

ETHICAL ASPECTS OF THE MANAGEMENT OF X/MDR TB IN THE MINING INDUSTRY.

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PRINCIPLES OF MEDICAL OR BIOETHICS

Non Maleficence- First do no harm!

Beneficence- Do Good

Respect Autonomy

Justice

“Autonomy” derived from Greek “Autos” = Self Rule

Autonomous action:

- ✓ Ability to act voluntarily,
- ✓ With sufficient understanding,
- ✓ Of adequate information
- ✓ And without undue influence.

Respect for Autonomy has become the corner stone of modern medical practice within a western “liberal individualism” paradigm.



Rules derived from the principle of “Respect for Autonomy”

- Informed consent
- Rights to privacy and confidentiality
- Truth Telling
- Right to “shared decision making”
- Right to refuse treatment.

Some Principles of Public Health Ethics:

■ The Utilitarian principle

- the right choice or the right public health policy is that which produces **the maximum amount of good (utility) for the most number of people involved/at risk.**
- The “right choice is the one that **produces the most gain,** e.g. the largest reduction in burden of disease” Robersts, M *The Lancet* Mar2002;359:1055

Some Principles of Public Health Ethics

- “For the utilitarian, a just act or policy is one which produces, on balance quantifiably greater benefits for the maximum number of people. It may be that a minority of people are gravely disadvantaged by the policy but these disadvantages or costs are outweighed by the benefits of the majority.”

(Charlesworth. *Bioethics in a Liberal Society*. 1993).

Some Principles of Public Health Ethics

■ **The Precautionary Principle**

- The obligation to protect populations against reasonably foreseeable threats, even under conditions of uncertainty.
(e.g. Quarantine in the SARS epidemic)

Public Health Ethics:

Communitarianism.

- Emphasis is on the balance or interplay between the community's responsibility to the individual and the individuals responsibility to the community.
- Community needs, preferences and welfare **may override** individual needs and preferences (and sometimes even welfare)

Has the pendulum swung to far?

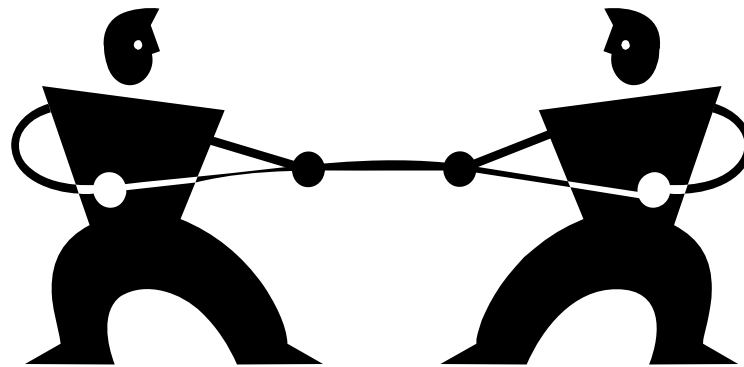
“..population based health requires a willingness to recognise that **the ethics of collective health** may require far more extensive limitations on privacy, as in the case of public health surveillance, and on liberty, as in the case of quarantine, then would be justified from the perspective of the autonomy-focused orientation of the dominant current in bioethics.”

(Bayer, Fairchild in *Bioethics* Nov 2004)

Ethical management of XDR TB-

Core Issue:

**Medical
(Bio)Ethics**



**Public
Health
Ethics**

“Individual Good”

Versus

“Common Good”

A 6 STEP ETHICS FRAMEWORK FOR PUBLIC HEALTH PROGRAMMES

Nancy E Kass- John Hopkins School of Public Health and Bioethics Unit

Step 1. What are the public health goals of the proposed program.
(clearly identified and defined and articulated)

Step 2. How effective is the program likely to be in achieving its stated goals. (at least some supporting data should be available before initiating a programme.)

Step 3. What are the known or potential burdens of the program?

Step 4. Can burdens be minimized? Are there alternative approaches?

Step 5. Is the programme fairly implemented? (i.e not discriminatory)

Step 6. How can the benefits and burdens of a program be fairly balanced.?

What are the Ethical Issues in the Management of XDR TB?

3 CORE ISSUES:

- Forced Hospitalization/quarantine.
- Forced/compulsory treatment.
- Limits to confidentiality and privacy, stigmatisation.

Others:

- Resource allocation
- Lack of new drug development
- Research related issues
- Rights of health care workers caring for XDR Patients

Current Legal Framework

■ CONSTITUTION AND BILL OF RIGHTS

- 10-The Right to have their dignity respected and protected
- 12(1)- The Right to Freedom and security of person, (not to be deprived of freedom arbitrarily or without just cause)
- 12(2)- The right to bodily and psychological integrity- to security in and control over their body; not to be subject to medical or scientific experiments with out their informed consent.
- 24-The Right to an environment that is not harmful to their health or well being.

