

What Would You Do? Personal and community ethics during a disease outbreak

A Community Conversation, February 24, 2015

Two viruses have recently been in the news: Ebola and Measles. While they have different modes of spreading between individuals and infected persons have different mortality rates, once the infections are present in a community, they can raise similar questions. What kinds of things do we need to consider and how do we decide how to ethically examine a disease outbreak? When are quarantines scientifically and ethically justified? To whom are we responsible during disease outbreaks?

	Ebola	Measles
Signs and symptoms	Fever, headache, muscle pain, belly pain, unexplained bleeding, diarrhea, weakness, fatigue	High fever, conjunctivitis, cough, runny nose followed a few days later by body rash
Mortality rate (how many die from infection)	25-90%, depending on strain and context	1-2 out of 1000=0.1-0.2%
Incubation period (how long until symptoms develop)	2-21 days, average 8-10 days	7-21 days
Transmission (how it is spread)	Direct contact (through broken skin or mucous membranes in, for example, the eyes, nose, or mouth) with blood or body fluids (including but not limited to urine, saliva, sweat, feces, vomit, breast milk, and semen) of a person who is sick with Ebola; also through sex up to 3 months after Ebola patient has recovered	Through the air when an infected person coughs or sneezes. It is so contagious that if one person has it, 90% of people around him or her will also become infected if they are not protected. An infected person can spread measles to others even before knowing he/she has the disease—from four days before developing the measles rash through four days afterward.
Prevention	Avoid direct contact with fruit bats/non-human primates who are carriers; avoid direct contact with infected persons	Vaccination; quarantine of healthy, non-vaccinated persons for 21 days after a measles rash develops in community; quarantine of infected persons for 4 days after rash clears
Treatment	Providing intravenous fluids (IV) and balancing electrolytes; Maintaining oxygen status and blood pressure; Treating other infections if they occur Some vaccines and other treatments not yet approved	There is no specific antiviral therapy for measles. Medical care is supportive and to help relieve symptoms and address complications such as bacterial infections. Severe measles cases among children should be treated with vitamin A.

What is the accepted standard for approving medicines as safe and effective?

Once the FDA has reviewed research with the medicine in animal models, researchers must administer the medication in 3 clinical phases with humans, each with increasing 1) confidence in the medicine's safety and effectiveness, 2) understanding of how the body processes the medicine and how the medicine affects the body, and 3) number of study participants. This research is overseen by groups of people (mix of professional and community members) in Institutional Review Boards (IRBs). Medicines are typically not prescribed until the FDA approves the medicine following a positive outcome of this research.

"Right to Try" initiatives in Oregon (HB 2300) and elsewhere would allow terminally ill patients the right to try to get access to drugs or devices not yet approved by the FDA.

Questions for Discussion

1. Are there equity issues related to access and 'field testing' of unproven medicines?
When giving unproven medicines, like the experimental Ebola treatments, who should receive them?
What ethics principles allow an exception to the typical process?
 - *Consider the vulnerable populations in West Africa*
 - *Consider the privileged few in the US who served in Africa and have access to a broad spectrum of treatments*
 - *Who stands to benefit? Who bears the burden?*
2. What is the balance between personal liberty and community good when it comes to quarantines?
(We'll discuss this question related to vaccines in May!)
 - *Consider that some people exposed to Ebola were quarantined in the USA, some snubbed the order without ramifications*
 - *How are quarantine issues different with Ebola and measles?*
 - *Are there alternatives?*
3. What kinds of things do we need to consider and how do we decide how to examine the ethics of emergencies during disease outbreaks (see framework diagram)?
 - Fair distribution of scarce resources (like hospital beds, ventilators, medicine, emergency services)
 - Community survival
 - Access to clean water and food
 - Duty of professionals (first responders, doctors and nurses, public servants)
 - Who should be making these decisions?

Resources for further reading—check the website <http://www.nwabr.org> and accept the Chatter invitation

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How Oregon Created an Ethical Decision-Making Matrix

by John F. Tuohey, *Providence Center for Health Care Ethics*

Like other states, Oregon needed an emergency preparedness plan to address public health and ethical issues that would arise in a pandemic. The state's Director of Public Health formed a Medical Advisory Group (MAG), which includes representatives from county health departments, health professional organizations, insurers, local governments and tribal organizations, plus a health care ethicist and an expert in mass communications, to develop this plan. MAG members developed a decision-making matrix as a tool to describe how to integrate ethical principles into the types of decisions that must be made prior to and during a pandemic or other emergency.

Oregon's matrix [see illustration, below] is based on those values MAG members believed to be most at risk during a pandemic: social solidarity; professional standards; and justice. The matrix lists the characteristics of these values: for example, "equality" is one of the characteristics of justice, because a just policy or practice assumes that people are equal, although their needs may be different. The matrix also lists ethical terms, or principles, that may be used when applying these values in a public health crisis: for example, because truth-telling is characteristic of a society that values justice, a just policy or practice will need to uphold this principle

when communicating with the public or with individual patients.

The overlapping areas of the matrix show where decisionmaking takes place, illustrating how each decision involves different relationships among different principles in each sphere. Every decision must be accountable to each facet of the matrix: there can be no assumption that any decision will involve only one set of principles. Decisions about public announcements during a pandemic, for example, must be accountable to the justice principle of truth telling as well as the social solidarity principle of public order and the professional principle of reciprocity.

This approach to decisionmaking anticipates the information crises that are likely to occur during a public health emergency. Rather than scripting ethical recommendations in advance for every possible public-information scenario, MAG members concluded that changing conditions during a pandemic will require decision-makers to consult with one another on an ongoing basis, using the matrix to assess the ethics of a given situation. MAG continues to consult with the Department of Public Health on how the matrix will be disseminated, and what will trigger its use.

