Rural and Remote Health



ISSN 1445-6354

The International Electronic Journal of Rural and Remote Health Research, Education, Practice and Policy

CONFERENCE REPORT

Reframing the HIV/AIDS debate in developing countries IV: does ethics have anything to offer?

J Gillies

Department of Public Health, NHS Borders, Newstead, Melrose, Scotland, UK

Submitted: 16 March 2004; Published: 17 June 2004

Gillies J

Reframing the HIV/AIDS debate in developing countries IV: does ethics have anything to offer?

*Rural and Remote Health 4 (online), 2004: no 284

Available from: http://rrh.deakin.edu.au

ABSTRACT

Dealing with HIV/AIDS is one of the major ethical challenges facing the world today. It is suggested that an expanded discourse on ethics, divided into three levels, can help give a fuller understanding of all aspects of the HIV/AIDS pandemic. The levels are: (1) micro level (doctor-patient relationship); (2) meso level (civic and public health ethics); and (3) macro level (ethics of international relationships). At the micro level, the four principles of respect for autonomy, beneficence, non-maleficence and justice apply to HIV patients, as to any other. However, the overwhelming demand for medical care, and the lack of doctor availability in developing countries seriously limits their application. At the meso level, the Tavistock principles give a framework for health systems. The principles are: rights to health and health care; balancing resources among competing needs; comprehensiveness; cooperation among patients, clinicians and managers; focus on improvement, safety and openness. In this context, rights are respected by not discriminating on the basis of sex, geography, tribe or race. A balance has to be struck between treatment and prevention. Comprehensiveness means not ignoring palliative care and health improvement strategies. Cooperation requires 'the reciprocity and interdependence that characterise community'. The remaining principles are self-explanatory, but frequently ignored in health planning. At a macro level, there is a need for ethical discourse about issues like increasing inequality between rich and poor countries; the use of economic levers by developed countries to the disadvantage of developing countries; the international debt crisis; the tiny health care spend (US\$5-10 per capita per annum) in Africa; and other problems like refugee and migrant labour movements. These factors fuel global instability and the HIV/AIDS pandemic, as well as contributing to the threat of terrorism and environmental degradation. We need to look at how the values of Western democracy can be revised to address these problems. For example, scientific knowledge should be made available to all who can benefit from it; individualism should be put into the context of the common good; and free market forces need to be modified to reflect the fact that we live in a



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

world that is increasingly interdependent. This article was first presented in the HIV/AIDS Workshop at the 2003 World WONCA Rural Health Congress in Santiago de Compostela, Spain and is presented here as the final in a four-part series.

Key words: ethics, HIV/AIDS, Africa.

Introduction

Does ethics have anything to offer? The question is a rhetorical one, and the answer, of course, is that it must. How to deal with the tragedy of the HIV/AIDS pandemic is one of the most important ethical issues that mankind has to address in the coming decades.

The moving case stories in the second part of this series tell us in stark terms how HIV affects individuals and communities from Nigeria and South Africa. There is also an increasing amount of high quality evidence on the clinical and cost effectiveness of both anti-retroviral therapy and preventive approaches, summarised by Logie in the third part of this series. However, the ethical issue at the heart of this is, as Logie says 'Why shouldn't Africans have the same treatment options as the developed world?' That question cannot be answered by an examination of scientific facts alone. Hume suggested in 1740 that you can't derive an 'ought' from an 'is'. The facts, he states, don't tell you what to do. I suggest that ethical discourse can help us put these facts in a wider context that will shed light on the problem, and help us to see clearly ways of addressing it.

Three levels of ethical discourse

Most clinicians' awareness of ethics is of the ethics of doctor-patient relationships, or of research ethics². The discussion in this article is based on a much broader approach, pioneered by Benatar³, which offers a fuller understanding of the many issues contributing to the pandemic.

