

ETHICAL ISSUES RELATED TO ACCESS TO TREATMENT FOR HIV/AIDS IN LOW-RESOURCE COUNTRIES

ASPECTOS ÉTICOS RELACIONADOS AO ACESSO AO TRATAMENTO DE PESSOAS COM HIV/AIDS EM PAÍSES COM RECURSOS LIMITADOS

Paul Ndebele & Edward Chigwedere

ABSTRACT

This paper examines ways that moral considerations come to bear on HIV/AIDS care and treatment in limited resource countries. We highlight various ethical issues that relate to access to antiretroviral therapy within limited resource countries as well as some of the questions that HIV/AIDS treatment programme managers have to think about when designing HIV/AIDS treatment programmes in limited resource countries in order to ensure fairness in terms of access to treatment. The paper includes recommendations on how to increase access to antiretroviral therapy in limited resource countries and how to overcome or minimise some of the ethical problems relating to access to care.

Keywords: access to treatment for HIV, antiretroviral therapy, limited resource countries

RESUMO

Esse artigo examina de que forma considerações morais estão ligadas ao tratamento de pessoas com HIV/AIDS em países com recursos limitados. Nesse trabalho são ressaltados diversos aspectos éticos que se relacionam ao acesso à terapia anti-retroviral nesses países, assim como questões a serem consideradas por gestores de programas de tratamento ao HIV/AIDS, a fim de garantir a justiça no acesso ao tratamento. O artigo também inclui recomendações sobre formas de aumentar o acesso à terapia anti-retroviral e de resolver ou minimizar problemas éticos relativos ao acesso à assistência.

Palavras-chave: acesso ao tratamento de HIV, terapia anti-retroviral, países com recursos limitados

ISSN: 0103-0465

DST – J bras Doenças Sex Transm 17(3):215-218, 2005

INTRODUCTION

Early in the history of the current HIV/AIDS epidemic, before antiretroviral therapy came onto the scene, HIV infection often quickly progressed to a terminal illness and was exclusively regarded as such¹. The subsequent availability of highly active anti-retroviral therapy during the past decade has prolonged survival (for those who have such access), and the crucial issue of access to treatment has gained prominence especially in low-resource countries where treatments for HIV/AIDS are not readily available for those who need them. HIV/AIDS has, in the eyes of many, now transitioned to become a manageable chronic disease². To that end, there have been multiple efforts to push phar-

maceutical companies to reduce prices for antiretrovirals, for countries to produce generics, and also for governments to provide funds for drug purchases. While impressive progress has been made in the area of HIV/AIDS treatment, numerous challenges and questions relating to access still remain. We contend that certain of such access considerations can be better informed by casting them within a moral framework

Ways of accessing treatment for HIV/AIDS

The antiretroviral landscape in developing countries is evolving quickly. People living with HIV/AIDS (PLHA) are finding and using various creative routes to access treatment including purchasing drugs through the private and often unregulated sector, participation in clinical trials, and through drug donations and recycling programmes. The lack of regulation, information, and relevant expertise is leading to problems of quality control and adherence as well as to great inequities in terms of access. In an ideal situation, appropriate drugs with few or no side effects are accessible and affordable to all those who need them. Along those same lines, those who use the drugs seek and adhere to treatment freely and do so without fear of stigmatization or discrimination³.

¹Assistant Professor
Center for Ethics in the Humanities and Life Sciences
Michigan State University

²Fogarty Bioethics Fellow
Center for Ethics in the Humanities and Life Sciences
Michigan State University

