

## PAPER

## Ebola: what it tells us about medical ethics

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## ABSTRACT

Good medical ethics needs to look more to the resources of public health ethics and use more societal, population or community values and perspectives, rather than defaulting to the individualistic values that currently dominate discussion. In this paper I argue that we can use the recent response to Ebola as an example of a major failure of the global community in three ways. First, the focus has been on the treatment of individuals rather than seeing that the priority ought to be public health measures. Second, the advisory committee on experimental interventions set up by the WHO has focused on ethical issues related to individuals and their guidance has been unclear. Third, the Ebola issue can be seen as a symptom of a massive failure of the global community to take sufficient notice of global injustice.

## INTRODUCTION

We are now living through the largest and most sustained Ebola epidemic that we have ever known and the projections suggest that things will get a lot worse before they get better.<sup>1</sup> It started in Guinea in December 2013, and at the time of writing the virus had already spread to at least six other countries (Liberia, Sierra Leone, Senegal, Nigeria, Spain, and the USA). Ebola is an infectious virus, causing serious fever, internal bleeding, septic shock and organ failure, resulting in death in at least half of all cases. It is passed on through contact with body fluids (sweat, blood, vomit, breast milk, semen and diarrhoea) of those infected. A significant problem is that there can be a 3-week incubation period between infection and symptoms, and in the early stages of the disease the infected individual is contagious but the fever might be mistaken for something else.<sup>2</sup> These characteristics mean that the virus can be spread easily within a population.

In this paper I use the ongoing Ebola outbreak and the response that there has been to it—and especially the response by the World Health Organization—as an example of some of the dangers of using medical ethics to think about public health issues. Medical ethics has been an area of sustained activity for over 40 years, and this journal has been at the forefront of the discussion of many important and novel issues. Much excellent work has been published in this journal, clarifying issues and arguments, and providing guidance to policymakers. However, there is a danger that when we think of medical ethics we focus on issues in clinical ethics, research ethics and new medical technologies, with little engagement with public health. As a result of this focus the medical ethics literature tends to invoke a narrow range of values, largely concentrated on individualistic

considerations, with a predominant focus on autonomy.<sup>3</sup> This can result in the marginalisation of more societal, population or community values and perspectives. What is it to do good medical ethics? A starting point is to say that it should have a broader interest than the issues and values that currently dominate medical ethics. We are all, as individuals, part of different communities, societies and states. It seems odd to ignore this in our ethical discussion. Much recent work in public health ethics has attempted to outline and discuss social considerations such as social justice, solidarity, community, common goods, etc, and explain how they may make a difference to thinking about bioethics. It would be good to see more of this work, represented, for example, by many of the papers in the journal *Public Health Ethics*, reflected in the medical ethics of the next 40 years.

This kind of individualistic focus can be seen in current responses to the Ebola epidemic. Approaching Ebola from the perspective of medical ethics frames the issues incorrectly, imposes the wrong priorities, and uses the wrong set of values. There has been a failure in the responses so far to engage with public health values, issues and literature. In this paper I argue that we can see the response to Ebola as marking a major failure of the global community in three ways. First, the focus has been on the treatment of individuals rather than seeing that the priority ought to be public health measures. Second, the advisory committee on experimental interventions set up by the WHO has focused on ethical issues related to individuals and their guidance has been unclear. Third, the Ebola issue can be seen as a symptom of a massive failure of the global community to take sufficient notice of global injustice.

## EBOLA IS A THREAT TO PUBLIC HEALTH

It seems odd to have to state that Ebola is a public health issue, but it is only fairly recently that the global community began to think about it in this way. It was August 2014 before the WHO declared it a threat to global health, and global resources began to be mobilised.<sup>4</sup> This lack of activity was in stark contrast to the time and resources given to the justification of individual experimental treatments for those that were sick and the use of protective vaccines for small groups that were the focus of policy discussion. Given the nature of Ebola as outlined above, a focus on clinical issues rather than on a public health approach cannot bring Ebola under control. While future drugs for treatment and vaccines for prevention may be useful, no licensed product is currently available. Even the much-discussed experimental ones are not available in



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sufficient quantities to help in tackling the major outbreak we now face. If Ebola is to be controlled, it will be because of old-fashioned public health measures aimed at the prevention of transmission, such as isolating those affected, tracing and following up with the contacts of victims and quarantining those potentially exposed to the virus, and reducing opportunities for transmission by placing restrictions on travel and on gatherings of people in public places, such as schools and for sports, music and religious events. Ebola is a public health emergency, not an opportunity to just treat a few patients. Vigorous discussion about whether or not to give experimental drugs is a distraction, given the realities of the situation we face. The focus of policy ought to have been on prevention of transmission and protection of the population at a much earlier stage. Ebola has long been a potential threat to global health and inadequate early public health control measures have made tackling the outbreak more difficult and more costly.

