

Are we censoring ourselves?

NEW ISSUES FACING THE HUMAN RIGHTS RESPONSE TO HIV/AIDS

There is wide acceptance by governments and civil society in SADC that a human rights-based response is justified in the implementation of HIV prevention and treatment programmes. However, policy and practice are usually different things. In this article, **Holo Hachonda** and **Richard Adudah** explain some of the key principles that inform the human rights approach to HIV and AIDS, but ask why these principles are not being applied to prisoners, sex workers and gay men who continue to be marginalised and denied access to HIV prevention. They conclude by introducing a debate which is currently taking place about new approaches to HIV testing – ‘routine testing’ or the ‘routine offer’ of testing.

Introduction

The spread of HIV/AIDS continues to present many challenges with respect to socio-economic and human rights in Africa. The virus continues to be marked by discrimination against various groups: those who live on the fringes of society or who are assumed to be at risk of infection because of behaviours, race, ethnicity, sexual orientation, gender, or whatever social characteristics happen to be stigmatised in a particular society.

Stigmatisation and discrimination impact on equitable access to HIV-related facilities and services for prevention and care, including access to treatment. As the number of people living with HIV and AIDS continues to rise in nations with different economies, social structures and legal systems, HIV/AIDS-related human rights issues are not only becoming more apparent, but also increasingly diverse. Yet human rights law and the institutions and standards of the global human rights regime provide a powerful set of tools that can be used to address the social, economic and political context of the causes and consequences of HIV/AIDS.

Most countries in the SADC region have committed themselves to regional developmental initiatives, which include an explicit commitment to rights-based responses to the HIV/AIDS pandemic. There are, however, renewed questions about, for example, whether there should be a less stringent commitment to confidentiality and disclosure, and whether the traditional model of voluntary counselling and testing (which ensures patient autonomy) should permit the introduction of 'routine' HIV testing; should health workers disclose to colleagues or close relatives of a person needing treatment? What about the rights of other marginalised groups like men who have sex with men, sex workers, prisoners, internally displaced persons?

Addressing HIV/AIDS through a human rights-based approach

Human rights are a universally recognised set of norms and standards for ensuring the human development, well-being and dignity of every person, and these principles have been codified in international law in the form of treaties, and in most constitutions. Virtually every country in the world has chosen to be bound by the terms of at least one of the major human rights treaties, and this places specific obligations on governments.

A rights-based approach is important because it is the most effective means of addressing the social, political and economic factors that contribute to the spread of HIV and

mitigating the social and economic impact of AIDS. It also carries a moral obligation on governments to protect and respect the human rights of their citizens.¹ Given the reality of violations that continue to occur in the context of HIV/AIDS, it is useful to consider the specific human rights responsibilities of governments, using education as an example.

- Respecting the right means that states cannot violate the right directly. This means that the right to education is violated if children are barred from attending school on the basis of their HIV status.
- Protecting the right means that a state has to prevent violations of rights by non-state actors – and offer some sort of redress that people know about and have access to if a violation does occur. This means that a state has to ensure, for example, that groups motivated by extremist ideologies are not allowed to prevent adolescents from accessing reproductive health education.
- Fulfilling the right means that states have to take all appropriate measures – legislative, administrative, budgetary, judicial, and otherwise – towards fulfilling the right. If a state fails to provide essential HIV/AIDS prevention education in enough languages and mediums to be accessible to everyone in the population, this in and of itself could be understood to be a violation of the right to education.

HIV/AIDS and the human rights debate

People with HIV may suffer from violations of their rights when, for example, they face marginalisation and discrimination regarding access to health, education and social services, when in fact they should have non-discriminatory access to treatment within a supportive social environment. The negative effects of the HIV epidemic on people's lives may be compounded by marginalisation and stigmatisation on the basis of such attributes as race, migrant status, behaviours, or kinship that may be perceived as risk factors for HIV infection. For HIV-infected people and people with AIDS, the concerns include mandatory HIV testing; restrictions on international travel; barriers to employment and housing, access to education, medical care or health insurance; and the many issues raised by name reporting, partner notification, and confidentiality. The violation of rights can also be as basic as the right to freedom of choice – women and girls, for example, often cannot choose who they have sex with, and whether or not they use some form of protection.

