

Humanitarian Aid, Infectious Diseases, and Global Public Health

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THIS CHAPTER EXAMINES ETHICAL CHALLENGES in humanitarian aid, infectious diseases, and global public health. It describes key tasks in emergency situations, ethical issues in global health work, and trends in neglected infectious diseases. It provides the relevant ethical principles needed to develop an ethical framework. The principles can be applied to particular situations, guiding desperately needed action in global health practice. The chapter ends with some words of caution and final thoughts on humanitarian aid and global health.

THE TOP TEN PRIORITIES OF INTERVENTION

The ethical challenges in humanitarian aid are plentiful, especially in humanitarian emergencies when we have to respond to multiple priorities with often very limited resources. Refugee crises are not a new problem but date back to the earliest days of humanity. Humanitarian organizations have developed experience-based priorities when assisting refugees. The necessary interventions in an emergency phase usually cover ten top priorities, which should be carried out simultaneously. They have to be implemented rapidly and attention must be given not just to quantity but quality. These ten top priorities include: (1) initial assessment, (2) water and sanitation, (3) food and nutrition, (4) shelter and site planning, (5) health care in the emergency phase, (6) control of communicable diseases and epidemics, (7) measles immunization, (8) public health surveillance, (9) human resources and training, and (10) coordination.¹

The initial assessment allows an informed decision on whether or not to intervene and identifies intervention priorities. It should be completed within three days, using simple, straightforward methods, and should result in quick decisions.² The mortality rate is often the

¹ See Médecins sans Frontières, *Refugee Health: An Approach to Emergency Situations* (London: Macmillan Education, 1997), 38.

² See Médecins sans Frontières, *Refugee Health*, 53.

best indicator for assessing the severity of a situation and should be established as a base-line for evaluating the effectiveness of an intervention. Security conditions must be clearly described since they can have limiting effects on the presence of intervention teams and affect the implementations of programs.

Water and sanitation play an essential role in the spread of communicable diseases and epidemics. In an emergency situation, priority must be given to meet drinking and cooking needs and basic hygiene requirements.³ Human excreta (mostly fecal matter) are always contaminated and must be disposed of in well-defined areas. Proper personal and environmental hygiene prevent vectors from developing and spreading disease. Dealing with the dead, which is often essential for infection control, can lead to social tensions with the community. During the recent Ebola epidemic in West Africa efforts to eliminate traditional mourning and burial rituals led to distrust and much worse.⁴

Food and nutrition intervention addresses basic food needs and decreases mortality and morbidity resulting from malnutrition. An assessment of the food and nutritional situation should always be part of the initial health assessment. The prevalence of acute malnutrition in children less than five years of age can generally be used as an indicator of this condition in the entire population since this group is more sensitive to changes in the nutritional situation.⁵ The food provided has to be adequate in quantity and nutrient content. The objectives are to treat severely and moderately malnourished persons and to prevent malnutrition in vulnerable groups. The main factors required for successful and regular distribution are political willingness, adequate planning of the food supply, registration of the population, good organization of the distribution, and regular monitoring.⁶ A major obstacle during conflicts is inequity in access and food diversion by powerful and often armed groups, especially if these groups are in control of distribution.

Early shelter and site planning minimize overcrowding and make it possible to organize efficient relief services. Priorities to take into consideration include security, access to water, environmental health risk, and the local population. Cultural and social patterns should be taken into account.

³ See Médecins sans Frontières, *Refugee Health*, 79.

⁴ See Junerlyn Agua-Agum et al., "Exposure Patterns Driving Ebola Transmission in West Africa: A Retrospective Observational Study," *PLoS Medicine* 13, no. 11 (2016): doi.org/10.1371/journal.pmed.1002170. See also Jacqueline Azetsop's chapter in this book.

⁵ See Médecins sans Frontières, *Refugee Health*, 111.

⁶ See Médecins sans Frontières, *Refugee Health*, 89.

Healthcare in the emergency phase has to be flexible; it must adapt to the evolving situation and changing needs. Whenever possible, existing facilities should be used and supported. However, in most camp situations, new services have to be set up. Health services should focus on basic curative care.

Communicable diseases are the primary cause of mortality among displaced populations and have to be controlled. Preventive measures are most effective and outbreaks require a specific response. The four diseases responsible for most mortality include diarrheal disease, respiratory infections, measles, and malaria.⁷ By affecting children, measles continues to be one of the most severe health problems in the world. Controlling measles includes an immunization campaign. The recommended strategy is the organization of a first and rapid mass campaign coupled with vitamin A supplementation, to be followed by a routine immunization program integrated within existing health facilities.

