

Left Out: Results Of A Survey Of Nursing Home Resident Representatives On The National Campaign To Improve Dementia Care

This brief presents the first of two assessments undertaken by LTCCC on the effectiveness, to date, of the national campaign to address the widespread, inappropriate and dangerous use of antipsychotic drugs on nursing home residents. In 2005, the FDA issued a “black-box” warning against the use of antipsychotics on elderly people with dementia. In 2011, the US Inspector General found widespread failure to comply with federal regulations designed to prevent overmedication. In early 2012, the Centers for Medicare and Medicaid Services (CMS) launched the federal campaign to reduce antipsychotic drugging. At that time, CMS promised swift, substantive change to protect nursing home residents and assure compliance with minimum standards. However, 3.5 years after the Inspector General’s report, approximately one in five nursing home residents (20%) are still being given powerful and dangerous antipsychotic drugs every day (as of December 2014).

Following are the results of a national survey of nursing home resident representatives, including residents, family council members, advocates and LTC Ombudsmen. The survey was conducted to gain insights into the extent to which residents and their representatives and advocates have been included in the CMS campaign. Has outreach been meaningful and effective? Has the resident voice been included or sidelined?

It is widely believed that the success of any movement – particularly one to improve public health care – is predicated on the ability to effectively communicate with and engage the communities who are directly affected by the problem. Indeed, the widespread use of antipsychotics as chemical restraints is, fundamentally, a problem of poor or inadequate communication by caregivers with residents and, often, their representatives. Thus, the purpose of this report is to provide insights into the effectiveness to date of CMS’s activities to engage and include nursing home residents and their representatives in efforts to reduce inappropriate antipsychotic drugging.

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For more information on dementia care and antipsychotic drugs, including educational & legal resources for consumers, providers and policymakers, visit www.nursinghome411.org.

The Long Term Care Community Coalition is pleased to offer expert services and trainings on a variety of elder care issues, including: (1) Improving dementia care & reducing the use of antipsychotic drugs; (2) Legal & regulatory standards for nursing home and assisted living care; and (3) Resident rights. For more information, e-mail info@ltccc.org or call 212-385-0355.

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Introduction

Dementia is increasingly recognized as one of the most significant issues facing the elderly and their loved ones. Among our growing numbers of older elderly (people 85 or older) 43% have Alzheimer's or another form of dementia. The majority of nursing home residents suffer from dementia.

The inappropriate antipsychotic drugging of these residents is a widespread, national problem. Despite the FDA's 'black box' warning against using powerful and dangerous antipsychotics on elderly patients with dementia, they are frequently used to treat symptoms of the disease, including so-called behavioral and psychological symptoms of dementia. These drugs are often used as a form of chemical restraint, stupefying residents so that they are easier to care for. In addition to destroying social and emotional well-being for these individuals, these drugs greatly increase their risk of stroke, heart attack, Parkinsonism & falls.

In 2011, US Inspector General Daniel R. Levinson issued a statement on "overmedication of nursing home patients" in which he stated

Too many... [nursing homes] fail to comply with federal regulations designed to prevent overmedication, giving nursing home patients antipsychotic drugs in ways that violate federal standards for unnecessary drug use. ...Potentially most alarming, **88 percent of the time these drugs were prescribed for elderly patients with dementia, a population the FDA has warned faces an increased risk of death** from this class of drugs.**Government, taxpayers, nursing home residents, as well as their families and caregivers should be outraged - and seek solutions.**¹

[Emphases added.]

Seeing this as a 'wake-up call' for federal and state oversight agencies, a small group of nursing home resident advocates met with then acting administrator of CMS Dr. Daniel Berwick. Dr. Berwick concurred with the concerns raised by the OIG and consumer advocates and promised action. This set in motion activities which led to the current federal campaign to address inappropriate and dangerous antipsychotic drugging, known as the National Partnership to Improve Dementia Care.

¹ Levinson, Daniel, *Overmedication of Nursing Home Patients Troubling* (May 9, 2011). Available at https://oig.hhs.gov/newsroom/testimony-and-speeches/levinson_051011.asp.