¹ The integral link between HIV/AIDS and human rights was recognised at the UN General Assembly Special Session on HIV/AIDS (UNGASS) in 2001 (UN General Assembly. Declaration of Commitment on HIV/AIDS, Paragraph 80. Available at www.unaids.org/UNGASS/index.html).

The right to health

Health as a human right is defined as a 'state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity'.² In the context of HIV/AIDS:

- Violations or lack of attention to human rights can have serious consequences on the spread of HIV/AIDS, persons living with HIV/AIDS and public health generally;
- Policies and programmes to combat HIV/AIDS can promote or violate human rights in the ways they are designed or implemented;
- Taking steps to respect, protect and fulfill human rights can reduce vulnerability and the impact of HIV/AIDS.

This would include, therefore, the adoption of a national health policy with a detailed plan for realising the right to health; positive measures to enable individuals and communities to enjoy the right to health; and actions that create, maintain, and restore the health of the population.

Such rights include access to medicines, and in recognition of this in 1998 the International Guidelines³ on HIV/AIDS and Human Rights were adopted by the UN Office of the High Commissioner for Human Rights and the Joint UN Programme on HIV/AIDS (UNAIDS). The UN Commission on Human Rights has now adopted, at successive sessions, two resolutions⁴ declaring that 'access to medication in the context of pandemics such as HIV/AIDS is one fundamental element' for realising the right to health. The resolutions further call upon states 'to pursue policies which would promote the availability and affordability of medicines and medical technologies' and 'to ensure that the application of international agreements is supportive of public health policies promoting broad access to safe, effective and affordable pharmaceuticals and technologies'.

In practice, government responsibility for health as codified in legal/policy documents differ in several ways. In most states in Africa, healthcare is a service for which citizens

² World Health Organization, *Constitution of the World Health Organization*, adopted by the International Health Conference, New York, 19 June-22 July 1946, and signed on 22 July 1946 by the representatives of 61 states.

³ *Guidelines on HIV/AIDS and Human Rights*, as adopted by the 2nd International Consultation on HIV/AIDS and Human Rights. See *Report of the Secretary General on the 2nd International Consultation on HIV/AIDS and Human Rights*, 20 July, 1997. E/CN.4/CN.1997/37, United Nations, New York.

⁴ UN Commission on Human Rights; Resolutions 2001/33 (23 April 2001) and 2002/32 (22 April 2002). Available on the website of the UN High Commissioner for Human Rights - www.unhchr.ch.

must pay. By turning health into a commodity for profit, a fertile environment for the spread of HIV has been created. The structural adjustment programmes imposed on countries such as Zambia and Zimbabwe have negatively impacted on the state's ability to provide for its citizens even the most basic health services. These countries have been forced to adopt a western model of providing services, which requires individuals to meet most of the costs when accessing health services. This system may work well in strong economies where the majority of the citizens can afford health insurance and other schemes. Unfortunately, this is not the case for dilapidated economies with the average salary of the labour force being less than \$100 per month, and millions of people trapped in permanent unemployment. For the majority of the population, this kind of policy automatically translates into discrimination in accessing health services; as the saying goes, 'If you can't afford it, you can't get it'. In reality, in terms of access to medicines, the privatisation of health care has converted this right into a lucrative trade in people's health. People who need to access health care now have to purchase or access it through medical insurance, yet often the insurance industry does not offer insurance to a person who is HIV-positive and the majority of Africans cannot afford medical insurance anyway.

With the dramatic increase on the African continent of those needing treatment for HIV and AIDS, African states are sorely challenged to uphold the right to health, particularly in the provision of treatment for all those in need. There is a responsibility on governments to use laws that allow for the compulsory licensing of essential medicines that are needed for treatment and to work together to ensure that there is a sustainable supply of these medicines between developing countries. Regrettably, most governments have neither the resources nor the infrastructure to provide treatment to those who qualify according to the international guidelines. This is another reason why, for example, co-ordinated calls for conditional debt cancellation are important.

