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INSIDE



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# Ebola spotlights growing tension between patient autonomy and public health

*Bioethicists "can and should" be part of conversation*

Should cardiopulmonary resuscitation (CPR) be given to end-stage Ebola patients, despite the risk to health care providers? What training is necessary at this point to ensure staff and patients are protected?

As hospitals grapple with these and other questions surrounding treatment of Ebola patients, bioethicists need to be involved, urges **Janet L. Dolgin**, PhD, JD, co-director of the Hofstra University Bioethics Center in Hempstead, NY. Dolgin is also director of the Hofstra University's Gitenstein Institute for Health Law and Policy.

"Without prescriptions and guidelines, we flail around and fail. But once they get cemented in stone, we're in trouble," she says.

One ethical concern with Ebola is to avoid treatment "that's a product of fear rather than well thought-out responses," Dolgin says. "We need policies. But at the same time we need to be ready to challenge them."

Bioethicists are well-suited to help

## EXECUTIVE SUMMARY

Bioethicist involvement is necessary as hospitals develop policies involving treatment of Ebola patients.

- Patient autonomy may have to be limited to protect the public health.
- There is a duty to provide necessary care, and to ensure a patient is not abandoned.
- Hospitals have an obligation to provide proper care for Ebola patients within the limits of their resources.

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**EDITORIAL QUESTIONS**
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craft organizational policies, suggests Dolgin, in light of their dual focus on population health and on the health of individuals.

**R. Alta Charo**, JD, Warren P. Knowles professor of law and bioethics at University of Wisconsin Law School in Madison, WI, points to other situations that posed similar challenges for bioethicists, such as the early years of the AIDS epidemic when there were no therapies for the disease.

"HIV infection was viewed as a near-term death sentence," she says. Many hospitals and medical practices had to decide whether any or all staff might refuse to provide care, based on fear for their own safety.

Many institutions viewed the duty to care as an institutional duty, and allowed individual providers to recuse themselves, provided that someone was there to care for the patient. "In other facilities, this was viewed as an unfair burden on those who would be left to provide the care, and [those facilities] insisted that all providers participate," says Charo.

## Limitation of patient autonomy

The history of the field of bioethics is very relevant to understanding the current ethical concerns involving treatment of Ebola patients in the United States, according to Dolgin.

"Bioethics was put together as a discipline in the 1970s, at a time when it looked like we could handle disease, particularly contagious diseases," says Dolgin. "We had all sorts of vaccines, and there really wasn't much threat to clinicians."

Bioethics' current "enormous stress" on patient autonomy is really a product of that era, says Dolgin. "That now comes up against public health issues, where today we are faced with a whole slew of serious illnesses that are contagious or highly infectious," she explains.

This spotlights the public's discomfort with the limitation of patient autonomy to protect the public health. "If Ebola is controlled fairly soon, then we won't face these issues in the context of Ebola," says Dolgin. "But we will face them with other conditions."

How to strike a balance between beneficience to an individual patient and respect for patient autonomy "is one of the most compelling questions in bioethics today," says Dolgin. "Similarly, bioethicists focus on balancing protection of the public and of clinicians with the preservation of liberty interests."

## No duty to provide futile care

Some have suggested that CPR not be given to end-stage Ebola patients both to protect clinicians and because it's essentially futile care.[1]

When developing policies to address this, Dolgin cautions against absolutes. "To say you will think very carefully before you offer 'everything,' including CPR, to Ebola patients is very different from saying you will 'never' do so," she says.

For many hospitals, it is not possible to ensure proper isolation and infection-control measures. "They don't have the space or personnel to do this without endangering other patients," Charo explains. There is an obligation, however, to provide proper care for Ebola patients within the limits of the hospital's resources.

Some procedures pose

significantly higher risk to providers than others, says Charo, but "those same procedures are typical of last-chance measures that, if needed by an Ebola patient, would indicate the disease had progressed to the point that heroic measures would likely be futile."

There is no duty to provide futile care. "But there is a duty to provide necessary care, and to ensure a patient is not abandoned," says Charo. "If a facility is unable to provide necessary care, the patient should be treated somewhere that can."

## Improving preparedness: "Ethical imperative"

Hospitals and the U.S. health care system are frequently criticized, "often justifiably so," says **Jason. L. Schwartz**, PhD, the Harold T. Shapiro Fellow in Bioethics at the Princeton (NJ) University Center for Human Values. "But overall, the response to Ebola has demonstrated the U.S. health care system at its finest."

However, he says, the experience with Ebola diagnosis and treatment in the United States, to date, has "shone a bright light" on the critical need to enhance training, education, and preparedness in hospitals nationwide.

"This is not simply an essential component of high-quality medical and public health practice," says Schwartz. "It is an ethical imperative as part of efforts to protect health care workers and to best serve patients."

Some uncertainty was inevitable in the response to such an unfamiliar disease threat. "But the experience in Texas underscored the importance of developing clear guidelines to protect health care personnel that are tailored specifically to the U.S. health care environment," Schwartz says.

This highlights the need to ensure that all health care personnel are adequately trained and prepared to translate those guidelines into practice as part of patient care activities. "The response to Ebola cases in the United States also exposed troubling gaps in coordination among federal health officials, state and local authorities, and hospitals," adds Schwartz.

A key task for the U.S. medical and public health community moving forward will be understanding and correcting the deficits revealed in the response to the tragic case in Texas and the subsequent infections among nurses caring for that patient. "Bioethicists can and should be part of such conversations," says Schwartz.

To achieve ethical care, he says, bioethicists "should aim to strike an appropriate balance among the needs, rights, and concerns of potential future Ebola patients, non-Ebola patients in those same facilities, health care personnel, and the community at large." ■

### REFERENCE


1. Altman LK (2014, October 20). Ethicist calls CPR too risky in Ebola. *The New York Times*. Retrieved from http://www.nytimes.com.


### SOURCES


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# ACA shifts liability to patients: Bioethicists must be "watchdogs" to ensure ethical care

*Unethical practices are concern*

The ethical justification for the Affordable Care Act (ACA) is distributive justice, with the goal of making health insurance available to more Americans, notes **Dennis M. Sullivan**, MD, director of the Center for Bioethics at Cedarville (OH) University.

"This has clearly succeeded, at least in part, but at the cost of a loss of autonomy. Is it worth it?" he asks. "Now, more than ever, there is a strong need for bioethicists."

Ethics professionals must be advocates, both for physicians who want to be compassionate clinicians, and "to defend the human dignity of the patients who get lost in the shuffle," says Sullivan.