



The National  
**CONSUMER VOICE**  
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## TROUBLING TRENDS IN ANTIPSYCHOTIC DRUG USAGE AND SCHIZOPHRENIA DIAGNOSES AMONG NURSING HOME RESIDENTS

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Consumer Voice Annual Conference  
November 4, 2021

# The New York Times

## ***Phony Diagnoses Hide High Rates of Drugging at Nursing Homes***

At least 21 percent of nursing home residents are on antipsychotic drugs, a Times investigation found.

*Sept. 11, 2021*

<https://www.nytimes.com/2021/09/11/health/nursing-homes-schizophrenia-antipsychotics.html?searchResultPosition=1>

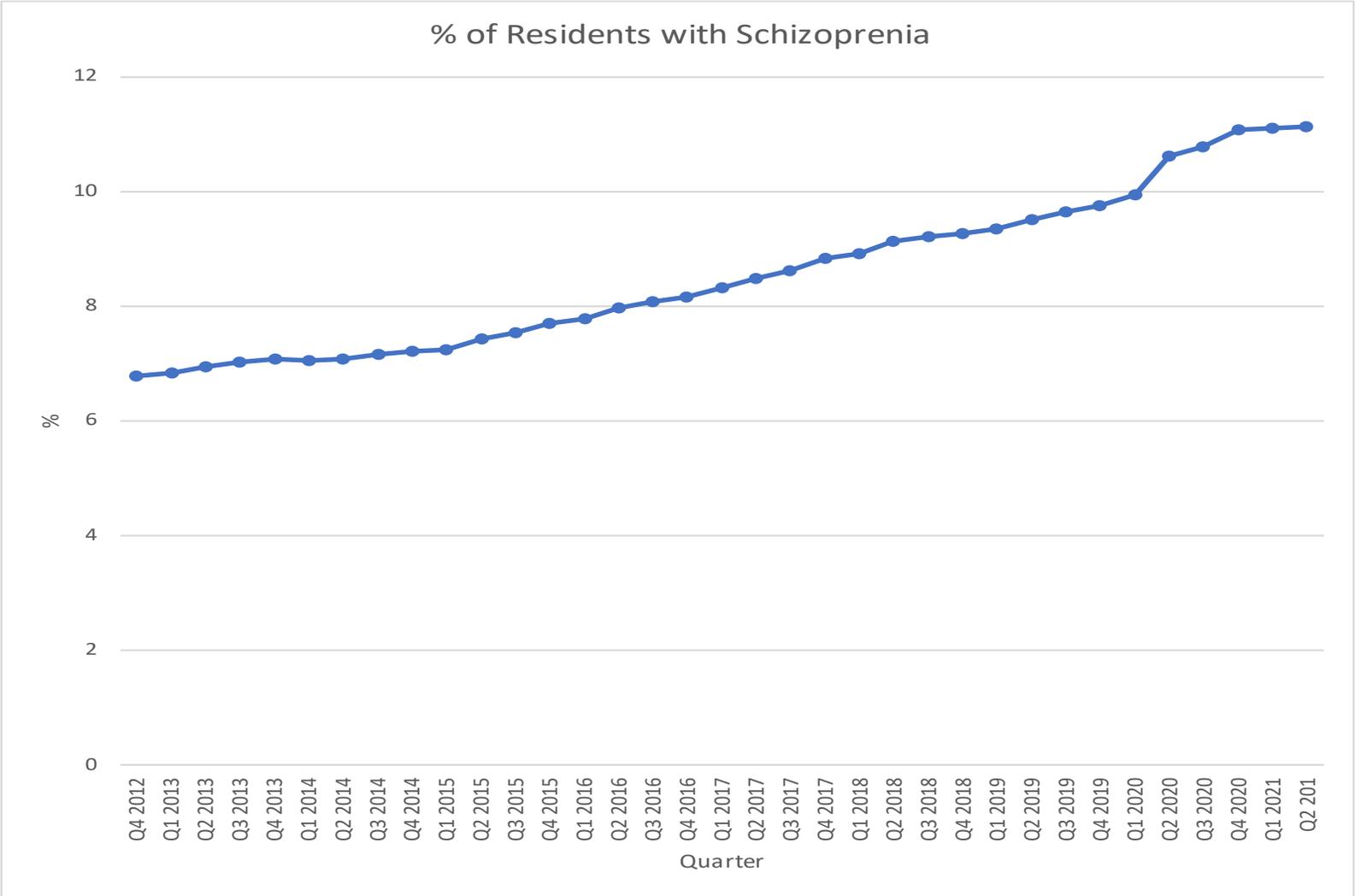


## ***A Racial Disparity in Schizophrenia Diagnoses in Nursing Homes***

*Oct. 15, 2021*

<https://www.nytimes.com/2021/10/15/upshot/schizophrenia-nursing-homes-race.html>

# MDS Data - Percentage of Residents with Schizophrenia Diagnosis 2012(Q4) – 2021(Q2)



“Nearly one-third of residents who were reported in the MDS as having schizophrenia – a diagnosis that excludes them from CMS’s measure of antipsychotic drug use – did not have any Medicare service claims for that diagnosis.”

Office of Inspector General, May 2021, OEI—7-19-00490



## CMS Could Improve the Data It Uses To Monitor Antipsychotic Drugs in Nursing Homes

### Key Result

CMS's use of nursing homes' self-reported information to count the number of residents receiving antipsychotic drugs has important limitations.

