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.

By Katie Thomas, Robert Gebeloff and Jessica Silver-Greenberg

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The handwritten doctor’s order was just eight words long, but it solved a problem for Dundee Manor, a nursing home in rural South Carolina struggling to handle a new resident with severe dementia.

David Blakeney, 63, was restless and agitated. The home’s doctor wanted him on an antipsychotic medication called Haldol, a powerful sedative.

“Add Dx of schizophrenia for use of Haldol,” read the doctor’s order, using the medical shorthand for “diagnosis.”

But there was no evidence that Mr. Blakeney actually had schizophrenia.

Antipsychotic drugs — which for decades have faced criticism as “chemical straitjackets” — are dangerous for older people with dementia, nearly doubling their chance of death from heart problems, infections, falls and other ailments. But understaffed nursing homes have often used the sedatives so they don’t have to hire more staff to handle residents.

The risks to patients treated with antipsychotics are so high that nursing homes must report to the government how many of their residents are on these potent medications. But there is an important caveat: The government doesn’t publicly divulge the use of antipsychotics given to residents with schizophrenia or two other conditions.

With the doctor’s new diagnosis, Mr. Blakeney’s antipsychotic prescription disappeared from Dundee Manor’s public record.

Eight months following his admission with a long list of ailments — and after round-the-clock sedation, devastating weight loss, pneumonia and severe bedsores that required one of his feet to be amputated — Mr. Blakeney was dead.

A New York Times investigation found a similar pattern of questionable diagnoses nationwide. The result: The government and the industry are obscuring the true rate of antipsychotic drug use on vulnerable residents.

The share of residents with a schizophrenia diagnosis has soared 70 percent since 2012, according to an analysis of Medicare data. That was the year the federal government, concerned with the overuse of antipsychotic drugs, began publicly disclosing such prescriptions by individual nursing homes.

Today, one in nine residents has received a schizophrenia diagnosis. In the general population, the disorder, which has strong genetic roots, afflicts roughly one in 150 people.

Schizophrenia, which often causes delusions, hallucinations and dampened emotions, is almost always diagnosed before the age of 40.
“People don’t just wake up with schizophrenia when they are elderly,” said Dr. Michael Wasserman, a geriatrician and former nursing home executive who has become a critic of the industry. “It’s used to skirt the rules.”

### 1 in 9 Residents Diagnosed With Schizophrenia

Schizophrenia diagnoses are soaring in nursing homes, but related behaviors like delusions and hallucinations are not.

<table>
<thead>
<tr>
<th>Year</th>
<th>Schizophrenia Diagnoses</th>
<th>Delusions</th>
<th>Hallucinations</th>
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<tbody>
<tr>
<td>2013</td>
<td>15% of nursing home residents</td>
<td>10%</td>
<td></td>
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<tr>
<td>2014</td>
<td>5%</td>
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<td>2015</td>
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<td>2018</td>
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<tr>
<td>2020</td>
<td>45%</td>
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<tr>
<td>2021</td>
<td>50%</td>
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By The New York Times | Source: Centers for Medicare & Medicaid Services MDS 3.0 Frequency Reports

Some portion of the rise in schizophrenia diagnoses reflects the fact that nursing homes, like prisons, have become a refuge of last resort for people with the disorder, after large psychiatric hospitals closed decades ago.

But unfounded diagnoses are also driving the increase. In May, a report by a federal oversight agency said nearly one-third of long-term nursing home residents with schizophrenia diagnoses in 2018 had no Medicare record of being treated for the condition.

For nursing homes, money is on the line. High rates of antipsychotic drug use can hurt a home’s public image and the star rating it gets from the government. Medicare designed the ratings system to help patients and their families evaluate facilities using objective data; a low rating can have major financial consequences. Many facilities have found ways to hide serious problems — like inadequate staffing and haphazard care — from government audits and inspectors.

One result of the inaccurate diagnoses is that the government is understating how many of the country’s 1.1 million nursing home residents are on antipsychotic medications.

According to Medicare’s web page that tracks the effort to reduce the use of antipsychotics, fewer than 15 percent of nursing home residents are on such medications. But that figure excludes patients with schizophrenia diagnoses.

