Chapter 13

Ethical Issues in Public Health*

ABSTRACT

The field of public health includes a wide scope of activities and professional disciplines, ranging from sanitation, health protection, epidemiology, environmental health, financing, health promotion, including supervision, or the provision of clinical care. Each of these disciplines works in systems that face ethical dilemmas, making it important that public health workers have motivation to understand and practice within the ethical guidelines of their profession, thus making ethics an important component of training and practice. The dangers of ethical lapses are overwhelmingly apparent in the case of the Eugenics movement of the early 20th century which metamorphosed from forced sterilizations in many liberal democratic countries into mass murder of physically and mentally handicapped children and adults in Nazi Germany. Between 1939 and 1941, 180 thousand psychiatric patients along with an equivalent number of handicapped children and adults were killed in an organized extermination program in Germany by lethal gassing. This method was then applied to the industrialized murder or Holocaust of six million Jews and millions of other "untermenschen" (sub human) in the greatest genocide in human history. Shortly after World War II ended the Nuremberg Trials of Nazi war criminals were conducted including medical doctors, and some were executed for crimes against humanity. This was followed by the 1948 United Nations Declaration on Human Rights and by the World Medical Association's Helsinki Declaration. Both are widely accepted as cornerstone documents—the latter specifically governing ethical standards related to human experimentation—and are revised regularly since being issued in 1964. But genocide has not disappeared, nor has unscrupulous experimentation such as the Tuskegee experiment on black Americans infected with syphilis and left untreated even after the availability of a cure, penicillin. Ethical standards are now required by "Helsinki Committees"— ethical review boards—in most medical facilities worldwide. Ethical frameworks have evolved in part due to bitter experience of ethical failures later recognized and affecting public health standards of practice. Future generations of public health leaders and staff will face many ethical issues such as mandatory immunization of health workers and school children, and assisted death of terminally ill patients.

Nuremberg Trial of Nazi war criminals, 1945−46. Available at: https://fcit.usf.edu/holocaust/resource/gallery/N1945.htm.

Entrance to the infamous Auschwitz-Birkenau death camp where 6,000 people were put to death in gas chambers daily by the Nazi regime in World War II. *Source: The Holocaust, public domain available at:* *http://www.history.com/topics/world-war-ii/the-holocaust/pictures/holocaust-concentration-camps/poland-auschwitz-birkenau-death-camp*

Hungarian Jews arriving at Auschwitz near end of WWII for immediate gassing/extermination. *Source: The Holocaust, public domain available at:* *http://www.history.com/topics/world-war-ii/the-holocaust/pictures/holocaust-concentration-camps/arriving-at-auschwitz*

Tuskegee Syphilis Study Participants. *Courtesy: National Archives Catalogue, Tuskegee Syphilis Study Administrative Records, 1929−72.*

Eleanor Roosevelt (1884−1962) former First Lady of the US, leading human rights diplomat reading the Universal Declaration of Human Rights, United Nations November 1949, United Nations, Lake Success, New York. Photo # 117539, United Nations Photo Library at http://www.unmultimedia.org/photo/.

BACKGROUND

The Universal Declaration of Human Rights (UDHR) is a milestone document in the history of human rights. Proclaimed by the United Nations General Assembly in 1948 it provides a "Magna Carta" as a common standard for all peoples and all nations. Arising from the horrors of genocide and mass civilian casualties of World War II, the Declaration of Human Rights sets out, for the first time, fundamental human rights to be universally protected. It also provides a context for the complex topic of ethics in public health.

Ethics is a branch of philosophy that deals with the distinction between right and wrong—with the moral consequences of human actions. The ethical principles that arise in epidemiologic practice and research include:

- Informed consent
- Confidentiality

- Respect for human rights
- Scientific integrity

The Centers for Disease Control (CDC) in the US defines public health ethics: "*As a field of study, public health ethics seeks to understand and clarify principles and values which guide public health actions. Principles and values provide a framework for decision making and a means of justifying decisions. Because public health actions are often undertaken by governments and are directed at the population level, the principles and values which guide public health can differ from those which guide actions in biology and clinical medicine (bioethics and medical ethics) which are more patient or individual-centered.*

As a field of practice, public health ethics is the application of relevant principles and values to public health decision-making. Public health ethics inquiry carries out three core functions,

1. *identifying and clarifying the ethical dilemma posed*
2. *analyzing it in terms of alternative courses of action and their consequences*
3. *resolving the dilemma by deciding which course of action best incorporates and balances the guiding principles and values (CDC)*."

Ethics in health is based on the fundamental values and concepts of a society. Medical ethics of the Hippocratic Oath hold the first obligation of a physician is to do no harm. The principle that saving a life is valued above all other religious considerations is of Biblical origins (i.e., Sanctity of Life or *Pikuah Nefesh*), where the saving of a life is equivalent to saving the world. This implies that all measures available are to be used, irrespective of the condition of the patient or the cost. But if sickness and death are seen as acts of God, possibly as punishment for sin, then prevention and treatment may be considered to be interfering with the Divine will, and ethical obligation may be limited to relief of suffering. Humanism balances these two ethical imperatives: saving of life and relief of suffering. Materialism may see health care as primarily a function to preserve health for societal well-being and economic prosperity.

The role of society in protecting the health of the population evolved during the latter 19th century with the sanitation movement and the gradual development of safe water supply, safe management of sewage and waste, and food safety with pasteurization, improving living conditions as well as medical care and the widespread implementation of national health insurance. Countries in Europe and the Americas began to recognize public health as societal obligations at municipal, state and national levels as part of fundamental values and concepts of a society. The astonishing success of public health over the past century increased life expectancy in high-income countries by some 30 years, mostly through improved sanitation, nutrition, living

conditions and disease control measures, as well as societal and medical advances making care available to all. In the 1970s, the Lalonde concept emerged that individual behavior was one of the key health determinants, along with human biology, environment and medical care (see Chapter 21). This placed much of the responsibility for illness and its prevention on individual behavior, but at the same time fostered the development of health promotion as an essential component of public health theory and practice. All these points of view are involved in the ethical issues of the New Public Health (see Box 13.1).

BOX 13.1 Values and Ethical Principles of Public Health

1. **Nonmalfeasance**: Hippocratic Oath—do no harm.
2. **Sanctity of human life**: Biblical edict—saving a life comes before all other religious acts.
3. **Universal Declaration of Human Rights**: All humans deserve protection of life, health and well-being.
4. **Individual human rights**: Liberty, privacy, protection from harm.
5. **Solidarity**: Sharing the burden of promoting and maintaining health.
6. **Beneficence**: Reduce harm and burdens of disease and suffering.
7. **Proportionality**: Restriction on civil liberties must be legal, legitimate, necessary, and use the least restrictive means available.
8. **Reciprocity**: All have a right to just treatment but share responsibility to ensure justice especially for those facing heavy social and health burdens.
9. **Transparency**: Honest and truthfulness in the manner and context in which decisions are made must be clear and accountable.
10. **Precautionary**: Duty to take preventive action to avoid harm even before scientific certainty has been established.
11. **Responsibility to Act**: Public health officials and policy-makers have a duty to act and implement preventive health measures demonstrated to be effective, safe, and beneficial to population health. Failure to enforce public health regulations with resulting disease or deaths may constitute negligence on the part of responsible officials with civil or even criminal penalties.
12. **Equity**: Reduce gender, ethnic, social, economic, geographic inequities.
13. **Cost and benefits**: Economic analysis and consideration of priorities.
14. **Stewardship**: Responsibility of governance to act in a trustworthy and ethical manner.
15. **Trust**: Cooperation between the many public and non governmental stakeholders in health.
16. **Evidence based**: Decisions should be evidence-based, and revised, considering new evidence.
17. **Responsive to needs**: Address challenges as they may be anticipated and occur with close monitoring of health status.

Source: Adapted from Tulchinsky TH, Varavikova EA. The new public health, 3rd edition. San Diego. CA: Academic Press/Elsevier, 2014. Chapter 15, page 809.

Resources for health care are limited even in high-income countries, so that priority setting and judicious allocation of resources is always an issue. Money spent on new technology with only marginal medical advantages is often at the expense of well-tried and proven lower-cost techniques to prevent or treat disease. The potential benefits gained by the patient from more interventions are sometimes very limited in terms of length- or quality of life. These are difficult issues when the commitment to do all to preserve the life of the patient conflicts with the patient's concept of quality of life and his or her right to decline, or terminate heroic measures of intervention. Terminally ill patients may endure suffering during radical treatment, which may prolong life by only hours or days, clashing with the physician's ethical obligation to do no harm to the patient. The ethical value of sustaining the life of a suffering, terminally ill patient is a growing medical dilemma. The issue is even more complex when economic values are part of the equation. There is a potential conflict between the economic issues, the role of the physician in preserving life, the physician's obligation to do no harm, the felt needs of the patient and his or her family, and the needs of the community. The right of patients to seek euthanasia or assisted suicide in end-of-life situations is increasingly recognized and practiced in some jurisdictions.

