Biomedical and development paradigms in AIDS prevention
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In the fight against the HIV/AIDS pandemic different approaches can be distinguished, reflecting professional backgrounds, world views and political interests. One important distinction is between the biomedical and the development paradigms. The biomedical paradigm is characterized by individualization and the concept of "risk". This again is related to the concept of the market where health is a product of services and progress a series of new discoveries that can be marketed. The development paradigm is characterized by participation of the different stakeholders and by community work. The concept "vulnerability" is important in the development paradigm and emphasis is placed on efforts to decrease this vulnerability in a variety of sustainable ways. Biomedical technology is definitely one of the tools in these efforts. In the beginning of the pandemic the biomedical approach was important for the discovery of the virus and understanding its epidemiology. Later, stakeholders became involved. In the light of absence of treatment or vaccines, the development paradigm became more important and the two approaches were more in balance. However, since the reports about effective treatment of AIDS and hope of development of vaccines, the biomedical paradigm has become a leading principle in many HIV/AIDS prevention programmes. There is a need for a better balance between the two paradigms. Especially in developing countries, where it is not realistic to think that sustainable biomedical interventions can be organized on a short-term basis, it would be counterproductive to base our efforts to deal with HIV/AIDS exclusively on the biomedical approach.

Keywords: acquired immunodeficiency syndrome, prevention and control; comparative study; socioeconomic factors; social justice; zidovudine, therapeutic use.

Introduction

In December 1998, almost simultaneously, two news items appeared on human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). One was the news about a paper by the EuroSIDA Study Group published in the Lancet showing that at the beginning of 1998, death rates in Europe due to HIV-1 were less than one-fifth of those in September 1995. Much of this improvement could be explained by the introduction of new treatments or combination therapy. This publication confirmed optimism about future projections for the HIV epidemic in Australia, North America, and Western Europe. Media response to the publication was positive and contributed to the idea that the worst of the HIV/AIDS epidemic was over. The other news was the UNAIDS press release on the occasion of World AIDS Day reporting that in 1998, 2.5 million people died of AIDS and that there were 10% more infections than in the previous year. The epidemic was said to be out of control in many parts of the world. About 95% of the total deaths due to AIDS occurred in developing countries. An even more pessimistic view was presented by UNAIDS in 1999 in Lusaka, Zambia, at the Eleventh International Congress on AIDS/ Sexually Transmitted Diseases (STDs) in Africa. In September 1999, it was estimated that more than 40 million people would be infected with HIV as we entered the new millennium. By 2010–15 life expectancy in the nine African countries with the highest prevalence of HIV infection will decrease on average by 16 years.

Both scenarios involve the same virus, but with dramatically different consequences, resulting in optimism for Australia, North America, and Western Europe and pessimism for the developing world. During the Twelfth World AIDS Conference in 1998 in Geneva, the leading theme was “bridging the gap”, and though it was criticized, it expressed concern about the differences in the HIV epidemics among rich and poor countries. The gap is seen by many as due largely to variations in the availability of medication. Though lack of access to medical treatment is one aspect of this gap, the main issue may be differences in the context of the epidemic, and the most effective ways of dealing with it that...
follow from the context. This article examines the paradigms that underlie these different ways of dealing with the HIV epidemic.

**The biomedical and developmental paradigms**

Opinions differ about the most effective way to deal with the HIV epidemic in the developing world. Seidel mentions the diversity of discourses about the HIV epidemic in sub-Saharan Africa: the “medical discourse”, the “development discourse”, the “medico-moral discourse”, the “legal and human rights discourse”, the “ethical discourse”, and the “activist discourse” (7). These discourses all seek to influence public policy on AIDS, and they often overlap. Seidel distinguishes between the discourses of “control and exclusion” and of “rights and empowerment”. In his opinion the medical and medico-moral discourses inhibit the process of empowerment, participation, and solidarity, and as such, they belong to the discourse of control and exclusion.