To determine the full number of residents being drugged nationally and at specific homes, The Times obtained unfiltered data that was posted on another, little-known Medicare web page, as well as facility-by-facility data that a patient advocacy group got from Medicare via an open records request and shared with The Times.

The figures showed that at least 21 percent of nursing home residents — about 225,000 people — are on antipsychotics.

The Centers for Medicare and Medicaid Services, which oversees nursing homes, is “concerned about this practice as a way to circumvent the protections these regulations afford,” said Catherine Howden, a spokeswoman for the agency, which is known as C.M.S.

“It is unacceptable for a facility to inappropriately classify a resident’s diagnosis to improve their performance measures,” she said. “We will continue to identify facilities which do so and hold them accountable.”

Representatives for nursing homes said doctors who diagnose patients and write the prescriptions to treat them are to blame, even though those doctors often work in partnership with the nursing homes.

“If physicians are improperly diagnosing individuals with serious mental health issues in order to continue an antipsychotic regimen, they should be reported and investigated,” Dr. David Gifford, the chief medical officer at the American Health Care Association, which represents for-profit nursing homes, said in a statement.

Medicare and industry groups also said they had made real progress toward reducing antipsychotic use in nursing homes, pointing to a significant drop since 2012 in the share of residents on the drugs.

But when residents with diagnoses like schizophrenia are included, the decline is less than half what the government and industry claim. And when the pandemic hit in 2020, the trend reversed and antipsychotic drug use increased.

### A Doubled Risk of Death

For decades, nursing homes have been using drugs to control dementia patients. For nearly as long, there have been calls for reform.

In 1987, President Ronald Reagan signed a law banning the use of drugs that serve the interest of the nursing home or its staff, not the patient.

But the practice persisted. In the early 2000s, studies found that antipsychotic drugs like Seroquel, Zyprexa and Abilify made older people drowsy and more likely to fall. The drugs were also linked to heart problems in people with dementia. More than a dozen clinical trials concluded that the drugs nearly doubled the risk of death for older dementia patients.

In 2005, the Food and Drug Administration required manufacturers to put a label on the drugs warning that they increased the risk of death for patients with dementia.

Seven years later, with antipsychotics still widely used, nursing homes were required to report to Medicare how many residents were getting the drugs. That data is posted online and becomes part of a facility’s “quality of resident care” score, one of three major categories that contribute to a home's star rating.

The only catch: Antipsychotic prescriptions for residents with any of three uncommon conditions — schizophrenia, Tourette's syndrome and Huntington's disease — would not be included in a facility’s public tally. The theory was that since the drugs were approved to treat patients with those conditions, nursing homes shouldn’t be penalized.

The loophole was opened. Since 2012, the share of residents classified as having schizophrenia has gone up to 11 percent from less than 7 percent, records show.

The diagnoses rose even as nursing homes reported a decline in behaviors associated with the disorder. The number of residents experiencing delusions, for example, fell to 4 percent from 6 percent.

**A Substitute for Staff**

Caring for dementia patients is time- and labor-intensive. Workers need to be trained to handle challenging behaviors like wandering and aggression. But many nursing homes are chronically understaffed and do not pay enough to retain employees, especially the nursing assistants who provide the bulk of residents’ daily care.

Studies have found that the worse a home's staffing situation, the greater its use of antipsychotic drugs. That suggests that some homes are using the powerful drugs to subdue patients and avoid having to hire extra staff. (Homes with staffing shortages are also the most likely to understate the number of residents on antipsychotics, according to the Times’s analysis of Medicare data.)

**Star Ratings and Antipsychotic Drugs**

Nursing home residents are more likely to receive antipsychotic medications at facilities with poor staffing.

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<thead>
<tr>
<th>0 star facilities</th>
<th>10%</th>
<th>20% of residents on antipsychotic drugs</th>
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<tbody>
<tr>
<td>2 star</td>
<td></td>
<td></td>
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<tr>
<td>3 star</td>
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<td>4 star</td>
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<tr>
<td>5 star</td>
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The pandemic has battered the industry. Nursing home employment is down more than 200,000 since early last year and is at its lowest level since 1994.

