



making elder care better every day

February, 13, 2018

Chairwoman Davis and Members of House Children and Seniors Committee:

I am Mitzi McFatrach, executive director of Kansas Advocates for Better Care (KABC). I appreciate the opportunity to address the serious concern of anti-psychotic drug use on older adults with dementia in Kansas nursing facilities. Thank you for carving out time to understand more about this life threatening health concern.

In October this year, the Centers for Medicare and Medicaid Services (CMS) announced that the national anti-psychotic drug reduction goals had been achieved and exceeded by the end of 2016. The national goal was a 30% reduction, and CMS reported a national aggregate reduction of 34.1% (in long-stay residents). At the beginning of the campaign in 2012 Quarter 2, use-rates were 23.9% and dropped to 15.7% as last reported nationally, 2017 Quarter 2. The states which reduced their rate by the most percentage include the District of Columbia (47.8%), Tennessee (43.5%), California (43%), and Arkansas (41.6%). Kansas use rate was 26.1% at the 2011 Q1 baseline; and has a current use rate of 19.8%. Kansas is ranked 51<sup>st</sup> worst nationally.

The CMS reduction campaign has not concluded. CMS announced a new goal of a 15% reduction by the end of 2019 for long-stay residents in those facilities which continue with high-use rates, using the baseline rate (fourth quarter of 2011). CMS intends to target specific homes with high use rates. KABC requested that they continue to focus on Kansas.

For example while California, a much larger, more populous, and more diverse state went from being ranked 49<sup>th</sup> worst to 4<sup>th</sup> best, Kansas went from 43<sup>rd</sup> to 51<sup>st</sup> worst. Arkansas and Tennessee relatively close neighbors of Kansas are both in the highest reduction listing noted above. Over the 5 years of this national initiative, Kansas reduced anti-psychotic use by about 5%. In 2012 one in four older adults in Kansas facilities were given anti-psychotics and now it's one in five. Not odds anyone should have to face when entering a nursing facility.

### **Why doesn't Kansas improve?**

- Lack of leadership for statewide reduction effort and too little oversight/enforcement from KDADS – Inadequate and delayed survey process, understaffed survey unit (nearly one-third unfilled), failure to use deficiency citations and civil monetary penalties to deter drug use at a serious level of harm (per former director of survey)
- KDADS failed to follow up inspections to assure corrections were made when deficiencies were cited. (OIG 2016 report “Kansas did not always verify correction of deficiencies identified during surveys of nursing homes participating in Medicare and Medicaid)

*continued – Why doesn't KS improve*

- Lack of meaningful health improvement goals in KanCare specific to this measure; and lack of public reporting on progress goal achievement (KDHE) See KanCare Attachment J, Appendix 11, page 124
- Lack of MCO awareness of the 10% annual reduction goal; lack of oversight of members in nursing facilities through care coordination engagement which largely non-existent for residents in the nursing facility setting
- The State lacks a financial incentive as it doesn't pay for most drugs for older adults which are covered by Medicare Part D
- Lack of informed consent by residents or their legal representative; threat of discharge for those who object to anti-psychotic drug use
- Physicians frequently don't follow the Standards of Care practice and meet with the resident for an assessment, or to explain the dangers and possible benefits to the resident or legal representative. Doctors are often responding to phone calls from facility nurses requesting the drugs
- Facilities are not using the Gradual Dose Reduction protocols in order to take residents off anti-psych drugs as soon as possible
- Facilities are not providing adequate or safe staffing levels to meet the medical and social needs of residents, nor is there consistent direct care staff for residents, and there is too little RN care
- Nurses and nurse aides do not receive training during degree or certification programs about dementia, it's progression, non-pharmacologic interventions and treatment, or the dangers of these drugs
- Nurse and nurse aides do not receive adequate on-going/continuing education in the topics listed above

**Is Kansas' use rate so high because of the Nursing Facilities for Mental Health?** No. Kansas does not have more mentally ill persons as a percentage of its population than other states. The only residents CMS uses to calculate use rates are those who are given anti-psychotic drugs without a diagnosis approved for anti-psychotic drug use. Approved conditions include Schizophrenia, Tourette's or Huntington's disease.