The Centers for Medicare & Medicaid Services (CMS) has oversight of Medicare- and Medicaid-certified nursing homes that are responsible for the health and safety of vulnerable residents. CMS is required to monitor nursing home activities, including how nursing homes use antipsychotic drugs to treat residents' various conditions. These drugs can be effective in treating a range of conditions, but they carry risk and must be prescribed appropriately. CMS uses the Minimum Data Set (MDS)—i.e., data that nursing homes self-report—as its sole data source to count the number of nursing home residents receiving antipsychotic drugs. CMS has acknowledged the risk for inappropriate use of antipsychotic drugs. CMS has taken important steps to reduce the use of antipsychotic drugs in nursing homes and could further that progress by collecting more complete data on residents' use of these drugs.

### Why This Issue Is Important

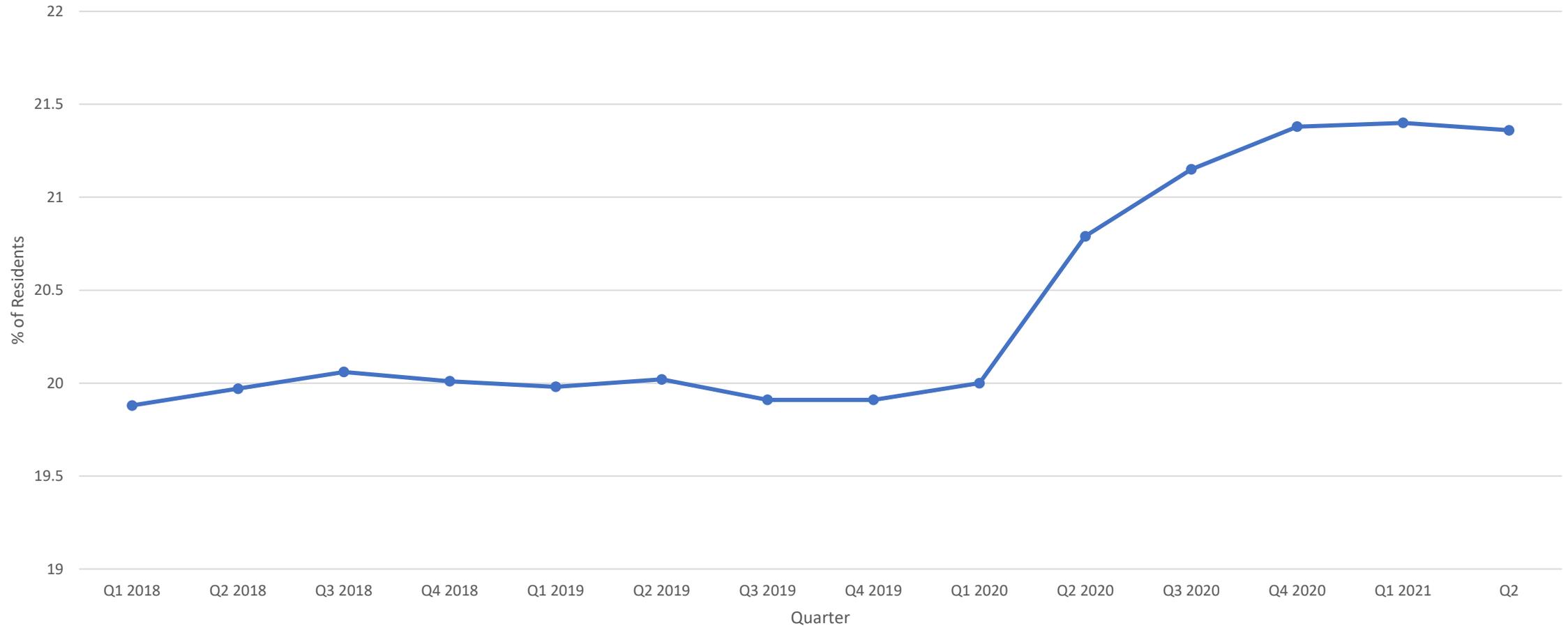
Nursing home residents and their families rely on nursing homes to provide quality care in a safe environment; however, there are reasons for concern specific to the use of antipsychotic drugs. Previous Office of Inspector General (OIG) work in 2011 raised quality and safety concerns regarding the high use of antipsychotic medications among nursing home residents. Since then, CMS has taken important steps to monitor the use of these drugs in nursing homes. However, CMS has acknowledged the potential for inconsistencies in the data—self-reported by nursing homes—that it uses to monitor nursing home quality and to monitor the safety of the use of antipsychotic drugs.

