

Do we need notification of tuberculosis? A public health perspective

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Abstract

Several instances of tuberculosis (TB) resistant to most drugs were reported in Mumbai in January 2012. Eventually, the Government of India declared TB to be a notifiable disease. This paper looks at the utility of notification and the ethical issues posed by it from a public health practice perspective. The paper argues that notification of TB in the absence of regulation of diagnostic practices, rational use of anti-TB medicines and availability of diagnostic and treatment facilities for drug-resistant TB will pose more ethical problems rather than provide solutions by way of adequate and rational treatment to patients.

Introduction

In 2011-12, the Hinduja Hospital in Mumbai detected 12 patients who were resistant to all drugs that could be tested, which raised an alarm among public health policy makers and programme managers (1). As a response to this emerging threat, on May 7, 2012 the Government of India declared TB to be a notifiable disease (2). Although, this might be viewed as an important step in the control of this disease, the question is: will it help control TB without violating the ethical principles of public health practice? To answer this question, this commentary discusses the utility of notification and principles of ethics in public health practice, followed by the specific ethical issues related to notification of TB.

Notification is one of the earliest measures in public health practice. It is especially employed for communicable and other acute diseases where public health action may be triggered by an individual case, or where an individual case may be the indication that a disease outbreak is occurring (3). Notification, if implemented effectively, informs policy makers and programme managers about the burden of disease in the community which helps in planning, implementing and evaluating health promotion and disease intervention programmes. Other possible benefits include prevention of transmission of infection from the notified cases to their close contacts and in providing healthcare to the notified cases. However, notification is also criticised as it affects the privacy and confidentiality of patients, and disregards their autonomy and human rights.

Ethical issues regarding notification

"A code of ethics for public health" (4) lays down the principles of ethical practice of public health, and four of the 12 principles are related to the ethical aspects of notification*. This raises a number of important questions. Can the information collected lead to actions that protect the health of the community? If yes, will it achieve community health without disregarding

individual rights? Will it be able to act in time? Notification is justified in certain situations where the ethical responsibility of safeguarding the health of other citizens outweighs the ethical issues affecting rights of individual patients. In view of this, we discuss the benefits of notification of TB to the general population, the affected individuals and their contacts, and examine whether notification of TB is justifiable.

Benefits of the notification of TB to the community

The primary purpose of notification is to help trigger a public health response in case of an outbreak or epidemic of a disease, for example, avian influenza where even a single case would warrant a public health response. Given India's status as a high TB burden country, notification will not lead to any mass public health response over and above the current TB control efforts (5). Proponents of notification might argue that notification may help in estimating the burden of disease. However, it is often marred by poor compliance from the private healthcare sector, often resulting in underestimation of disease burden. Estimates of disease burden could be reliably obtained from more cost-effective options like conducting focussed and special studies. Moreover, in such studies, data of the participants/ respondents are kept confidential, unlike notification. Though the fifth ethical principle relates to a mandate to seek information to inform actions, with no public health action likely to be based on notification, could collection of personal data still be justified?

Benefits to individuals with notification

The first principle of ethical practice of public health acknowledges that public health will also concern itself with the treatment of curable infections. Also, treatment of curable infections is important to the prevention of transmission of infection to others and therefore is viewed as an ethical responsibility of public health professionals. Does notification of TB help in provision of treatment to patients and protect persons in contact with patients from developing the disease? Studies indicate that in most cases in the private sector, the diagnosis is not based on sputum smear microscopy, and private practitioners do not follow standard diagnostic practices (6,7). The diagnosis of drug-resistant TB is further complicated by the fact that very few laboratories are certified to diagnose Multiple Drug-Resistant TB (MDR), and there is only one laboratory in the entire country to diagnose Extremely Drug-Resistant TB (XDR). It is feared, therefore, that many physicians in the private sector are diagnosing MDR/ XDR TB either clinically alone, or on the basis of results of uncertified laboratories. Studies have also described irrational prescriptions of private providers that would result in inadequate treatment (6,7).

Will notification bring about a change in this scenario? The answer is that this is unlikely, because notification typically stops at diagnosis and does not look at provision of treatment and the final outcome for the patient. Unless, there are measures aimed at rational use of anti-TB medicines, notification will not result in provision of rational treatment to patients. Rational measures could include enforced prohibition of over-the-counter dispensing of anti-TB medicines, regulatory approaches to restrict prescription and dispensing rights to accredited facilities, and developing guidelines and recommended practice. There is a need to scale up public-private mix approaches for TB care and control, which would promote rational use of anti-TB medicines among all healthcare providers. Moreover, access to treatment of MDR/XDR TB in India is limited to select districts at present. Expansion of this access is making slow progress. Thus, many patients notified with such forms of drug-resistant TB are not offered treatment. What is the ethical value of a public health practice that makes a patient's data available to public authorities, but neither ensures rational treatment to patients nor prevents the transmission of infection to contacts?

Isolation

The current government order mentions only notification. It does not talk about measures like "isolation" of patients to safeguard the health of other citizens. Isolation, itself would raise more ethical issues. To what extent is coercive restriction of movement ethically justified in the name of TB prevention? If XDR cases are untreatable, should they be segregated for life? Selgelid argues that if coercive confinement of an individual is necessary to save others' lives, then infringement of liberty may be justified. The infringement of liberty would not be justified when there are no good reasons for believing that it would lead to substantial benefits in the context in question (8).