The state represents organized society and has, among its responsibilities, a duty to promote healthful conditions and to provide access to both medical care and public health services. The dissonance between individual rights and community needs is a continuous issue in public health. Application of accepted public health measures for the benefit of people in society may require applying an intervention to everyone in a community or a nation. A democratic society ruled by law and legal protection of human rights may justifiably need to place limits on individual liberties to achieve the goal of reducing disease or injury in the population. Raising taxes and other restrictions on alcohol and tobacco products, laws on mandatory speed limits, driving regulations including seat belt usage, car seats for children and mandatory immunization for school attendance are examples of public health restrictive interventions which place limits on individuals but protect those individuals, their neighbors and the community-at-large from harm.

Some forms of mass medication are accepted methods of public health practice to reduce the risk of disease in the population. Chlorination of community water supplies is a well-established, effective, and safe intervention to protect the public health. Fluoridation of drinking water to prevent tooth decay in children means that other persons are also drinking the same fluoridated water, which is of less direct benefit to them. Mandatory pasteurization of milk is an important standard for public health. Fortification of basic foods with vitamins and minerals is also a cost-effective community health measure and banning of trans fats to reduce heart disease, are all topics with advocates and opponents. The addition of folic acid to food as the most effective way to prevent neural tube defects (NTDs) in newborns is an intervention mandated by the US Food and Drug Administration (USFDA) and in

over 80 other countries since 1998 (see Chapter 20). Use of mass immunization is essential for infectious disease control and mass medication is successful for control of "Neglected Tropical Diseases".

Individual and Community Health

Confidentiality to assure the right of the individual to privacy involves ethical issues in the use of health information systems. Records of birth, death, reportable communicable and selected noncommunicable conditions (such as cancers, birth defects, neurological conditions), and hospitalization data—e.g. admissions by cause, length of stay—are essential data bases providing basic tools of epidemiology and health management. The use of detailed individual data, such as in mandatory reporting of infectious diseases and birth defects, e.g., is needed for case-finding and follow-up activities which is vital for population health monitoring and good epidemiologic management of disease outbreaks and routine monitoring functions of public health. However, caution is needed in data use to avoid individual identification to prejudice privacy, or that could be used punitively, such as in denial of access to health insurance or employment for smokers, alcoholics, or AIDS patients on the grounds that these are known causes of health damage that may be attributed to self-inflicted risk factors or preexisting conditions. This may become even more important if preexisting conditions or genetic susceptibility come to be used as determining factors to access health insurance or employment. Reporting is mandatory for physical for sexual abuse and criminally linked injuries as a measure essential for protection of vulnerable groups such as children, women, elderly, ethnic minority groups, or the general public from serious harm from bullying, abuse, violence or incitement to genocide.

Protection of the individual's rights to privacy, and freedom from arbitrary and harmful medical procedures or experiments may clash with the rights of the community to protect itself against harmful health issues. This conflict comes into much of what is done in public health practice, which has both an enforcement basis in law and practice as well as a humanitarian and protective aspect based on education, persuasion, and incentives. Society permits, indeed requires its governments to act for the common good, but sets limits that are protected by the constitution, laws, courts and administrative appeal mechanisms.

Democratic societies have the right and obligation to legislate work, including mine and construction safety regulations, and traffic safety including speed permitted, wearing seat belts, use of car seats for small children and non-use of cellphones during driving. Offenders may be punished by significant fines and be subjected to strict educational efforts to persuade them to comply. Similarly, the community must ensure sanitary conditions to prevent hazards or nuisances for neighbors. Society must act to protect the environment against the unlawful poisoning of the atmosphere, water supply, or earth. Enforcement is a legitimate and necessary activity of the public health network to protect the community from harm. Table 13.1 shows topics where individual rights and responsibilities

TABLE 13.1 Individual and Community Rights and Responsibility in Health: Ethical/Legal Issues

Ethical/Legal Issues	Individual Rights and Responsibilities	Community Rights and Responsibilities
Sanctity of human life	Individuals responsible to avoid behavior damaging their own health and that of others	Responsible for providing a feasible basket of service; equitable access for all
Individual vs. community rights	Immunization for individual protection	Immunization for herd immunity and community protection; education; community may mandate immunization
Right to health care	All are entitled to needed emergency, preventive, and curative care	Community right to care regardless of location, age, gender, ethnicity, medical condition, and economic status
Personal responsibility	Individual responsible for health behavior, diet, exercise, and nonsmoking	Community education for health-promoting lifestyles; avoid "blame the victim"
Corporate responsibility	Management accountability to criminal and civil action	Producer, purveyor of health hazard accountablity for individual and community damage
Provider responsibility	Professional, ethical care, and communication with patient	Ensure access to well-organized health care, accredited to accepted standards
Personal safety	Protection from individual, family, and community violence	Public safety, law enforcement, protection of women, children, vulnerable groups and elderly, safety from terrorism
Freedom of choice	Choice of health provider, limitations of gatekeeper functions, control costs function, right to second opinion, and right of appeal	Confidentiality, informed consent, birth control ensuring individual rights, limitations of self-referrals to specialist
Euthanasia	Individual's right to assisted death within limitations by societal, ethical, and legal standards	Assure individual and community interests; prevention of abuse by family or others with conflict of interest

(Continued)

TABLE 13.1 (Continued)

Ethical/Legal Issues	Individual Rights and Responsibilities	Community Rights and Responsibilities
Confidentiality	Individual's right to privacy, limitation of information	Mandatory reporting of specified diseases; data for epidemiological analysis
Informed consent	Right to know, risks vs. benefits; agree or disagree to treatment or participation in experiments	Helsinki Committee approval of research; regulate fair practice in right to know; Patient's Bill of Rights
Birth control	Right to information and access to birth control and fertility treatment; woman's rights over her body	Political, religious limited promotion of fertility; alternatives to abortion; legal protection of women's right to choose
Access to health care	Universal access, prepayment; individual contribution through workplace or taxes	Solidarity principle and adequate funding; right to cost containment, limitations on service benefits
Regulation and incentives to promote preventive care	Social security for hospital delivery, attendance for prenatal care; primary care, ambulatory care; home care	Incentive grants to assist communities for programs of national interest; limit institutional facilities
Global health	Human rights and aspirations; economic development, health, education, and jobs	Reduction of health risks; occupational hazards and environmental damage
Rights of migrants and minorities	Equality in universal access	Pro-active outreach for high-needs groups
Prisoners' health	Human rights	Security and human rights; reduce inequalities in sentencing convicts, harsh dangerous conditions in prisons; prohibition of torture and execution
Allocation of resource	Lobbying, advocacy for equity and innovation	Adequate resources for health; equitable distribution, targeting high-risk groups; cost containment

Source: Adapted from Tulchinsky TH, Varavikova EA. The new public health, 3rd edition, San Diego, CA; Academic Press/Elsevier, 2014. Chapter 15, page 807.

predominate, and a second set of rights that are the prerogative of the community to protect its citizens against public health hazards. Sometimes the issues overlap with political, advocacy, or legal action so that court decisions or new laws are needed to adjudicate precedents for the future.

Genocide

The 20th century was replete with mass murders, executions, and genocide with nationalistic, ideological, and racist motives perpetrated by fascist, Stalinist, and radical xenophobic political movements when gaining governmental power by election or by revolution, in some cases using then-common public health terminology and concepts. In the 21st century, radical jihadist terrorist groups and governments such as in Syria not only conduct mass killing of civilians, but also target ethnic minorities and religious groups with active genocide including deliberate use of chemical weapons, mass starvation, rape, murder and enslavement against civilians with bombings of civilians, medical workers, and hospital facilities.

Public health policy is guided by two distinct but interactive paradigms; the biotechnological disease and the social-ecological health paradigms. In the 19th century these were the Germ Theory and the Miasma Theories, long at loggerheads, yet both produced enormous gains in public health. The biomedical paradigm addresses alleviation of disease risk or manifest diseases, with immunizations, screening and risk-factor reduction. The social health paradigm addresses the improvement of the physical and socioeconomic environment and healthy living, with the objectives of reducing disease and inequities in health between socioeconomic and regional population health disparities.

During the early part of the twentieth century, a segment of the social hygiene movement adopted ideas of racial improvement by compulsory termination of pregnancies and sterilization of the mentally ill, retarded, and other "undesirable persons." By 1935, when the Nazi sterilization laws were passed, about 20 states in America already had sterilization laws in effect with concurrence of the US Supreme Court. American eugenics policies were praised by Hitler, and these ideas were adopted in Nazi Germany leading to execution of half a million "undesirables" under the eugenics concept, and were adapted for mass extermination of Jews, Gypsies, homosexuals, and others during the Holocaust.