The demand for anti-AIDS drugs far outstrips supply in many African countries. Zambia appears to be an exception to this rule – at first glance. The Director of Technical Services at the country's Central Board of Health, Victor Mukonka, said recently that people were not coming to clinics to obtain the life-prolonging antiretrovirals (ARVs). 'People were demanding ARVs before we had them. Now, very few are turning up. The turn-out cannot be compared to the pressure that we received to have them in the country'. Mukonka said clinics had recorded a very low response to the programme in outlying towns like Kasama in northern Zambia, where three people had applied for ARVs. The University Teaching Hospital, the largest in Zambia, had recorded about

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400 people on the drugs. However, Clement Mfuzi, of the Network of Zambian People Living With HIV/AIDS, says government is not being honest about the reasons why people are not applying for the drugs. He denies the claim that people are reluctant to be tested, pointing to the fact that many who live with AIDS have already gone public with their HIV status. 'It is not possible', he adds, 'that they would suddenly become too 'shy' to seek treatment. Mfuzi says the NZP has a membership in excess of 1 million people, but that none of these members has been able to take advantage of the drug programme. 'We do not know who is accessing the drugs, certainly none of our members. As a person living with HIV, I have tried unsuccessfully to access ARVs. We are told we are on a waiting list and that is the end of the story,' said Mfuzi, who further alleges that the current system of drug allocation is open to abuse and favouritism. Gertrude Mwashibantu, who is on the government-sponsored ARVs, agrees. She is only able to get drugs because she paid a nurse about 30 dollars to jump the queue. 'I collected the drugs at lunch time when there was no doctor around...'

Zambia, November 13, 2003

Freedom from discrimination/right to equal treatment and healthcare:

'We are censoring ourselves'

Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. Stigma, discrimination, and human rights violations form a vicious cycle. Stigma causes discrimination; discrimination leads to violations of human rights; human rights violations legitimize stigma; and the stigma leads to more discrimination. The effects of discrimination against persons living with HIV/AIDS and those otherwise affected by the disease are devastating not only for the individuals themselves, but also for the community and, in particular, for efforts to prevent the spread of HIV. Discrimination hurts the fight against AIDS and related human rights like employment, housing, access to education, medical care and so on. Discrimination is also prevalent in prison systems, where the spread of HIV/AIDS is preponderantly high. In most jurisdictions, there are no support structures for inmates living with HIV and other infections.

Prisoners' access to reproductive health services

South Africa is one of a few countries in the region that has a policy on dealing with HIV/AIDS in prisons.⁵ The first policy was formulated in 1992, and at that time, the policy of the Department of Correctional Services was that of segregation of HIV-positive prisoners. However, human rights activists in South Africa contested this approach and threatened legal action under South Africa's new constitution. As a result, the practice of segregation was disallowed. Instead of recommending prisoners for HIV testing on admission, prisoners were only to be tested when they requested a test or upon recommendation by the district surgeon. In either case, the prisoner's informed consent was required. The amendment also introduced a number of specific programmes to be implemented at a provincial as well as prison level. This included: provision of services in clinics at all prison hospitals run by nurses, the services to include STI diagnosis and treatment, HIV testing, treatment for opportunistic infections (but not antiretrovirals), counselling and provision of information regarding sexually transmitted infections (STIs) for prisoners. However, most countries in the region are still struggling with the issue of providing condoms to male prisons as most societies find it easier to turn a blind eye to the fact there are men who have sex with men, not only in the prisons but also in our communities (See 'Re-Sexualising the Epidemic' in this journal).

Most governments in Southern Africa refuse to provide condoms in prisons because they claim it would encourage homosexuality among the prisoners, something which is still illegal in all countries except South Africa. However, this refusal to acknowledge a very real problem means that prisoners, forced by circumstances into same-sex relationships, are denied the right to safer sex. According to a recently published report by UNAIDS, thousands of prisoners in Southern African jails face the constant threat of HIV-infection because conservative authorities are unwilling to provide them with condoms. There are no official statistics documenting the number of rape cases or men who have sex with men in most African prisons, but the UNAIDS report, compiled with the help of Southern African non-governmental organisations, claims that studies reveal that sex between men is common in prisons. 'In Malawi and Zambia at least one in eight men has sex in prison', it claims. Homosexuality in prison is either consensual or the result of rape or another form of exploitation. 'It may also be a mutually beneficial arrangement whereby a younger or weaker man receives protection or benefits such as food from an older, stronger man in exchange for sexual services', the report stated. Mnguni Simelane, the commissioner for correctional services in Swaziland, said that the government does not recognise homosexuality and would not encourage it by providing prisoners with condoms.