This critique of the biomedical paradigm with regard to HIV/AIDS is often seen. Packard & Epstein (8), for instance, argue that work carried out by Western-trained medical researchers and a lack of knowledge of African societies and cultures result in theories that lead to biomedical research and privileged lines of inquiry, while largely marginalizing other forms of research. This may seem mere academic discussion, but Schoepf claims that “if the dominant paradigms reflect limited perspectives, then the policy conclusion they suggest or legitimate may be ineffective or even counterproductive” (9). This warning is in agreement with experience from efforts to improve almost any aspect of health in developing countries. If we concentrate on biomedicine exclusively, we may miss the context in which health and disease are produced. Health and disease cannot be viewed in a vacuum (10). They are experienced in the real world, and influential factors such as social and economic conditions, and cultural interpretation, are essential for our understanding. Fee & Krieger (11) stress the importance of recognizing the failure of a purely biomedical paradigm. According to them, the alternative to this biomedical paradigm “emphasizes that AIDS is at once a social and biological disorder; its course cannot be understood or altered without attention to its social and political context”.

**The need for balance**

What seems to emerge from this discussion is a need for balance between the biomedical and the development paradigms. In the relatively short history of the HIV epidemic we can distinguish certain changes in this balance.

In the early 1980s, understanding the infection and its causes was mainly a biomedical affair. In the initial prevention programmes the emphasis was on education concerning routes of transmission and potential risks in order to stimulate people to change their behaviour. This approach helped nations and individuals to recognize the need to react to the pandemic. For the medical profession the new epidemic provided enormous challenges and possibilities for building a career. Weeks wrote: “The road to the Nobel prize is paved with AIDS research” (12).

However, the limitations of the biomedical paradigm soon became clear. First of all, changing behaviour is not a simple consequence of receiving information about risky activities, and Bandura’s social learning theory (13) cannot be applied to complex behaviours such as sexuality. Behaviour is embedded in a context that is influenced by many factors. Hiring a few social scientists to tell the medical profession how to present a message of prevention is not sufficient. An analysis of the factors and what people can do themselves has a greater chance of success, though it is not an easy process. Participatory approaches involving communities appear to be effective in many fields (14, 15), so using them in AIDS prevention seemed an obvious choice. The second limitation of an exclusive biomedical message appeared to be the connection that was made between a deadly threat and specific behaviours. This resulted in moral interpretations of these behaviours that often led to stigmatization and discrimination. Weeks wrote: “AIDS has become the symbolic bearer of a host of meaning about our contemporary culture: about its social composition, its racial boundaries, its attitudes to social marginality; and above all, its moral configurations and its sexual mores” (16). Stigmatization and discrimination did not only have undesirable effects on already marginalized populations, they also lessened the impact of prevention programmes because people did not want to identify with these marginalized populations. Public health experts were quick to understand potential threats to the human rights of individuals and to prevention programmes (17).

Initially, in, Australia, USA, and Western Europe the gay population was the most affected by the AIDS epidemic. In research on therapy choices of HIV-infected people in the Netherlands, we discovered that this population had educational and income levels significantly above the average (18), which told us that we were dealing with an empowered population. In addition, the gay movement in developed countries had just gone through a process of empowerment and emancipation and appeared to be a powerful advocacy group. Consequently, the gay movement deserves much of the credit for bringing HIV/AIDS to community and political platforms. At the same time, in developing countries, where communities were facing multiple health hazards, HIV/AIDS prevention campaigns had to be integrated into existing or planned community approaches. All this resulted in a better balance between biomedical and development paradigms.
In 1996, with the advent of more effective treatments and optimism regarding vaccine development, the emphasis shifted from a balanced approach. The availability of treatment and hopes for an eventual vaccine meant for many public health workers that efforts to change human behaviour through complicated community interventions were a thing of the past. Governments could walk away from the challenges they had been facing to introduce drastic and social reforms. They could now claim that resource constraints on the purchase of drugs and scientific obstacles to developing safe and effective vaccines were the main limiting factors in their investment in HIV/AIDS work. This shift in the balance was expressed dramatically in 1996 in a lecture given by Jonathan Mann during the Eleventh International AIDS Conference, in Vancouver. In his talk, Mann shared his observation that the coalitions between the different stakeholders in the fight against HIV/AIDS were falling apart, and he pleaded for their revival.

