LTCCC LONG TERM CARE COMMUNITY COALITION
Working to improve long term care through research, education & advocacy

United States Senate

Special Committee on Aging

Overprescribed: The Human and Taxpayers' Costs of Antipsychotics in Nursing Homes

November 30, 2011

Statement by the Long-Term Care Community Coalition

Introduction

The Long Term Care Community Coalition (LTCCC) is a New York State based non-profit organization dedicated to improving care for the elderly and disabled and ensuring that long-term care consumers in all settings are cared for safely and treated with dignity. To those ends, LTCCC researches national and state policies, laws and regulations affecting care for the elderly and disabled; advocates for policies to improve care; addresses systemic problems in the delivery of long term care; identifies good practices and develops recommendations to improve care and dignity of the elderly and disabled, and better conditions for professional caregivers; and educates and facilitates the advocacy of the elderly and disabled.

We commend the Special Committee on Aging for putting the spotlight today on this serious and pernicious issue. Inappropriate drugging of nursing home residents is a silent epidemic in our nation's nursing homes. Every day, approximately one out of four nursing home residents is given powerful antipsychotic drugs, despite the FDA's black box warning that they are dangerous and contraindicated for the elderly and people with dementia. In addition to being physically dangerous, antipsychotic drugs have enormous emotional and intellectual consequences for the elderly; in short, they render residents sedated and stupefied. While reliance on inhumane physical restraints to control nursing home residents has decreased markedly over the years, the increasingly widespread use of antipsychotics signifies an equally abhorrent, yet more insidious, reliance on chemical restraints to subdue and control residents without regard for their needs, underlying conditions or basic humanity.

We strongly support the written and oral testimony and recommendations of Toby Edelman, senior policy attorney of the Center for Medicare Advocacy, the testimony of Dr. Jonathan Evans, president-elect of the American Medical Directors Association, and the findings and recommendations in the two resolutions adopted this month by members of the National Consumer Voice for Quality Long-Term Care that address this critical issue. In addition, we would like to submit the following comments for the Committee's consideration.

I. Federal Law and Standards Provide Strong Protections Against Unnecessary Drugging

The federal Nursing Home Reform Law[1], promulgated almost 25 years ago, and implementing regulations set forth strong standards for care of nursing home residents. Under the law, each resident must be provided the care he or she needs, as an individual, to attain and maintain his or her highest practicable physical, emotional and psychosocial well being. As well noted in other testimony and statements to the Committee for this hearing, the law includes explicit safeguards to prevent the widespread inappropriate use of antipsychotics on nursing home residents.

Importantly, in recent years federal law and standards have made substantial and substantive advances in fighting resident abuse and recognizing the right to individualized care and decent quality of life for all residents (including individuals with dementia). For instance, in 2009, CMS issued guidance to the state survey agencies on resident dignity and autonomy.[2] This guidance does not promulgate new standards but, rather, was meant to improve enforcement of the longstanding requirements pertaining to specific indicia of resident self-direction, choice and self-determination. The goal of the new Quality Indicator Survey, now undergoing implementation across the country, is "to improve the consistency and accuracy of care and quality of life problem identification for LTC residents."[3] The 2010 Affordable Care Act includes a number of important provisions aimed at reducing elder abuse and, specifically, improving care, quality of life and accountability in our nation's nursing homes. These include provisions to increase adoption of nursing home culture change (the movement to provide care that is resident centered and resident directed in a home-like environment), to improve identification and reporting of suspected crimes and abuse against nursing home residents and to expand the ways in which Civil Money Penalties are used to improve resident care and quality of life beyond regulatory minimums.

Underlying this movement to a large degree, at least intellectually, is the U.S. Supreme Court's ruling in *Olmstead,*[4] in which the Court held that disabled individuals, including those with mental disabilities, have the right to receive care in the least restrictive setting possible for them as individuals. While that case has been most influential in the movement to access long term care outside of nursing homes, it is hard to imagine any situation more restrictive (or

[1] Omnibus Budget Reconciliation Act of 1987, Pub.L. 100-203, 101 Stat. 1330.
[2] CMS Manual System, Pub. 100-07 State Operations Provider Certification, Transmittal 48 (June 12, 2009).
[3] Klusch, L., "Are You Ready for the New Survey: The QIS (Quality Indicator Survey) is coming—and now is a good time to start gearing up," *Long-Term Care Living* (December 2008).
[4] *Olmstead v. L.C.*, 527 U.S. 581 (1999).

emblematic of the horrors of institutionalization) than being chemically restrained with powerful antipsychotics, as thousands of Americans in nursing homes are every day.

As progress made over the years in the law and our understanding of (and perceptions about) aging and disability indicates, it is now incontrovertible that everyone, no matter their age and/or frailty, retains the right to be cared for as an individual and to receive services that meets their needs and helps them to maintain their health and functioning in a humane setting.

II. Widespread Antipsychotic Drug Use: A Significant Systemic Failure With Catastrophic Personal Consequences

Unfortunately, the ordinary experience of nursing home residents in this country often runs counter to our present-day understanding of human dignity and fundamental rights. Perhaps nowhere is this more evident than in the situation with antipsychotic drugs. As noted above and in other statements and testimony made to the Committee today, an astounding number of nursing home residents are given antipsychotic drugs every day, despite the black box warning that they are extremely dangerous (potentially life-threatening!) for the elderly, despite the studies indicating that they are largely ineffective as a treatment and despite the fact that they are outrageously expensive, both in terms of human life and suffering for residents and families and financially, for the American public as a whole.