The policies of eugenics were widely promoted by medical professionals in Sweden, the United States and Canada. This led to adoption of policies and programs to force legally sanctioned sterilization of mentally handicapped or mentally ill patients. This practice was attractive to Nazi policy before and after its rise to power in 1933, with wide support among the medical and psychiatric professions. Between 1939 and 1941, 180,000 psychiatric and physically handicapped patients were killed in Germany with the active participation by medical

doctors, psychiatrists, nurses, and ancillary personnel under direct guidance of the so called T4 program, named after the address of Hitler's headquarters from where it was directed.

This corruption of public health distorted a socially oriented concept of public health to a racially oriented policy with horrendous actions of mass murder in the name of racial purity as a public health policy. This policy was supported and implemented by leading psychiatrists in a number of western liberal democratic countries providing a precedent adopted and expanded in monstrous manners in Nazi Germany with nearly total support and participation of a highly Nazified medical profession. The T4 program utilized starvation and gassing to kill helpless people and these methods became the direct antecedent to the mass murder of Jews, Gypsies, homosexuals, Soviet prisoners, and other "undesirables."

A noted Cambridge professor of modern history, Sir Richard Evans wrote:

"At the heart of German history in the war years lies the mass murder of millions of Jews in what the Nazis called "the final solution to the Jewish question in Europe". This book provides a full narrative of the development and implementation of this policy of genocide, while also setting it in the broader context of Nazi racial policies toward the Slavs, and toward Gypsies, homosexuals, petty criminals and 'asocials'." (preface xiv).

Evans continues: *"For many years, and not merely since 1933, the medical profession, particularly in the field of psychiatry, had been convinced that it was legitimate to identify a minority of handicapped as 'a life unworthy of life', and that it was necessary to remove them from the chain of heredity if all the many measures to improve the health of the German race under the Third Reich were not to be frustrated. Virtually the entire medical profession has been actively involved in the sterilization programme, and from here it was but a short step in the minds of many to involuntary euthanasia" (page 82).*
"By the time the main killing programme had ended, in August 1941, a large part of the medical and caring professions had been brought in to operate the machinery of murder.... the circle of those involved had grown inexorably wider, until general practitioners, psychiatrists, social workers, asylum staff, orderlies, nurses and managers, drivers and many others had become involved, through a mixture of bureaucratic routine, peer pressure, propaganda and inducements and rewards.... Having proved itself in this context, it was ready to be applied in others, on a far larger scale." (p. 101).

The T4 euthanasia program was administered directly from Hitler's main office *"The euthenasia program was preceded by mass sterilization of nearly 400,000 'unfit' Germans before the war broke out" (p. 105).*

(Evans RJ. The Third Reich at War. New York: Penguin Press, 2006).

The human and national cost of genocide lasts for generations. The hatred and fear may wane, but the trauma goes deep. It lasts with the victims and

their descendants, but also with the perpetrating country and its culture. The Nazi Holocaust has downstream effects in public health in German-speaking countries over 65 years since the events took place. The eugenic theory assumption was that a healthy population must be "free" of "racially contaminated" individuals and inferior groups which led to a public policy to eliminate racially "unclean" members through forced sterilization and murder opening the door to a euthanasia program of mass execution of mentally and physically handicapped Germans and others in psychiatric facilities, which provided a working model for the industrialized murder of the Holocaust. This was in direct conflict to a 200-year tradition of Germany's socially-oriented public health grounded in the political philosophy of human rights and social justice, many of whose advocates were mostly exiled or murdered. Many of the Nazi oriented academic medical leaders during World War II remained in key positions in the German public sector for many following decades.

The Nuremberg Doctors Trial in 1946−47 convicted many leading Nazi physicians of crimes against humanity with severe punishments including hanging or long prison terms. However, many in the medical profession aligned with these horrors remained in leading positions in the medical community—one even being elected to head the World Medical Association then discussing the Helsinki Declaration of Ethics in Biomedical Research before being forced to resign. The Nuremberg Trials and the subsequent Helsinki Declaration laid the fundamentals of biomedical ethics with regulations and requirements of ethical procedures and the Institutional Research Board, often referred to as Helsinki Committees. These were established by individual research centers, universities, hospitals, and other health care facilities to supervise and approve (or refuse) applications seeking funding, conducting, and publishing research involving human subjects.

The reappearance of genocide in the late twentieth century in the Balkans and Rwanda and in the twenty-first century in Darfur with over 300,000 deaths and 2.5 million displaced persons highlight this as a public health concern and its prevention as a public health and international political responsibility. Incitement to genocide is now considered a crime against humanity and was the basis for trials and convictions of leaders of the Rwandan Tutsi tribe, as well as inciters to ethnic violence and the political leaders and perpetrators of mass murders in the former Yugoslav republic. The threat and practice of genocide is still present, whether it is the murderous raids of Sudanese Janjaweed militias in Darfur and South Sudan, or the threats of genocide by Iran and associated terrorist organizations against Israel and Jews in general, the killing of Christians in northern Nigeria, Muslims in Myanmar and the genocidal civil war in Syria. Incitement to genocide is now accepted as part of international discourse, including the United Nations, which acted to accommodate the Rwanda massacres in 2003.

The risk of "silent" genocide is present in the 21st century with forced migration, limiting access rights of refugees to host countries, use of chemical weapons against civilian targets, use of starvation, mass rape and abuse

of civilian displaced persons, and persecution including mass murder, expulsion, and slavery of minority ethnic, religious and refugee populations.

The UNICEF report of 2017 states: "*2016 was one of the most dangerous years to be a child in recent memory. Millions of children were threatened and displaced by crises around the world. Millions more faced poverty, deprivation, violence, exploitation and discrimination.*" There are 66 million displaced persons in the world in 2017 who are refugees from war, endemic violence, terror, sexual violence and slavery, ethnic violence, chemical warfare, bombing civilians and medical facilities, hazardous journeys to "safety," and starvation as a tool of warfare, all forms of genocide. All of this in the 21st century when "Never Again: was the slogan following the Holocaust and other horrors of the 20th century.

Genocide represents the most extreme assault on human rights and protection for life. In the 20th century, an estimated 200 million have perished from genocide. An outline of genocides of the past 100 years is seen in Box 13.2. The Turkish genocide of Armenians in 1917 was followed by horrific genocides carried out under the flag of communism in Soviet USSR in the 1920s, in the Peoples' Republic of China under Chairman Mao in the 1950s and the Khmer Rouge in Cambodia in the 1980s, nationalism in the former Yugoslav republics in the 1990s and ethnic hatred in Darfur in the early years of the 21st century, and in civil war in Syria in the second decade of the 21st century. Totalitarian dictatorships, past war and defeat, ideologies of exclusiveness, ethnic purity and religious fundamentalism increase risks for genocide. Perpetrators use dehumanizing, demonizing and delegitimizing hate speech to desensitize or intimidate bystanders and to incite, mobilize, order and instruct followers to carry out mass murder.

The UN Convention on Prevention and Punishment of the Crime of Genocide (UNPPCG) of 1948 defines acts committed with intent to destroy, in whole or in part, members of a national, ethnical, racial or religious group as crimes against humanity. The UNPPCG specifies that incitement to genocide is itself a crime against humanity. Legal action should focus on state-sanctioned incitement as a recognized early warning sign. The UNPPCG convention defines genocidal acts including the following as punishable under international law:

- Genocide.
- Conspiracy to commit genocide.
- Direct and public incitement to commit genocide.
- Attempt to commit genocide.
- Complicity in genocide.

Genocide prevention requires international surveillance networks for monitoring and reporting incitement and hate speech in media, textbooks, places of worship, and the internet. Surveillance should monitor and identify the sources, and map their distribution and spread. Dehumanization,

BOX 13.2 Eugenics and Genocide: "the Slippery Slope"

Eugenics was a movement within the "Social Hygiene" concept of the early part of the 20th century. It was widely promoted to improve the population by reducing births among mentally ill and handicapped people. Legislation in some states in the US was upheld in decisions of the Supreme Court.

In 1942, the *American Journal of Psychiatry* published three articles, one arguing that "feebleminded" people should be killed (i.e., euthanasia). A rebuttal argued against euthanasia. An unsigned editorial position was that "euthanasia" would be appropriate in some cases, and that parents' opposition to this procedure should be the subject of psychiatric concern. The arguments referred to the context of eugenics and the murder of mental patients in Germany. The editorial pointed out that those genetic theories in psychiatry could be a precursor for future similar proposals. Forced sterilization was also practiced in Canada and Sweden.

This idea was promoted by Hitler in *Mein Kampf* and adopted by the Nazi party, which was legally elected to office in 1933. Organized massacres of mentally-ill and handicapped children and adults led to practices of various modes of killing, including starvation and gas chambers. These methods were then applied in concentration camps and the Holocaust murder of six million Jews and millions of others.