### What OIG Found

We found that CMS's use of the MDS as the sole data source to count the number of nursing home residents using antipsychotic drugs may not always provide complete information. This means some residents' use of antipsychotics may not have been detected by CMS's quality measure intended to monitor these drugs. By analyzing a separate data source—Medicare claims—we found that using the MDS did not always result in a complete assessment of the number of residents who are prescribed antipsychotic drugs. Specifically, in 2018, 12,091 Part D beneficiaries who were long-stay residents age 65 and older—5 percent of all such beneficiaries—had a Part D claim for an antipsychotic drug but were not reported in the MDS as receiving an antipsychotic drug. Further, nearly one-third of residents who were reported in the MDS as having schizophrenia—a diagnosis that excludes them from CMS's measure of antipsychotic drug use—did not have any Medicare service claims for that diagnosis. Finally, even for those residents included in the MDS counts, the MDS does not provide important details about the drug use (e.g., which antipsychotic drugs were prescribed; at what quantities and strengths; and for what durations).

# MDS Data - Antipsychotic Drug Usage in Nursing Home Residents 2018 – 2021(Q2)

Antipsychotic N0410A



*“As staffing levels decrease AP drug use increases.”*

*A Review Exploring the Relationship Between Nursing Home Staffing and Antipsychotic Medication Use, T. Joseph Mattingly II, Neurol Ther (2015) 4:169-175*



## A Review Exploring the Relationship Between Nursing Home Staffing and Antipsychotic Medication Use

T. Joseph Mattingly II

To view enhanced content go to [www.neurologytherapy-open.com](http://www.neurologytherapy-open.com)  
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### ABSTRACT

Staffing level requirements for nursing homes exist at state and federal levels in the United States. While quality of care measures may include antipsychotic (AP) prescribing, the appropriate use of APs as chemical restraints in nursing homes continues to be debated. Although the two variables appear to be related, improved research methods and availability of accurate staffing data will be needed to understand causal relationships regarding AP use for facility dwelling patients.

**Keywords:** Antipsychotics; Long-term care; Nursing home; Quality; Staffing

**Electronic supplementary material** The online version of this article (doi:10.1007/s40120-015-0032-2) contains supplementary material, which is available to authorized users.