Benatar suggests that to address problems like HIV properly, we need an expanded discourse on ethics, divided into three levels:

- 1. Micro level (doctor-patient relationship)
- 2. Meso level (civic and public health ethics)
- 3. Macro level (ethics of interdependence and international relationships).

Micro level

The commonest approach at this level is that of Beauchamp and Childress⁴, well known to clinicians. The four principles are:

- 1. Respect for autonomy
- 2. Beneficence
- 3 Non-malificence
- 4. Justice

These should apply to treating patients with HIV, as to any other patient. Autonomy is reflected by respecting confidentiality and human dignity and by ensuring that HIV testing is performed with informed consent, as discussed in this series. We have a duty to help our patients and to avoid harm. We should discuss the balance between benefit and harm with each individual patient, where possible. However, the practice of these principles is obviously hindered by the overwhelming demand for medical care, and the lack of capacity, including doctor time and doctor availability in developing countries, well illustrated by Couper and Etokidem in parts I and II in this series.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

Meso level

However, it can be argued that the last principle, justice, fits better at the meso level than at the micro level. If, as Logie suggests in this series, scarce resource is diverted from a malaria or TB program by a new HIV project, justice may not be served.

The Tavistock principles, developed 'for those who are responsible for [a] health care system, those who work in it, and those who use it' represent an attempt to provide a meso level ethical framework. The principles are:

- Rights: people have a right to health and health care
- Balance: care of the individual must be weighed against what's best for a population.
- Comprehensiveness: treatment, relief of suffering, prevention and health promotion are all important.
- Cooperation: among patients, clinicians and those in other sectors.
- Improvement: a continuing responsibility.
- Safety.
- Openness: being open, honest and trustworthy.

These are as applicable to developing countries as they are to developed countries. Human rights are respected by not discriminating on the basis of sex, geography (especially important for rural populations), race or tribe. A balance between resources spent on treatment and prevention has to found. We should not focus on the 'medical model' discussed by Logie, at the expense of health promotion and education. Relief of suffering, for example in ensuring that morphine is available to those dying from HIV/AIDS, cannot be ignored⁶. Although those and the other principles may seem blindingly obvious when set out in this way, an examination of almost any health system will show that when health planning fails, it is often because one or several of these principles has been ignored. Benatar suggests that in this area 'morality...requires an institutional component embracing attention to public health and the management of resources' (p. 171).

A critical issue here is the need for further work on public health ethics, which have been neglected relative to micro level ethics⁷. Robertson's suggestion, that we need to consider a language of public health that 'speaks to the reciprocity and interdependence which characterise community', suggests a way forward⁸.

Macro level

In 1998, the former Director of WHO suggested that 'poverty in Africa is the greatest threat to health'9. The stories from Nigeria show how poverty leads to the spread of HIV/AIDS and, conversely, how HIV/AIDS, with its attendant socio-economic impact, leads to poverty. The result, not just for individuals but also for communities and countries, is a vicious downward spiral. This has obvious local aspects, but Benatar suggests that we must not ignore the contribution of global instability to the HIV/AIDS pandemic³.

Increasing inequality between rich and poor countries, the fixing of economic systems to the advantage of the developed world, the debt crisis (amounting to modern slavery for the developing world), the minuscule amounts (US\$5-10 per capita per annum) available for health care, and the movements of refugees have had a profound effect in contributing to the rise in infectious disease including, of course, HIV.

He goes on to say that if we accept this view, then dealing with the pandemic is not solely a matter of securing funding for HIV treatment and prevention, but addressing these root causes at a *global* level. The widespread belief in the developed world is that solutions are to be found within the underlying values of Western democracy. These are: a belief in advance based on scientific knowledge, free-market forces and the concept of human rights as applied to individuals. Security is based on the prevailing concept of geo-political realism, or 'might is right'.