What does this systemic failure mean for elderly nursing home residents and their families? Following are a few cases that came in to our local hotline:

1. A caller's father is living with dementia in a nursing home. The nursing home informed the family that his father was annoying other residents because he screams at night. Therefore the nursing home wanted to give his father Seroquel. The family has initially agreed but has seen their father become lethargic and more disoriented. The nursing home now wished to increase the Seroquel dosage but the family is considering refusing. The family feels the nursing home has intimated that they will ask the resident to leave the facility if the family refuses more Seroquel.
2. A caller's mother entered nursing home and was given Haldol and Depakote. The caller noted a marked decrease in her mother's ability to communicate, eat and ambulate. The nursing home recognized the caller as the health care proxy but allegedly told her that she could not make decisions about medication because she was not a doctor. Therefore she could not ask for discontinuation of the Haldol and Depakote. The caller had her lawyer write a letter to the nursing home stating they must recognize a health care agent's right to refuse medication for an incapacitated loved one. The physician's assistant stopped the medication but the nursing home medical director reinstated the order to give Haldol and Depakote. The caller then filed a complaint with the Department of Health which was unsubstantiated. Subsequently, the DOH entered the nursing home for yearly inspection and as per DOH advice caller is not trying to reopen the complaint.

3. A caller placed his friend in a nursing home which touted its person centered care. However, the nursing home not only fed the friend breakfast while making her sit in her soiled night briefs, but also forced the resident to bathe when she did not want to bathe. As a result the resident became agitated and kicked her legs at staff. The nursing home subsequently medicated her with Haldol. The friend, who is the health care proxy noted a marked decline in the resident's condition following Haldol and asked that the medication be discontinued. The nursing home complied. After 6-8 weeks the facility stated they would have to reinstate Haldol because the resident continued to be agitated. No behavioral redirection or person centered care was offered, according to caller. Caller told facility he did not want Haldol restarted and the facility allegedly responded, "Then we will have to send your friend to the psych hospital."

III. Recommendations and Conclusion

As noted above, LTCCC strongly supports the recommendations made in the written statement and oral testimony of Toby Edelman and in the two resolutions relating to antipsychotic drugs submitted by the National Consumer Voice for Quality Long-Term Care (of which LTCCC is a longstanding member).

Fundamentally, the problems resulting from the inappropriate, non-therapeutic use of powerful antipsychotic drugs lay bare the significant underlying problems in our nursing home system. As research data and direct experience indicate, the widespread use of these drugs by nursing homes to manage residents (and, specifically, residents' behavior) functions, in effect, as a band-aid that stanches the symptoms of poor care and minimizes cost to the facility, with little to no regard for the financial costs to taxpayer or the staggering personal toll on residents and their loved ones.

These problems include:

1. **Inadequate Staffing**. From federal and academic studies to anecdotal reports from LTC Ombudsmen and consumer groups across the country, year after year, we are well informed as a nation that the vast majority of U.S. nursing homes lack sufficient staff to provide the care and quality of life that residents need. Yet (and despite the fact that the American public pays for the majority of nursing home care), there are no federal requirements whatsoever for nursing home staffing. State requirements are inadequate in the minority of states where they exist. The result is that that the U.S. nursing home industry is entrusted with the care of close to 1.4 million vulnerable residents, at a cost of many billions of dollars a year, with no meaningful requirements as to levels of direct care staff. The industry has been very successful, on both the state and national levels, in preventing promulgation of meaningful staffing requirements. One of the consequences of the lack of staffing standards, however, is the widespread use of chemical restraints, and the resulting harm to residents, loss to families and enormous costs to the public in terms of billions spent on unnecessary drugs and costs to care for the harmful effects of the antipsychotic drugs.

2. **Inadequate and Circumscribed Enforcement**. Though current law and regulation merit improvement, strong protections already exist in the current laws and standards which nursing homes are obliged to follow. Unfortunately, all too often, these obligations are ignored with impunity. As noted above, the Nursing Home Reform Law has long required that nursing homes provide a quality of life and quality of care sufficient to ensure that every individual entrusted to their care is able to attain and maintain their highest practicable physical, emotional and social well-being. "Highest practicable" does not refer to what the providers deem they are willing to provide, or feel they can afford to supply or what coincides with their goals for their bottom-line that month or year; it refers to what they are promising to provide for each and every individual that they take in, in particular what they agree to when they participate in the Medicare and Medicaid programs. Whose mother should be zonked out on powerful and dangerous medications, because they have dementia and are unable to verbally express when their back is out and their pain is excruciating? Who deserves to be sedated on Seroquel because their behavior is annoying or cumbersome to their nursing home's staff?

   Unfortunately, our system has evolved in a way that often results in accountability being a last resort. State and federal oversight agencies are regularly compelled to work "collaboratively" with providers that fail to meet minimum standards. Our studies of state and national enforcement indicate longstanding weaknesses in the identification and rating of nursing home deficiencies, including those directly relating to care, safety and quality of life. These findings have been collaborated by the GAO and others. Yet, despite these findings and the clear personal and financial costs, as amply exemplified in the case of antipsychotic drug use, we continue to underfund and undermine oversight agencies on both the state and federal levels.

These are but a couple of the potential avenues by which we can begin to better address the widespread and pernicious issue of inappropriate antipsychotic drug use. We hope that the Committee will use these as a basis for continuing momentum and progress to combat this critical problem.