Challenges to implementation

Declaring a condition or disease notifiable is only the first step; more important is effective implementation of the notification. There is enough evidence of ineffective implementation of existing regulations in India (9). If a few private providers (both practitioners and laboratories) comply with notification and others do not, patients may opt for a facility which does not notify as they may fear the dangers of notification i.e. breach of privacy with consequent stigma and discrimination. This might shunt patients from a facility that notifies to a facility that does not notify; the latter is not likely to meet any adequate standards of care. The possibility of notification leading to such an adverse outcome cannot be ruled out.

Ethical issues around HIV notification

In contemporary practice, no other health condition has stimulated as much ethical debate, conflict and attention as HIV. Debates over whether AIDS and HIV should be made reportable to public health officials, and whether such reports should contain the names of those diagnosed, have regularly recurred during the epidemic, and remain ongoing. The UNAIDS best

practice document states that while surveillance may justifiably limit some elements of privacy, such limitations are only justifiable to the extent that they in fact benefit the public's health (10). Although some public health professionals justify the use of personal information collected by HIV notification for public health action, the justification is based upon public health gains, chiefly the therapeutic prospects of individual patients, and the potential for interrupting transmission in the population (11). In the absence of these two public health gains, mandatory testing and notification were viewed in India as an unproductive means of social control, resulting not in effective disease prevention, but in unproductive government restrictions. Instead, India adopted unlinked anonymous sentinel surveillance to estimate the burden of disease in order to control the epidemic (10). In the absence of both the therapeutic prospects for individual TB patients and potential for interruption of transmission, the notification of TB would unjustifiably limit the privacy of medical information, a central element of the human rights of patients.

To summarise, notification poses various ethical and practical challenges in handling the TB situation in India. Notification is an important public health measure to safeguard the health of populations but it has also to be balanced against the rights of patients whose personal details will be shared. There is no doubt that the Revised National TB Control Programme in India has improved healthcare access to TB patients, saving the lives of thousands so far, and also attempting to improve the management of MDR TB. With the cases from the public healthcare sector getting notified, the issue is whether notification in the private sector serves any purpose. If notification does not serve any purpose, is it ethically justifiable to notify cases of TB (or MDR TB) in the private sector and not do anything for the patients, their contacts and the communities where they live?

As discussed in this paper, there are no mechanisms to ensure that the private sector follows appropriate diagnostic and treatment practices. Therefore, notification does not improve the chances of patients getting adequate and rational treatment of TB. Nor does it address the issue of transmission to others. Irrational and unsupervised treatment propagates drug resistance and notification cannot halt drug-resistance. In the absence of any benefits to the masses, should the personal data of TB patients be collected centrally and maintained? If the health of patients and of populations is of prime concern, then efforts should be made to ensure that international standards of diagnosis and treatment are followed. There is a need to work on rational use of anti-TB drugs as well as involvement and regulation of the private sector. Such measures could then, create some benefits in terms of protection of the health of patients and their contacts. Notification would be justified if such a multi-pronged approach could save some lives. Without such an approach, it would only infringe upon the rights of patients and is, therefore, not justifiable.

**Note: The four principles are: Principle one: Public health should address principally the fundamental causes of disease and*

requirements for health, aiming to prevent adverse health outcomes. Principle two: Public health should achieve community health in a way that respects the rights of individuals in the community. Principle five: Public health should seek the information needed to implement effective policies and programs that protect and promote health. Principle seven: 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.

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Moral consensus theory: paradigm cases of abortion and orthothanasia in Brazil

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Abstract

Bioethics is a relatively new way of thinking about relationships in medical practice. It enables reflection on ethical conflicts, and opens up management options without dictating rules. Despite this historical context, medical ethics has been sidelined in the course of the development of bioethics.

Bioethical reflection does not automatically result in changes to conflict resolution in daily doctor-patient relationships. However, these reflections are important because they promote the search for a "moral consensus" that establishes new ethical rules for day-to-day medical practice. We suggest that there is no conflict between bioethics and medical ethics; rather, these areas interact to establish new standards of behaviour among physicians. The legalisation of orthothanasia in Brazil is one example of how this theory of moral consensus might operate. On the other hand, the legal battle on abortion illustrates how the law cannot change without such a moral consensus.

Introduction

Bioethics has received tremendous impetus as a fresh and non-traditional assessment of ethics in medicine since the 1970s. It is primarily viewed as the humanistic exercise of reflecting on the natural conflicts of a profession in which two parties,

originally the doctor and the patient, attempt to relate in a complex manner.

Bioethics is a new discipline that aims to combine biology and human values, "but it has gradually shifted its attention away from the medical field and biological technology" (1). The moral codes of the medical profession were relegated to the sidelines. Many bioethicists believed that the professional codes were no more than rulebooks listing duties to be strictly fulfilled without the power to stimulate thinking in those who fulfil these duties.

Some view these moral codes as merely inelegant, but others view them as obsolete and even hypocritical (2). The latter perspective suggests that the codes of medical ethics, which originated from the Hippocratic Oath and the code of the British physician Thomas Percival (3), have no place in a globalised society with many conflict-provoking situations and moral issues. Therefore, while bioethics, which espouses a novel assessment of relationships and ethical conflicts, would open a range of management options without dictating rules of behaviour, bioethical reflection does not always modify the general practice of conflict resolution in daily doctor-patient relationships.