However, given that these values self-evidently feed into and reinforce global instability, they bring with them, Benatar³



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

suggests, more major threats to all of us: terrorism; rise in infectious diseases, including HIV; and ecological degradation (SARS may be the latest manifestation). They reflect what Benatar calls 'selective moral blindness'. They also ignore the fact that we are all interdependent, those of us in the developed *and* the developing world.

The argument, therefore, is that given global instability *and*a set of values which seem destined to make things worse, that ethical discourse based at a micro or meso level may be necessary, but is insufficient to deal with global problems like HIV, which cannot be properly dealt with without consideration at a macro level as well.

A revision of these values to better address problems like HIV might include the following:

- Scientific knowledge
- Individualism
- Interdependence

Scientific knowledge: Scientific knowledge, to be made available to *all* who need it. Medical care is becoming more effective: more is always becoming possible. It should be used *for the good of all, wherever they live, in developed and developing countries*. Ethical discourse should focus on how best to make these treatments available.

Individualism: Individualism, to be put into the context of the common good. Tudor Hart has stated¹⁰:

The intelligence of patients everywhere has always been the most important and valuable resource for prevention, for their own care and that of their families, friends and communities. It can expand without limit in states that encourage solidarity and citizenship, but will certainly diminish in states that encourage consumerism and social division.

Siedentop¹¹ and Marinker¹² and others argue that the object of concern of modern Western governments is not the citizen but the consumer. We seem increasingly in the West to

express our citizenship through consumerism or litigation. Ivan Illich¹³, thirty years ago, suggested that in a consumer society, there are inevitably two kinds of slave: the prisoners of addiction, and the prisoners of envy. We need to move beyond this philosophical dead-end to ethical discourse that includes concern for the common good and for citizenship alongside individualism. Individualism has grown apace since the fall of communism in 1989. However, as Bamforth¹⁴ has said, what looked like a victory for democracy was in fact a victory for the market, not the same thing at all.

Public Health has a huge potential role here, and we are finally beginning to see scholarly work on the ethics of public health, on the relationships and structures which protect and promote public and population health⁷. In Ignatieff's view¹⁵, 'civil and political rights need supplementing with social and economic ones'. Individual rights per se, cannot be about achieving 'the good' for all.

We need, Benatar concludes, ethical approaches that address the understanding of interdependence and community at local, national and international/global levels. When we discuss the rights of individuals, we also need to be clear about the obligations that *satisfying* these rights has on others, and about the opportunity costs of these rights.

Interdependence: The principle of interdependence is especially important in international relationships, in attempting to achieve global security and a safe environment. Arguably, the ethics of 'might is right', which we have seen at work in the Middle East over the past year, has the potential to lead us all to disaster, which may come about by infectious disease, environmental catastrophe, or war. We need new concepts of security based on cooperation and a pursuit of the long-term interests of all.

Buddhist thinking¹⁶ contrasts foolish selfishness with wise selfishness. Wise selfishness means acknowledging that, because of interdependence, my wellbeing depends on the wellbeing of others. Foolish selfishness means looking only at my own wellbeing and ignoring that of those around me.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

Our current Western values, it can be argued, reinforce foolish selfishness, with major risks for our future, and that of our children.

Conclusion

We all live in families, in communities, in autonomous regions, in nation states, in economic communities, and in the world. The strength of the expanded ethical discourse sketched above is that it reflects all these aspects of our interdependence as human beings. The declaration adopted by the WONCA World Health Congress at Santiago de Compostela, Spain, in September 2003, published with the first in this series and repeated at the end of this article, suggests ways forward.

To address the tragedy of the HIV/AIDS pandemic in an interdependent world, we, as doctors and citizens, need to think long and hard about each of these levels, and act. Millions of lives are at stake here.

Antonio Gramsci, in another context, suggested that when we are confronted with a serious situation, we may have pessimism of the intellect, but to deal with it, we must also have optimism of the will¹⁷. Never was this truer than now.

