

January 15, 2014

Senator Ayer and members of the Health and Welfare Committee,

Thank you very much for inviting me to testify on this important issue. My name is Robert Macauley, and I am a physician and bioethicist. I direct the Department of Clinical Ethics at Fletcher Allen Health Care and am a Professor of Pediatrics at the University of Vermont College of Medicine.

To state the obvious, the question of whether, when, and how to involuntarily medicate patients suffering from mental illness is a complex and emotionally-charged one. In my experience with situations such as this, the various sides often become so entrenched in their respective positions that it is difficult to see the other's rationale and good intentions. The role of ethical analysis is not so much to specify which side is "right," but rather to identify the ethical underpinning of competing views. In so doing, I hope to set the stage for constructive and respectful dialogue by highlighting common interests as well as the fundamental sources of disagreement.

In terms of the current debate, I'd venture to say that all of us agree on three primary goals:

1. Respect individual rights, which includes not overriding a patient's refusal without sufficient reason
2. Help patients in need
3. Protect others—whether other patients, or medical staff—from harm

A perfect solution would achieve all three of these goals, but if a perfect solution existed we wouldn't be here discussing the question. We're faced with an ethical dilemma—a conflict of values—which can have several causes. One is **prioritization**, when different sides emphasize different goals. For example, someone who prioritizes respect for individual rights probably cares deeply about the welfare of patients, but believes that a patient should be able to refuse the help that some people feel he needs.

Another source of disagreement is **definitional**. We probably all agree that a patient's refusal shouldn't be overridden without sufficient reason, but the different sides in this debate disagree as to what constitutes "sufficient reason," and some people go so far as to say that *no* reason is sufficient.<sup>1</sup>

The last point of disagreement goes to the core of the debate: **What does it mean to be mentally ill?** Many patients—such as those suffering from schizophrenia, or bipolar disorder with psychotic features—deny that they are ill at all, or believe that the "mentally ill" version of themselves is truer to who they really are than the "medicated, healthy" version. (I've certainly met patients diagnosed with bipolar disorder who report feeling much happier—and who are clearly more productive—when experiencing mania.) Psychiatrists, on the other hand, would classify this as a lack of insight (the technical term for it is *anosognosia*). They point to studies which show that anosognosia has an anatomical basis,<sup>2-6</sup> which explains why it's common in stroke patients, who may claim that a clearly paralyzed limb is functioning perfectly.<sup>7</sup>

Viewed in this light, one might be tempted to conclude that “ethics” is entirely relative, and anyone’s position carries equal ethical merit. I don’t believe this to be the case, since the three goals noted above provide a solid ethical starting point that a position founded on disregard for a patient’s rights or well-being does not. But once we establish a solid foundation—and acknowledge that there is no perfect solution that achieves every stated goal—the rest of the discussion becomes a choice based on the values of our community. So rather than saying that one’s opponent’s views are “unethical,” I’d prefer us to say that we prioritize or define our common values differently.

In the rest of my testimony, I’m going to spend a fair bit of time on the concept of “autonomy,” which some people erroneously reduce this debate to a question of. I’ll go on to identify some ethically and clinically relevant issues which the competing sides view differently, and conclude with an overview of the process.

## **Autonomy**

### ***“Liberal” versus communitarian ethics***

Largely in response to the spirit of paternalism that previously ruled medicine—and especially psychiatric practice—the pendulum swung in the other direction in the last quarter of the 20<sup>th</sup> century, which some have referred to as “the era of radical autonomy.” This reflects a “liberal” world view, with the term not referring to a political party but rather to an emphasis on individual rights, which have become the trump card in much modern ethical discourse.<sup>8</sup> The “right of autonomy” becomes preeminent, and any potential compromise of this right is rejected out of hand.

It’s important to note, though, that some hold more of a communitarian ethic that prioritizes cooperation and the common good rather than the absolute right of the individual. For example, it would seem morally justified in certain situations to compromise one person’s freedom to protect others, like by taking away a drunk person’s car keys. In a medical context, patients sometimes are compelled to accept medical treatment on behalf of others, such as in the case of a patient with multi-drug-resistant tuberculosis.

I think we’d all agree that both individual and communal rights are important, but different people prioritize them differently. Ultimately, the question we’re addressing today may boil down to a debate between “let me live my life on my own terms” and “how do we all live together.”

