand the signs and symptoms of Alzheimer's disease.

- In at least a dozen states – from Massachusetts, to Texas, Kansas, and California -- the Alzheimer's Association has worked with Attorneys General and state and municipal police departments to integrate dementia training into curricula at state police academies and in regular police roll calls.

- In Wisconsin, when mandatory arrest in domestic abuse cases became state policy, the Association enlisted community service providers, adult protective services, local law enforcement agencies and the Governor to develop a community response to cases involving persons with dementia. As a result, all police officers in the state now receive mandatory dementia training. And, nursing homes and community based residential facilities have been recruited to provide temporary placement, as an alternative to jail, when a violent person with dementia needs to be removed from the home.

- In Indiana, as a result of a highly publicized incident of deadly assault by one nursing home resident against another, the Association convened a broad-based working group of long term care providers, state law enforcement and mental health agencies, consumers and others to address the issue of aggressive behavior within nursing homes. The group identified the real scope of the problem, identified underlying reasons, and made specific recommendations to improve the ability of facilities to deal with difficult residents and for a high quality alternative care facility for the small number of cases that could not be managed in regular facilities. A copy of the Executive Summary of this important study is attached to my statement.

- The Alzheimer's Association continues to educate law enforcement and judicial personnel about dementia, through presentations at their national meetings and publications like the recent article that appeared in a national journal widely read by state and local judges (which is also attached to my testimony.)

Conclusion

Ultimately, management of a person with Alzheimer's disease who is at risk of violent behavior will depend upon very direct response from physicians, from law enforcement personnel, from long term care providers, and from community agencies. But Congress and the federal government have a lot to say about making those responses possible. In that regard, I have some very specific recommendations to make to you:

- Provide adequate funding for the essential research on understanding, managing and treating behavioral issues in persons with dementia – research that will be jeopardized unless you agree to add funds beyond the President's budget for Alzheimer research at the NIH.

- Continue funds to the Department of Justice to support Safe Return.

- Maintain funds, and the quality requirements attached to those funds, for state Medicaid long term care programs.

- And, perhaps most important, change Medicare policy to provide payment not just for evaluation and diagnosis but for ongoing management and care coordination for beneficiaries who have Alzheimer's disease and other chronic health conditions that require such medical care.