References

- 1. Hume D. *A treatise of human nature*. (1740). E C Mossner (Ed.). London: Penguin Books, 1969, 514
- 2. World Medical Association. Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2000; **284**: 3043-3045.
- 3. Benatar SR. The HIV/AIDS pandemic: a sign of instability in a complex global system. *Journal of Medical Philosophy* 2002; **27:** 163-17.
- 4. Beauchamp T, Childress J. *Principles of Biomedical Ethics*, 5th edn. Oxford: Oxford University Press, 2001; chapters 3-6.

- 5. Berwick D, Davidoff, F Hiatt H, Smith R. Refining and implementing the Tavistock principles for everyone in health care. *BMJ* 2001; **323**: 616-620.
- 6. Sepulveda C, Habiyambere V, Amandua J et al. Quality care at the end of life in Africa. *BMJ* 2003; **327:** 209-213.
- 7. Bankowski Z, Bryant JH, Gallagher J (Eds). *Ethics, Equity and Health for All.* Geneva: Council for International Organisations of Medical Sciences, 1997; 49.
- 8. Robertson A. Critical reflections on the politics of need: implications for public health. *Social Science and Medicine* 1998; **47:** 1419-1430.
- 9. Bruntland GH. Address to the WHO Regional Committee for Africa, 48th session, Harare, Zimbabwe. 31st August 1998.
- Tudor Hart J. Keynote address at WONCA World Rural Congress, September 2003. Santiago de Compostela, Spain.
- 11. Siedentop L. *Democracy in Europe*. London: Allen Lane, 2000, 34-35.
- 12. Marinker M. *Sense and sensibility in health care*. London: BMJ Books, 1996; 13.
- 13. Illich I. *Tools for Conviviality*. London: Calder and Boyars, 1973.
- 14. Bamforth I. The medical profession and human rights: handbook for a changing agenda. *Bulletin of WHO* 2001; **79:** 997. [Book review].
- 15. Ignatieff M. *Human rights as politics and idolatry*. A Gutman (Ed.) Princeton: Princeton University Press, 2003; 89.
- 16. His Holiness the Dalai Llama. *Ancient wisdom, modern world*. London: Little, Brown and company, 1999; 48.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

17. Indire. (Online) 2004. [*Notes on Antonio Gramsci*]. Available: http://www.bdp.it/~caps0002/gramsci/biogcont.htm (accessed 21 May 2004). (In Italian)

This article concludes with the 2003 WONCA World Rural Health Congress' concluding 'Santiago de Compostela Statement on HIV/AIDS' as adopted on September 2003 at the Congress. It is offered here as a suggested way forward.

The Santiago de Compostela Statement on HIV/AIDS

We as rural practitioners at the 6th World Rural Health Conference in Santiago are deeply concerned about the extent of the growing HIV/AIDS pandemic and the way that it exacerbates the problems of poverty, inequity and underdevelopment in the world.

We recognise this to be a global problem. We live in an interdependent world. None of us can remain uninvolved. All of us are affected if not infected.

We believe:

- It is critical to address HIV/AIDS in terms of primary health care, healthcare systems and international
 organisations.
- The developed world has a moral responsibility to work towards equitable care of those infected with HIV/AIDS in all parts of the world.

We therefore:

- Commit ourselves to work with other health professionals, non-governmental organisations and communities to
 ensure a comprehensive, equitable response to HIV/AIDS at a primary care level, within the philosophy of
 Health for All.
- Support a comprehensive approach to the problem which includes both adequately resourced, appropriate
 treatment and broad-based preventive strategies (including safe medical practices, education about risks,
 promotion of behavior change, prevention of mother-to-child transmission, etc).
- Call on WONCA
 - o To recognise the critical importance and urgency of the situation regarding HIV/AIDS
 - o To lobby member countries and international agencies to commit resources to the problem, especially in the developing world, recognising the importance both of strengthening local healthcare systems and of addressing the issues of global poverty, injustice and inequity which fuel the spread of HIV/AIDS.