

EDITORIAL

Government-funded anti-retroviral therapy for HIV/AIDS: new ethical challenges

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In September 2003, an international initiative was launched to treat 3 million people living with HIV/AIDS by 2005—the 3-by-5 initiative. According to WHO estimates, 95% of the 40 million people living with HIV/AIDS (PLHA) are in developing countries. Less than 8% of those needing anti-retroviral therapy (ART) receive it—compared with 84% in the West (1). The Director General of WHO described the lack of access to ART as ‘a global health emergency’ and declared: ‘To deliver anti-retroviral treatment to the millions who need it, we must change the way we think and change the way we act.’ (1)

The 3-by-5 initiative found its echo in India where there are an estimated 4.58 million PLHA as of 2002. On the World AIDS Day 2003, the Indian government announced that from April 1, 2004 it would provide free ART in six high prevalence states: Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland. Later, the government added Delhi to the list, a low prevalence state, due to its ‘high vulnerability’ (2). The National AIDS Control Organisation’s (NACO) draft guidelines on the internet state that the first phase would cover sero-positive mothers, sero-positive children below the age of 15 years and people with AIDS seeking treatment in government hospitals. An estimated 0.1 million patients would be covered by the end of 2005 (3).

Two factors are responsible for these major announcements. First, organisations of PLHA all over the world have pressurised governments and international organisations to recognise their right to treatment and care. Second, there is a growing realisation of the economic and social impact of the HIV/AIDS epidemic, as well as of its human rights implications. In fact, HIV/AIDS has been responsible for orienting the public health community to human rights—particularly the right to health.

The obligation to care and treat

The medical profession has extensively practised discrimination against PLHA. Hospitals test patients for HIV infection without their knowledge or consent, without pre-test counselling contrary to national and international guidelines. In the private sector, patients found to be HIV-positive are shunted to government hospitals, discharged on some pretext or charged extra for treatment with ‘special protection’. In government hospitals, patients with HIV infection are referred to the sexually transmitted diseases wards regardless of the source of their infection. Some are refused emergency treatment while others are isolated, thus making their HIV status public.

Interestingly, the private health sector has for long delivered ART to those who can afford it, while also increasing its discriminatory practices. This makes one sceptical of the claim that stigma and discrimination will reduce as treatment options become available. More important, the government’s programme commits to cover only around 2% of PLHA. It is not clear how the technical guidelines and medical criteria will make the selection of this 2% impartial. How can the selection process be impartial and objective if the profession that is supposed to implement it has shown discriminatory behaviour? The introduction of free ART to a select few must be accompanied by the strict enforcement of the fundamental obligation of health professionals’ to treat patients without discrimination.

Being just and seen to be just

Justice and ethics are the casualties when political choices favour corporate profit over patients' lives. Current policies pricing essential drugs out of people's reach are responsible for the public health and ethical crises in HIV/AIDS. The problem of justice is also evident at the micro-level of the new policy.

Clearly the new ART strategy does not intend to cover all those needing treatment. PLHA living in states other than the seven named are left out. Even within the seven states, only certain categories are eligible. Unless the government explains and justifies the logic of its policy, it faces an enormous ethical crisis. For instance, Delhi's belated inclusion is not due to medical vulnerability but political power.

The policy also needs to be seen as just, or what Norman Daniel describes as having 'perfect procedural justice'. If the states are selected on the basis of sound public health logic, it must be strictly adhered to without giving in to political exigencies.* The location of treatment facilities ought to be such that physical access is easy. Ten of the 15 institutions identified in the NACO guidelines are in Maharashtra and Tamil Nadu. This physical imbalance carries forward the past unjust distribution of health services.

Another issue relates to the prevention of drug resistance due to poor adherence to the treatment protocol and compliance to treatment. NACO needs to clarify whether besides the medical selection criteria, there will be a value judgement of patients who are best placed to comply with treatment. Further, the private health sector has been irresponsible in the treatment of other communicable diseases. Irrational prescription practices, discarding patients half-way through the therapy when they run out of money, etc. have contributed to the development of drug resistance. Since the private sector has long used ART and will continue to use them, stringent regulation of its prescription practices must be brought in the policy agenda. Without this, the policy will suffer reversals, again jeopardising PLHA's right to treatment.

There is also the danger of corruption leading to the rejection of deserving patients and the availability of 'free' treatment for a bribe.

Other health needs

Finally, just process demands an explanation of why people suffering from other diseases—many of them life-threatening—should be made to pay in government centres for drugs and user charges when ART will be freely available. The new health policy and even the Common Minimum Programme of the new government has promised that the government expenditure on health care will be increased from 0.8% of the gross domestic product (GDP) to over 2% of GDP. Just process demands transparency about when it will be achieved and whether the increased funding will go primarily for HIV/AIDS programmes or distributed fairly across suffering patients of all types.

For all this, the medical ethics movement in India must make the connections between ethics, human rights and public health and keep a sharp eye on this programme. This will not only prevent its unethical implementation but also make the ethics movement learn from public health and human rights concerns.

References

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