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### INTRODUCTION

Patients are admitted to nursing homes (NHs) to receive an increased level of care for a variety of clinical reasons; however, prescribing patterns of some psychotropic medications have raised concerns regarding the appropriateness of therapy [1–6]. Some studies have shown negative effects of inadequate nurse staffing ratios on quality of care as well as an increase in malpractice paid losses in facilities with lower registered nurse (RN) ratios [7–9]. More specifically related to antipsychotics (APs), a study of 590 patients in Austria, United Kingdom, and Norway found that Norwegian homes with higher staff–resident ratios had relatively less resident agitation and a decrease in the use of APs; however, the authors acknowledged the small sample size of their study as a limitation [10]. Evidence also suggests that many NH patients on long-term AP regimens do well after reducing and discontinuing the AP, supporting claims that AP use may be influenced by more factors than clinical necessity [11]. The NH industry faces many organizational and operational challenges including nursing staff turnover, high staff position vacancy rates, and nursing

# Disproportionate increases in schizophrenia diagnoses among Black nursing home residents with ADRD.

Shekinah A. Fashaw-Walters, PhD

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# Background

- Nursing home racial & ethnic disparities have been well documented
- Structural racism likely contributes to these health disparities
- “Colorblind” policies are forms of structural racism and may have unintended consequences for communities of color

Policies that do not  
account for the potential  
unintended  
consequences that may  
disproportionately impact  
people of color due to  
historic structures of  
disadvantage

Colorblindness

**Overt White Supremacy  
(Socially Unacceptable)**

- Lynching
- Hate Crimes
- Blackface The N-word
- Swastikas Neo-Nazis Burning Crosses
- Racist Jokes Racial Slurs KKK

**Covert White  
Supremacy  
(Socially  
Acceptable)**

- Calling the Police on Black People White Silence **Colorblindness**
- White Parents Self-Segregating Neighborhoods & Schools
- Eurocentric Curriculum White Savior Complex Spiritual Bypassing
- Education Funding from Property Taxes Discriminatory Lending
- Mass Incarceration Respectability Politics Tone Policing
- Racist Mascots Not Believing Experiences of BIPOC Paternalism
- "Make America Great Again" Blaming the Victim Hiring Discrimination
- "You don't sound Black" "Don't Blame Me, I Never Owned Slaves" Bootstrap Theory
- School-to-Prison Pipeline Police Murdering BIPOC Virtuous Victim Narrative
- Higher Infant & Maternal Mortality Rate for BIPOC "But What About Me?" "All Lives Matter"
- BIPOC as Halloween Costumes Racial Profiling Denial of White Privilege
- Prioritizing White Voices as Experts Treating Kids of Color as Adults Inequitable Healthcare
- Assuming Good Intentions Are Enough Not Challenging Racist Jokes Cultural Appropriation
- Eurocentric Beauty Standards Anti-Immigration Policies Considering AAVE "Uneducated"
- Denial of Racism Tokenism English-Only Initiatives Self-Appointed White Ally
- Exceptionalism Fearing People of Color Police Brutality Fetishizing BIPOC Meritocracy Myth
- "You're So Articulate" Celebration of Columbus Day Claiming Reverse-Racism Paternalism
- Weaponized Whiteness Expecting BIPOC to Teach White People Believing We Are "Post-Racial"
- "But We're All One Big Human Family" / "There's Only One Human Race" Housing Discrimination

# Background

- Nursing home racial & ethnic disparities have been well documented
- Structural racism likely contributes to these health disparities
- “Colorblind” policies are forms of structural racism and may have unintended consequences for communities of color
- The 2012 CMS National Partnership to Improve Dementia Care in Nursing Homes is an example of a “colorblind” policy
- The Partnership may have unintentionally encouraged the labeling of Black residents with ADRD as schizophrenic
- Limited prior work reveals that schizophrenia nearly doubled between 2011 and 2013 for long-stay NH residents enrolled in Virginia Medicaid

# Objective & Hypothesis

- The purpose of this work was to examine the effects of the Partnership on the rate of schizophrenia MDS-based diagnoses among long-stay NH residents considering the intersection between ADRD status and race.
- Following the Partnership, there would be a racial difference where Blacks would experience greater increases in schizophrenia diagnoses than their non-Black counterparts.