As staffing dropped, the use of antipsychotics rose.

Even some of the country's leading experts on elder care have been taken aback by the frequency of false diagnoses and the overuse of antipsychotics.

Barbara Coulter Edwards, a senior Medicaid official in the Obama administration, said she had discovered that her father was given an incorrect diagnosis of psychosis in the nursing home where he lived even though he had dementia.
“I just was shocked,” Ms. Edwards said. “And the first thing that flashed through my head was this covers a lot of ills for this nursing home if they want to give him drugs.”

Homes that violate the rules face few consequences.

In 2019 and 2021, Medicare said it planned to conduct targeted inspections to examine the issue of false schizophrenia diagnoses, but those plans were repeatedly put on hold because of the pandemic.

In an analysis of government inspection reports, The Times found about 5,600 instances of inspectors citing nursing homes for misusing antipsychotic medications. Nursing home officials told inspectors that they were dispensing the powerful drugs to frail patients for reasons that ranged from “health maintenance” to efforts to deal with residents who were “whining” or “asking for help.”

In more than 99 percent of the cases, inspectors concluded that the violations represented only “potential,” not “actual,” harm to patients. That means the findings are unlikely to hurt the homes’ ratings.

‘He Was So Little’

Mr. Blakeney’s wife of four decades and one of his adult daughters said in interviews that he had never exhibited any mental health problems. Then he developed dementia, and his behavior became difficult to manage. His wife, Yvonne Blakeney, found that she could no longer care for him.

Over the next several months, Mr. Blakeney was in and out of medical facilities, where he was treated for problems including a urinary tract infection. He became increasingly confused and upset.

In April 2016, he went to the Lancaster Convalescent Center, a nursing home in Lancaster, S.C., where a doctor labeled him with schizophrenia on a form that authorized the use of antipsychotic drugs. That diagnosis, however, did not appear on his subsequent hospital records.
Lancaster’s administrator declined to comment.

Six months later, Mr. Blakeney arrived at Dundee Manor, a 110-bed home in Bennettsville, S.C. At the time, it received only one out of five stars in Medicare’s rating system. The low score reflected poor marks from government inspectors who had visited the facility. It was also penalized for inadequate staffing.

When Mr. Blakeney was admitted, schizophrenia did not appear in his long list of ailments, which included high blood pressure, pneumonia and advanced dementia, according to medical records disclosed in a lawsuit that his widow later filed against the home.

Two weeks after his arrival, Dundee Manor’s medical director, Dr. Stephen L. Smith, instructed the home to add the schizophrenia diagnosis so that Mr. Blakeney could continue to receive Haldol. He was also prescribed Zyprexa, as well as the sleeping pill Ambien and trazodone, which is often given to help patients sleep.

Ms. Blakeney’s lawyer, Matthew Christian, said he had not seen any evidence that anyone conducted a psychiatric evaluation of Mr. Blakeney.

Mr. Blakeney, who had worked for decades as a farmhand, was once tall and muscular. But the drugs left him confined to his bed or wheelchair, exhausted. When his wife and sister visited, they couldn't wake him, even when they brought his favorite meal of fried chicken. Over eight months, his weight dropped from 205 to 128 pounds.

“I cried because he was so little,” Ms. Blakeney said. “You could see his rib cage, just sticking out.”

Mr. Blakeney’s medical records show that several people warned that he was too sedated and receiving too many drugs.

Three weeks after he arrived at Dundee Manor, a physical therapist noted his extreme lethargy, even when she washed his hands and face. In mid-November, after Mr. Blakeney lost 12 pounds in a single week, a dietitian left a note for the doctor. “Consider medication adjustment,” she wrote, adding that he was “sleeping all day and through meals.”
That month, an outside pharmacist filled out a form recommending that Mr. Blakeney’s doses of Haldol and Zyprexa be reduced to comply with federal guidelines that require nursing homes to gradually reduce doses of antipsychotics.

On a form with Dr. Smith’s name and signature, a box labeled “disagree” was checked. “Staff feels need” for the continued doses, the form noted.

