The Ethics of Antipsychotics in Alzheimer’s

**The Case**
An 86-year-old woman with Alzheimer’s disease was involuntarily discharged from a nursing home for wandering, agitation, and fighting. These undesirable behaviors persisted despite medication management by a consulting psychiatrist throughout her 6-month stay. She received escalating doses of quetiapine (475 mg/24 hours) and venlafaxine (225 mg/24 hrs) and underwent a 10-day involuntary psychiatric hospitalization for medication management.

Facility staff reported that the resident wandered into others’ rooms and slept in their beds. She fought with other residents over a baby doll. On more than one occasion, she struck staff when they awoke her or when they attempted to remove her undergarments to provide incontinence care.

The patient was ultimately transferred to a facility 40 miles away. At the time of admission there, she was somnolent, slouched in a wheelchair, and unable to walk. She required assistance with all activities of daily living. Over the next 2 weeks, the quetiapine and venlafaxine were discontinued.

Her level of alertness promptly improved. In discussion with her family, it was learned that she had osteoarthritis for which hip replacement had been recommended many years ago but never performed. Acetaminophen four times per day was added. Physical and occupational therapy was provided.

She regained the ability to ambulate. She would periodically wander into other residents’ rooms and nap in another resident’s bed, as did many other residents. After a brief period of distress caused by a misplaced baby doll (which she believed to be her infant child), three more identical dolls were purchased by the facility and kept in the unit manager’s office to replace her doll as needed.

Facility staff responded to periodic episodes of agitation with reassurance, conversation, organized activities, distraction, and walking. At mealtime, she believed that she was the hostess at a large party and would not eat until others had eaten. Facility staff went along with her belief and offered her food at other times along with frequent snacks, in addition to meals in the dining room.

**Discussion**

The case above illustrates, in the first facility, common “undesirable” behaviors in a patient with Alzheimer’s disease: conflict between the patient, other residents, and staff; and the use of antipsychotic and other psychotropic drugs to control behavior and prevent conflict—without success. The patient was in conflict with her environment, and the environment (human and otherwise) was not capable of or willing to change.

There are many ethical and philosophical issues surrounding the use of medications to control behavior, particularly in patients who are unable to give informed consent. There is concern for patient autonomy (even the right to behave in a certain way) vs. paternalism, beneficence (the obligation to do good) and nonmaleficence (the obligation to do no harm, including harm caused by medication), and justice, in which resources are allocated fairly and the rights of an individual are balanced against the rights of others. There is also concern about medications given over a patient’s objections or possibly hidden in food, raising basic issues of honesty and trust.

Ethical decision making day to day often is based more on pragmatic than philosophical choices. What might seem like a moral or ethical dilemma can often be resolved by collecting and evaluating facts that show potential courses of action to be obvious or impossible. If the facts themselves can point the way, then at least some amount of moral anguish can be avoided.

In this case, the questions should have been, “Do antipsychotic drugs control behavior in dementia? Do they cause problems? Does the benefit, if any, outweigh the risks?”

**By the Book**

The literature on antipsychotic drug use in dementia can be summarized as follows: These drugs are harmful, they are ineffective in treating behavior, and their use varies significantly from facility to facility according to the culture of the facility, not patient characteristics.

The use of antipsychotic drugs in elderly patients is discouraged by the Food and Drug Administration and other regulators. Many consumer groups are strongly opposed to their use as well. Antipsychotic drugs have no FDA-approved indication for treatment of patients with dementia. On the contrary, each carries a “black box” warning against the use in elderly patients with dementia.

In 2005, the FDA issued a warning of increased risk of death in elderly patients receiving antipsychotic drugs. That risk emerges even after a very short period of taking such drugs. Antipsychotics slow brain functioning in patients whose brain function is already diminished by dementia. Along with many other medications (including venlafaxine in this case), antipsychotic drugs reduce levels of acetylcholine in the brain. The majority of drugs used to try to maintain brain function in dementia (cholestase inhibitors) work by raising acetylcholine levels in the brain.

Although anecdotal reports by many clinicians trumpet the drugs’ ongoing use, the best evidence indicates that antipsychotics are ineffective at treating behavior in dementia. In a well designed, large multicenter double-blind placebo-controlled study (the CATIE-AD trial), antipsychotic drugs were ineffective against behaviors in elderly patients with dementia but had significantly more adverse effects, including confusion and sedation, than did placebos.

Based on the principles of beneficence and nonmaleficence, therefore, as well as the concept of futility, the ethical foundation for prescribing antipsychotic drugs to patients with dementia appears quite shaky. Why then are these medications still so widely used, even in nursing facilities with their own rules against them? I think it comes back to the notion, “If all you have is a hammer, everything looks like a nail.”

The widespread use of antipsychotic drugs to control behavior in confused elderly patients, particularly in health care settings, often represents either a fundamental misunderstanding of behavior in dementia, if not a fundamental misunderstanding of the disease itself, or an unwillingness or inability to change the environment, alter one’s approach to the patient, or to acknowledge the reality of the patient’s status.

There also tends to be an exaggerated and unrealistic hope and expectation among prescribers and other caregivers, bordering on fantasy, that a medication will simply make a person stop doing something undesirable, and quickly. In patients with dementia, trying to change behavior with a drug is like trying to treat infection with acetylamphen. The situation is emblematic of a health care system characterized by a culture expecting conformity and obedience. Patients are supposed to comprehend and conform to their environment, no matter how restrictive, while providers are ill-trained to understand, interpret, and respond to behavior. Their culture tends to blame the patient. Likewise, inappropriate antipsychotic prescribing is emblematic of a broader culture that tends to medicalize all aspects of human existence and consequently regards the normal human condition as a drug-deficient state.

**A Different Paradigm**

Simply put, behavior is communication. Behavior itself is not a disease. In people whose ability to communicate with words is limited (such as patients with dementia), communication tends to be more nonverbal (i.e., behavioral).

Many of the behaviors that are common in patients with dementia and that are often labeled as difficult, challenging, or bad—such as agitation, wandering, yelling, inappropriate urination, and hitting—are typically reactive, almost reflexive behaviors that occur in response to a perceived threat or other misunderstanding. These people, by definition of their underlying illness, have an impaired ability to understand.

Moreover, all of the challenging behaviors exhibited by confused elderly patients in health care settings across the country every day are identical to behaviors by normal, healthy, very young children in day care centers and preschools. While the behaviors are often the same, the expectations and responses are often quite different, particularly in health care settings.

What is necessary is for caregivers to try to figure out the meaning of the behavior: What is this person trying to say? What is he or she responding to? What is my behavior telling this person? Interpreting behavior is helped by some understanding of a person’s life experience, as well as some understanding of his or her underlying health.

Identifying factors such as pain, anxiety, and loss of a familiar object, person, or place may be invaluable to the caregiver in developing an appropriate response. In most instances, the key to behavior management in dementia is environmental modification, which may be as simple as changing our approach to prevent and minimize distress.

Even if there were a magic pill to make people behave a certain way, we probably wouldn’t make anyone (but ourselves) take it. And we should probably be suspicious of anyone who suggests that we are doing it ourselves. The fundamental basis of health care is caring for others. The fundamental basis of caring is love and acceptance.

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