An ethical framework for providing access to treatment

Because of the controversies and complexities surrounding HIV/AIDS, action on HIV/AIDS treatment needs to be carried out within an ethical framework. There are widely recognized principles in the area of bioethics that apply to the provision of health care in general; these principles include **respect for persons, beneficence, justice and nonmaleficence**. **Respect for persons** entails respecting the decisions of autonomous persons and protecting persons who lack decision-making capacity. This principle also imposes an obligation to treat persons with respect by maintaining confidentiality and keeping promises. Beneficence imposes a positive obligation to “do good” and to act in the best interests of the patient. The principle of nonmaleficence is the exact opposite of the principle of beneficence and imposes an obligation on health workers and providers to “do no harm”. The principle of justice requires that people be treated fairly⁴. In terms of access to treatment these moral teachings can be summarized in the following guideline issued by one center for excellence in HIV/AIDS:

“Health care providers have the obligation to provide care. It is unethical for health care providers to refuse to treat any person who is HIV positive or who has AIDS”⁵.

According to the above statement, people living with HIV/AIDS have the same right to both health care and respectful treatment as any other person. Generally the duty to provide treatment for HIV/AIDS could arguably be based on the understanding of medicine as a moral enterprise, hence the principles “do not harm” and “do good”. In this regard, treating HIV constitutes a virtuous act, which meets both the individual patient’s as well as society’s health needs and moreover, such treatment affirms the moral mission of health care⁶. Therefore, policy in the area of health care should in this regard be scientifically rational and should seek to protect the public from discrimination in both access and treatment. While the moral imperative to provide the best possible treatment for people living with HIV is widely recognized to lie with governments, it is unfortunate to note that the governments are not always willing to commit resources towards providing treatment for all their citizens. Governments cite numerous reasons for their inability or unwillingness to provide treatments for HIV/AIDS including the high cost of antiretrovirals, the inability of the health delivery system to provide such treatment, and the inability of patients to adhere to treatment regimens. Some of these excuses are excessively weak. The HIV/AIDS treatment Programmes that have been implemented by Countries such as Brazil, Haiti, Thailand and other countries provide convincing evidence that even in developing countries PLHA are capable of effectively adhering to complicated treatment regimens, and health care institutions have shown that they are capable of providing such treatments. It is also relevant to note that the cost of antiretroviral therapy continues to decrease and antiretrovirals are now available through the private sector and other means in many countries. Initiatives by

Governments of Countries such as Brazil, India and Thailand in manufacturing generic drugs, have contributed significantly in forcing the reduction in the prices of drugs.

The role of governments in ensuring access to treatment

While governments of most countries continue to be unwilling and unprepared to provide resources for HIV/AIDS treatment, these governments and their Ministries of Health need to be increasingly sensitized on their duty to provide treatment. After all, governments commonly spend excessively on expensive military hardware and on large governmental bureaucracies and in so doing, ignore the fact that HIV/AIDS is inversely related to economic growth. The incremental cost of not providing anti-retroviral therapy can be expressed in terms of rising morbidity and mortality, declining agricultural and industrial productivity, increasing numbers of orphans, and cumulative economic hardships for affected families.

Notable exceptions in this regard are countries such as Botswana, Thailand, Brazil and Senegal which alternatively have made antiretrovirals available to PLHA through public sector efforts. Other exceptions include those countries that have initiated pilot antiretroviral treatment programs. Problematically, within countries, differences in the capacities of district health care systems also result in differential and unequal access to treatment. Issues of equity therefore need to be addressed at all levels if society is to fulfill the demands of the principle of justice. In accordance with the above principles, the values of our society will be tested and judged by our ability or lack thereof to care adequately for those living with HIV/AIDS.

People living with HIV/AIDS deserve to be treated in the same way as any other people suffering from any other disease. It is common for governments to be able to provide treatments for other conditions such as diabetes which are also expensive and require a lifelong commitment⁷.

The role of health care workers

A crucial element of a healthcare system is its staff. Concern is expressed by PLWA and their support groups about the problems they face in trying to obtain access to quality health care and treatment. Problems range from simple refusal of treatment to ill-treatment and breaches of confidentiality by staff. Frequently, health workers in limited resource countries are overworked and underpaid. They lack supplies, support and supervision. They suffer from low morale and poor motivation and not surprisingly, some are concerned about the potential of occupational exposure to HIV infection. It is a challenge to our moral sensibilities that care for PLHA is often seen as a waste of resources because those patients are expected to die anyway. Those care workers involved in HIV/AIDS treatment provision need to have the appropriate knowledge, skills and attitudes to

effectively deliver necessary aid. The attitude of health care workers can have a profound difference on such care.