It was exactly the sort of decision — prescribing powerful drugs to help the nursing home and its staff, not the patient — that the 1987 law was supposed to ban.

Dr. Smith declined to comment. Dundee Manor didn’t respond to requests for comment.

According to Medicare’s public database of nursing home ratings, only 7 percent of Dundee Manor’s long-term residents were getting antipsychotic drugs in the third quarter of 2018. That put the nursing home in a good light; the national average was roughly double.

But Dundee Manor’s relatively low figure was a mirage created by the large number of residents who were diagnosed with conditions like schizophrenia. In reality, The Times found, 29 percent of Dundee Manor’s residents were on antipsychotics at the time, according to unpublished Medicare data obtained through public records requests by California Advocates for Nursing Home Reform.

A Growing Gap in Antipsychotic Drug Reporting

Official rates of antipsychotic drug use by nursing homes exclude residents diagnosed with schizophrenia. Unfounded diagnoses contributed to a decline in recent years, which appears less sharp when all residents are included.

25% of residents on antipsychotics

Overall rate
Includes all residents
20%

Official rate
Excludes schizophrenia, other disorders and short-term residents
15%


By The New York Times | Sources: National Partnership to Improve Dementia Care in Nursing Homes; Centers for Medicare & Medicaid Services MDS 3.0 Frequency Reports

Five-Star Problems

False schizophrenia diagnoses are not confined to low-rated homes. In May, the inspector general of the Department of Health and Human Services, for example, identified 52 nursing homes where at least 20 percent of all residents had an unsupported diagnosis. Medicare rated more than half of those homes with at least four of the maximum five stars. (The inspector general’s report didn’t identify the nursing homes. The Times obtained their identities through a public-records request.)

One was the Hialeah Shores Nursing and Rehabilitation Center in Miami, a 106-bed home bordered by palm trees and a white painted fence. It is a five-star facility that, according to the official statistics, prescribed antipsychotics to about 10 percent of its long-term residents in 2018.

That was a severe understatement. In fact, 31 percent of Hialeah Shores residents were on antipsychotics, The Times found.

In 2018, a state inspector cited Hialeah Shores for giving a false schizophrenia diagnosis to a woman. She was so heavily dosed with antipsychotics that the inspector was unable to rouse her on three consecutive days.

There was no evidence that the woman had been experiencing the delusions common in people with schizophrenia, the inspector found. Instead, staff at the nursing home said she had been “resistive and noncooperative with care.”

Dr. Jonathan Evans, a medical director for nursing homes in Virginia who reviewed the inspector’s findings for The Times, described the woman’s fear and resistance as “classic dementia behavior.”
“This wasn't five-star care,” said Dr. Evans, who previously was president of a group that represents medical staff in nursing homes. He said he was alarmed that the inspector had decided the violation caused only “minimal harm or potential for harm” to the patient, despite her heavy sedation. As a result, he said, “there's nothing about this that would deter this facility from doing this again.”

Representatives of Hialeah Shores declined to comment.

Seven of the 52 homes on the inspector general’s list were owned by a large Texas company, Daybreak Venture. At four of those homes, the official rate of antipsychotic drug use for long-term residents was zero, while the actual rate was much higher, according to the Times analysis comparing official C.M.S. figures with unpublished data obtained by the California advocacy group.

More than 39 percent of residents at Daybreak’s Countryside Nursing and Rehabilitation, for example, were receiving an antipsychotic drug in 2018, even though the official figure was zero.

A lawyer for Daybreak, Charles A. Mallard, said the company could not comment because it had sold its homes and was shutting its business.

A Sprinkle of Depakote

As the U.S. government has tried to limit the use of antipsychotic drugs, nursing homes have turned to other chemical restraints. Depakote, a medication to treat epilepsy and bipolar disorder, is one increasingly popular choice. The drug can make people drowsy and increases the risk of falls. Peer-reviewed studies have shown that it does not help with dementia, and the government has not approved it for that use.

But prescriptions of Depakote and similar anti-seizure drugs have accelerated since the government started publicly reporting nursing homes’ use of antipsychotics.