# Methods

- 2011-2015 Minimum Data Set 3.0 long-stay US NH resident quarterly assessments
- Presence of a schizophrenia diagnoses
- ADRD and Black race
- Controlling for differences in:
  - Age, sex, measures of function and frailty (ADL and CHES scores), and behavioral expressions of dementia

# Demographic Changes Over Time for Nursing Home Residents

Year	2011	2012	2013	2014	2015
<b>Assessments, <i>n</i></b>	3,960,600	3,950,871	3,890,268	3,910,761	3,846,368
<b>Residents, <i>n</i></b>	1,272,958	1,260,554	1,239,831	1,237,807	1,223,290
<b>Schizophrenia, %</b>	4.9%	5.1%	5.4%	5.6%	6.0%
<b><i>Demographic characteristics</i></b>					
<b>Age, years, mean (SD)</b>	83.8 (8.5)	83.7 (8.6)	83.6 (8.7)	83.5 (8.8)	83.3 (8.9)
<b>Sex, %</b>					
<b><i>Female</i></b>	73.0	72.5	72.0	71.4	70.9
<b>Race, %</b>					
<b><i>Black</i></b>	12.1	12.2	12.5	12.5	12.8
<b><i>Health-related characteristics</i></b>					
<b>ADL Scale Score, mean (SD)</b>	16.9 (7.5)	17.1 (7.2)	17.1 (7.0)	17.1 (6.8)	17.1 (6.6)
<b>CHESS Scale Score, mean (SD)</b>	0.8 (1.0)	0.8 (0.9)	0.8 (0.9)	0.8 (0.9)	0.7 (0.9)
<b>ADRD, %</b>	63.3	63.8	63.6	63.4	62.6
<b>Agitated and Reactive Behavior Scale Score, mean (SD)</b>	0.5 (1.3)	0.5 (1.3)	0.5 (1.2)	0.4 (1.2)	0.4 (1.1)

# Schizophrenia Reporting among Nursing Home Residents with and without ADRD documentation, by Race.

	Pre-Initiative	Post-Initiative	Relative Change	P-Value	
<b>Without Dementia</b>					
Non-Black Residents	5.3%	5.2%	-1.9%	0.007	
Black Residents	5.0%	4.9%	-2.0%		
<b>With Dementia</b>					
Non-Black Residents	5.8%	5.7%	-1.7%		
Black Residents	5.8%	5.9%	1.7%		