Genocide represents the most extreme assault on the respect for life. During the 20th century, an estimated 200 million have died during genocide. Totalitarian dictatorships, past wars and defeat, ideologies of exclusiveness, ethnic purity, and religious fundamentalism increase risks for genocide. Perpetrators use dehumanizing, demonizing, delegitimizing incitement by hate speech and propaganda to desensitize or intimidate bystanders and to promote, organize, order, and instruct followers ready to carry out mass murder. Consider the following list:

- 1915−17: Armenian genocide by Ottoman Turkish Empire—1.2 million killed.
- 1920−40s: Eugenics movement—United States, Sweden, Canada.
- 1920s: Mass executions, deportations, starvation as policy in Soviet Union Stalinist regimes killed millions.
- 1930−40s: Mass sterilization of "defectives" in the US and Sweden.
- 1930−40s: Mass murder of "defectives" in Nazi Germany (750,000).
- 1940s: Quarantining as pretext for ghettos by Nazis.
- 1940s: Concentration camps, human experimentation.
- 1940s: Holocaust; six million Jews and genocide in Nazi occupied Poland and the Soviet Union.
- 1947: Nuremberg Trials; convictions and capital punishment for crimes against humanity, genocide and criminal experimentation on humans by Nazi leaders and medical doctors.
- 1950s: Mass starvation in Maoist China—estimated deaths of 21 million people.
- 1948: Convention on the Prevention and Punishment of the Crime of Genocide.
- 1975−79: Cambodian political genocide of 1.7 million; genocide of Hmong in Laos.
- 1988: Iraqi genocide of Kurds in town of Halabja by poison gas.

(Continued)

BOX 13.2 (Continued)

- 1988: Brazil genocide of Tikuna people.
- 1992−95: Serbian rape, starvation and massacres in Srebrenica in Bosnia, Croatia and Herzegovina.
- 1994: Rwandan genocide of Tutsi tribe with 800,000 killed over a 100-day period from April to July.
- 2003−12: Sudanese genocide in Darfur (400,000 plus).
- 2011−17: Sudanese genocide of Nuba people.
- 2012−17 Iran incitement to genocide of Israel.
- 2012−17: Syria: Civil war; mass civilian deaths by bombardment and gas, displacement of millions; genocide of Yazidis and Christians.
- 2012−17: Democratic Republic of Congo massacres of Kivu minority; mass violence and refugee flow from South Sudan.
- 2017 Expulsion and mass violence against over 600,000 Rohingya Muslim population of Myanmar.

Source: Adapted from Tulchinsky TH, Varavikova EA. The new public health, 3rd edition. San Diego, CA: Academic Press/Elsevier, 2014, chapter 15 page 810. United Nations. Convention on the Prevention and Punishment of the Crime of Genocide. Available at: http://www.hrweb.org/ legal/genocide.html (accessed 4 May 2017). Richter ED. Commentary. Genocide: can we predict, prevent, and protect? J Public Health Policy. 2008;29(3):265−274. Available at: http://www. genocidewatch.org/images/Articles_Can_we_prevent_genocide_by_preventing_incitement.pdf. United to Prevent Genocide. The Bosnian war and Srebrenica. Available at: http://endgenocide.org/ learn/past-genocides/the-bosnian-war-and-srebrenica-genocide/ (accessed 15 April 2017). Joseph J. The 1942 'euthanasia' debate in the American J Psychiatry. Hist Psych. 2005;16(62 Pt 2): 171−179. Abstract available at: https://www.ncbi.nlm.nih.gov/pubmed/16013119 (accessed 16 April 2017).

demonization, delegitimization, disinformation, and denial are danger signs of potential genocidal actions. Genocide results from human choice and bystander indifference. One lesson of the Holocaust and subsequent genocides is that silence by nations and international organizations constitutes complicity. The public health community has a responsibility to speak out publicly on genocidal threats and its early warning signs (See Box 13.1).

Human Experimentation

Human experimentation has been a subject of great concern since the Nazi and Imperial Japanese armed forces' horrific experiments on prisoners and concentration camp victims during World War II. The Nuremberg trials set forth ten principles of professional responsibility to comply with internationally acceptable medical behavior in regard to research on humans (see Table 13.2).

The Helsinki Declaration was first adopted by the World Medical Assembly in 1964, and amended in 1975, 1983, 1989, 1996, and 2013. It delineates standards of medical experimentation and requires informed consent from subjects subjecting themselves to medical research. These

TABLE 13.2 Ethical Issues of Medical Research Derived from the Nuremberg Trials, the Universal Declaration of Human Rights and Declaration of Helsinki

Nuremberg Doctors Trial, 1946—47	The voluntary consent of a human subject is absolutely essential, with the exercise of free power of choice without force, fraud, deceit, duress, or coercion
	Experiments should be such as to bear fruitful results, based on prior experimentation and the natural history of the problem under study. They should avoid unnecessary physical and mental suffering
	The degree of risk should not exceed the humanitarian importance of the experiment
	Persons conducting experiments are responsible for adequate preparations and resources for even the remote possibility of death or injury resulting from the experiment
	The human subject should be able to end his participation at any time
	The scientist in charge is responsible to terminate the experiment if continuation is likely to result in injury, disability, or death
Universal Declaration of Human Rights, 1948	Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services
Declaration of Helsinki, 1964	Research must be in keeping with accepted scientific principles, and should be approved by specially appointed independent committees
	Biomedical research should be carried out by scientifically qualified persons, only on topics where potential benefits outweigh the risks, with careful assessment of risks, where the privacy and integrity of the individual is protected, and where the hazards are predictable. Publication must preserve the accuracy of research findings
	Each human subject in an experiment should be adequately informed of the aims, methods, anticipated benefits, and hazards of the study. Informed consent should be obtained, and a statement of compliance with this code
	Clinical research should allow the doctor to use new diagnostic or therapeutic measures if they offer benefit as compared to current methods
	(Continued)

TABLE 13.2 (Continued)	
	In any study, the patient and the control group should be assured of the best available methods. Refusal to participate should never interfere with the doctor—patient relationship. The well-being of the subject takes precedence over the interests of science or society

Note: Summarized from the Nuremberg Trials (1948) and World Medical Association, Declaration of Helsinki.
Source: Adapted from Tulchinsky TH, Varavikova EA. The new public health, 3rd edition. San Diego, CA: Academic Press/Elsevier, 2014, chapter 15 page 812. United Nations. Universal Declaration of Human Rights. Available at: http://www.un.org/events/humanrights/2007/hrphotos/declaration%20_eng.pdf. World Medical Association. Available at: http://www.wma.net/ (accessed 3 May 2017).

standards have become the international norm for experiments, with national-, state-, and hospital-Helsinki committees regulating research proposals within their jurisdiction. Funding agencies require standard approval by the appropriate Helsinki committee, sometimes called Institutional Review Boards (IRBs) or Ethical Review Boards (ERBs), before considering any proposal, with informed consent on any research project. The process recognizes that medical progress is based on research that must include studies involving human subjects, but medical research is subject to ethical standards that promote and ensure respect for human subjects and protect their health and rights. The key issues examined include:

- Research objectives should outweigh the risks and burdens to the research subjects.
- Research should conform to generally accepted scientific principles and literature.
- Participants are volunteers.
- Informed consent must be obtained including warning of potential risks.
- Risks are minimized and monitored.
- Respect for privacy and confidentiality.
- Respect for human rights.
- Scientific integrity.
- Social solidarity and paternalism.
- Fairness and equity.
- If the results are definitively positive, the research should be stopped.

The Tuskegee experiment (see Box 13.3) conducted in Alabama from 1932 to 1972 by the US Public Health Service (USPHS) was a grave and tragic violation of medical ethics. It was initiated in the context of the 1930s and consistent with widespread and institutionalized racism, detached from

BOX 13.3 The Tuskegee Experiment

The Tuskegee experiment was carried out by the US Public Health Service between 1932 and 1972. It was meant to follow the natural course of syphilis in 399 infected African-American men in Alabama and 201 uninfected men. The men were not told that they were being used as research subjects. The experiment had been intended to show the need for additional services for those infected with syphilis. However, when penicillin became available in 1942, the researchers did not inform or offer the men treatment, even those who were eligible when drafted into the army in 1942. The experiment was stopped in 1972 as "ethically unjustified" when the media exposed it to public scrutiny.

The case is considered unethical research practice because, in the time it was conducted, it did not provide the patients with information on the research nor on the availability of curative care when it became available. The patients' well-being was put aside in the interest of a descriptive study.

A similar experiment was conducted by the US Public Health Service in full cooperation with the Guatemala Ministry of Health during 1946−1948 in which soldiers, prisoners, and others were deliberately exposed to prostitutes known to be infected with syphilis. This experiment was terminated when it was revealed in the US media by a historian.

