



ETHICAL ISSUES IN TUBERCULOSIS PREVENTION, CARE AND CONTROL

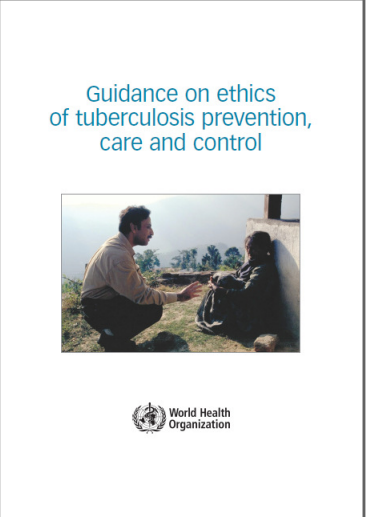
BACKGROUND

Prevention, care and control of tuberculosis (TB) raise strategic, technical and operational challenges. They also raise **important ethical issues** that must be addressed. For instance, TB particularly affects poor and vulnerable populations, and therefore **social justice and equity** must be at the heart of the response. TB is a lethal infectious disease, and care of patients and control of the disease raise questions of how to ensure balance of **individual rights and liberties**: protecting the rights of patients *and* those who are at risk of infection. Success in pursuing the Stop TB Strategy requires the application of ethical principles.

FREQUENT ETHICAL DILEMMAS IN TB CARE:

- Do patients have the right to refuse treatment?
- Is it ever legitimate to isolate contagious patients against their will?
- Do health-care workers have an obligation to provide care, even when it involves significant health risks?
- Should a patient's TB status ever be disclosed to third parties against his or her will?
- Should financial incentives be offered to increase adherence to treatment?
- Should patients be diagnosed in the absence of adequate treatment?
- What are the obligations towards patients who cannot be cured?

Based on the work of a **WHO Task Force on Addressing Ethical Issues in TB Care and Control Programmes**, and broad consultations with other experts and stakeholders, the World Health Organization (WHO) published a guidance document entitled **"Guidance on Ethics of TB Prevention, Care and Control"** in December 2010. It complements the implementation of documents such as the Patients' Charter for Tuberculosis Care. The following are some key guidance points developed in the document.



Read the WHO guidance

http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf



A TB patient receives a food basket, United Republic of Tanzania. The use of "enablers" is an ethically sound way of helping TB patients complete therapy.

MAJOR ETHICAL CONSIDERATIONS ASSOCIATED WITH TB

Governments have a responsibility to provide free and universal TB services

Governments have an ethical responsibility to provide free and universal access to TB diagnostic and treatment services. This obligation is grounded in their duty to fulfil the **human right to health**. Not only does TB treatment significantly improve the health condition of individuals, it also benefits the broader community by stopping the spread of a highly infectious disease.

This duty extends to the **provision of M/XDR-TB services**. While countries are in the process of scaling up treatment, providing testing is a legitimate interim measure to estimate the magnitude of the problem and guide decisions about how best to treat M/XDR-TB patients.

Patients need to be fully informed and counselled about their treatment

Individuals have a **right to know what is being done to their bodies**; therefore patients undergoing TB testing and treatment should receive comprehensive information about the risks, benefits and alternatives available to them. As with any other significant medical intervention, the **voluntary and informed decision of the patient** is necessary to start TB treatment. Considerations of informed consent are also particularly relevant when diagnosis is offered although no treatment can be provided.

Health care workers have obligations to provide care, but also a right to adequate protection

Health care workers have an ethical obligation to care for their patients, even if doing so involves some degree of risk. However, they should not be expected to assume risks that result from inadequate conditions to provide care: **governments and health-care institutions must provide the necessary goods and services** to allow for a safe working environment. Also, health-care workers who are at heightened risk of contracting TB themselves, such as those who are HIV positive, may be exempted from their duty to care.

Involuntary isolation is rarely justified and should be a very last resort

TB treatment should be provided on a voluntary basis. If a patient refuses treatment, this is likely to be due to insufficient counselling or lack of treatment support. In very rare cases, where all efforts to engage a patient to adhere to treatment fail, the rights of other members of the community might justify efforts to isolate the contagious patient involuntarily. However, **involuntary isolation should always be used as a very last resort**, and it is essential that the manner in which it is implemented complies with applicable ethical and human rights principles.



A girl observes her mother taking her TB medications in a clinic, India.

WHO, UNAIDS and the Stop TB Partnership are developing guidance on **human rights and TB**. For more information, see: <http://www.stoptb.org/global/hrtf/>

FURTHER LINKS AND DOCUMENTS

WHO's STOP TB website:

<http://www.who.int/tb/en/>

WHO's Ethics and Health website:

<http://www.who.int/ethics/en/>

WHO's activities on Ethics & TB:

<http://www.who.int/tb/challenges/mdr/ethics/en/>

Health care providers have an obligation to support patients' ability to complete therapy

There are several ethically sound strategies to support patients' ability to adhere to treatment, including directly-observed therapy. Financial incentives can be useful, but should be managed carefully. It is crucial that **patients should be engaged as partners in the treatment process**, respecting their autonomy and privacy. If many patients have problems with adherence, this suggests the system has failed in providing a person-centred approach.

TB programmes and practitioners have a duty not to abandon their patients

There is a fundamental ethical **obligation to provide palliative care** to all patients in need. This means that even when all available curative treatments fail, patients should never be abandoned.

Also, it is **unacceptable to deny treatment based on predictions about non-adherence** by particular patients.

Research on TB is necessary and should be conducted in an ethical manner

There is a need for further research on TB prevention, diagnosis, treatment and support. It is crucial that **research be guided by the ethical principles articulated in international guidelines for biomedical research** involving human subjects (such as the CIOMS & Declaration of Helsinki). In general, research should always ensure the dignity of the research subjects, and results should lead to a benefit for the affected population.

WHO's STOP TB STRATEGY

Main Objectives

1. Achieve universal access to high-quality diagnosis and patient-centred treatment
2. Reduce the human suffering and socioeconomic burden associated with TB
3. Protect the poor and vulnerable populations from TB, TB/HIV and MDR-TB
4. Support development of new tools and enable their timely and effective use
5. Protect and promote human rights in TB prevention, care and control

Read the complete Stop TB Strategy:

<http://www.who.int/tb/strategy/en/>