A surveillance system is essential to provide early warnings of epidemics. Data collection should be simple and limited to public health problems that can and will be acted upon; crude mortality rate is most useful to measure the gravity of the situation.⁸

Human resources and training should follow specific procedures and be supervised by experienced staff. Labor laws of the host country have to be considered. Training will be necessary, but it should be preceded by an assessment of training needs. Proper coordination is essential and, when neglected, an intervention will often become disastrous. The involvement of local stakeholders is key, and information exchange should be formalized.

ETHICAL ISSUES IN GLOBAL HEALTH WORK

Humanitarian aid workers constantly face ethical challenges during the emergency phase. I became aware of these challenges while working in Angola with the Doctors Without Borders/Médecins sans Frontières (MSF)—an international humanitarian group dedicated to providing medical care to people in distress. The conflict in Angola started before independence in 1975. The main players were UNITA (National Union for the Total Independence of Angola), a powerful, totalitarian guerilla movement supported by the United States, on one side, and the MPLA (Popular Movement for the Liberation of Angola), a repressive Marxist-Leninist party-state, allied and supported by Cuba and the Soviet Union initially, and Angola's oil

⁷ See Médecins sans Frontières, *Refugee Health*, 152.

⁸ See Médecins sans Frontières, *Refugee Health*, 204.

wealth at the time, on the other side.⁹ Between 1998 and 2002, the last years of the conflict were especially gruesome and violent.¹⁰ At the end of the civil war in Angola, we suddenly had access to the battle zones and rebel areas without assistance or protection, the so-called “gray zones.” Tens of thousands of Angolans, unable to find food, perished in these gray zones during the last years of the war and the first weeks of peace. During our initial assessment, we encountered thousands of severely malnourished civilians, too weak to move, waiting to die. The numbers were overwhelming. For the first days and weeks, we had to decide whom to take with us for treatment and whom to leave behind for certain death. We identified hundreds of patients who needed immediate treatment in our feeding centers, but only had very limited transportation capacity. What guides a decision on whom to leave behind to perish? Can an ethical framework be applied in this situation?

What are some of the main ethical issues and conflicts encountered in global public health work? The goals of public health include promoting health and preventing disease and achieving the ethical and human rights principle of health equity. Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.¹¹ Therefore, reducing and eliminating health disparities is fundamental to reaching health equity. Considerations of justice are central to global health. The global health care status quo reflects a collective failure of the international community to meet the most basic needs of the world’s population.¹² Lack of global justice and solidarity, combined with corruption in the public and private sector, are major hurdles. As the example from Angola demonstrates, the injustice of limited resource allocation has to be addressed.

Often the problem of limited access to health care in resource-poor countries is exacerbated by a “brain drain”: the loss of trained professional personnel to wealthier countries that offers greater opportunity and pay. The issue of “brain drain” raises additional ethical issues regarding the acceptability of such recruitment and of

⁹ See Christine Messiant, “Angola: Woe to the Vanquished,” in *In the Shadow of ‘Just Wars’: Violence, Politics and Humanitarian Action*, ed. Fabrice Weissman (London: C. Hurst, 2004), 109–136, at 111.

¹⁰ See Messiant, “Angola: Woe to the Vanquished,” 118.

¹¹ See Paula Braveman et al., *What Is Health Equity? And What Difference Does a Definition Make?* (Princeton, NJ: Robert Wood Johnson Foundation, 2017).

¹² See World Health Organization, *Global Health Ethics: Key Issues* (Geneva: World Health Organization, 2015), 19.

actions to hinder migration.¹³ The conflict is between the freedom to relocate and associate freely on one side and the need to improve the health of vulnerable people on the other. How does global public health navigate the relationship between the liberty of the individual and broader societal concerns? Infectious disease outbreaks—like the COVID-19 pandemic—threaten the health and welfare of others, and it may be legitimate to restrict people’s liberty in order to protect the community. But how far should authorities be allowed to go in the name of the “greater good” of disease control? Or would the refusal to implement strict travel restrictions, cancel social gatherings and implement quarantine signal a lack of solidarity with the most vulnerable?

Global health action needs good data. How can the needs for accurate surveillance be balanced against the principle of individual autonomy?¹⁴ Should individuals be tested for a disease when providers are unable to offer them appropriate medications due to poor resource allocation but the collected data might allow access to medications for the community in the future? Testing might help the community but can bring devastation to the individual. I have seen persons who tested positive for HIV being ostracized by their community, but it was data from these tests that eventually convinced the international community to provide HIV treatment for resource-poor countries. Would it have been more or less ethical not to provide the individuals with their test results (as was also often done)?