### ***“Autonomy” is infringed upon in non-psychiatric medicine***

A larger issue that is relevant to today’s discussion is the degree to which patients suffering from psychiatric illness are treated differently than those suffering from non-psychiatric illness. Some have argued that this distinction should be eliminated, but without addressing that larger question it may still be helpful to note that the refusal of treatment by a patient with non-psychiatric illness may legally be overridden in certain situations, even without

judicial involvement. Vermont statute permits treatment over objection when three conditions are met:

1. The principal lacks capacity;<sup>a</sup> and
2. The principal will suffer serious and irreversible bodily injury or death if the health care cannot be provided within 24 hours; and
3. If the principal has an agent who is reasonably available or an applicable provision in an advance directive, then the agent or advance directive authorizes providing or withholding the health care. (Vermont Statute §9707.g.1.B)

The classic example is an otherwise healthy college student who contracts meningitis, which is causing sufficient confusion to lead him to refuse the antibiotics that are necessary to save his life. I think even the fiercest defender of “autonomy” would be hard-pressed to criticize treatment over objection here, as in this case the refusal is “the disease speaking,” rather than the patient. (A shot of penicillin in this case could, technically, be termed “involuntary drugging,” which I think highlights the benefits of using terminology free of burdensome connotations.)

### ***We’re really not talking about autonomy***

The reason I’ve sometimes put the word *autonomy* in quotation marks is because not every refusal of treatment is truly “autonomous.” Some people reduce autonomy to a freely made choice that doesn’t hurt anybody else, but that is an awfully low bar that doesn’t do justice to how we as a community take care of each other. If that’s all “autonomy” is—and the right of autonomy is sacred—then we should let the college student with meningitis die for lack of antibiotics, and watch passively as a drunk person staggers out of a lakeside bar to test just how thick the ice on Lake Champlain is these days. I don’t think any of us would do that, precisely because those are not truly “autonomous” decisions.

Autonomy literally means “self rule,” and an autonomous decision requires three things:

1. The person understands the situation in which they find themselves;
2. The person understands the risk and benefits of various options; and
3. The person applies their own values to making the decision.<sup>9</sup>

It might be helpful to provide examples of non-autonomous refusals that involve mental health. An oft-cited one comes from a recent magazine article describing the case of Linda Bishop, a fifty-one year old college graduate who suffered from bipolar disorder with psychotic features, who refused psychiatric medication. She died in early 2008 from starvation, after breaking into an unoccupied home in New Hampshire and subsisting for months entirely on apples, while she waited for a casual acquaintance whom she hadn’t seen in over a decade—whom she considered her husband—to come rescue her.<sup>10</sup>

Another example comes from a patient I once consulted on, who had heart failure and schizophrenia. She felt her cardiac symptoms were caused by ray beams shot by aliens through her apartment walls. She refused her heart medications because she believed (correctly) that the

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<sup>a</sup> The right of patients with capacity to refuse any treatment—even one that is life-sustaining—is clearly codified in ethics and the law.

medications were powerless against alien ray beams. Hers was not an autonomous refusal because it was predicated on a fundamental misunderstanding of reality.

Both Linda Bishop and the woman with heart failure lacked the capacity to make an autonomous decision. Usually the first step in such cases is to attempt to restore that capacity. There are many remediable causes of incapacity in a patient with non-psychiatric illness (such as sedation from pain medication), but for a patient with psychiatric illness, it is the illness itself that causes the incapacity. This creates a Catch-22: we can only restore capacity by treating the illness, and we can't treat the illness because the patient lacks capacity (and is refusing the treatment). The purpose of involuntary medication is not merely to make the patient "better," but to restore their decisional capacity so they'll be able to make autonomous choices.

I want to be clear that even if the refusal of a patient who lacks decisional capacity is not truly autonomous, it still carries moral weight. Treating a patient over her objections is, at the very least, a violation of her bodily integrity, and how much scarier must it be to be subjected to compulsory treatment when you don't understand the reason for it?

Clarifying the role of autonomy in no way lessens our obligation to be extremely thoughtful about treating a patient over her refusal. And concluding that a patient is incapable of making an autonomous decision doesn't necessarily mean we should override their refusal. Both the burdens of treatment and the ramifications of non-treatment need to be considered, and here it's worth noting that I recommended against involuntary treatment of the patient with heart failure, because I felt the overall burdens of involuntary treatment outweighed the benefits.