# Schizophrenia Reporting among Nursing Home Residents with and without ADRD documentation, by Race.



# Summary of Findings

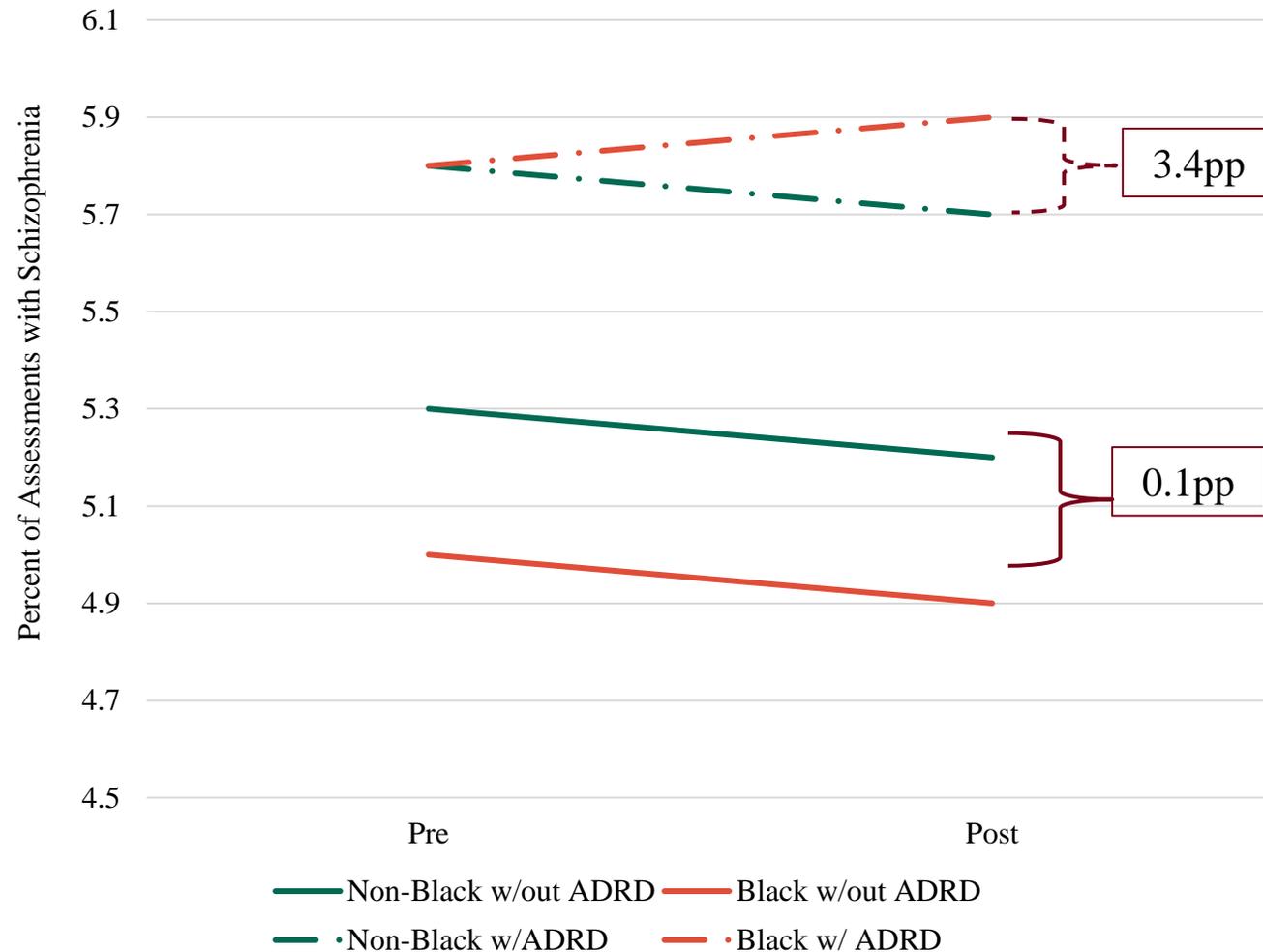
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- Following the partnership, schizophrenia reporting rates increased for Black NH residents but decreased for their non-Black peers
- The greatest difference in change was seen among residents with ADRD

# Implications

- Findings could reflect:
  - racial disparities in schizophrenia diagnoses
  - quality differences in NHs for Blacks versus non-Blacks
  - staff perceptions of how to manage problematic behaviors
  - structural racism manifesting through the unintended consequences of a colorblind policy
- There may be important implications for how we measure the trend in inappropriate antipsychotic use
- Work is needed to determine if schizophrenia labels are appropriately applied in NH practice, particularly for Black Americans and those with ADRD

# Questions & Discussion



## Disproportionate increases in schizophrenia diagnoses among Black nursing home residents with ADRD

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### Abstract

**Background:** Previous research demonstrated an increase in the reporting of schizophrenia diagnoses among nursing home (NH) residents after the Centers for Medicare & Medicaid Services National Partnership to Improve Dementia Care. Given known health and healthcare disparities among Black NH residents, we examined how race and Alzheimer's and related dementia (ADRD) status influenced the rate of schizophrenia diagnoses among NH residents following the partnership.

**Methods:** We used a quasi-experimental difference-in-differences design to study the quarterly prevalence of schizophrenia among US long-stay NH residents aged 65 years and older, by Black race and ADRD status. Using 2011–2015 Minimum Data Set 3.0 assessments, our analysis controlled for age, sex, measures of function and frailty (activities of daily living [ADL] and Changes in Health, End-stage disease and Symptoms and Signs scores) and behavioral expressions.