Attention should be paid to areas such as maintaining confidentiality, seeking non-discrimination and ensuring the equitable distribution of available resources. Comprehensive treatment information is essential to ensure that PLHA seek such treatment. Information is important in empowering the patient to forthrightly claim what is available and what is rightfully his/hers. To this end, patients need to know about the costs of drugs, potential side effects, drug resistance, and costs of laboratory tests. They require a full disclosure explaining that antiretroviral therapy is lifelong, and that antiretroviral therapy is not a cure for HIV as well as the problem of drug resistance that may be caused by poor adherence.

Focusing on marginalized or specific groups

Each person with HIV/AIDS leads a unique life with a unique set of influences, needs and resources. Health care services need therefore to respond to these respective differences in a timely and efficient manner. This responsiveness also applies to specific groups or communities, especially those marginalized from society because of their gender, behavior, profession, or status. Members of such marginalized groups may experience further barriers to treatment on top of those already experienced by other PLHA. Paradoxically, it should however also be pointed out that even with the best of intentions, providing HIV/AIDS treatment for specific populations in a way that identifies them as members of specific populations is not always appropriate and can potentially expose them to even further stigma and isolation. Children living with HIV also have specific challenges with regard to accessing treatment. Services often tend not to be 'child friendly' and in some cases, the only medicines that are available are those that are meant for adults.

While this state of affairs is true for marginalized communities and groups, there are those who would argue that resources should instead flow in the opposite direction. This line of argument suggests that HIV resources should first be for public benefit with anti-retroviral therapy directed at select groups of importance to the public such as health care workers, teachers, uniformed forces, sex workers etc. Another group that finds itself being given special consideration is that of women who are found to be HIV-positive in programmes aimed at reducing vertical transmission of HIV/AIDS and who play a crucial role as caretakers in the family. Vertical transmission prevention programmes now commonly referred to as Prevention of Parent to Child Transmission (PPTCT) have come under attack for focusing on saving the children only and ignoring the women and their partners and for increasing the orphan problem when the mothers die later on and also for creating large female headed households hence the call for PMTCT "plus" which now seek to also take care of the women and their partners.

Human rights and access to treatment

Successful HIV/AIDS treatment programs demand careful attention to human rights issues, especially the rights of people living with HIV/AIDS. Some of these rights include the right to know one's status, the right to confidentiality, the right to refuse participation in clinical trials, and ultimately, the right to be treated with dignity and respect. Such vital human rights are severely compromised by stigma and discrimination, which still prevail in many countries today. Fear of social stigma will limit the number of people seeking voluntary counseling and testing (VCT) and treatment for HIV in situations that might threaten their desired confidentiality regarding their status. Pervasive discrimination by health care workers and society in general also reduces access to care and treatment for people living with HIV/AIDS. In many settings, the availability of antiretrovirals may lead to a decrease in stigma and discrimination as HIV is then viewed just like any other disease such as malaria and diabetes which are manageable. Equally, limited availability of treatment and care might potentially have an inverse effect on stigma and discrimination.

Design of HIV/AIDS treatment programmes

In the design of HIV treatment programs, many questions remain to be addressed about who has, or who will have, access to treatment, and about which specific criteria should ideally be applied to determine the eligibility for antiretroviral treatment. The application of clinical criteria might seem at first blush to be straightforward and largely uncontroversial, but problematically, criteria regarding ability to pay, membership within a particular community, expectations concerning drug regimen adherence, and geographic location are all likely to result in considerable inequity. Choices concerning the range of antiretrovirals available within a country or programme also raise ethical questions. What are the implications of introducing a cheaper, but not necessarily optimal combination of antiretrovirals?

