The Case
An 87-year-old woman with Alzheimer’s disease, visual impairment, and hearing loss hit a facility caregiver while the person was attempting to change the patient’s clothing during her morning routine. Nursing staff responded by administering 1 milligram of injectable lorazepam, as the patient would not take the medication orally.

Subsequently, the patient was seen by a psychiatrist, who prescribed risperidone as well. The patient would then frequently refuse to take the medication or spit it out. Consequently, facility staff administered her medication surreptitiously by hiding it in her food.

As a result, the patient often refused to eat, claiming that facility staff were poisoning her. With her hearing loss, she could see staff members talking but could not hear them. Her caregivers described her as “frequently agitated,” “yelling out constantly,” and “paranoid.” One noted, “She says people are whispering about her.” In response, twice daily quetiapine was added.

The patient had a daughter who had cared for her mother in her own home for 3 years and now visited the facility frequently. The medications administered to her mother had not been specifically discussed with her. When she realized that her mother was not eating well, the daughter began bringing her mother favorite foods from home, which she appeared to enjoy.

Discussion
This case illustrates several phenomena that are fairly common in the care of patients with dementia, as well as in patients with an impaired ability to communicate. This resident had difficulty comprehending her situation and so assumed that others were whispering about her. This is common in older patients with hearing loss, even those without dementia. The woman did not understand that she was “yelling” because she could not hear how loud her voice was to others.

The resident thought that she was being poisoned, with good reason. She was, at least, that what her food tasted like to her. Administering medication with food such as applesauce or yogurt for people who have trouble swallowing pills is one thing, but hiding medication in food is a bad idea all the way around. In the first place, it makes food taste bad, so people eat less and end up losing weight. More importantly, it is dishonest and destroys trust. What better way to make someone paranoid than to lie to them?

Using a drug urgently to treat a behavior that has already occurred is a lot like slamming the barn door after the horse has left. Many medications take quite some time to work, and the onset of their effects may be further delayed in elderly people.

Urgent drug administration is often associated with the prescriber’s and the staff’s unrealistic expectations for almost magical, immediate, and complete cessation of undesirable behavior. The use of these medications often distracts from the real work of trying to understand what the behavior means in order to address the underlying issue itself.

Moreover, these drugs are simply not at all what they are cracked up to be, in terms of controlling behavior. They simply don’t work very well for that, to say nothing of their significant risks. Such drug administration after the fact may be seen as chemical restraint or even punishment.

This patient had a daughter who was very interested in her mother’s welfare. In the absence of a written advance directive, in almost every state, the daughter as next of kin would be the lawful surrogate decision maker. Nevertheless, neither the daughter nor the patient was informed of the medications to be administered or the goals, risks, or benefits of their administration, and neither woman was given an opportunity to consent to or decline drug therapy.

This case also illustrates the problem of multiple prescribers. The attending physician is ultimately responsible for all of the medications his or her patient takes and therefore should be required to approve all orders prior to any new drug being administered.

Autonomy, the fundamental right to make decisions on your own behalf, is the first ethical issue broached by this case. In some cases, autonomy equals freedom. It is an essential civil liberty. In the context of health care, autonomy consists largely of making medical decisions on your own behalf.

To do so requires adequate information about the choices available; their risks, burdens, and benefits; and the underlying condition for which treatment is being considered. Of course, autonomy without power is meaningless. Knowledge is power, or at least a prerequisite. That is, knowledge is a basic requirement of autonomy; hence, the principle of informed consent.

Informed consent is autonomy in action, and it is the principal way autonomy is assured. It is making an informed decision about testing or treatment after receiving sufficient information to be able to reasonably choose among options.

When the patient is unable to make or communicate decisions, informed consent must be obtained from the person’s surrogate. In both cases, informed consent requires that the health professional providing the information be knowledgeable about treatment choices and able to give accurate, factual information free from bias regarding the options’ risks, benefits, advantages, and disadvantages. And the provider must be capable of answering reasonable questions completely.

Informed consent is an individualized and ongoing process, not an event. It involves two-way communication. Merely signing a consent form after reading information about a test, treatment, or procedure does not constitute informed consent. At the heart of informed consent is respect for individual patient choice. A minimum requirement of patient-centered care is informed consent.

Maintaining autonomy requires planning and communication when times are good as well as when times are bad. It involves discussing goals of care for the moment as well as for the future. Perhaps most importantly, it involves time, the scarcity of which limits our success more than anything else.

A lack of information makes communication with families and knowing what to do difficult. It undermines our ability to promote autonomy. Advance directives as well as something as basic as family phone numbers are often missing in an elderly patient’s medical chart.

Identifying goals of treatment in advance of an emergency or any treatment is a basic aspect of care planning for patients in long-term care settings, if not all care settings. We also must be mindful that in clinical situations, our desire to do something, anything, is strong. We almost always believe that our intentions are good. The desire to act may be so strong, however, that if we are not careful, it can trump both good judgment and a patient’s fundamental right to self-determination or a surrogate’s right to assume that responsibility.

Informed consent is the primary means by which we assure patient autonomy. It is the basis for patient-centered care. Despite the prime importance we place on individual freedom in this nation, we still have a long way to go to promote and protect individual liberty in health care.

Medical Ethics

By Jonathan Evans, MD, MPH, CMD

Informed Consent With Psychotropic Drugs Involved

It is a problem in this country that many people are not given the choices they have a right to. No consent means no autonomy. It is as much a problem that many people have their choices (often expressed in the form of an explicit advance directive) overruled or ignored. And many people are given a false choice based upon incomplete or bad information regarding likely outcomes.

Ordinarily, autonomy trumps beneficence; the obligation to do good. Very occasionally, however, beneficence trumps autonomy: when an individual’s choice is not known and an emergency requires an immediate decision to save a life.

This may certainly be true during a seizure or cardiac arrest, but it is not true in the face of reactive, almost reflexive behaviors in a person with dementia. These almost always represent a conflict between an individual and his or her environment (often the human environment). Moreover, identifying goals of treatment in advance of an emergency or any treatment is a basic aspect of care planning for patients in long-term care settings, if not all care settings. We also must be mindful that in clinical situations, our desire to do something, anything, is strong. We almost always believe that our intentions are good. The desire to act may be so strong, however, that if we are not careful, it can trump both good judgment and a patient’s fundamental right to self-determination or a surrogate’s right to assume that responsibility.

Informed consent is the primary means by which we assure patient autonomy. It is the basis for patient-centered care. Despite the prime importance we place on individual freedom in this nation, we still have a long way to go to promote and protect individual liberty in health care.

Medicalizing behavior as illness tends to undermine individual liberty. Antipsychotic and other psychotropic drugs should not be administered without informed consent. The argument that they must be administered, in order to prevent harm to self or others, is seriously undermined by the reality that the controlling effect of these medications on behavior can be minimal at best, and that their onset of action is often too slow to have even a tranquillizing effect on a patient in immediate distress.

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