# Apocalypse or redemption: responding to extensively drug-resistant tuberculosis

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Responding to drug-resistant tuberculosis is possibly one of the most profound challenges facing global health. Leading experts have used apocalyptic language in describing the scope of the challenges posed by extensively drug-resistant TB (XDR-TB), even suggesting that we resort to prayer as a solution.[1,2] Recent reports indicating that aggressive treatment confers benefit raise hope that the situation may not be so dire.[3] However, the structural and political changes and resources needed to prevent and treat XDR-TB on a large scale are not sufficient to assure that the tide of XDR-TB will be stemmed any time soon.

Drug-resistant TB is not the result of catastrophic natural forces such as earthquakes, tsunamis and hurricanes. It is not caused by malign human intent, as are terrorism and war, nor is it fostered by our dysfunctional relationship with the animal kingdom as are severe acute respiratory syndrome (SARS) and avian influenza. The locus of risk and control is entirely within the human domain. Our response to the emergence of drug-resistant TB is profoundly ethical as it raises issues of how justice and human rights are realized in our collective response to a disease. It also underscores how the global community responds to its most disadvantaged members.

The progressive worsening of resistance of TB to pharmacotherapy has raised the spectre of a response to TB without medication – what some have labelled the dawn of the post-antibiotic age. The combination of high rates of TB infection with high seropositivity rates for HIV in sub-Saharan Africa adds new levels of complexity to diagnosis and treatment and has raised the ante of global TB control.[4]

WHO has launched an eight-point plan to respond to XDR-TB.[5] This paper provides an elaboration of these recommendations and adds some additional considerations as moral correlates to the current WHO plan (Box 1).

## Adherence research and drug development

The main financial response to drug-resistant TB favours the development of new drugs and vaccines, both long-term strategies offering little succour to those currently or soon to be afflicted. Developing less-toxic drugs with greater potency that could shorten treatment is an important goal, but this must go hand in hand with investment in adherence research. We know some, but not enough, about how to enhance medication adherence.

## Infection control

Health care institutions in under-resourced areas are often poorly equipped to implement adequate infection control measures, leaving health-care providers (and other health service users) at particular risk for TB infection. Ensuring adequate numbers of health-care providers willing to care for patients with drug-resistant TB will be difficult if they are not protected from infection themselves.

While the WHO plan calls for the development of infection control measures, existing approaches have an underappreciated potential. The use of UV light, air exchange, cohort nursing and personal protective equipment used by health-care providers are effective ways to reduce the spread of disease and are remarkably cost effective. Operational research is required into simple and effective infection control modalities that can be employed in primary-care contexts in low-resource environments. Funding effective infection control modalities in these contexts should be a high priority.

Box 1. **The WHO eight-point plan and additional considerations**

**WHO recommendations**

1. Strengthen quality of basic TB and HIV/AIDS control
2. Scale up programmatic management of MDR-TB and XDR-TB
3. Strengthen laboratory services
4. Expand MDR-TB and XDR-TB surveillance
5. Develop and implement infection control measures
6. Strengthen advocacy, communication and social mobilization
7. Pursue resource mobilization at all levels
8. Promote research and development of new tools

**Additional considerations**

1. Adherence research
2. Building the evidence-base for infection control practices
3. Supporting communities
4. Enhancing public health response while addressing the social determinants of health
5. Embracing palliative care
6. Advocacy for research

MDR-TB, multi drug resistant tuberculosis; XDR-TB, extensively drug-resistant tuberculosis; TB, tuberculosis.

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## Supporting communities

Communities hardest hit by drug-resistant TB are among the most disadvantaged in the world and responses to the problem that worsen this disadvantage threaten to perpetuate injustice. Yet, if therapy loses its effectiveness, the response will have to be constrained and may involve unpalatable options such as isolation until death, the use of sanitaria or therapeutic communities. As has been seen in South Africa, isolative measures may have negative consequences, fuelling stigma and driving people underground, thereby reducing case detection and increasing transmission in the community. In such instances, innovations in community-based care should be developed.