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⁵ HIV/AIDS Policy in South African prisons, monograph No 79, February 2003.

On this issue, the South African government is an exception. A 1996 amendment to the Department of Correctional Services policy states that condoms are to be provided to prisoners 'on the same basis as condoms are provided in communities'.

People engaged in high risk behaviours such as sex workers and intravenous drug users are largely marginalised by both government and foreign donor policies that seem to take a more conservative and 'moralistic' stance in providing reproductive health and HIV/AIDS services.⁶

A significant number of states continue to deny that HIV is a rights issue, or to allow human rights to intrude into certain areas of HIV prevention on the grounds of religion, custom or law. In Zimbabwe, Namibia, and many other countries in Africa and Asia, discrimination against men who have sex with men prevents HIV prevention strategies from targeting or reaching millions of vulnerable people (Heywood, 2004).

It is increasingly important to think about health and the right to health in a holistic or comprehensive approach that recognises the underlying socio-cultural determinants that affect health, especially in the context of a pandemic such as AIDS. With regard to a holistic right to health, government obligations include providing health services, sanitation, clean air, clean water, housing, universal access to health, education, living wages, sustainable development, and securing other social and economic conditions of peace and progress. Additionally, the right to health cannot be meaningfully actualised when governments fail to eradicate oppressive social or cultural practices that jeopardise the health of women.

Privacy, confidentiality and testing

The HIV/AIDS epidemic has brought with it a profound re-examination of the practical implications of the principle of confidentiality and the tenets of medical ethics generally, and has triggered intense public and academic debate. Confidentiality is a concept encompassing a duty inhibiting the repetition to others of knowledge about another person or entity. In Anglophone legal tradition, the right to confidentiality can perhaps

⁶ The Global Gag Rule has created great concern among service providers and NGOs that young people especially will not have access to the knowledge they need to make informed, life-saving choices. (The Impact of the Global Gag Rule in Zambia, Access Denied. 2003. Population Action International, Planned Parenthood Federation of American, Inc., Ipas, Pathfinder International and Engender Health.)

be described as deriving from a right to privacy, which in turn, stems from the right to dignity and human autonomy. Every human being is therefore intrinsically entitled to some personal autonomy, and the right to make decisions about and for oneself, whether physical, mental and/or moral.

In the case of HIV/AIDS, some have argued that there is a paradox of morality and ethics in upholding the right to confidentiality, and this is perhaps one of the biggest challenges faced by medical practitioners and service providers in providing good, quality and equitable services to their client while at the same time ensuring that the client's condition does not put other individuals at risk.

Dr. Wilbert Okana recounts the time he was attending to a client during his residency at a hospital in Uganda: 'The client showed symptoms that are common in patients with AIDS, and after treating him for month or so, I talked to him about considering an HIV test for us to fully determine how best to treat him. He consented to this and the test came out positive and we talked about it for a while. The client begged me not to tell his wife who was waiting in the corridor as he feared she would abandon him to die alone in the hospital. My dilemma came when the wife asked me if her husband had this new disease AIDS, since she had seen other AIDS patients with similar symptoms. I felt that this woman had every right to know, but then if I broke the oath now, I would be going against the most important principle of health care.'

In 2004 the commitment of the medical profession to maintaining patient confidentiality is coming under scrutiny again. Many people ask 'How far should health workers go in protecting the patient's right to privacy? What happens when such confidentiality poses a direct health risk of transmitting HIV to another individual? Is it still solely the patient's duty or discretion to inform the third party of their condition, or can other instruments be put in place to clearly define this? Where do we draw the line? How do we uphold the right to confidentiality without neglecting those that may be put in harm's way if confidentiality is maintained?'