### WHAT'S WRONG WITH THE WHO COMMITTEE'S ADVICE?

Given the nature of Ebola, and the need for a robust public health response, it seems odd that the WHO's priority in terms of policy discussion involving ethical issues was whether or not it was permissible to use experimental drugs for treatment. The WHO's initial summary report<sup>5</sup> generated a vigorous discussion, and a whole range of issues were raised about such things as the poor representation on the committee from affected countries and the absence of ethicists with expertise in relevant areas.<sup>6</sup> My own initial reactions were to ask why the focus was on an issue affecting a few individuals rather than on seeing Ebola as a major public health problem. While the later and more substantive WHO document stated (on page 5) that public health measures "remain the main priority in outbreak control" this only highlights the oddness of focusing on experimental interventions.<sup>7</sup> If such experimental drugs and vaccines should have been the starting point for WHO's consideration of 'good medical ethics' in response to Ebola, there remain many problems with the report of the committee and many of them stem from its individualistic approach to medical ethics.

First, it is surprising that the document treats drugs and vaccines as though they can be considered to be a single issue, for treatment and prevention actually raise quite different questions. It is welcome that the report states that it is permissible to use experimental drugs in cases of 'compassionate use' where no other treatment is available. I agree with this conclusion, but arguably the world did not need this committee to provide this answer: it follows directly from a physician's general duty to do what is best for their patients, and is already explicitly endorsed by the Helsinki Declaration.<sup>8</sup> However, the issues are arguably very different when thinking about preventive vaccination. If I am infected with a virus with a 50% chance of death, I may be very willing to accept quite high risks from a possible life-saving treatment. But it is not so clear that when not infected I would or should be willing to accept an unknown risk from an unlicensed preventive vaccine, given that other measures such as good quality protective equipment, if properly used, may reduce the risk of infection to an acceptable level. And if I have been exposed to the risk of infection but show no signs of having been infected, the risk and benefit issues concerning post-exposure ('treatment') vaccination are different again—and should be considered separately.

Second, the aim and structure of the documents produced are ethically confusing. Given the relatively clear questions set for the committee by WHO (on page 3),<sup>7</sup> one would have expected clear answers with reasons and arguments in favour of the chosen position and responses to possible objections. Instead we

are given a long list of ethical 'criteria' in the document. The very notion of ethical 'criteria'—part of the brief given to the WHO panel—is somewhat mysterious, and not one I've come across before. A charitable interpretation is perhaps to see the use of the term as meaning something like 'ethical considerations'. However, although these 'criteria' are listed towards the start of both documents they are hardly ever used or mentioned again. Perhaps these criteria are supposed to provide us with some insight into the values that guided the discussion or were used to support the report's conclusions. Perhaps this list is supposed to be some kind of ethical framework<sup>9</sup>—if not, its role is very unclear. But if it is an ethical framework it does no obvious contribution to the decisions that are outlined in the paper.

Third, there are major problems with the ethical 'criteria' that they suggest are 'among' those that might guide whether or not to provide interventions. The list given in their first document<sup>5</sup> is as follows:

- ▶ transparency about all aspects of care
- ▶ informed consent
- ▶ freedom of choice
- ▶ confidentiality
- ▶ respect for the person
- ▶ preservation of dignity
- ▶ involvement of the community.

All except for the last one focus on individualistic considerations, commonly seen as important within medical ethics. There is a certain amount of repetition which reinforces this individualistic emphasis: don't informed consent and freedom of choice cover similar ground? Isn't preservation of dignity part of what it is to respect the person? And the focus on issues relating to the autonomy of the patient is surely inappropriate for those victims of Ebola for whom experimental interventions are contemplated and who are semi-conscious or unconscious and unable to debate the relative merits of the risks involved? In such cases one would have expected discussion of such considerations as best interests and welfare. One would have anticipated mention of the ethical objectives of promoting patient benefits and protecting patients from harm, surely central components of both clinical and research ethics. Even if the WHO report wished to prioritise individual choice over harms and benefits, this is not an argument for not even mentioning them.

There is only one rather lonely mention of a non-individualistic ethical concern, when it is suggested that we should "involve the community", but it is unclear what this means, how it might help, how it is to be done or how it fits with the individualistic focus of the other criteria. This links to a larger problem for the criteria, in that it is unclear how they are supposed to work together and how conflicts between them are to be settled. Do these 'criteria' have any ranking? How are they to be operationalised?

The full report,<sup>7</sup> issued a few days later, and no doubt taking into account some of the initial criticism, only adds to the confusion by listing the criteria in a slightly different order on pages 1 and 5, and proposing three additional criteria to be added to the list above as follows:

- ▶ trust
- ▶ fair distribution in the face of scarcity
- ▶ promotion of cosmopolitan solidarity.

These additional 'criteria' at least boost the number of non-individualistic values, although it is unclear how they link to those mentioned above. If all three are to be promoted then further ethical issues arise in relation to trust. Is trust always a good thing? How does it fit with the other elements? Are we to promote trust even if this can only be achieved through a reduced amount of transparency?