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The National Partnership: Goals & Outcomes

The Partnership campaign was launched in March 2012 with the goal of a 15% reduction of antipsychotic drug use by the end of that calendar year.² When consumer advocates expressed concern regarding the modesty of that goal, given the significant harm associated with these drugs and the fact that longstanding requirements mandate the avoidance of unnecessary drugs and prohibit the use of chemical restraints, they were told that this initial goal was modest in order to “get the ball rolling” and that more ambitious goals would follow.

In fact, nursing homes failed to meet this modest goal in 2012. As a result, despite both the prohibitions in the 1987 Nursing Home Reform Law³ against inappropriate drugging and chemical restraints and the federal campaign launched in 2012, at the end of 2014 close to one in five nursing home residents are still being given dangerous and debilitating antipsychotic drugs in US nursing homes every day. Failure to prevent this inappropriate drugging imposes considerable, often devastating, personal costs to residents and their families and considerable financial expense to US taxpayers.

Purpose of this Report

As advocates to improve care, quality of life and dignity for nursing home residents, we were alarmed by the shocking extent of inappropriate and dangerous antipsychotic drugging identified in the OIG’s 2011 assessment. Given the Reform Law’s specific prohibitions, we turned to CMS to take action. Initially we were gratified by CMS’s promises to both improve enforcement of the Reform Law’s standards and engage the nursing

1987: U.S. Nursing Home Reform Law prohibits inappropriate drugging and the use of chemical restraints.

2004: FDA issues “black-box” warning against use of antipsychotics on elderly with dementia.

2011: Inspector General decries failure of “too many” nursing homes to comply with minimum standards for unnecessary drug use.

2011: U.S. Senate hearing: “Overprescribed: The Human and Taxpayers’ Cost of Antipsychotics in Nursing Homes.”

2012: CMS launches national campaign to stop widespread inappropriate drugging.

2014: Close to one in five nursing home residents still being medicated with dangerous antipsychotics.

² Nursing Home Initiative on Behavioral Health & Antipsychotic Medication Reduction, available on CMS’ YouTube channel at https://www.youtube.com/watch?v=U1_rpO0bwbM.

³ Nursing Home Reform Law, 42 U.S.C. §§1395i-3(a)-(h), 1396r(a)-(h) (Medicare and Medicaid, respectively) (December 1987). The Reform Law’s text is available at: <http://law.justia.com/cfr/title42/42-3.0.1.5.22.html#42:3..15.22.2>. For information on the numerous regulatory standards relevant to protecting nursing home residents from inappropriate drugging, see LTCCC’s report, *Federal Requirements & Regulatory Provisions Relevant to Dementia Care & The Use Of Antipsychotic Drugs* (2013). Available at <http://www.nursinghome411.org/?articleid=10066>.

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home industry and other stakeholders, including consumers, by setting goals and conducting outreach activities. However, three years after our initial meeting with then Acting Administrator Berwick, we are deeply concerned that over 200,000 residents are still being administered antipsychotic drugs inappropriately every day.

We believe (as noted earlier) that it is crucial to directly communicate with and include the consumers of care in any effort to change public health care practice. To borrow the slogan used by many in the larger disability community, "Nothing About Us Without Us!" This is especially relevant given that the use of chemical restraints on people with dementia is essentially a problem of poor or inadequate communication with those individuals and their families or representatives. Thus, the purpose of this report is to provide insights into the effectiveness to date of CMS's activities and strategies to engage and include nursing home residents and their representatives in this important campaign.

Survey Results

The survey was distributed via email and list-serve postings to consumers, citizen advocacy groups and state and local LTC Ombudsmen throughout the United States. A total of 143 responses were received. The survey was conducted anonymously.

Question1: Basic Awareness of the National Campaign to Improve Dementia Care

The intent of this threshold question was to find out the extent of knowledge of the campaign.

Question 1 text: Are you aware of the federal campaign to improve dementia care and reduce antipsychotic drugging in U.S. nursing homes?