The global position⁷

According to Jurgens, 'health service providers also have an ethical obligation to maintain the confidentiality of the information that is given to them by their patients. This duty has roots that date back to the Hippocratic oath written during the fourth

⁷ Declaration of commitment on HIV/AIDS - 'global crisis-global action'. UNAIDS General Assembly, June 2001.

century BC, which contains the vow, whatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken abroad, Will not divulge, as reckoning that all such should be kept secret'. However, the declaration of commitment on HIV/AIDS adopted by the United Nations General Assembly in June 2001, states that the commitment to address the HIV/AIDS crisis should 'take into account the diverse situations and circumstances in different regions and countries throughout the world'. The question therefore is whether the scale of the HIV pandemic justifies a weakening of these principles.

The arguments

It is clear that the world perceives confidentiality and privacy as key elements in delivering equitable quality health services to all. Invading a client's privacy and eroding confidentiality would most certainly destroy the patients' trust in the health service. It is probable that it would deter many people from seeking voluntary counselling and HIV testing.

However, there is a school of thought that argues against the right to confidentiality for people with HIV. Some have gone as far as using the analogy of a psychiatrist whose patient tells him or her that he/she might murder someone; the psychiatrist is required by law to break confidentiality because another person is at risk, so the principle is that life endangerment should be applied in HIV/AIDS cases, especially when patient or client is reluctant to inform his or her sexual partner about their status. This presents medical personnel with the dilemma of either maintaining confidentiality when someone's life may be at risk, or breaking confidentiality and compromising professional ethics by disclosing a patient's HIV status.

In this vein, the South African Constitution, for example, accepts that there can be limitations to the right to privacy:

Section 36 implicitly recognises that in a democracy, a fundamental right cannot be enforced in isolation from the interest of others or the state. Instead, it may be limited to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality, and freedom and taking into account the nature of the right, the importance of the purpose of the limitation, the nature and extent of the limitation, the relationship between the limitation and its purpose and the least restrictive means to achieve the limitation. At the very least,

given the sexual dimension to HIV, the spouse or sexual partner of the patient has a right to know and that the person privy to the relevant information has a duty to inform. It is not sufficient merely to confer discretion on the health care worker. For the health care worker may choose not to disclose for reasons that are not compelling. The law must impose a duty to disclose and place upon the health care worker the onus of justifying non-disclosure. If the matter is left entirely at the level of a professional discretion in what sense then can it be said that the spouse or sexual partner has a right to know when what he or she has is a mere privilege to know?

Such a position, however, remains extremely contentious from the perspective of both human rights and public health.

Another issue with human rights dimensions attracting new debate concerns the approach to HIV testing. At the XV International AIDS Conference in Thailand in July 2004, UNAIDS and the World Health Organization put forward their new position on testing,⁸ explaining that in countries where HIV is widespread and where treatment is available there should be a routine offer of HIV testing which allows for patients to opt out. According to the Executive Director of UNAIDS, Peter Piot, 'Patients who visit clinics 'for whatever reason' and are not offered HIV tests represent 'millions of missed opportunities' for early diagnosis of AIDS' (Piot, 2004).

In some countries of Southern Africa such a shift has already taken place. For example, in October 2003 the government of Botswana announced that it would introduce routine HIV testing with consent effective from January 2004. This was the outcome of a lengthy process of discussion and consultation with various stakeholders, including a seminar convened by the Botswana Network on Ethics, Law and HIV/AIDS (BONELA). According to the seminar report, it was established that routine testing is testing commonly done by a medical practitioner on any individual he or she encounters in the consulting room, in the interests of that patient's continued health. The patient, however, can always decide to opt out of routine testing. Compulsory testing, on the other hand would involve the testing of all patients whether or not they agree to be tested; the patient has no option but to test. The BONELA report highlights arguments both for

⁸ UN and other experts call for routine HIV/AIDS testing in developing countries (Emma Ross, in *Health and Fitness*).

and against routine testing. Reasons advanced for supporting routine testing included the desire to avert a health crisis, assisting women to have healthy pregnancies, to alert medical staff to the necessity for interventions in pregnancy and delivery for either the mother's or the baby's health. It was argued that the issue of stigma, including around all sexually transmitted diseases, could be addressed by everyone being tested, thus not isolating a particular individual from 'other people' (Mozonde, 2003). As Dr Mozonde explained, 'Many people who need assistance are coming in too late, and we are therefore getting minimal returns on a huge expenditure of time, human and financial resources. Knowing people's status early allows us to budget for them; and ultimately, it will enable us to attain what we have been talking about in Vision 2016 – an AIDS-free generation'. The supporters of routine testing for HIV/AIDS insist that it is an ethically defensible public policy option, since it promotes common good (public rights) and individual rights in the context of an overwhelming public health emergency.

