

Hospitals rationing drugs behind closed doors—a civil rights issue

February 23 2016, by Wendy F. Hense And Leslie E. Wolf, Georgia State University



Credit: Karolina Grabowska from Pexels

The United States is facing a shortage of prescription drugs, ranging from antibiotics to cancer treatments. These shortages are putting the

medical profession in the frequent position of deciding who will get the drugs that are in short supply and, more importantly, who will not.

Physicians and hospitals always have had to make rationing decisions in times of shortage. But these decisions usually are made behind the scenes. A recent [New York Times article](#) about the drug shortages shines a light on the rationing that is occurring.

According to the article, the decision-making process varies considerably across institutions. For instance, in some hospitals formal ethics committees make these decisions. At others, these decisions are made by individual physicians, pharmacists or even drug company executives.

And, as the article also reports, [patients](#) typically are not told of the shortage and have no idea that their choice of [treatment](#) has been limited, even though the decision may delay their recovery, increase their pain or, in some cases, potentially accelerate their death.

As legal experts in medical ethics and disability law who have conducted research on the allocation of medical resources, we were struck by the general lack of awareness of the law evident in the article. The fact is, there are [civil rights](#) laws and state laws governing informed consent that apply to such decisions, even in times of public health emergencies and medical shortages.

These laws constrain physician decision-making and must be taken into account on the front end in making treatment or distribution decisions for all patients and in particular, we would argue, for patients with disabilities.

Bias against people with disabilities

In 1990, Congress passed the Americans with Disabilities Act (ADA) to provide protection to people with disabilities and assure equal opportunity, access and participation in all areas of public life. The ADA applies to both public and private hospitals, as well as physicians providing care to patients.

The ADA prohibits the use of any eligibility criteria that would screen out people with disabilities from receiving necessary services, including medical care.

But, in the past, drug and treatment allocation protocols or distribution plans created by medical professionals in times of shortage have failed to acknowledge that the ADA limits their discretion.

In 2013, [we reviewed the allocation protocols](#) developed by public health and medical organizations in providing critical care, such as ventilators, to guide medical decision-making in the event of shortages during an H1NI flu pandemic.

Some of these groups have made recommendations that physicians restrict access to treatment based on patients' diagnosed disability, their anticipated quality of life, the duration or intensity of their need for care and the treatment effectiveness.

All of these criteria to varying degrees raise the troubling potential for disability bias to play a role.

For example, categorically preventing all individuals with severe mental retardation from all access to ventilators clearly violates the ADA. Likewise, refusing to treat an individual with cystic fibrosis for swine flu because he will still have cystic fibrosis after treatment, and thus a "poor quality of life," is unlawful.

Quality of life assessments allow the prejudices of health professionals and laypeople, who systematically underestimate the quality of life experienced by people with disabilities, to result in the denial of treatment.

To stop bias, decisions should be made in the open

Given this background, there is little reason to believe that allocation decisions in other situations where medicine or equipment is in short supply will be free from bias against people with disabilities.

The *New York Times* article coincided with the publication of an ethical framework for [allocating pediatric cancer drugs](#) in the *Journal of the National Cancer Institute*. The authors bring attention both to a persistent problem of drug shortages and to the need for a more transparent and inclusive process for deciding who should get rationed drugs.

Although this particular decision framework laudably rejects consideration of disability, it fails to recognize or discuss the fact that such consideration is legally impermissible under the ADA. As to the kinds of [ad hoc decision-making described in the *New York Times* article](#), they are even less likely to appreciate what the ADA requires.

Secrecy prevents informed consent

The secrecy surrounding allocation decisions is also in conflict with state laws concerning informed consent.

Patients have a right to know when and why their physicians restrict their access to viable treatment options. State [tort](#) law governs when a physician must give this information to her patients. Indeed, state courts explicitly lay out when a physician must give this information to her

patients.

Just over half the states have adopted [a physician-centered standard](#) that allows the profession to determine when disclosure is desirable. Other states have adopted the more [liberal patient-centered standard](#), which requires physicians to disclose information that most patients would find relevant to their treatment. Under either standard, physicians have a legal obligation to inform patients of shortages when the shortages affect their care, the risks they face, or their prognosis.

Patients have the right to make informed decisions about their treatment options. This includes knowing when they are being denied effective and otherwise recommended treatment because there is a drug shortage.

The [drug shortages](#) are not likely to go away any time soon. Although the [medical profession](#) must make hard choices about how to allocate care, these decisions need not and should not be shrouded in mystery.

We need to acknowledge that rationing decisions are being made in the U.S. health system. The limitations on care, the reasons for them and how care will be dispensed should be debated openly.

And those discussions must include the voices of people with disabilities, who so often have been impacted by such decisions. They should also include civil rights experts who can ensure that any allocation protocol incorporates the legal protections society already has put in place.

It is neither fair for physicians to bear this burden alone nor right for people with disabilities unknowingly to be affected at the most fundamental level by decisions made behind closed doors.

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