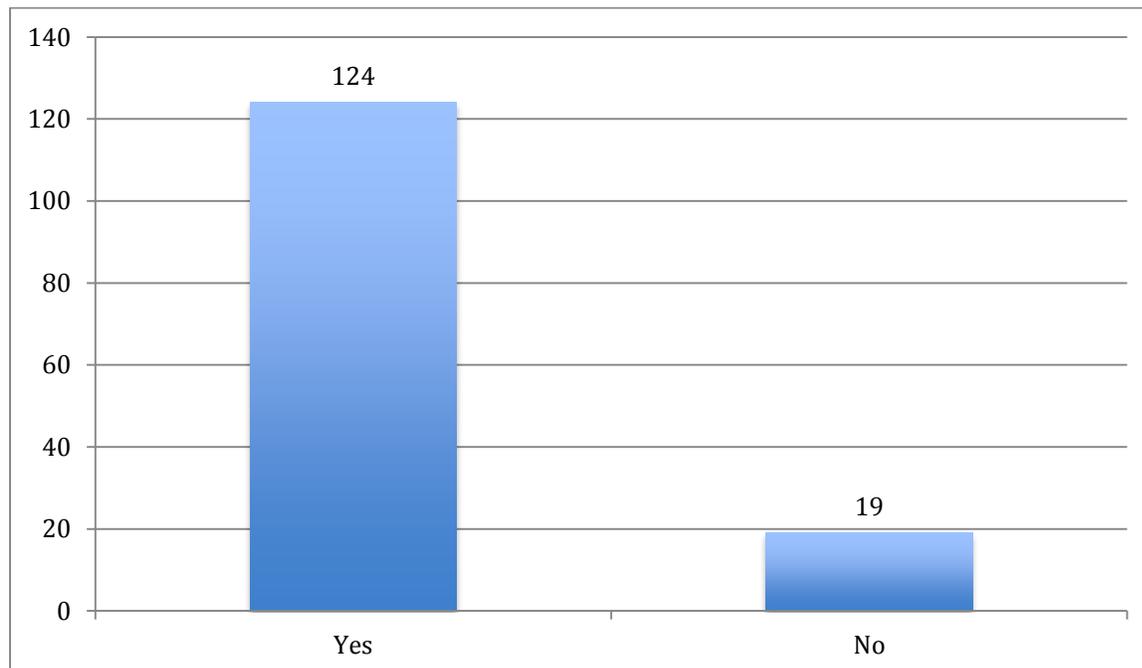


Table 1: Consumer Awareness of CMS Campaign

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The large majority – though not all – of the respondents are aware of the campaign. While an 87% awareness rate might generally be considered highly successful for an outreach/advertising campaign, considering that the survey was limited to groups and individuals who are focused on nursing home care and quality issues, and that the national campaign has been dedicating significant staff time and resources on both the state and national levels, one might expect this number to be higher.

Eighteen respondents left comments in the space provided. These comments ran the gamut from “Have participated as a State level partner in my state” to “I know very little about it” to “My role as an ombudsman limits me to addressing resident or their advocate's complaints and of any obvious abuse. In relation to psychiatric drug use, I have neither witnessed nor received any such complaints.”

Question 2: Knowledge of and Participation in the CMS Partnership Calls

The major, ongoing public activities of the CMS campaign are quarterly calls, which are open to all stakeholders, including providers, quality improvement organizations (QIOs), state survey agencies and the consumer community. These calls provide information and updates on the campaign to reduce inappropriate drugging, presentations on promising practices, etc....

Though the point of campaign is to improve resident care, and the need for investment and ‘buy-in’ by the consumer community has repeatedly been recognized as essential, there have been concerns raised that CMS practice has *not* encouraged consumer participation and, in fact, has been largely geared to the provider industry in both publicizing and carrying out the calls and most other outreach. For instance, in fall 2014, the CMS Division of Nursing Homes sent out several emails promoting forthcoming calls. One was in a newsletter called “*MLN Connects™ Provider eNews.*” The subject line of that email stated: “Now Released: CY 2015 Payment and Policy Changes.” The announcement for the Partnership call was listed under the heading “MLN Connects™ National **Provider** Calls.” [Emphases added.]

Another email, which is the focus of this question, had the subject line “National Partnership to Improve Dementia Care - November Qrtly Stakeholder Call.” Its sole content⁴ was a file called “Mail Attachment.eml.” If the recipient clicked on that attachment (which, given the lack of context provided and widespread fears of downloading viruses or other malware, is questionable for someone not familiar with CMS email addresses or communications) a new message opened with text stating “Audio conference information 1. Please call...” and five more attachments.

Question 2 text: CMS holds quarterly stakeholder calls on the dementia care campaign. Please indicate below your level of knowledge and participation in these calls. The subject line in the email for the most recent call stated: "National Partnership to Improve Dementia Care - November Qrtly Stakeholder Call."