In 1997, President Bill Clinton apologized to the survivors and families of the men involved in the experiment on behalf of the US government. The Tuskegee experiment is the source of widespread lingering suspicion of public health in the African-American community to the present time.

Source: Adapted from Tulchinsky TH, Varavikova EA. The new public health, 3rd edition. San Diego, CA: Academic Press/Elsevier, 2014, chapter 15 page 813. (accessed 5 May 2017). Reverby SM. Ethical failures and history lessons: the U.S. Public Health Service research studies in Tuskegee and Guatemala. Public Health Rev. 2012;34(1):189206. Available at: https:// publichealthreviews.biomedcentral.com/articles/10.1007/BF03391665 (accessed 3 December 2017).

humanist values and historical medical ethics of "first, do no harm." The Tuskegee experiment, and a following similar study conducted by the USPHS in conjunction with the Ministry of Health in Guatemala, are remembered as important ethical transgressions which have had repercussions until the present time resulting in suspicion of public health endeavors, particularly among the African-American community in the US, even after a public apology in 1997 by then president Bill Clinton.

Ethics in Public Health Research

The line between practice and research is not always easy to define in public health, which has surveillance of population health as one of its major tasks. This surveillance is mostly anonymous, but relies on individually identifiable

data needed for reportable and infectious disease control as well as for causes of death, birth defects, mass screening programs, and other special disease registries. It may also be necessary to monitor the effects of chronic disease, for example, to ascertain repeat hospitalizations of patients with congestive heart failure to assess the long-term effects of treatment, and the effects strengthening ambulatory and outreach services to sustain chronic patients at a safe and functional level in their own homes.

Preventive care practices—e.g., sanitation, healthy and safe food and diets, health promotion, immunizations, prenatal care, newborn screening, Pap smears, mammography, and colonoscopies—as well as access to medical care and hospital utilization, are all part of public health. Monitoring and impact assessment of preventive programs may require special surveys, such as those conducted by the US National Health and Nutrition Studies (NHANES) and are important to assess health and nutritional status as well as other measures of health status and risk factors such as smoking and exercise. Every effort in public health research must be made to preserve anonymity and privacy for the individual, but in some cases such as reporting of contagious diseases or birth defects, case contact is crucial. This can entail identifying people who attended an event or were on an airplane where an infected person may have been — such as with measles or antibiotic resistant tuberculosis — so as to take appropriate preventive measures.

The general distinction between research and practice has to do with the intent of the activity. Clinical research uses experimental methods to establish the efficacy and safety of new or unproven interventions; many drugs and procedures in common use have never been subjected to randomized controlled trials. In practice, many methods are devised that are held to be effective and safe by expert opinion and documented as such. Researchers comparing HIV or hepatitis B transmission rates among intravenous drug users not using needle exchange programs would be doing unethical research, according to accepted current standards, by giving safe needles to the experimental group and withholding them from the control group. The scientific justification of an experiment must be made explicit but would not likely be approved by an Ethical Review Board (Helsinki Committee). In some cases of new therapy for life threatening conditions, the FDA will "fast track" what are called "orphan drugs" urgently needed as happened with the NIH recommendation for antiretroviral (ART) drugs for HIV/AIDS. This turned out to be a major success for treatment and prevention of HIV (Faucci, 2014). Clinical equivalence is a necessary condition of all clinical and public health research and provision of standard of care treatment to control groups is a minimal requirement for most research ethics boards. Determination of the standard, and whether it should be place, time, and community specific, is an area of ongoing controversy.

A 1996 US Public Health Service study supported by the US National Institutes of Health (NIH) and WHO compared a short course of zidovudine

(AZT) to a placebo given late in pregnancy to HIV-positive women in Thailand, measuring the rate of HIV infection among the newborns. The experiment was terminated when a protest editorial appeared in a prominent medical journal. This study confirmed previous findings that AZT given during late pregnancy and labor reduced maternal-fetal HIV transmission by half. The findings indicate that AZT should be used in developing countries, and the manufacturers agreed to make it available at reduced costs. The result has been a major success with more recent medications to reduce maternal−fetal transmission of HIV in many places in Africa with important financial and professional support from the Global Alliance for Vaccine Initiatives (GAVI), international donors, and a slowing of the spread of HIV- and AIDS-related deaths.

An outstanding case of breach of ethics in public health research occurred with the "Wakefield Effect" as described in Box 13.4. The importance of responsible medical journalism to keep a watchful eye on the possibilities of misleading scientific publications is of great importance for the ethical and legal aspects of public health.

CURRENT RELEVANCE

A preeminent ethical issue in public health is that of assuring universal access to services, and/or the provision of services according to need. While all industrialized countries except the United States have universal health care insurance or national health service evolving since the 19th century (see Chapter 8); the United States is still struggling with the issue in the 21st century. The solidarity principle of societal shared responsibility for funding universal access to health care is based on equitable prepayment for health care for all by nationally regulated mechanisms through place of work or general revenues of government. A society may see universal access to health care as a positive value, and at the same time utilize incentives to promote or place limits on use of services or benefits to the individual such as hospital care, immunization, screening programs, prescription drugs and others. Some services may be arbitrarily excluded from health insurance, such as dental care, although this is to the detriment of children and a financial hardship for many. Strategies for program inclusion are often based on historical precedent rather than cost-effectiveness or evidence. While efforts are being made to include more children in the program, the Medicaid system in the US defines eligibility at income levels up to 133 percent of the poverty line, thus excluding a high percentage of the working poor. This is a topic of current and continuing political importance in electoral platforms in the US to address the challenge of the uninsured and poorly insured working poor population (i.e., Obamacare versus Trumpcare). Health is also a political issue in countries with universal health systems where funding may be inadequate or patient dissatisfaction common.

BOX 13.4 The Wakefield Effect

In 1998, one of the top medical journals in the world, *Lancet*, published an article by a number of well-known researchers headed by Dr. Andrew Wakefield. The article reported on 12 cases of autistic children and allegedly showed a connection to immunization with MMR vaccine (measles-mumps-rubella).

The immediate effect of this "revelation" was widespread alarm in the United Kingdom and abroad concerning MMR vaccine and a drop in immunization coverage with measles-containing vaccines in the United Kingdom and elsewhere. This was mainly triggered by mothers refusing to have their child vaccinated with the "risk of autism". As a result, measles epidemics occurred in the United Kingdom and in many other countries with the disease again becoming endemic in many parts of Europe and spreading to North and South America by travelers and tourists.

After a long series of investigative journalism in the British press, the article came under scientific scrutiny and the withdrawal of many of the coauthors, but consistent insistence by the lead author of its authenticity. Coauthors admitted to having been credulous and insufficiently vigilant in agreeing to be associated with the paper. British medical authorities later found Dr. Wakefield guilty of medical fraud and the UK General Medical Council withdrew his license to practice medicine. In 2000, 12 years after the original publication, *Lancet* formally withdrew the article. This fraudulent scientific publication caused a serious loss of the credibility of immunization in general, and especially regarding MMR vaccine, one of the greatest life savers of public health.

The return of measles in Europe to endemicity with frequent international transmission, fostered loss of confidence by mothers in immunization. Measles-containing vaccines were particularly affected due to the publicity given to the Wakefield case and issues of scientific integrity. Fraud and conflict of interests were proven in this case. The journal editors failed to ensure the scientific integrity of the lead author and coauthors, and were negligent in failure of the journal to retract fraudulent and disproven publications in real time, instead of waiting 12 years after publication.

In other public health issues, single publications of findings of small sample and poorly assessed studies published in haste without adequate critical review occur frequently. In electronic media, the problem of disinformation provokes great anxiety and rejection of well-established successful public health interventions such as fluoridation, and folic acid fortification of flour, with unsubstantiated and disproven claims that they may cause cancer, asthma, and other ill effects.

The interface between ethics, law, and science in public health requires continuous sensitivity to the downstream effects of reducing public trust and reduced parental compliance with immunization of their children and putting other children at risk.

Source: Adapted from Tulchinsky TH, Varavikova EA. The new public heath, 3rd edition. San Diego, CA: Academic Press/Elsevier, 2014, chapter 15, Box 15.18, page 814. Wakefield AJ, Murch SH, Anthony A, Linnell J, Casson DM, Malik M, et al. Ileal lymphoid nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children [retracted]. Lancet. 1998;351:637–641. (accessed 17 April 2017). Office of Research Integrity. Definition of research misconduct. Available at: http://ori.hhs.gov/misconduct/definition_misconduct.shtml. Murch SH, Anthony A, Casson DH, Malik M, Berelowitz M, Dhillon AP, et al. Retraction of an interpretation. Lancet. 2004;363:750. Available at: https://www.ncbi.nlm.nih.gov/pubmed/15016483 (accessed 21 April 2017). Godlee F, Smith J, Marcovitch H. Editorial. Wakefield's article linking MMR vaccine and autism was fraudulent. BMJ 2011;342:c7452. Available at: http://www.bmj.com/content/342/bmj.c7452 (accessed 17 April 2017). Tulchinsky TH, Varavikova EA. The new public health, 3rd edition. San Diego, CA: Academic Press/Elsevier, 2014. Page 814.