Another set of ethical issues arises when assigning foreign workers for deployment during emergencies. As a strict rule, foreign aid workers should be deployed only if they are capable of providing necessary services not sufficiently available in the local setting.¹⁵ Assignment of outside health workers has to take into consideration their relevant skills and knowledge as well as their linguistic and cultural competencies.¹⁶ It is inappropriate to deploy unqualified or unnecessary workers mainly to satisfy a personal or professional desire to be “helpful.” Following the tsunami in Southeast Asia, there was an unprecedented outpouring of international aid and humanitarian workers.¹⁷ But being on site and having worked in Banda Aceh in the days and months after the tsunami, it became obvious to me that a large number of foreign aid workers were ill-prepared and

¹³ See World Health Organization, *Global Health Ethics*, 19. See also Daniel J. Daly’s chapter in this volume.

¹⁴ See World Health Organization, *Global Health Ethics*, 15.

¹⁵ See World Health Organization, *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks* (Geneva: World Health Organization, 2016), 47.

¹⁶ See World Health Organization, *Guidance for Managing Ethical Issues*, 48.

¹⁷ See Richard M. Zoraster, “Barriers to Disaster Coordination: Health Sector Coordination in Banda Aceh Following the South Asia Tsunami,” *Prehospital and Disaster Medicine* 21, Suppl. 1 (2006): S13–S18.

their presence had more to do with disaster tourism than humanitarian aid. Any foreign aid workers deployed during crises, especially where resources are scarce, should carefully consider (before departure!) whether they are prepared to deal with ethical issues that may lead to moral and psychological distress.¹⁸

Finally, we have to acknowledge that people in different countries and societies may hold different values or place different weights on common values. Cultural relativism is the idea that a person's beliefs, values, and practices should be understood based on that person's own culture, rather than be judged against the criteria of another. Applying global health ethics may lead to accusations of ethical imperialism. In a refugee camp in Sierra Leone, one very early morning, I surprised some of the staff performing female genital mutilation on a young girl in the clinic. My intervention to stop the procedure led to the mutilation being done with unsterile instruments somewhere else and to mistrust from the local staff which saw the mutilation as an integral part of their culture. Still, while some might argue that condemning female genital mutilation and other practices as human rights violations constitute an ill-advised form of ethical imperialism, others argue that we must stand up for the women and children who are at risk of being harmed.¹⁹

Global health ethics should protect individuals and the public from harm and promote the highest attainable standard of care. Issues of standards of care in resource-poor settings are a real practical concern. All of these ethical issues are made worse during natural disasters, armed conflict, and infectious disease outbreaks.

GLOBAL TRENDS IN INFECTIOUS DISEASES AND NEGLECTED INFECTIOUS DISEASES

What are global trends in infectious diseases? After having devastated humankind for most of history and keeping human life expectancy well below forty years of age, infectious diseases receded in Western countries in the twentieth century due to urban sanitation, improved housing, personal hygiene, and vaccination.²⁰ Antibiotics further suppressed morbidity and mortality. But since the last quarter of the twentieth century, we see new and resurgent infectious diseases.²¹ Examples of new infectious diseases include HIV, Lyme disease, Lassa Fever, Nipah Virus, H1N1 influenza, SARS, MERS-CoV, and COVID-19. Examples of re-emerging/resurging infectious

¹⁸ See World Health Organization, *Guidance for Managing Ethical Issues*, 48.

¹⁹ See World Health Organization, *Global Health Ethics*, 20.

²⁰ See Joshua Lederberg, "Infectious History," *Science* 288, no. 5464 (2000): 287–293.

²¹ See David M. Morens et al., "The Challenge of Emerging and Re-Emerging Infectious Diseases," *Nature* 430, no. 6996 (2004): 242–249.

diseases include cholera, the plague, dengue, yellow fever, Chikungunya fever, West Nile fever, and multiple drug resistant/extensively drug resistant (MDR/XDR) tuberculosis. According to the WHO, infectious diseases are spreading more rapidly than ever before, and new infectious diseases are being discovered at a higher rate than at any time in history.²²

Especially in low-income countries, neglected infectious diseases continue to cause significant morbidity and mortality. Yet, of the eight hundred fifty new therapeutic products approved between 2000 and 2011, only four percent (and only one percent of all approved New Chemical Entities) were indicated for neglected diseases, even though these diseases account for eleven percent of the global disease burden.²³ Although some of these illnesses are finally getting the priority that is necessary to control or even eradicate them, others are still barely recognized except by the individuals who suffer from them. Selected examples include sleeping sickness, leishmaniasis, Chagas, pediatric HIV, filarial diseases, hepatitis C, and mycetoma.