⁴ As received by the author, using the Mail program on a 2013 MacBook.

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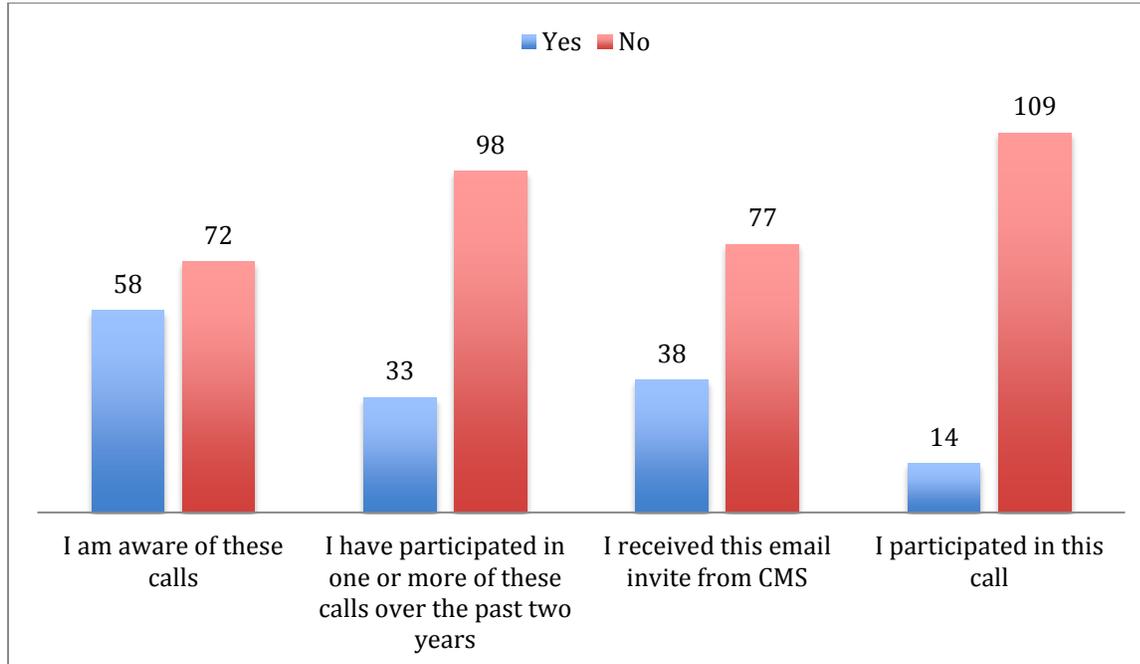


Table 2: Consumer Awareness of & Participation in CMS Partnership

As the chart indicates, there is modest awareness of the Partnership calls in the consumer community: close to half of respondents (45%) are aware of the CMS calls. However, only about 25% have ever participated in a call. For the November 2014 call, one-third of respondents indicated that they had received the email invite from CMS. However, only 11% participated in the call.

Similar to responses to Question 1, we received a range of comments from respondents, including:

- “I am not aware of the invite to participate in calls the last two years.”
- “I'd like to know more about this.”
- “[Advocacy group] has specific volunteers who attend these calls.”
- “I have absolutely zero interest in "calls." They take infinitely more time than reading useful material, and I am not so idle as to be able to participate at a fixed time. So, even if I were aware of the calls, I would have firmly refused to even consider them, despite my keen interest in the topic(s)....”

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Question 3: Interest in Participating in the Calls

Question 3 text: If you indicated that you are not aware of the campaign or the quarterly calls on the campaign, please tell us if this is something in which you would be interested.