Between 2015 and 2018, the most recent data available, the use of anti-seizure drugs rose 15 percent in nursing home residents with dementia, according to an analysis of Medicare insurance claims that researchers at the University of Michigan prepared for The Times.
And while Depakote's use rose, antipsychotic prescriptions fell 16 percent.

“The prescribing is far higher than you would expect based on the actual amount of epilepsy in the population,” said Dr. Donovan Maust, a geriatric psychiatrist at the University of Michigan who conducted the research.

About half the complaints that California Advocates for Nursing Home Reform receives about inappropriate drugging of residents involve Depakote, said Anthony Chicotel, the group's top lawyer. It comes in a “sprinkle” form that makes it easy to slip into food undetected.

“It’s a drug that’s tailor-made to chemically restrain residents without anybody knowing,” he said.

In the early 2000s, Depakote's manufacturer, Abbott Laboratories, began falsely pitching the drug to nursing homes as a way to sidestep the 1987 law prohibiting facilities from using drugs as “chemical restraints,” according to a federal whistle-blower lawsuit filed by a former Abbott saleswoman.

According to the lawsuit, Abbott's representatives told pharmacists and nurses that Depakote would “fly under the radar screen” of federal regulations.

Abbott settled the lawsuit in 2012, agreeing to pay the government $1.5 billion to resolve allegations that it had improperly marketed the drugs, including to nursing homes.

Nursing homes are required to report to federal regulators how many of their patients take a wide variety of psychotropic drugs — not just antipsychotics but also anti-anxiety medications, antidepressants and sleeping pills. But homes do not have to report Depakote or similar drugs to the federal government.

“It is like an arrow pointing to that class of medications, like ‘Use us, use us!’” Dr. Maust said. “No one is keeping track of this.”

**Lobbying for More**

In 2019, the main lobbying group for for-profit nursing homes, the American Health Care Association, published a brochure titled “Nursing Homes: Times have changed.”

“Nursing homes have replaced restraints and antipsychotic medications with robust activity programs, religious services, social workers and resident councils so that residents can be mentally, physically and socially engaged,” the colorful two-page leaflet boasted.

Last year, though, the industry teamed up with drug companies and others to push Congress and federal regulators to broaden the list of conditions under which antipsychotics don't need to be publicly disclosed.

“There is specific and compelling evidence that psychotropics are underutilized in treating dementia and it is time for C.M.S. to re-evaluate its regulations,” wrote Jim Scott, the chairman of the Alliance for Aging Research, which is coordinating the campaign.

The lobbying was financed by drug companies including Avanir Pharmaceuticals and Acadia Pharmaceuticals. Both have tried — and so far failed — to get their drugs approved for treating patients with dementia. (In 2019, Avanir agreed to pay $108 million to settle charges that it had inappropriately marketed its drug for use in dementia patients in nursing homes.)

**‘Hold His Haldol’**

Ms. Blakeney said that only after hiring a lawyer to sue Dundee Manor for her husband's death did she learn he had been on Haldol and other powerful drugs. (Dundee Manor has denied Ms. Blakeney's claims in court filings.)

During her visits, though, Ms. Blakeney noticed that many residents were sleeping most of the time. A pair of women, in particular, always caught her attention. “There were two of them, laying in the same room, like they were dead,” she said.

In his first few months at Dundee Manor, Mr. Blakeney was in and out of the hospital, for bedsores, pneumonia and dehydration. During one hospital visit in December, a doctor noted that Mr. Blakeney was unable to communicate and could no longer walk.

“Hold the patient's Ambien, trazodone and Zyprexa because of his mental status changes,” the doctor wrote. “Hold his Haldol.”

Mr. Blakeney continued to be prescribed the drugs after he returned to Dundee Manor. By April 2017, the bedsore on his right heel — a result, in part, of his rarely getting out of bed or his wheelchair — required the foot to be amputated.

In June, after weeks of fruitless searching for another nursing home, Ms. Blakeney found one and transferred him there. Later that month, he died.

“I tried to get him out — I tried and tried and tried,” his wife said. “But when I did get him out, it was too late.”