### ***Ethically and clinically relevant issues in determining if and when to involuntarily medicate a patient***

In the interest of time I'll move through these issues rapidly, with the intention of highlighting the sources of disagreement:

- **Capacity to make an autonomous decision:** Does the patient understand their situation and the relevant treatment choices, and is he or she able to apply his own values to the decision? I want to be very clear that these are not necessarily society's values, or the choice advocated by the medical establishment. People have the right to their own unique beliefs and idiosyncrasies, but it seems tragic to allow someone to suffer or even die based on the delusion of alien ray beams, or a relationship that never existed.
- **Benefits of involuntary medication**
  - To the patient
    - Expedient treatment lessens global psychopathology, leads to fewer positive and negative symptoms, and improves functional outcomes, at least for first episodes of schizophrenia.<sup>11</sup>
      - Here it's relevant to note that even some vocal opponents of involuntary medication in general grant the validity of treating the initial presentation of conditions such as

schizophrenia, when there was no prior opportunity to complete an Advance Directive with a Ulysses Clause<sup>12</sup> (which I'll discuss in further detail in a moment).

- Involuntary treatment without medication is not value-neutral
  - Confinement constitutes a “massive curtailment of liberty.” (U.S. Supreme Court, *Humphrey v. Cady* [1972])
  - Medication-refusal leads to higher rates of restraint and seclusion.<sup>13-18</sup>
- To medical staff
  - Refusal of medications increases the risk of assaultive behavior in the hospital.<sup>15,16,18-23</sup>
- To other patients
  - Less violent/disruptive behavior protects the “therapeutic milieu.”
  - A prolonged process leading to involuntary medication leads to longer length of stay,<sup>15,17,18,21</sup> which can delay admission and treatment of other patients (whether voluntary or involuntary).
- **Drawbacks of involuntary medication**
  - Violation of bodily integrity (not “autonomy”)
  - Profound impact on one’s sense of self, which would less restrictively be accomplished by spontaneous improvement
  - Potential for rare but significant side effects (such as malignant hyperthermia)
  - Contribution to well-known long-term side effects (such as tardive dyskinesia), since over time “short-term” logically becomes “long-term”
- **Evidence as to what the patient would have chosen, if he had capacity:** The gold standard for medical decision-making is the autonomous decision of a competent patient, so if a patient currently suffering from mental illness is unable to make an autonomous decision in real time, ideally he or she would have previously completed an Advance Directive with a Ulysses Clause, specifically granting the right—or explicitly refusing—to be medicated over objection at a time of incapacity. Studies have shown that some patients who were involuntarily treated are subsequently glad this occurred and some are not,<sup>24</sup> so it behooves us to make a concerted effort to address future similar occurrences with patients who have regained their decisional capacity.

### ***When: assuring due process***

The process of determining whether to involuntarily medicate a patient depends on two elements:

1. Acquiring relevant information, including independent psychiatric evaluation and prior evidence of the patient's wishes, at a time of capacity
2. Giving the patient an opportunity to spontaneously improve, regain decisional capacity, or voluntarily agree to accept medication—all of which are less invasive than involuntary administration—counter-balanced against the clinical deterioration that may accompany waiting periods

In my opinion, logistical or systems-related delays in accomplishing #1 have no ethical relevance, and if the timing of a hearing for involuntary medication is dependent on *others* finding the time to do the work the patient requires, then ours is a capricious system, indeed. I would argue that all steps should be taken to acquire this information without delay, and whatever interim period is allotted between that and the hearing be a conscious, thoughtful choice, based on the likelihood of spontaneous improvement, regaining of capacity, or voluntary acceptance, which would be evaluated on a case-by-case basis and substantially influenced by the patient's psychiatric history, if any.

That Vermont has one of the longest waiting periods for an order for involuntary medication is, according to the 2008 report, a fact. Whether we wait too long or other states don't wait long enough is a question of values (in other words, an ethical question). It's also a bit of a misleading question, as I believe our concern should not be with averages but with particulars, for I could imagine some cases where expediting involuntary treatment is indicated (such as for a patient who experienced significant benefit from involuntary treatment in the past) and others where it is not (such as for a patient who in the past spontaneously improved after a reasonable period of time). I trust that whatever system is put in place views patients as individuals, and not the basis of statistics.

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