The HIV/AIDS epidemic which appeared suddenly in the early 1980s and became a global pandemic in 1990s raised a host of medical and public health ethical issues. Management of the epidemic was in some respects in conflict with the long-established role of public health of contacting and quarantining persons suffering from selected communicable diseases. It was not acceptable or feasible in modern society to require follow-up of case contacts or to isolate HIV carriers, at a time when there was no clinical cure with medications. However, this led to failure or delay of public health authorities, even in the late 1980s, to close public bathhouses in New York and other US cities where exposure to multiple same-sex partners promoted spread of a lethal disease, which could have been interpreted as negligence. During the 1980s, the politics of HIV/AIDS in the US centered on concerns in the community of men who have sex with men (MSM) that HIV testing could be used in a discriminatory manner. AIDS was initially addressed as a civil liberties issue and not as a public health problem. Screening, reporting, and case contact follow-up were seen as an invasion of privacy and counterproductive by increasing resistance to and avoidance of testing.

In these political circumstances, the educational approach was adopted as most feasible and acceptable. The AIDS epidemic and public anxiety about contracting AIDS through casual sexual contact reinforced the need for public education on safe sex. This has been raised as an ethical issue because such education may be construed as condoning teenage and extramarital relations. The issue of HIV screening of pregnant women in general or in high-risk groups took on a new significance with the findings that treatment of the pregnant woman reduces the risk of HIV infection of the newborn, and that breastfeeding may be contraindicated.

A similar issue arose anew in the past decade in the context of using the new human papillomavirus (HPV) vaccine for prevention of cancer of the cervix. Initially the vaccine was recommended for preteen girls to create protective antibodies to the virus before they became sexually active to prevent the possibility of sexually transmitted infection of the virus. Controversy arose over concern that this immunization of young girls might promote early onset of sexual activity. Gradually acceptance increased and other age groups of women were urged to take the vaccine. Boys were added to the recommended immunization target groups so as to reduce transmission of the virus, and to address male-to-male transmission via oral and anal sex. Inclusion of HPV vaccination requirement for school entry is under debate in the US, but parental refusals are increasing. CDC reports that HPV infects a large proportion of people in the US. Among adults aged 18−59 it was 45 percent in men and 40 percent in women. Nearly 10,000 women in the US are diagnosed with cervical cancer each year and 3,700 women die. Cancer of the cervix has been massively reduced by routine Pap smears for early case-finding and treatment. The advent of an effective HPV vaccine promises to lower cancer of cervix rates even further. The disease is much more

common in low-income countries where screening and HPV immunization are still very low on the health priorities list, so that cervical cancer is the second leading cancer killer of women worldwide. A recent survey conducted by the American Academy of Pediatrics result indicated that nearly 90 percent of pediatricians reported that they experienced parental vaccine refusals in 2013 compared to 75 percent in 2006. The vaccines most likely to be refused, mainly due to misinformation, are HPV, influenza, measles, mumps, and rubella vaccines, all strongly recommended by public health and clinicians.

Choices in health policy are often between one "good" and another. Limitations in resources may make this issue even more difficult in the future, with aging populations, increasing population prevalence of physical disabilities, and rapid increases in technology and its associated costs. For example, the UK's National Health Service at one point refused to provide dialysis to persons over age 65. When computed tomography (CT) was first introduced, Medicare in the US refused to insure this service as an untested medical technique. Due to a lack of facility resources such as incubators and poor prospects for the survivors, the Soviet health system considered newborns as living only if they weighed over 1,000 grams and survived more than seven days. Those under 1,000 grams who would be considered living by other international definitions, would be placed in a freezer to die. At the opposite extreme, many western medical centers use extreme and costly measures to prolong life in terminally ill patients, preserving life temporarily, but often with much suffering for the person and at great expense to the public system of financing health care.

In many countries, such as those in the former Soviet system, spending for hospital services, in some cases was grossly overemphasized and in excess of need, accompanied by lack of funds for community care such as adding new vaccines for the immunization program for children, although coverage rates were high. In the US, there was a lack of funds for immunization of poor children, but this has gradually improved over the past decade with changes in health insurance for the poor as well as by using food supplement programs to promote immunization.

Research Misconduct

The Office of Research Integrity of the US Department of Health and Human Services defines research misconduct as: "fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results:

- *Fabrication* is making up data or results and recording or reporting them.
- *Falsification* is manipulating research materials, equipment, or processes, or changing or omitting data or results such that the research is not accurately represented in the research record.

- *Plagiarism* is the appropriation of another person's ideas, processes, results, or words without giving appropriate credit.
- *Research misconduct* does not include honest error or differences of opinion."

The prevalence and publication of erroneous information and compromised research findings is an ongoing issue in the 21st century, which can spread false information in the media such as the internet. This can have serious negative consequences for population health. Pseudoscience can feed populist movements with tragic consequences in public health.

Helsinki Research Ethics Committees (or Institutional Review Committees) are responsible to ensure that ethical principles are maintained in research proposals and publication of results of such research. These principles include informed consent, confidentiality, and scientific integrity. Publication in peer-reviewed journals is essential for establishing and advancing the evidence base for public health practice. Poor, or fraudulent science, can have a substantial adverse impact on public opinion both on health issues and on the priorities in the allocation of resources. It is essential that journal editors and reviewers adhere to high ethical and professional standards. They must be vigilant to avoid allowing poor professional standards of articles to be published or allowing non-professional factors or conflicts of interest to distort decision-making processes. Professional integrity and high scientific standards are vital to advance public health practice.

Ethics in Patient Care

Ethical issues between the individual patients and health care providers are important in health systems. A doctor is expected to use diligence, care, knowledge, skill, discretion, and caution in keeping with practice standards accepted at the time by responsible medical opinion, and to maintain the basic medical imperative to "do no harm" to the patient. Patients should have the right to free choice of provider and treatment, to observance of quality standards, access to high quality health services, to be informed of his or her condition, give informed consent, to confidentiality of personal and health information, and to physical privacy during care and diagnosis, to available alternatives for treatment, to be informed of the risks and benefits involved, and to complain and seek compensation for negligence. Ideally, patients have the right of access to high quality health services, to safety and freedom from harm caused by lack of resources, geographic inequality, poor functioning of health services, and from medical malpractice and errors. Patients' rights include the right of access to innovative procedures, including diagnostic procedures, according to international standards and independent of economic or financial considerations. Patients may seek alternative medical opinions, but this right is not unlimited, as any insurance plan or health service may place

restrictions on payment for further opinions and consultation without the agreement of a primary care provider, which is called "the gatekeeper" role.

Health insurance providers have responsibility beyond that of payment for health service and individual care by a physician, in institutions, or through services in the community or the home. The contract for service is becoming less between an individual physician and the patient, but increasingly among a health system provider group staff and a client. This places a new onus on the physician to ensure that patients receive the care they require. Conversely, the US provider often faces the dilemma of knowing that a patient may not access needed services because of a lack of adequate health insurance, and the terrible practice of exclusions due to "prior health conditions".

Sanctity of Life Versus Euthanasia

The imperative to "save a life" is an important ethical and practical issue in health care. Principles of physician-assisted euthanasia were based on a legal process including psychiatric assessment. Physician-aided suicide of a patient is facilitated by providing the means or information—e.g., indication of a lethal medication dosage—provided by a physician who is aware of the patient's intent. Both are based on the right of the patient to decide to die with dignity when their illness is terminal and the individual is suffering excessively. This is not a medical decision alone. It is also an agonizing issue for society to address.

The Nazi euthanasia program in Germany in the 1930s and its subsequent application as mass extermination in the Holocaust with grossly unethical human experimentation provided the direst of warnings to societies of what may follow when the principle of the sanctity of individual human life is breached. The issue, however, returned to the public agenda in the 1980s and 1990s as advances in medical science have allowed the prolongation of human life beyond hope of recovery.

Legislation in the Netherlands, Belgium, the US ("assisted suicide" in six US states, Washington DC, Oregon, Vermont, California, Colorado, and Montana as of April 2017), northern Australia and Canada legally sanctioned passive euthanasia (i.e., withdrawing medical assistance) with various safeguards in a variety of circumstances, such as long-term comas or late stages of terminal illnesses. The legislation in Canada, known as "dying with dignity", is the federal regulatory framework with strict criteria for eligibility and procedures, provides for medical assistance in dying for those persons with a "grievous and irremediable medical condition; they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering." The person must be eligible for

government-funded health services and be over 18 years. Doctors, patients, relatives, and health care organizations need clear guidelines, orientation, procedures, legal protection, and limitations where failure to take the utmost steps to "save" the patient by intubation, resuscitation, or transplantation may cause legal jeopardy. Protection of the elderly or chronically ill from malicious application of this form of merciful death must ensure that it is truly the patients' wish. This requires well defined procedures with legal, social, psychiatric and medical participation.