Current Legal Framework

■ HEALTH ACT 61 OF 2003-

- Framework legislation, non specific w.r.t public health and control of epidemics.
- **Chap1(3)**The Minister must.....determine the policies and measures necessary to protect, promote and improve and maintain the health and well being of the population.
- **Chap 2.**
- 6(1)(d)Users right to refuse health services.
- (7) Informed consent
- (8) Users right to participate in decisions
- (9) Health service without consent. If a user is admitted to a health care facility without his/her consent the provincial head within 48 hours and supply “information that may be prescribed”

Current Legal Framework

- **REGULATIONS RELATING TO COMMUNICABLE DISEASES AND THE NOTIFICATION OF NOTIFIABLE MEDICAL CONDITIONS. OCT 30 1987 (Health Act 63 of 1977 which has been repealed)**
 - Section 8-Quarantine
 - Section 14- Carriers of Communicable diseases

Forced Hospitalization/Quarantine for MDR and XDR TB?

■ Is it justifiable?

- **YES**, if an objective assessment of the risks to individuals in contact with those infected indicates significant risk on a case by case basis:
- Conditions in the mining industry environment may contribute to significant risk to contacts-estimated 30% of work force HIV+ve, silicosis, crowded living and working conditions, physically demanding work.
- Assessment of each individual case
 - -degree of smear positivity, productive cough etc
 - Assessment of his/her living and working environment, contacts and circumstances.

(NB Above recommendation may be contrary to the Precautionary Principle)

Forced Hospitalization: Conditions of Application:

1. **Regulated Fair Process:**

1. Mechanisms for formal and regular review of forced hospitalization.
2. Rights of the affected individual “to be heard” must be entrenched in the process
3. Urgent need for legislative reform e.g. in line with the new Mental Health Act.

Forced Hospitalization: Conditions of Application:

2. Obligation to acknowledge extent of limitation of constitutional rights (prolonged detention 24 months or until death) through no direct fault of the individual involved. (Some may dispute this but a punitive attitude should be avoided.)
3. **Obligation to balance this limitation of rights with adequate and swift financial and other support of dependents!!**
 1. Effective legal framework is required to do this.
 2. Who should bear this burden?? State? Employer? Both?

Forced/compulsory treatment for XDR TB:

- Is this ever Justified? **NO (NB- My Opinion!)**
- **ETHICALLY:**
 - Principle of “respect for autonomy” and “informed consent” require that a patient should retain the right to make an informed, autonomous decision to refuse treatment, **even if the consequences of the decision may mean remaining in isolation indefinitely.**

Forced/compulsory treatment for XDR TB:

- **LEGALLY:** (Need a constitutional court test case!)
 - Bill of Rights-Right to security in and control over their body.
 - Health Act- Right to refuse treatment.

VS

- Regulations Relating to Communicable Diseases. 1987
 - 17(c) **Compulsory medical examination, hospitalisation or treatment of persons.** “ A person must.....subject himself to the medical treatment prescribed by the medical officer of health or a person assigned by him”

Limits to confidentiality and privacy.

- XDR TB- **Notifiable disease**. Therefore the treating clinician has an obligation to supply information including name, address ID, etc to the central health authority who have an obligation to transfer sufficient information to those who need to know, in order to protect others at risk.
- Pitfalls:
 - Interpreted as a licence to place no limits on breach of confidentiality and privacy- Everyone has a right to know all the details!
 - Significant risk of stigmatisation and negative repercussions to patient and family members.- “TB Time Bomb!!”
 - Known/assumed close association of XDR TB and HIV compounds the problem

Limits to confidentiality and privacy

- Formal mechanisms needed to limit breaches of confidentiality and privacy, to what is necessary to protect those at risk.
- Effective management may often be possible without exposing patients identity and details of illness.
- Often punitive attitude of HCW contribute to problem- Re-education w.r.t complexity and causes of XDR/MDR TB may be needed.

IN CONCLUSION:

- The public health management of an XDR TB epidemic inevitably may involve purportedly justifiable, but never-the-less gross violations of individual rights to privacy, freedom and dignity, in the interests of the common good.
- A reciprocal moral obligation exists to balance (in part) these violations, by ensuring an adequate and timely support system for the patient and his/her dependents, which goes far beyond what has, up until now, been made available to patients requiring prolonged hospitalisation for MDR TB.