Policy-makers and donors need to fully appreciate the overwhelming difficulties of the practical requirements of daily living for people in sub-Saharan Africa. The ability to work meaningfully for a living, to feed oneself and family, or to access social benefits, are currently not being met and, as noted recently in the South African context, there is a disincentive to seeking effective and appropriate care as welfare benefits are suspended to those TB patients who are hospitalized.

Progress has been made in overcoming stigma and normalizing HIV in the community and it may well be time to consider what TB-friendly communities would look like. What parameters of education for patients, family members and communities would be required to provide care of resistant TB in the home? Can known transmission in the community to family members be tolerated if they are willing to assume the risk in order to maintain care relationships with loved ones (taking into account that this is a trade off against unknown transmission in the community as long as people reject the centralized approach to care)? This strategy may entail countenancing a form of ethics that challenges the predominance of autonomy-based approaches. Such support arises from principles of public health ethics.

Autonomy has become a prominent first principle in modern bioethics and is enshrined in human rights doctrine. However, there is an equal need for communities to be protected from harm. Infectious diseases underscore our universal vulnerability – how individuals can be both victims and vectors of disease and how we are related in a common cause in controlling diseases. Relationality and solidarity may serve as important principles in our response to TB. We also need to embrace reciprocity and put it into action – articulate what we can do for each other in order to build healthy communities. This is only possible if we create communities in which individuals with infections are facilitated and supported in discharging their obligations to others.

## Addressing the social determinants of health

Social justice is arguably the foundational animating principle of public health action. Social justice concerns direct attention to the upstream causes of TB and the broader social determinants of health. Global poverty fuels TB. In order to create communities that work towards health for all and therefore contribute to human beings flourishing in the long run, the social determinants of health must be addressed on an equal footing with medical approaches. The onus is on the global community to change perceptions and create conditions where, through solidarity, we are united in addressing a grave threat to human health. This means addressing social determinants as an explicit goal of TB control strategies. Some of the reasons for poor adherence and loss-to-follow up involve the competing priorities faced by poor populations: the need to earn money on a daily basis, duties towards family members, substance misuse as a coping strategy for impoverishment. Overcoming these problems requires a level of social support that is rarely available in an overburdened and understaffed health system.

Responding to social justice does not only mean providing support but also avoiding negative practices. For example, recent studies have shown that the attachment of economic conditions to donor assistance has potentially contributed to worsening the TB epidemic in some regions.[6] Such policies need to be addressed.

## Embracing palliative care

Persistent non-adherence fosters resistance and so we need to consider imposing limits to the number of times that a patient can stop and restart therapy. The ethical basis for withdrawing treatment is sound, provided patients know this possibility at the outset and all means of assisting their adherence have been provided. It should therefore be exceptional. However, withdrawing treatment does not mean withdrawing care. Palliative care should be offered to all who no longer qualify for active treatment to ensure that those who are no longer capable of being treated are permitted to live out their life with minimal suffering and loss of dignity. Home and community-based solutions can be pursued, supporting families to provide palliative care at home: it may cost less to build an extra room to a house than confine someone to a hospice.

## Advocacy and research

The WHO Plan calls for greater advocacy but the objective is not stated. One area that requires major advocacy is research and development. The political momentum around HIV is arguably responsible for the rapid progress in rolling out treatment and care. HIV was discovered in 1981; within two years the virus was isolated; two years after that the first test was developed, and two years after that the first antiretroviral drug (AZT) was launched. This is in stark contrast to the TB world, where diagnostics and vaccines are decades old and the newest treatment method was developed more than 30 years ago. Advocacy and activism can spur a research agenda, motivate collective action and attempt to redress the problem we have created in the first place.

Drug-resistant TB, particularly the emergence of XDR-TB, is evidence of a new form of regression: we have taken the curable and made it nearly incurable. The tendency has been to blame the most vulnerable and powerless – the patients who were unable, for a multitude of reasons, to follow treatment through to completion. It is time to recognize that we collectively bear responsibility for this. The serious task of stopping the progression to complete drug resistance is also a collective responsibility of all involved in health care. If we cannot manage a disease as well known as TB, we have little justification to be stewards of the significant amount of resources given to health care globally. ■

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