Even though a distinction can be drawn theoretically between permitting and facilitating death, in practice, doctors in intensive care units face such decisions regularly where the line is often blurred. Hospital doctors routinely take extreme measures to prolong the life of hopeless cases. Such decisions should not be considered for economic reasons alone, but in practice the costs of care of the terminally ill will be a driving force in debate of the issue. Living wills allow a patient to refuse heroic measures such as resuscitation, with "do not resuscitate" standing orders and assignment of power of attorney to family members to make such decisions. Family attitudes are important, but the social issue of redefining the right of a patient to opt for legal termination of life by medical means will be an increasingly important issue in the 21st century.

The Imperative to Act in Public Health

As in other spheres of medicine and health, in public health the decision whether to intervene in an issue is based on identification and interpretation of the problem. A case must be made of importance even if a rare condition, establishing evidence of the potential of the intervention to improve the situation, to do no harm, and to convince the public and political leaders of the need for such intervention along with the resources to carry it out. This process requires patience and a longer time frame than many other fields in health.

Some interpretations of ethics in health consider that the only purpose for which power can be rightfully exercised over any member of a democratic community, without asking individual permission and possibly against their will, is to prevent harm to others. However, this is a dictum that is not always applied to public health, which is obliged to act to protect health in so many spheres such as water, sanitation, food and drug safety, and environmental health on a spectrum that extends to banning smoking in public places, mandating food fortification, and many other areas for improved population health in a civil society.

Failure to act is an action, and when there is convincing evidence of a problem that can be alleviated or prevented entirely by an accepted and demonstrably successful intervention, then the onus is on the public health leader/authority to advocate such action and to implement it as best as possible under the existing conditions. Failure to do so is a breach of "good

standards of practice" and could be unethical. Inertia of the public health system in the face of evidence of a demonstrably effective modality such as adoption of state-of-the-art vaccines or fortification of flour with folic acid to prevent birth defects would come under this categorization and may even constitute neglect and unethical practice. This is not an easy categorization because there is often disagreement and even opposition to public health interventions, as was the case in opposition to vaccination long after Jenner's crucial discovery of this procedure in the late eighteenth century. This idea is also a significant problem true today with opposition to many proven measures such as immunization, fluoridation or fortification of basic foods. Box 13.5 shows the ethical standards of the American Public Health Association of 2002.

The problem of refusals of vaccination has become an issue in the US mainly among upper middle class families. In Western Europe delay in updating immunization programs such as the two doses of measles policy in the past has created a situation of measles outbreaks across Europe since 2010 with many cases among unimmunized children or among young adults or those with only one dose and waning immunity. In many low- and medium-income countries funding levels for health are minimal leading to the delay in professional or governmental acceptance of "new" vaccines. This has been a serious issue but international donors have helped countries in sub-Saharan Africa to expand the range of vaccines in their routine programs with important life saving vaccines such as rotavirus and hemophilus influenza B. Underfunding for health is an ethical dilemma in many low- and medium-income countries. In former Soviet countries including the Russian Federation much of the overall low level of funding for health is due to their declining, but still relatively high, acute-care hospital bed supply with much longer average length of hospital stay leaving primary care and upgrading of immunization lagging.

Closure of hospitals involves difficult political and ethical decisions and is a source of dispute between central health authorities, the medical professions, and local communities. Health reforms in many industrialized countries, such as reducing hospital bed supplies, managed care systems, promoting cost containment, and reallocation of resources raise ethical and political issues often based on vested interests such as private insurance systems, hospitals, and private medical practitioners (see Chapters 8 and 15).

Where there is a high level of cumulative evidence from professional literature and from public health practice in "leading countries" with a strong scientific base and case for action on a public health issue, when does it become bad practice or even unethical public health practice to ignore and fail to implement such an intervention? Such ethical failures occur frequently and widely. For example, is it unethical to not fortify grain products with folic acid and salt with iodine when there is overwhelming evidence of safety and cost effectiveness? Should there be a recommended European

BOX 13.5 **Principles of Ethical Public Health Practice: American Public Health Association, 2002**

1. Public health should address the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.
2. Public health should achieve community health in a way that respects the rights of individuals in the community.
3. Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.
4. Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.
5. Public health should seek the information needed to implement effective policies and programs that protect and promote health.
6. Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.
7. Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.
8. Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.
9. Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.
10. Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the likelihood of significant harm to the individual or others.
11. Public health institutions should ensure the professional competence of their employees.
12. Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Source: American Public Health Association. Principles of the ethical practice of public health Version 2.2, 2002. Available at: https://www.apha.org/~/media/files/pdf/membergroups/ethics_brochure.ashx (accessed 15 April 2017).

immunization program; should milk be fortified with vitamin D; should vitamin and mineral supplements be given to pregnant and lactating women, and children; should all newborns be given vitamin K intramuscularly routinely? Other examples include the issues of fluoridation of water supplies and opposition to genetically modified crops or generic drugs in African countries. These issues are continuously debated and the responsibility of the trained public health professional is to review the international literature on a topic

and formulate a position based on the cumulative weight of evidence. It is not possible to wait for indisputable evidence because in epidemiology and public health, this rarely occurs. This is another reason that guidelines established by respected agencies and professional bodies free from financial obligations to vested interest groups are essential to review evidence which accumulates on a continuing basis on many issues thought to have been resolved or which appear de novo.

A recent public health issue has been the banning of trans fats in baking and cooking, with legislation in New York City and some upstate New York State counties. The US Food and Drug Administration (USFDA) has declared trans fats, found in many popular processed foods, like baked goods and frozen foods, to be unsafe for consumption as they contribute to heart disease. The USFDA promotes manufacturer compliance and will regulate banning of use of trans fats by 2018, which is expected to reduce coronary heart disease and prevent thousands of fatal heart attacks every year. The USFDA reports that between 2003 and 2012, consumer trans fat consumption decreased about 78 percent and that the labeling rule and industry reformulation of foods were key factors in informing healthier consumer choices and reducing trans fat in foods. While trans fat intake has significantly decreased, the current intake remains a public health concern. The Institute of Medicine (IOM) recommends that consumption of trans fat be as low as possible while consuming a nutritionally adequate diet.

The WHO European Region reports that five European countries are in the process of banning trans fats through regulation, while others have decided to use self-regulatory mechanisms. On the other hand, virtually no countries in the European Region fortify flour with folic acid to prevent birth defects (neural tube defects), a lapse in current international public health standards. Along with rising incidence of rickets in infancy due to lack of sun exposure and lack of vitamin D supplements in pregnancy care, birth defects and severe rickets are increasing especially among dark skinned mothers in full body clothing for religious reasons. Most consumers do not know that some processed food categories contain large amounts of trans fats. Consumption in some population groups, particularly poorer people, can be very high. Removing trans fats from the food supply is one of the most straightforward public health interventions for reducing the risk of cardiovascular diseases and some cancers, and improving diets. A study comparing myocardial infarctions in New York counties that banned trans fat usage to counties that did not showed a greater reduction in acute myocardial infarctions in the counties that had banned trans fats. The ethical issue will be to see the rate of acceptance of this finding in other jurisdictions versus traditional opposition to too much interference by the state. The same issue regarding folic acid fortification of flour to reduce birth defects is similarly both a professional and ethical question. Virtually all European countries have ignored the evidence and fail to adopt mandatory fortification thus

harming poorer population groups with less money to buy healthier foods. The delay in implementation of proven safe and effective public health measures is one of the key ethical issues in public health practice.

ETHICAL ISSUES

Coleman et al. discuss global issues in public health ethics with emphasis on disparities in health status; access to health care and the benefits of medical research; responding to the threat of infectious diseases; efforts to contain the spread of infectious diseases; international cooperation in health monitoring and surveillance (e.g., International Health Regulations); exploitation of individuals in low-income countries; health promotion, participation, transparency, and accountability. The global Millennium Development Goals (MDGs) and the follow-up Sustainable Development Goals (SDGs) reflect a consensus on objectives and a respectable degree of international support by donor countries. Strong networks such as the Global Vaccine Alliance involve international organization (e.g., WHO, UNICEF, World Bank), donor countries and private donors (e.g., Bill and Melinda Gates Foundation, Carter Foundation, Rotary Club and many others), with a strong track record of mobilizing funds and cooperation with private industry to raise immunization coverage and inclusion of new vaccines in many low income countries and in NTD elimination programs.