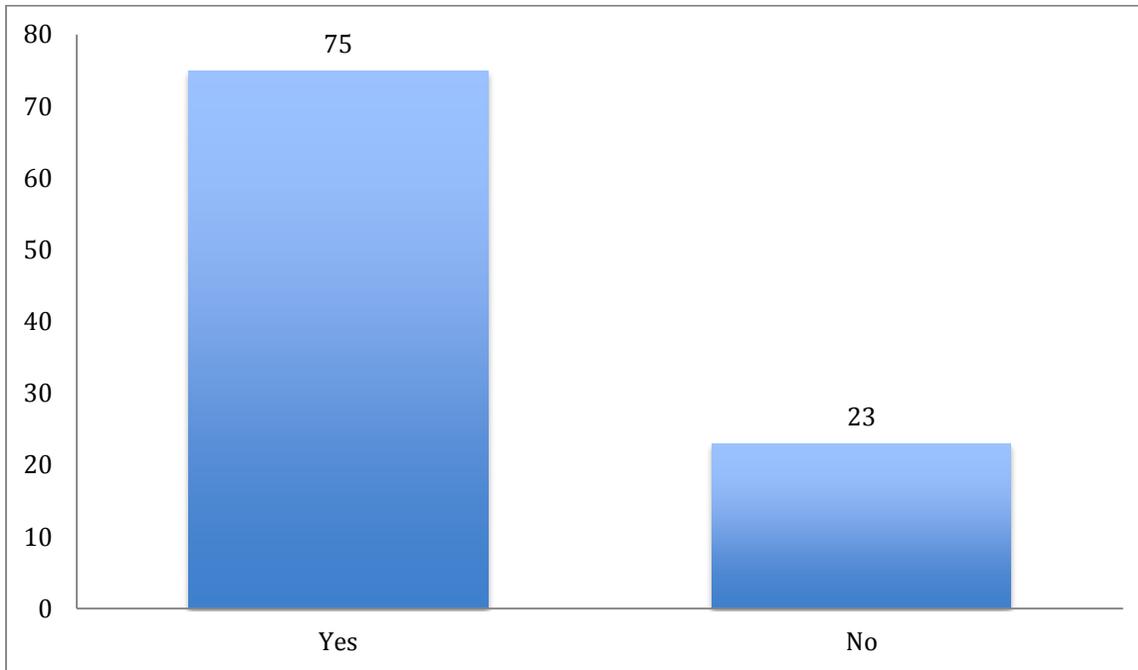


Table 3: Consumer Interest in Participating in CMS Stakeholder Calls

The overwhelming majority (75%) of respondents who are unaware of the campaign and/or the quarterly stakeholder calls expressed an interest in participating in them.

Conclusion & Recommendations

The survey findings indicate significant deficits in consumer awareness of, and participation in, the National Partnership to Improve Dementia Care. At the same time, the majority of survey participants expressed a strong interest in participating in the campaign if provided the opportunity. Given the importance of including health care consumers in making and implementing policies affecting their care – both as a matter of respect and to ensure that such policies are appropriate and successfully implemented – we recommend that CMS take immediate and substantive measures to improve consumer outreach and participation in the campaign. We do not anticipate that implementing any of the recommendations will be particularly costly or time consuming.

Specific recommendations:

1. **Tailor messaging for Partnership calls and other communications so that they are more “consumer-friendly.”** It is unlikely that consumers and advocates (including family and resident council leadership, citizen advocacy group staff and LTC Ombudsmen) will

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expect that something called a “provider call” is meant for them or necessarily relevant to them. Even for those who are familiar with CMS communications, this gives the distinct impression that CMS activities are geared toward the provider industry, not nursing home residents and other interested members of the public.

In addition, all campaign email and web announcements (etc...) should include basic, clear and concise information on the issue or activity about which CMS is endeavoring to communicate.

2. **The content of campaign calls and other communications should be made more relevant to consumers.** Promising provider practices and initiatives such as the dementia care pilot survey are important and valuable things to discuss on the Partnership calls. However, consumers have in effect been sidelined because both the messaging and content of CMS Partnership activities have been provider focused. Consumers turn to CMS because they want to know what CMS is doing to protect residents. In particular, consumers are interested in what CMS is doing in respect to its mandates to (1) protect residents and (2) hold providers accountable for meeting standards of care (particularly, here, those most relevant to dementia care and antipsychotic drugging).
3. **Hold calls and provide other communications that are consumer friendly and focused.**
Examples:
 - a. CMS should hold a quarterly call on updated antipsychotic drugging rates in which CMS staff discuss the relevance of the current data and data trends to consumers and advocates.
 - b. CMS should hold periodic calls to discuss what it is doing to ensure appropriate dementia care, i.e., how is it fulfilling its mission to uphold the law and enforce minimum standards (both nationally and through the CMS Regional Offices)? How are state agencies being held accountable for effectively identifying violations of the standards and hold providers accountable?