**Results:** There were over 1.2 million older long-stay NH residents, annually. Schizophrenia diagnoses were highest among residents with ADRD. Among residents without ADRD, Black residents had higher rates of schizophrenia diagnoses compared to their nonblack counterparts prior to the partnership. Following the partnership, Black residents with ADRD had a significant increase of 1.7% in schizophrenia as compared to nonblack residents with ADRD who had a decrease of 1.7% ( $p = 0.007$ ).

**Conclusions:** Following the partnership, Black NH residents with ADRD were more likely to have a schizophrenia diagnosis documented on their MDS assessments, and schizophrenia rates increased for Black NH residents with ADRD only. Further work is needed to examine the impact of “colorblind” policies such as the partnership and to determine if schizophrenia diagnoses are appropriately applied in NH practice, particularly for black Americans with ADRD.

# Contact Information

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A decorative graphic consisting of several blue dots of varying sizes arranged in a cluster, positioned behind the main title text.

*Avoiding Drugs As*  
*Chemical Restraints*

**Changing the Culture of Care**

**A CONSUMER EDUCATION CAMPAIGN**

The National Consumer Voice for Quality Long-Term Care & AARP Foundation

<https://theconsumervoice.org/stop-chemical-restraints>

## Avoiding Drugs as Chemical Restraints

### CONSUMER FACT SHEET

Everyone who enters a nursing home has a right to individualized, person-centered care. Some nursing facilities, however, are giving residents antipsychotic drugs, not to treat a medical diagnosis, such as Schizophrenia or Bipolar Disorder, but rather to control the resident's behavior or for the staff's convenience. When used this way, as a chemical restraint, these drugs pose special risks for older people and increase the risk of death in persons with dementia.

### Signs of Someone at Risk for Chemical Restraints

When individuals, including residents with medical conditions such as dementia, are unable to express themselves using words, they express themselves through actions. For example, a resident may repeatedly moan to show they are in pain. These actions should not be dismissed. Instead, they should be evaluated to identify what the resident is trying to communicate. Other examples of behavioral communication that require further evaluation include:

- Anger, Distress, Agitation
- Screaming, Swearing, Spitting
- Hitting, Lashing out
- Confusion, Paranoia, Delusions
- Crying, Sadness, Fear
- Continuous wandering, Repetitive actions, Failure to cooperate

These actions or behaviors  
are signals that something  
is wrong!

### Signs that A Resident May Have Been Chemically Restrained

Negative effects often associated with chemical restraints can also be the result of other factors such as illness or adverse effects of other drugs. However, if a resident has the following symptoms, raise questions and ask that their drug regimen be reviewed.

- Sedation (difficulty waking the resident to eat or for a visit)
- Disordered thinking, delirium, depression, hallucinations, delusions
- Distress
- Dry mouth
- Decreased appetite
- Tardive Dyskinesia (repetitive, involuntary movement of the head, tongue, and sometimes the trunk, fingers, and toes)
- Parkinsonian symptoms



Avoiding Drugs as Chemical Restraints: Consumer Fact Sheet

A CONSUMER EDUCATION PODCAST

## PURSuing QUALITY LONG-TERM CARE

## Know Your Drugs & Know Your Rights

Questions to ask your care provider  
and a list of drugs often used  
as chemical restraints

Medications can be helpful if they are treating an illness. It is important to be aware of whether a drug is being used for treatment or as a restraint. You should be told about any drug before it is given to you so you can decide if you consent or want to refuse it.

Questions to ask your healthcare provider about medications that have been prescribed for you or a loved one:

- 1 Why was this drug ordered? What symptoms or behavior prompted it?
- 2 Could an illness be causing these symptoms?
- 3 Is this medication specifically for the cause/symptoms?
- 4 What are our non-drug options?
- 5 What was done to treat or eliminate the cause/symptoms before resorting to this medication? Was enough time given to figuring out the causes?
- 6 Is the drug one of those with a black box warning?
- 7 What are the side effects/risks of the medication?
- 8 Why do you believe the benefits outweigh those risks?
- 9 What possible interactions will it have with other drugs?
- 10 What is your plan for monitoring the use of the drug and weaning off/stopping it?

### Avoiding Drugs As Chemical Restraints

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[https://theconsumervoice.org/get\\_help](https://theconsumervoice.org/get_help)

Q&A