The additional 'criterion' of 'fair distribution' rather than social justice or equity suggests a procedural approach to distributing limited resources, and this raises further questions such as whether or not prior existing inequalities should be taken into account?

The term 'cosmopolitan solidarity' is unclear. Is this a reference to the importance of solidarity in general?<sup>10</sup> It is difficult to understand it in this way, given the addition of the word 'cosmopolitan'. What is 'cosmopolitan solidarity' supposed to be? Is this a reference to the need for solidarity with others in far off places, rather than only with those within one's own community or state? If so, it is not clear how solidarity differs, if at all, from beneficence. And it is unclear why 'promotion' of solidarity is explicitly mentioned, while promotion of the other criteria is not and whether or not this difference is significant.

Later on in the final document there are yet further 'criteria for the prioritisation and allocation of investigational interventions' mentioned. Here there is some overlap with the 'essential considerations' and 'criteria' listed before (page 6),<sup>7</sup> but there are also several new 'criteria' mentioned for the first time such as 'reciprocity and social usefulness', 'likelihood of a positive impact' from the intervention, and mention of providing 'special protections' for those most vulnerable (assumed to be children and pregnant women). How do these new criteria link to those previously stated? Why are they different from those previously listed?

Fourth, the committee's report concluded, in surprisingly strong and absolute terms, that evaluations of any experimental interventions must be conducted. It is held that: "[t]here was unanimous agreement that there is a moral duty to also evaluate these interventions (for treatment or prevention) in the best possible clinical trials under the circumstances in order to definitely prove their safety and efficacy or provide evidence to stop their utilization".<sup>5</sup> However, it is not obvious that a trial is the best way to evaluate unproven drugs or vaccines. Where so little is known about possible risks and benefits, it might be better to conduct cohort studies, comparing perhaps those that agree and refuse participation, rather than conducting a trial. In addition, given the numbers of cases likely to be involved in such research it is not clear that safety and efficacy could be 'definitely prove[n]' without doing much larger trials. For example, a rare side-effect from an early rotavirus vaccine was only picked up post-licensing once used in large populations.<sup>11</sup> In discussion of these issues, some mention might have been expected of the fact that the main beneficiary of such experimentation is likely to be society in general and not these individuals with Ebola. Again, this suggests the need to think about how more societal values are relevant to these issues rather than only invoking individualistic values.

Of course, the committee produced these reports quickly and we should not expect perfection. However, the documents are disappointing in a number of respects. First, they could have more clearly articulated all relevant values, not just defaulting to the individualistic traditions of clinical and research ethics. Values outlined and discussed in public health ethics should be taken into account. Second, the committee could, and in my view should, have called much more clearly and loudly for a robust and urgent public health response to Ebola as well as global action to assist countries without the means to protect their own citizens. This links to my third point.

## WHAT ABOUT GLOBAL INJUSTICE?

I think it's important to see this Ebola outbreak against the background of global injustice in relation to health, and this is another reason why the individualism of much medical ethics is

problematic. Even if the use of experimental drugs and vaccines is permissible, who gets them? Most likely it will not be the local population. Why has the media suddenly got excited about a disease that has up until now been mostly ignored since the outbreak started? Because a few westerners died doing excellent work in Africa on behalf of the victims, and because of a belated realisation that Ebola might affect richer nations after all. But we can ask broader questions such as: why are there no adequate treatments and vaccines for this devastating disease? Part of the answer is that pharmaceutical companies see no market for disease prevention and treatments in such poor populations. Those caring for others in far-off places need to be supported, but so do the people living in low-income countries with inadequate public health infrastructure, including the capacity for surveillance, security, and quarantine of those who may have been exposed and isolation of those infected. Such disadvantage impacts upon health, as does a history of colonialism and conflict, as well as the tendency of many aid programmes to focus on single diseases rather than seeking to construct and enhance general public health infrastructure. The most important lesson for 'good medical ethics' to be learned from this Ebola outbreak is that we live in an interconnected world and that ensuring the best possible health outcomes for all requires us to tackle global health inequities.

## CONCLUSION

So what is it to do good medical ethics? Much contemporary medical ethics focuses on the values considered to be crucial in protecting the individual. Such values are important, but other values, more visible in public health practice and related to societies, populations and communities, are just as important. When we are responding to major public health threats it is even more important that the latter values are articulated and are involved in shaping our policy responses.

The global response to the Ebola epidemic has so far been a catastrophe. Sadly, given what we already know about the infrastructure available in the three main African countries involved, this was completely predictable. The focus on issues relating to unlicensed drugs and vaccines has been mostly a distraction from the need for a robust and urgent public health effort to contain and combat the disease. Citizens in these states have been failed by global inaction, both before the Ebola outbreak through continuing neglect of the poor public health infrastructure, and since it began. Once notification of an outbreak was received, so many months ago, appropriate action should have been taken immediately. As a result of the failure of the global community, tens of thousands, perhaps even hundreds of thousands, of people will now die from what were preventable deaths. Good medical ethics should take note and seek to change policy and practice so that this does not happen again. Public health values are central to this aim.

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