Sleeping sickness or Human African Trypanosomiasis is endemic in thirty-six African countries and about sixty-five million people are at risk of being infected.²⁴ Sleeping sickness is transmitted by the tsetse fly and is fatal without treatment. Over 1 billion people are at risk of leishmaniasis worldwide.²⁵ The parasite that leads to infection is called *Leishmania* and transmitted by sandflies. Existing treatments are difficult to administer, toxic, and costly. Drug resistance is also an increasing problem. Chagas disease is endemic in twenty-one Latin American countries, where it kills more people than malaria. In total, seventy million people are at risk worldwide. Less than one percent of patients have access to treatment.²⁶ 1.7 million children below fifteen years of age are living with HIV globally, mainly in sub-Saharan Africa.²⁷ Three hundred of them die every day. Filarial diseases—such as lymphatic filariasis (elephantiasis), onchocerciasis (river blindness), and loiasis (*loa loa*)—cause chronic illness and life-long disabilities leading to great suffering and social stigmatization. Over twenty-one million people are infected with river blindness alone, and

²² See World Health Organization, *World Health Report 2007—A Safer Future: Global Public Health Security in the 21st Century* (Geneva: World Health Organization, 2007).

²³ See Belen Pedrique et al., “The Drug and Vaccine Landscape for Neglected Diseases (2000–11): A Systematic Assessment,” *Lancet Global Health* 1, no. 6 (2013): doi.org/101016/S2214-109X(13)70078-0.

²⁴ See Drugs for Neglected Diseases initiative, “Diseases and Projects,” <https://www.dndi.org/diseases-projects/>.

²⁵ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

²⁶ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

²⁷ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

two hundred five million people are at risk.²⁸ Seventy-one million people worldwide are chronically infected with hepatitis C. Seventy-five percent of them live in low- and middle-income countries. Effective medicines are now available, but their high cost means that only thirteen percent of hepatitis C patients globally have access to treatment.²⁹ Mycetoma is a stigmatizing disease often resulting in devastating deformities, amputation, and morbidity. The exact route of infection is unknown. Treatment success for eumycetoma is less than thirty-five percent.³⁰ An ethical framework would not only include the goal that these diseases will cease to be neglected but that society will also cease to neglect the people suffering from them. New partnerships, leading to innovative research and to developing therapies for these diseases, are needed.

KEY ETHICAL ISSUES IN GLOBAL HEALTH RESEARCH

That brings us to some key ethical issues in global health research. Global health research aims to improve lives by testing existing and new treatments, preventive measures, and systems and procedures. It has produced great public health benefits, but it has also been the cause of concerns.³¹ Key ethical questions that have to be addressed include: Does the research have social value for the communities that take part or from which the participants are drawn? Who benefits from the research?³² When studies are carried out in resource-low settings, the individuals who take part and are put at risk may not be able to benefit from any knowledge gained by the study due to their poor economic status. Often the research agenda is driven by the potential profit and commercial success of new drugs and devices. Due to market forces, the pharmaceutical industry is reluctant to invest in the development of drugs to treat the major diseases of the poor because return on investment cannot be guaranteed. For example, for many years, eflornithine—a proven cure of human African trypanosomiasis (sleeping sickness)—was not produced due to market failure.³³ The disease surged, and patients had to be treated with worse, more toxic, and painful alternatives.³⁴

Before any research is started, stakeholders should make sure implementation will not take away resources—including personnel, equipment, and health-care facilities—from other critical clinical and

²⁸ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

²⁹ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

³⁰ See Drugs for Neglected Diseases initiative, “Diseases and Projects.”

³¹ See World Health Organization, *Global Health Ethics*, 15.

³² See World Health Organization, *Global Health Ethics*, 16.

³³ See Albert Sjoerdsma and Paul J. Schechter, “Eflornithine for African Sleeping Sickness,” *Lancet* 354, no. 9174 (1999): 254.

