Ethics and epidemiology

Conflict sometimes arises between the rights and freedoms of individuals and the needs of society. Epidemiologists can benefit from the formulation of ethical guidelines.

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Ethics is the branch of philosophy dealing with the distinction between right and wrong, with the moral consequences of our actions. Everything we do in every aspect of our daily lives has ethical implications; but there are few hard and fast rules in ethics. The purpose of illuminating our actions with ethical considerations is to clarify the issues so that logical and ethically acceptable decisions can be made in ambiguous situations. Some ethical issues that can arise in epidemiological practice and research illustrate the importance of applying logic to the steps in decision-making. Several concepts that have been defined in biomedical ethics can help us to arrive at logical as well as ethically acceptable decisions.

Epidemiology, the basic science of public health, is the study of the distribution and determinants of health-related states and events in populations, and the application of this study to control health problems. Like public health itself, it is often more concerned with the well-being of society as a whole than with the well-being of individuals. Sometimes there is a conflict between the rights and freedoms of individuals and the needs of society. This conflict can arise over the use of personal information. Epidemiology relies on information obtained about individual people, either from the people themselves, or from other sources such as medical records. Individuals value their privacy, so they may be reluctant to agree to release personal information to the epidemiologist.

When the information carries a social stigma, as it does most obviously in cases of infection with the AIDS virus, powerful social and emotional barriers can impede the flow of information that may be essential to the epidemiologist, and therefore to society in whose interest the information is being gathered. This is at the heart of an increasingly common ethical dilemma: the interests of society require access to personal information, but access may threaten or even violate confidentiality.

This dilemma has been the topic of debate, sometimes heated argument, between contending interest groups who are concerned about surveillance and reporting of persons infected with the AIDS virus. On one side are the guardians of public health, who assert the right to know the identity of infected persons so that they and their sexual partners can be counselled and receive care and, (in the rare cases who behave irresponsibly), so that the safety of the community can be protected. On the other side are the advocates of persons who have often been stigmatised, rejected and despised by society once their identity as carriers or cases of AIDS has been revealed. Sometimes innocent children have been victimised, adding force to the argument that the identities of such people should be kept secret. The plight of AIDS patients is especially poignant when they are abandoned by family and friends, left to die alone among uncaring strangers.

Privacy at risk?

Many other ethical dilemmas in epidemiology relate to this theme of conflicting community needs and individual rights. Both in routine surveillance of disease and in epidemiological study, it is necessary to identify individuals, yet equally necessary to safeguard their privacy. Many people are anxious about the risk that their privacy may be invaded by inquisitive, perhaps unjustified, investigation. The fear that this may happen is often enhanced by the belief that information stored in computers is accessible to anybody who possesses the right code-words. In reality, information written down in medical records in a hospital or clinic is more readily accessible to others than the information stored in a computer.

Medical records held in old-fashioned files may be more readily accessible to outsiders than information stored in a computer.

Photo WHO/P. Larsen
Moreover, the risk of such invasion of privacy is minimal. Epidemiologists, like other medical scientists, have ethical codes of conduct and, when they work for government agencies, are sworn to preserve the secrecy of information about individuals just as are census-takers who also gather personal information that is used only to compile aggregate statistics. In short, this high-profile concern about possible conflict between personal privacy and the need for information in the interests of the community or nation turns out, when examined, not to be a matter for serious concern after all. What is more, the information that it is in the interest of the community to collect almost always serves the interests of the individual as well.

Nevertheless, other concerns remain, and professional societies and associations of epidemiologists in many countries have become increasingly anxious about questions pertaining to ethical conduct by epidemiologists. Several professional associations to which epidemiologists belong have established procedures to review and formulate ethical guidelines. The International Epidemiological Association, the Society for Epidemiologic Research (in the United States) and a number of groups in European nations, Australia and elsewhere have examined the ethical issues that epidemiologists have to confront, and have in some instances begun to formulate guidelines.

The ethical issues that arise in epidemiology can be summed up in the concepts of autonomy, nonmaleficence, beneficence and justice. Autonomy is the term we use to describe preservation of human dignity, individual rights and freedoms. Beside the right of the individual to privacy, autonomy is upheld when individuals who are the subjects of research are fully informed and voluntarily consent to take part in the research. This is the principle of informed consent, which is central to all aspects of health care. A situation which is common and requires informed consent is the form of epidemiological experiment called a randomised controlled trial (RCT). The aim here is to test the efficacy or effectiveness of two or more preventive or therapeutic regimens by allowing the choice of regimen to be determined by chance. This removes the element of bias due to any preconceived notions that either the investigator or the persons in the trial may already have. It is essential for all persons who participate in randomised trials to understand fully what it is they are being asked to do, to be aware of the risks as well as the benefits, and to give their consent freely. RCTs also pose problems in the case of severe and new diseases such as AIDS. While it is generally accepted that they represent the preferred way of assessing the value of a treatment, it is increasingly common to accept that, as soon as the advantages of a treatment...
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Epidemiologists tracked down the source of a fatal brain disease – kuru – in certain parts of Papua New Guinea, and helped to stamp it out.

Photo WHO

For instance, when research workers are studying occupational hazards, they may not come from an impartial academic base, but may be working either for management or for a labour union. If so, there may be a temptation to selectively reveal or withhold information that is in the interests of one or other of these traditionally adversarial parties. Or, when epidemiologists are studying the efficacy of a new drug, there may be a temptation to analyse the data selectively to demonstrate the action of the drug in the most favourable light. This may happen if there is not an “arm’s length” relationship between the investigator and the manufacturer of the drug in question. Like all other scientists, the epidemiologist must always strive to be honest, truthful and impartial.

Data-dredging

There is also great pressure to publish results – “publish or perish,” as the saying goes. So it is tempting to use all sorts of statistical manipulations until a “significant” finding emerges. This unsavoury practice, known by the pejorative name of data-dredging, is increasingly regarded as unethical.

One fascinating topic for epidemiological research is the relationship between lifestyle and health. Groups of people with unusual lifestyles – remote tribes in tropical rain-forests, for instance – have been intensively studied. To what extent, if any, is it justifiable or morally acceptable for epidemiologists to intervene in the lives of such people, perhaps to initiate measures that will change these ways of life forever? One instance when intervention was justifiable was among the members of the Fore tribe in Papua New Guinea; these people were afflicted with a fatal brain disease, kuru, which epidemiological investigation showed to be due to a virus transmitted by cooking and eating the brains of deceased victims (some of whom were clubbed to death first). The disease has died out since the mode of transmission was identified and stopped.

Formulating ethical guidelines for epidemiological practice and research will not resolve the moral ambiguities that are encountered almost every day. Guidelines can, however, achieve several useful ends. They can draw attention to the necessity of considering the ethical implications of professional actions; they can thus lead to elevation of professional standards, not only in introducing consistently humane and caring attitudes, but also in raising the quality of the science itself.