**Are older adults in the community receiving anti-psychotic drugs at the rate of those in nursing facilities?** No. Use rates for older adults with dementia living at home is half the use rate in nursing facilities.

**Kansas ranks best in the nation for not using physical restraints – is that because it is easier to use chemical restraints.** It is harder to detect inappropriate use of chemical restraints because you can't see the ties binding older adults, it takes more time and is more difficult for surveyors to unravel the harm to an older adult done by anti-psychotic drugs, and

## So what is the harm?

The boxed warning for all atypical antipsychotic medications, including clozapine, states:[23]

### **WARNINGS: INCREASED MORTALITY IN ELDERLY PATIENTS WITH DEMENTIA-RELATED PSYCHOSIS**

**Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. Analyses of seventeen placebo-controlled trials (modal duration of 10 weeks), largely in patients taking atypical antipsychotic drugs, revealed a risk of death in drug-treated patients of between 1.6 to 1.7 times the risk of death in placebo-treated patients. Over the course of a typical 10- week controlled trial, the rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group. Although the causes of death were varied, most of the deaths appeared to be either cardiovascular (e.g., heart failure, sudden death) or infectious (e.g., pneumonia) in nature. Observational studies suggest that, similar to atypical antipsychotic drugs, treatment with conventional antipsychotic drugs may increase mortality. The extent to which the findings of increased mortality in observational studies may be attributed to the antipsychotic drug as opposed to some characteristic(s) of the patients is not clear. [Established medication name] is not approved for the treatment of patients with dementia-related psychosis.**

### **Additional potential for harm of older adults include:**

Some side effects, such as extrapyramidal effects and tardive dyskinesia, can be irreversible and untreatable.

Antipsychotic medications commonly produce extrapyramidal symptoms as side effects. The extrapyramidal symptoms include acute dyskinesias/abnormal, uncontrolled, involuntary movement, and dystonic reactions, tardive dyskinesia, Parkinsonism, akinesia/impairment or loss of voluntary muscle activity, akathisia/inner restlessness and compelling need to be in continuous motion, and neuroleptic malignant syndrome/life threatening reaction to anti-psych drug.

<https://www.ncbi.nlm.nih.gov/pubmed/1359485>



Medication induced dystonia/involuntary contractures of muscles-Medication induced tardive dyskinesia.

**Additional Potential for Harm:** Falling. Confusion. Orthostatic Hypotension. Cognitive Impairment. Delirium.

Imagine being an older adult with dementia and having any or all of these added to your already challenged cognitive ability and functional ability.

CMS Surveyor Guidance lists these as **NOT appropriate reasons to use an anti-psychotic drug** on elders with dementia (*in the absence of a diagnosed mental illness which would benefit its use*):

Wandering, restlessness or mild anxiety

Poor self-care or inattention or indifference to surroundings

Impaired memory

Insomnia

Sadness or crying alone that is not related to depression or other psychiatric disorders

Fidgeting or nervousness

Uncooperativeness (e.g., refusal/difficulty receiving care)

Severe distress

Consideration is given to **use an anti-psychotic drug if there is clearly documented evidence that a resident is threatening substantial harm to self or others AND that appropriate non-drug interventions that are person-centered have been implemented and are documented in the resident's chart.** There are protocols for anti-psychotic use in such emergency situations.

#### **What are the intersections between staffing, deficiencies, and anti-psychotic use?**

KABC asked Dr. David Kingsley, PhD Health Statistician, to look at the data and provide preliminary analysis and modeling. While early in the work, Dr. Kingsley has noted a number of things that bear a closer look.

“Given the data provided by CMS, we set about to discover models that would provide the best scientific evidence for levels of anti-psychotic use. The question is: “What predicts the number of patients with dementia receiving anti-psychotics in a nursing facility?” Hence, what we have available to us are: (1) percentage of patients receiving anti-psychotics, (2) results of state inspections, and (3) staffing levels. None of these measures are voluntary. Rather, CMS requires the submittal of them by each facility. It is our intention to enhance these data with other demographic and epidemiological sources.