Highly active antiretroviral therapy might offer the highest success rates, but due to associated high costs, the government might also preclude wider coverage of the program. Therapy with somewhat cheaper drugs, while potentially less effective, might instead be offered to a much larger proportion of the eligible population.

The role of clinical trials in promoting access to care

Concerning research, a number of ethical issues also arise, especially regarding clinical trials. A significant proportion of PLHA gain access to treatment through participation in clinical trials. A major ethical problem associated with clinical trials relates to the uncertain obligation of researchers after the trial has ended. Should the researchers continue to provide lifelong antiretroviral treatment to "former" study participants? Is there an obligation to expand such treatment to others such as partners of

people enrolled in the clinical trial – or perhaps even to all eligible persons in the community?

CONCLUSION

This paper has attempted to highlight some of the various ethical issues relating to access to treatment for HIV/AIDS. It should however be noted that while it strictly concentrated on access to treatment, the authors openly acknowledge that treatment of HIV/AIDS is but only one component of a morally defensible comprehensive HIV/AIDS program that also includes prevention and other support and care activities. These components, whilst being complimentary to one another, also mutually reinforce each other.

While universal access to cost-effective drugs for treatment of HIV/AIDS is undeniably the ultimate goal, choices have to be made in the meantime that will always result in inequities in access. Collaborative partnerships are crucial in addressing issues of access to treatment, as they can ensure that multifaceted efforts are complementary and mutually reinforcing. Such partnerships also help to ensure that the relevant resources of all those involved are put to best use. Partnerships need to be developed among a broad range of players including PLHA groups, rural communities, church organizations, human rights bodies, pharmaceutical giants, donor agencies, governments and others.

The voices of those with direct experience of the epidemic need to be strategically raised. Effective strategies that include the creation of structures and processes which actively promote the involvement of PLHA need to be put in place. In addition to creating this enabling social environment, society needs to continue with all efforts to counter stigma and discrimination. Broad based advocacy for access to treatment, as happened in Brazil and Thailand, may increase the demand for and availability of treatment. As the most deeply affected by the many issues described here, developing countries should have no room for

complacency. Any effort to increase the access of their populations to treatment for HIV/AIDS should be welcomed.

ACKNOWLEDGEMENTS

We are grateful to Libby Bogdan- Lovis and Tom Tomlinson for their useful comments.

REFERENCES

1. Wolf EL. Ethical dimensions of HIV/AIDS. University of California, San Francisco. USA. 2001
2. Horizons. Access to treatment for HIV/AIDS: Report of a meeting of international experts. 12-13 June 2001. Washington D.C. 2001
3. International HIV/AIDS Alliance [homepage on the Internet]. United Kingdom. Improving access to HIV/AIDS related treatments. NAM Publications: United Kingdom [cited 2003 May 17. AIDS map HIV Worldwide; [About 2 screens]
4. Beauchamp TL and JF Childress. Principles of Biomedical Ethics. Press. New York: Oxford University. 1994.
5. British Columbia Centre for Excellence in HIV/AIDS. Prevention and Management of Occupational Exposure to HIV/AIDS. *Journal of the B.C. Centre for Excellence in HIV/AIDS* 1993; 1(3).
6. Zuger AM. Physicians, AIDS and occupational Risk. *Journal of the American Medical Association*. 1987;258:1924.
7. Gramelspacher GP, Siegler M. Do physicians have a professional responsibility to care for patients with HIV disease? *Issues in Law and Medicine*. 1988;4 (3):383-393.

Correspondence

PAUL NDEBELE

Center for Ethics in the Humanities and Life Sciences

Michigan State University

C-208 East Fee Hall,

East Lansing MI-48824, USA.

Tel: 1 517 355 7550

Fax: 1 517 353 3289

E-mail: ndebele@msu.edu

Recebido em: 31/08/05

Aprovado em: 16/11/05