Communicable disease outbreaks

Ethics in an outbreak

Jeanette E Ward

The role of the general practitioner (GP) as the medical expert at the centre of Australia's multidisciplinary primary healthcare system is never more acute than when populations are threatened by a communicable disease epidemic. This series is a refresher covering key concepts. This fifth article explores ethical aspects of public health action, information disclosure and research in an epidemic.

Until 2017, the World Health Organization (WHO) had issued ethical guidelines for outbreak management specific to particular epidemic pathogens. Finding an international consensus on five general ethical principles, the WHO now encourages their global adoption.[1] These principles are: 1) public health necessity, 2) reasonable and effective means, 3) proportionality, 4) distributive justice and 5) trust and transparency.[1] As described in this article, ethics in an outbreak response must move beyond these abstract principles into operational actions, often in highly charged, time-pressured situations.

Ethical decisions in an outbreak or pandemic do not occur in a vacuum. In response to extant evidence about the specific outbreak underway, what might seem unethical and extreme in one country as a public health response may be considered entirely ethical and routine in another. By its very nature, public health reflects a society's sense of itself, including its resilience, anxieties, culture and risk tolerance. Ethical outbreak management decisions occur in circumstances in which there will be profound cultural differences in how people comport themselves collectively, their values and trade-offs. This is readily illustrated by comparing differences in how nations such as Sweden, Japan, Taiwan or the USA reacted to COVID-19 in 2020, yet transmission and virulence were equivalent in each country. Isolation and quarantine have been described as '... the most complex, not to mention legally and ethically controversial, of the public health powers. Quarantine and isolation represent the tension between the interests of society in protecting and promoting the health of its citizens and the individual's rights of privacy, non-discrimination, freedom of movement, and freedom from arbitrary detention'.[2]

There are also profound differences in health system design, functionality and access that influence what is accepted as 'normal'. This defines what is perceived as 'unethical' or 'unfair' in health. Health protection is the invisible safety net for effective, prompt public health action. In Australia, we would be unlikely to tolerate highly inequitable public health responses because of our cultural value of the 'fair go'.

Communication is a central requirement of public health action to control an outbreak. Universal messages aim to reduce exposure risk. Ethically, these should be evidence based and credible. Targeted messages aim to reach contacts and communicate steps these contacts need to take in response to their documented exposure. Communications about risk, testing, isolation and contact tracing are usually drafted well ahead of need, creating a library of immediately accessible communication messages and media releases. When dealing with a known pathogen, there will be little in the way of unresolved ethical concern about trade-offs between public health and other social values, as previous outbreaks will have exposed and resolved significant tensions between the public good, individual liberty and benefits from specific health advice. Explaining interventions in outbreaks, such as booster vaccinations or prophylactic antibiotics, to asymptomatic close contacts will reflect a respective disease-specific evidence base. With a new pathogen, however, the public health response and its communications will be inevitably affected by greater epidemiological and microbiological uncertainty. Public health advice may be contested in these circumstances.[3] An ethical approach is required to disclose what is known, what is not known and what enquiry is underway to reduce the gap in critical knowledge. Decision making should be as transparent as possible.

Research conducted during a communicable disease outbreak requires ethical approval. Research might be needed to establish causative pathogenic strains. Research might be needed swiftly to evaluate sensitivity and specificity of new tests such as point-of-care technology when compared with a known gold standard.[4] Similarly, research might also be needed to evaluate new treatments for those developing serious complications from their infection or its sequelae. In all cases, there should be clear articulation of the purpose of data collection to all

stakeholders: is it being done to inform individual treatment, the collective public health response or for future (non-pandemic) decisions?

Ethically, there is a clear line distinguishing tests that should be ordered for each notifiable communicable disease case in order to inform the contemporary public health responses versus data collection for a research study. For example, in the case of a mumps outbreak,[5] polymerase chain reaction (PCR) testing of all cases is no longer required once public health authorities determine the culpable mumps genotype. Continuation of mumps PCR testing beyond that time is clearly unethical, as it means nothing for individual care. If there is a clear research question, prospective human research ethics approval is required. In the crisis of an outbreak, sharing case studies or small cohort series may be useful but only for a very short period. Larger cohort studies with patient samples of sufficient size recruited from hospital admissions or community sampling are required to identify risk factors for significantly worse outcomes.

To inform treatment decisions, more rigorous study designs – such as randomised controlled trials – are needed. Here, bioethical principles apply. It is unethical to proceed with clinical treatment trials that are statistically underpowered, even if otherwise methodologically sound. If the absolute number of admissions to hospitals in Australia for patients with severe complications of a communicable disease infection is low, it is better to contribute to a globally coordinated research effort in which multinational trials are undertaken with strict eligibility criteria, randomisation, treatment protocols, statistical power and outcome measurement. If there is a sufficient prodromal period between symptom onset and serious complications, these natural histories similarly need substantial clinical trials with sufficient statistical power to prove the net benefits of early treatment intervention such as antivirals or prophylactic medication. Without ethically acquired data, it will be impossible to give evidence-based recommendations in the future.

Vaccination trials also require ethical clearance. The population stakes of a new vaccine must withstand rigorous evaluation to ensure the benefits clearly outweigh the harms. Publication enables scrutiny of vaccination technology, vaccine administration and dosage, outcome measures and absolute benefit. Publication of all vaccine trial data allows different viewpoints to be applied and alternative preventive actions to be ethically compared.[6]

This article has presented examples of operationalised ethical principles. Compromising individual liberty for a greater common good presupposes a resolute sense of ethical accountability among decision makers.

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