

Geriatrics Interest Group

Confessions of Country Doc: “Dementia with Behaviors” is Not a Diagnosis

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You may have never heard the term “dementia with behaviors” and that would make me happy. However, as Epic and other electronic health records continue their slow, crushing domination of our work lives, you probably will. I first came across the term when trying to populate a “problem list” for a patient with dementia. The computer gave me only two choices when I typed in “dementia.” I was forced to choose

between “dementia with behaviors” and “dementia without behaviors.” I was immediately incensed and stewed on this new twist forced upon my medical judgement. (I know, I should probably get out more). Not only do I think that neither of the choices are actual diagnoses, but I’m weary of forever labeling a person as having “behaviors.”

Our current understanding of dementia and its treatment is less than satisfying. We can’t tell an alive person exactly which subtype they have, we can’t predict how it will progress, and we don’t have good medicines to treat it. If you’re looking for a simple and refreshing definition for dementia, consider Dr. G. Allen Power’s reflection, “Dementia is simply a different way of looking at the world.” (If you’re interested, his enlightening books include *Dementia Beyond Disease and Dementia Beyond Drugs*). In my opinion and experience, the best and most effective treatments for dementia are love and compassion, not drugs.


The problems with diagnosis “dementia with behaviors” are many. First, it implies that the person with dementia has bad behaviors. Second, it implies that the person with dementia has chosen to make those bad behaviors. (In fact, in this sense, it would be more accurate to label people as “diabetes with behaviors,” “COPD with behaviors,” “heart disease with behaviors,” etc.). Third, it forever links the person’s dementia diagnosis with bad behaviors — a rap sheet that will forever color the decisions of the dozens or hundreds of providers down the line. Finally, and most distressing, the diagnosis “dementia with behaviors” seems to allow doctors to prescribe antipsychotic medications with reckless abandon.

Let me tell you about Ken. I looked after Ken for years in the locked dementia unit where he was captive lived. Ken’s dementia was profound, he spent his days sitting quietly and smiling. He never spoke a complete sentence to me. Ken had previously been diagnosed with “dementia with behaviors.” Ken was also a championship defecator. One day, he struck out at a caregiver and was sent to the emergency department. He was admitted to a geriatric psychiatric unit where his “behaviors” were treated with antipsychotic medications during a week-long admission.

The problems, it turned out, were me and the caregiver. I incorrectly had him on an aggressive chronic bowel regimen he didn’t need. On the day in question, the caregiver decided to clean him up with three BOXES of wipes. At some point during the cleaning, Ken had enough and communicated in the only way he could — a push. So it was really not Ken’s

“behavior” that was the problem, it was ours. When I figured out the issue and when Ken came back to me, I did my best to scale back his bowel regimen and antipsychotics.

Don’t get me wrong, people with dementia can have behavior problems. However, the “behaviors” are often very human and natural responses to things none of us would like: being in an unfamiliar place, being scared, being cold, being in pain, being wiped excessively, suffering an acute medical illness, and the list goes on. People with dementia can also have depression, anxiety and other conditions that should be treated. Finally, I don’t pretend to claim that I have never prescribed antipsychotics to old people with dementia. I will admit, however, that I am embarrassed that I have.


 A photograph of an elderly man with white hair and glasses, wearing a light-colored shirt. He is looking out a window, with his back to the camera. The window shows a bright, outdoor scene.

“Pry apart the ‘behavior’ from the ‘dementia’ and free your mind.”

So, on your next shift when you meet a patient branded “dementia with behaviors,” remind yourself that it is at best a sloppy term and at worst a dangerous label that could lead to misdiagnosis and antipsychotic medications. Pry apart the “behavior” from the “dementia” and free your mind.

Consider what is really going on. Is the patient delirious? Is there a new underlying medical condition or adverse drug event? Was the “behavior” simply situational? As is often the case, family is present and you’ve already called the facility for more information. During their time in the ED, you have an opportunity for concentrated doctoring — focused and intense time with a patient, the family, and their caregivers. That time, along with ability for rapid testing, can be worth weeks of office visits.

Ok, I’ve ignored Epic for too long, she’s getting jealous. I need to get back to figuring out how to diagnose people again; six clicks for an ankle sprain, seven clicks for pneumonia, etc. Not to mention being the transcriptionist, coder, and biller that medical school and two residencies trained me for. (But that’s a different rant).

I look forward to hearing from you. info@aaem.org ●