Indeed, we noticed stark differences in the level of patients receiving anti-psychotics and the size of the community in which facilities are located. In the smallest communities of less than 1000 population, facilities, on average, had 25.8% of residents receiving psychotropic medications. As communities increased in size from 1000 to 100,000 a clear pattern of decreasing average levels of psychotropic drug use appeared in the data. However, the average in nursing facilities in communities of 100,000+ population increased rather sharply.

<u>Population</u>	<u>Percentage of Psychotropics</u>	<u>N*</u>	<u>SD**</u>
Less than 1000	25.7	39	18.0
1000 to 4,999	19.6	100	12.5
5,000 to 29,999	17.4	68	13.5
30,000 to 49,999	15.5	13	8.2
50,000 to 99,999	16.5	9	7.2
100,000+	22.0	55	21.9

\*Number of facilities in the analysis

\*\*Standard Deviation (this is a measure of the spread of the data and perhaps the homogeneous nature of the facilities).

Because facility direct-care staffing levels are for the first time available which are taken from an auditable data source/payroll, we were able to explore the relationship between staffing and the size of communities. **Again, we saw an interesting pattern in the data: the level of average RN hours in facilities was related to the level of anti-psychotic drug use.**

<u>Population</u>	<u>Average RN Hours</u>	<u>SD**</u>
Less than 1000	.40	.19
1000 to 4,999	.43	.21
5,000 to 29,999	.48	.48
30,000 to 49,999	.43	.25
50,000 to 99,999	.46	.24
100,000+	.48	.29

The third variable of interest, the number *serious deficiencies*, appears to also be related to the level of anti-psychotic drug use and to the level of staffing. Hence, the number of serious deficiency citations for “immediate jeopardy,” “abuse and neglect,” and “actual harm” were summed for each facility as a new variable. The sum of these serious deficiencies were categorized into a new four level variable with 1 as the least number of deficiencies and 4 being the most. A clear pattern is evident when the average RN hours and the average percentage of anti-psychotic drug use are crossed with the four levels.

<u>Serious Defect Category</u>	<u>Avg. %Psychotropics</u>	<u>Avg. RN Hours</u>
1	15.6	.43
2	20.7	.53
3	20.2	.43
4	21.8	.37

We believe that we have identified important variables for further research pertaining to the utilization of anti-psychotic drugs. The model presented in this report is tentative. We cannot

state with any certainty what causes over-medication of nursing facility patients. However, we are encouraged by the patterns we have identified and our initial modeling results.

### **What could create positive change for older adults in Kansas?**

- Require written, signed informed consent by the resident or their legal representative before administering an anti-psychotic drug to an older adult without diagnosis supporting a CMS approved condition.
- A fully staffed and trained KDADS adult care home survey/inspection unit; direct KDADS to fully utilize the oversight tools it has to cite deficiencies for actual severity of harm levels residents experience, cite appropriate state and federal deficiencies specific to chemical restraint, apply Civil Monetary Penalties for non-compliance
- KDADS create policies and provide leadership for a single focused, statewide reduction effort
- KDHE provide oversight and direction to MCO's to achieve the 10% annual reduction in the KanCare contract; publish progress result data; set higher reduction goals
- Empower K-TRACS to identify and educate prescribing physicians on the dangers of anti-psychotic drug use on older adults with dementia; and to contact residents or their legal representative to inform them about dangers of anti-psych drug use
- Include dementia disease progression, intervention and treatment (non-pharmacologic and pharmacologic) in administrator, operator, nurse and nurse aide curriculums. Include requirement for continuing education for administrators, operators, nurses and nurse aides working in adult care facilities.
- Address the need for safe staffing levels on all shifts and consistent staffing for residents in facilities

Mitzi E. McFatrach, Executive Director - On behalf of Board of Directors, Members and Volunteers

KABC is a not-for-profit organization, beholden to no commercial interests and is supported almost entirely by donations from citizens who support our mission of improving the quality of elder care in all long-term settings. KABC was among a handful of non-profit consumer advocacy groups which worked to win passage the Nursing Home Reform Act of 1987. Our interest is in quality elder care at home, and in licensed adult care facilities.