³⁴ See Michael P. Barrett, “The Fall and Rise of Sleeping Sickness,” *Lancet* 353, no. 9159 (1999): 1113–1134.

public health efforts.³⁵ This can be especially an issue in emergency situations. How will the rights and well-being of individual research participants be protected? In low-income countries, the only chance for medical care might be linked to participation in biomedical studies.³⁶ In these often-complicated circumstances, interests, and conflicts, well established integrity and distance are necessary. Experience has shown that researchers and research organizations cannot guarantee ethical trials by themselves, and unethical trials continue to be conducted.³⁷ Local research ethics committees should be established and independently assess the potential risk and benefits involved. Ongoing monitoring is necessary. In practice, global health research should be collaborative research. This means a fair sharing of data and samples between partners, the development of scientific capacity across the network, the allocation of scientific resources, joint decisions about authorship, and joint ownership of intellectual property.³⁸ According to the WHO,

Individuals and communities that participate in research should, where relevant, have access to any benefits that result from their participation. Research sponsors and host countries should agree in advance on mechanisms to ensure that any interventions found to be safe and effective in research will be made available to the local population without undue delay, including, when feasible, on a compassionate use basis before regulatory approval is finalized.³⁹

ETHICAL DECISION-MAKING FRAMEWORK

Ethics involves judgements about the way we ought to live our lives, including our actions and intentions. The following ethical principles should be applied to any global health practice as a framework, helping to guide our actions. They are based on the World Health Organization's Global Health Ethics Unit recommendations.⁴⁰

- Justice or fairness (equity-fairness in the distribution of resources and outcomes, and procedural justice-fair process for making important decisions).
- Beneficence (acts that are done for the benefit of others, referring, in global health, to society's obligation to meet the

³⁵ See World Health Organization, *Guidance for Managing Ethical Issues*, 32.

³⁶ See World Health Organization, *Global Health Ethics*, 16.

³⁷ See Michael Carome, "Unethical Clinical Trials Still Being Conducted in Developing Countries," *The Huffington Post*, www.huffpost.com/entry/unethical-clinical-trials_b_5927660.

³⁸ See Michael Parker and Susan Bull, "Ethics in Collaborative Global Health Research Networks," *Clinical Ethics* 4, no. 4 (2009): 165–168.

³⁹ World Health Organization, *Guidance for Managing Ethical Issues*, 34.

⁴⁰ See World Health Organization, *Guidance for Managing Ethical Issues*, 8.

basic humanitarian needs such as nourishment, shelter, good health, and security).

- Utility (the rightness of actions are measured by the degree they promote the well-being of individuals or communities).
- Respect for persons (includes letting individuals make their own choices).
- Liberty (including religious and political freedoms).
- Reciprocity (consists of making a “fitting and proportional return” for contributions that people have made, and it is an important means of promoting the principle of justice).
- Solidarity (standing together; solidarity justifies collective action in the face of common threats).

In practice, setting up decision-making systems and procedures in advance is the best way to ensure that ethically appropriate decisions will be made. The more intrusive the proposed action, the greater the need for robust evidence that what is being proposed is likely to achieve its desired aim. When specific evidence is not available, decisions should be based on reasoned, substantive arguments and informed by evidence from similar situations, to the extent possible.⁴¹

Promoting global health ethics and principles, I want to voice some caution. I think of a friend of mine who spent a lot of time in the former Yugoslavia. He told me how local UN staff was complaining that under the old regime they had to learn Titoism and Marxism, while now it is human rights and ethics. For the majority of the local staff, who was looking for a job to feed their family and loved ones, it was the same indoctrination. While their boss and the message might have changed, the conditions remained the same.

We also have to accept that there will always be a downside to our action, even when, and because of, applying these principles. It may be just the dysfunction and imperfection of being human. However, not dealing openly with this limitation is unethical.

FINAL THOUGHTS

The humanitarian imperative requires responding to human suffering. We cannot accept that millions of people continue to die of curable and treatable diseases. At the same time, we should remember that it is ultimately the responsibility of governments to protect the health and well-being of their citizens. Humanitarian work is temporary and cannot be part of the permanent solution. Proximity to the patients and their suffering is fundamental. Keeping the individual at the center of the work also means that we should approach overwhelming or unimaginable problems without despair. Thirty-eight million people living with HIV/AIDS is an overwhelming global

⁴¹ See World Health Organization, *Guidance for Managing Ethical Issues*, 9.

health problem; a twenty-two-year-old woman with AIDS is a human being who inspires compassion, who should be listened to and known. She can be treated, and her life be made better. We must strive to offer the best possible care, treatment, and prevention. This gives us the credibility to point out and address the root causes of the problem. Humanitarian action provides a human touch in an inhumane environment, and it may ultimately help to reestablish human dignity. Humanitarian global health is practiced according to universal ethics based on a moral approach that values human life and dignity. Such an approach is not utopian; it is very realistic ... and desperately needed. **M**

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