Why we should stand our ground to uphold human rights

However, while routine HIV testing does have its supporters who argue that it could improve the performance of some of our prevention strategies, there are other things we need to consider in deciding on this issue, other than simply maximising the numbers of people who know their HIV status:

- Control of HIV infection and transmission requires the patient's co-operation not alienation, we must instead interrupt HIV transmission by reducing stigma and vulnerability and promote the rights and welfare of HIV infected and uninfected people;⁹
- Confidentiality is also an essential prerequisite for the accessibility of the health care system, an important aspect of the right to health: '...effective health care requires that people feel free to come forward to seek information of a personal nature', while non-observance of the principle of confidentiality endangers the enjoyment and exercise of health rights;
- Where voluntary testing programmes have been well-designed and implemented, they have been demonstrated to be effective. For example, the New York City Health and Hospitals Corporation (HCC) has reported that 90 per cent of pregnant women using HCC facilities who receive HIV pre-test counselling voluntarily consent to HIV testing and return for test results. In Soweto 9 per cent of women today accept the offer of HIV counselling, and 90 per cent follow this up with an HIV test. Other

⁹ HIV testing and confidentiality: Final Report prepared by Ralf Jurgens, published by the Canadian HIV/AIDS Legal Network & Canadian AIDS Society.

model programmes have also reported high rates of voluntary testing, showing that a range of factors regarding design of the testing and the delivery of counselling can improve testing uptake rates. Before moving to more coercive approaches, these factors would have to be exhausted as less restrictive approaches;

- Routine testing cannot work in most countries in the Southern region of Africa, as most lack the necessary resources including skilled manpower, and equipment such as testing and monitoring kits. In most countries of the SADC region, the health system is not presently able to maintain or sustain an effective routine testing programme;
- There is already an overwhelming shortage of health staff, especially trained counsellors, and these needs must be addressed before such proposals can be considered;
- Routine programmes are expensive and there is need to have all the necessary resources mobilised; funding, drugs, staff, policies to prevent exploitation, and leadership, before countries can start considering the UNAIDS and WHO recommendation;
- Debt relief programmes need to be effectively implemented to reduce the economic burden that prevents most countries from effectively responding to the pandemic by scaling up important programmes such as treatment.

Given the opposing views, it is likely that this debate will continue. In November 2004, for example, UNAIDS is organising a consultation with over 40 countries on how to scale up HIV testing. However, while it is recognised that this is necessary it must not be done in a way that – by overriding human rights – does damage to HIV prevention and treatment.

Conclusion

The SADC, NEPAD and African governments need to follow through on the region's declarations with regard to HIV/AIDS. The region has the institutions, experiences to learn from, and in many respects the capacity to manage HIV/AIDS, and also the capacity to mobilise required resources, yet every year we continue to concede defeat to the escalating death rates. There are many grey areas of policy and implementation that must be resolved. All people have human rights, particularly groups that our governments consistently marginalise and stigmatise. But we must also be flexible in assessing what human rights mean practically, as the epidemic grows beneath our feet.

While we must avoid censoring others because of 'moral' objections to their behaviour, we must also avoid censoring ourselves by refusing to consider new policies and practices that might accelerate the reversal of the impact of HIV/AIDS in the region.

Specific recommendations would include:

- Gays, Lesbians and Sex Workers: Most governments in the region fail to recognise the existence of these groups as people whose choices or circumstances place them at high risk of HIV infection, but also people with a right to attention and inclusion in the respective strategies including the SADC response.
- Prisoners: Prisoners have a right to both information and condoms to protect themselves from HIV infection.
- Young People: Most reports and strategic documents highlight this group as a priority in turning the tide, yet limited resources are being committed to programmes specifically targeting them. Most youth programmes scrounge for resources and are usually just given enough to see them through to the next year. There are very few programmes that are long-term, and there is thus a need for governments and international agencies to put their money where their mouth is. Talk alone will not reduce the incidence of HIV among young people – there is need to act aggressively.

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