Recent public health emergencies involving anthrax, severe acute respiratory syndrome (SARS), Ebola, and Zika viruses have been declared "public health emergencies" and dramatized the need for restrictive public health measures. These include quarantine, isolation, and rationing of vaccines in short supply. Policy-makers and front-line care providers face difficult ethical questions in such cases which can be expected to occur with new challenges in the future. Support during the Ebola outbreak in West Africa in 2014−16 and Zika spreading out from Brazil in 2016−17 has been criticized as bumbling and inadequate, but did indicate strong levels of international cooperation and shared global concern. This most recent Ebola epidemic was the longest and most deadly in history, resulting in nearly 29,000 cases and over 11,000 deaths in Guinea, Liberia, and Sierra Leone. Several potentially useful therapeutic agents were available in 2014 that had been tested on animals, and limited early studies of the safety of vaccine candidates for humans. However, the affected countries struggled to deal with the rapidly escalating epidemic and the growing number of patients. Médecins sans Frontiére (MSF) provided the front-line treatment and infection control, and warned that the epidemic was "out of control" and would require a massive international response. First responders in many settings show the way in ethical behavior in calamitous situations such as the Syrian civil war where civilians as well as medical facilities are bombed and gassed deliberately by government and foreign forces.

National, international, and local representatives play a critical role in preparing the global community for unexpected epidemics. Research, with sound clinical trials based on best practices for improving clinical care and vaccines for prevention to protect at risk populations, are needed during and between public health emergencies. Research efforts to develop vaccines for these emerging infectious diseases and others such as malaria and dengue are impressive and will hopefully bring forth lifesaving vaccines on large scales in the coming decade. In the case of Ebola, none of the clinical trials have reached definitive conclusions about efficacy in the search for therapeutics, but vaccine trials have identified vaccines that are safe and effective. The availability of financial, organizational, and professional resources to tackle such issues is an underlying problem of priority decision-making with professional, ethical, and moral standards.

Public health may face the challenge of pandemic influenza—such as the avian flu—with decisions regarding allocation of vaccines, treatment of massive numbers of patients arriving at hospitals in acute respiratory distress with very limited resources to cope, coping with sick or absent staff, and many other issues such as not only individual life-and-death situations, but large scale mortality. The ethical questions will be replaced by struggles to cope. Preparation for such potential catastrophic events will be a challenge to public health organizations and the health system generally.

Public health is tasked with monitoring population health and implementing measures to reduce morbidity or mortality of the population within ethical norms of societal acceptability. Advancing public health goals, with minimal restriction of individual liberties, will reduce the burden of disease and mortality, while reducing inequities and advancing social justice. This requires trained professionals to monitor population-based data and research with translation of new science into practice. Programs to achieve these objectives must be evidence-based to substantiate that they will achieve these goals with minimal restrictions, but with public support for those vital to ethical and successful public health.

Teaching Public Health Ethics

The aim of ethics education in public health should be to enhance the ability of public health professionals, policy makers and citizens to reason rationally about the moral dilemmas and value conflicts inherent to human rights, social justice, and the application of knowledge and technology in the health sciences and in public health measures.

Ethics analysis typically involves the capability to identify the public health issue and its contribution to health of the population. This requires a review of the professional literature to know the state-of-the-art techniques and to be able to articulate the factual information to the decision-makers and the public. This

requires identification of the ethical issues of the case and to identify the "stake-holders"—those whose rights and interests will be most directly affected by the decisions made and the values, concerns, and information at stake in the case. The ability to identify options available to decision-makers in the case is vital to making the "case for action" and the decision-making process, before, during and after a public health event or process as in pandemic preparedness. The cost of action versus inaction is a vital factor.

Training current faculty on public health ethics issues should be mandatory in schools of public health in order to incorporate ethics into existing courses of formal educational programs. This requires specific and mandatory courses on public health ethics along with incorporation of discussion of ethical issues in core courses in the program.

CONCLUSION

Defining and applying ethical and high standards of practice of medical care as well as public health requires an ideological commitment to individual and community sanctity of life. Ethics in health also requires commitment to advancement of health care and use of best practices of international standards to the maximum extent possible under the local conditions in which the professional is working. This is not an easy commitment as there is often dispute and outright hostility to public health activities in part because of past ethical distortions of great magnitude. But this is an optimistic field of activity by virtue of the great achievements it has brought to humankind. Preparation for disasters and unanticipated health emergencies can raise issues of security, quarantine, isolation, rationing of vaccines due to insufficient supplies—e.g., in influenza epidemics—or restrictions on community events or family burials as in the case of Ebola in West Africa in 2014−16.

Public health also faces slow responses to advances in the science of vaccines or in health promotion measures with proven efficacy. Addressing current issues is a vital part of the "New Public Health" and our ethical and professional commitments. The role of public health in climate change is both a professional and ethical issue, as are many other topics such as food fortification, fluoridation of community water supplies, access to birth control and other longstanding and new topics. Advancement in global health requires consensus of national governments and international bodies working together to alleviate poor health conditions with available professional standards and resource mobilization to achieve this goal. Most issues in public health have ethical aspects so that education on future public health requires adequate attention to the topic, perhaps best presented in case studies.

Ethical issues in public health include both definition of, and decisions to act on a problem, but also delay, avoidance, or inaction when best evidence available indicates action prevents harm to the population. Failure to act in a timely fashion or to allocate resources to meet clear health needs of a

population can be unethical just as much as acting in a harmful way. While resource allocation is a political decision, failure to act can be as injurious and unethical as being directly responsible for harmful acts. Public health as a profession and a movement or ideology must be willing to point out the effects of nonaction as well as of ethical or nonethical acts. Compliance with evil is unethical and the preparation of public health workers requires understanding of how to differentiate, and to how to advocate for the better choices in policy and its implementation.

RECOMMENDATIONS

1. Ethics should be incorporated in all courses in public health as well as health policy and management programs.
2. Dedicated courses in ethics should be included in public health education curricula to provide interested students with an opportunity for more in-depth study.
3. Public health ethics along with public health law should be included in criteria for curricula as "cross cutting" courses required by accreditation agencies.
4. Public health ethics orientation workshops should be provided to help teachers in all topic areas of the curriculum, core and elective, incorporate ethics in their teaching material.
5. The topic of public health ethics should be incorporated in ongoing educational programs for practitioners in the broad multi-disciplinary fields of public health.
6. Public awareness and engagement efforts that accompany public health programs and interventions should incorporate some measure of ethics education.
7. Critical thinking about the values involved in a public health controversy is vital to combat the public health problem in question.
8. Recognition that the concepts of social solidarity and obligations as well as individual rights are fundamental in public health practice.
9. Recognition that emergency preparedness and response includes mandatory immunizations such as measles and other public health measures as in influenza or cholera control immunization.
10. Training in ethical studies should be part of public health training at all levels including continuing education.
11. Curriculum development should include awareness of ethical issues of artificial and natural catastrophes of the past century as well as current topics.
12. Case studies are valuable teaching tools and incorporated and examined in class discussion.

13. Teachers of other aspects of public health including epidemiology and health promotion should include ethics in their syllabi and course content.
14. Consideration should be given to development of Helsinki Committee procedures and review criteria for public health-related research based on data sets without individual identification in public health research proposals.
15. Teachers of ethics in public health should have dual training in public health and ethics.

STUDENT REVIEW QUESTIONS

1. Why was eugenics a popular topic in western countries among intellectuals during the early part of the 20th century?
2. How was eugenics practiced in liberal democratic countries?
3. How did the eugenics idea become translated into mass murder of the handicapped in Germany, and then adapted to genocide of Jews and others in the Holocaust?
4. Why is incitement to genocide seen as a precursor and crime against humanity?
5. Why is approval of a "Helsinki Committee" needed before applying for a research grant?
6. Why is assisted death permitted in some jurisdictions, and what steps are needed to ensure this is solely based on the patient's wishes?
7. Discuss the ethics of requiring children to be fully immunized before they can attend school.
8. What is the "Wakefield Effect", and how is it affecting attitudes to immunization?
9. How should practicing doctors and public health explain mandatory chlorination, and fluoridation of community water supplies?
10. Is banning cigarette smoking in public places an infringement of individual rights?
11. Is parental refusal of immunization without a valid medical reason ethical?
12. Discuss what you think are ethical issues in public health.
13. Discuss what you think are ethical issues in medical practice.
14. Discuss public health ethics issues in global health.
15. Discuss ethical issues in medical and public health research.
16. Describe the historical and current meaning of the Nuremberg Trials, the Universal Declaration of Human Rights, the Helsinki Declaration and the Tuskegee experiments on public health and medical research ethics.

17. Discuss the role of the news and social media in investigation of public health issues and in spread of "pseudoscience" disinformation on public health topics such as vaccination, fluoridation, and food fortification.

18. Describe the lasting implication of the Tuskegee experiment for attitudes towards the public health profession in the US.

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