The new imbalance resulted in increased demands for programmes based on the biomedical paradigm, for example, to prevent perinatal transmission and to reconsider the role of HIV testing in prevention. Although HIV testing does not appear to be effective in the primary prevention of HIV infection (19), and although protecting the identity of people who test positive for HIV was the cornerstone of HIV-testing policies, some now argue that the “secrecy” surrounding HIV testing and status should be done away with.

**Characteristics of the biomedical paradigm**

Processes similar to the competition between the biomedical and developmental paradigms have been observed with other health issues. The introduction of primary health care (PHC) and the discussion of vertical versus horizontal PHC and of selective versus comprehensive PHC that followed (20–23) demonstrate how the two paradigms compete. The discussion between family planning advocates and feminist reproductive health advocates turns on the same issues (15). The family planning programme “was a programme that medicalised fertility and the control of fertility, creating a new elite corps of biomedical scientists and demographers at the helm of population control” (24). On the other hand, the feminist paradigm can be compared with the concept of comprehensive PHC or the developmental paradigm in HIV prevention: the perspective of the people themselves and their communities should be decisive in directing the change that will take place. It is therefore important to look at the characteristics of the paradigms and the way they relate to people’s world view.

The biomedical paradigm fits within the philosophical perspective of logical positivism, in which a truth is assumed that is unchangeable and unrelated to human perception. Health is defined by scientists and by quantitative outputs rather than by people’s experiences. It gives those who measure health outputs control over those who experience health and well-being. The views of the latter become irrelevant, unless they can be translated into categories defined by biomedical scientists. There is a strong belief in progress and that science will find the technological means to control the embarrassing deficiencies in nature. The biomedical paradigm assumes that health has a priority over other human needs.

The biomedical paradigm gives priority to the individual over the context in which the individual lives: his family, community, environment, culture. Assigning individuals this priority places them in a vacuum. The biomedical paradigm fits in a neoliberal culture in which the market is seen as the organizing principle of society. Health is seen as a product, and developments in biomedical science are presented as a series of new products. In that sense, it is not surprising that the footnotes to the article by the EuroSIDA Study Group (1) acknowledge the support of grants from Pharmacia Upjohn, Glaxo-Wellcome, Roche, and Merck. This demonstrates a driving force in development of biomedicine.

In the biomedical paradigm the individual infected with HIV has to be identified. The idea is that individuals are infected as a result of their behaviour, and for this, they are personally responsible. In biomedicine one speaks of risk behaviour, and many researchers make the mistake of assuming that groups with risky behaviour can be easily identified: injecting drug users, sex workers, and so on. Initially, these were called “high-risk groups”, a concept challenged by critics of the biomedical paradigm because it compounds stigmatization. Isolating the individual from the realities in which his or her health is produced leads to a decontextualization for the benefit of medical science and epidemiology. This in turn engenders a travesty of reality, which unfortunately is often legitimized by the fact that the dehumanized, decultured, desocialized description of that reality was based on controlled scientific methods. In our research with sex workers in developing countries we have seen how inefficient epidemiological categories such as sex workers are (25, 26). Economic factors, education, employment possibilities, cultural beliefs, and gender differences are all important for understanding the fluent borders between women, the exchange (or not) of sex services for money or favours, how they are seen by themselves and others, and the consequences for their behaviour.

The assumption of the biomedical paradigm that individuals can influence their behaviour by making the correct choices and that providing the right education will make people change their behaviour is again closely linked to the idea that our society is organized through the principle of the market. In market philosophy individuals are con-
Characteristics of the development paradigm

In the development paradigm the emphasis is not on the individual and risk, but on society and vulnerability. Risk is a concept in which responsibility is placed on the individual, whereas using the term vulnerability emphasizes the conditions that create the risk and as such expresses a different view. Tarantola has defined vulnerability in the following terms (27): absolute (people are unprotected); relative (exposure to higher-than-average risks); epidemiological (exposure to higher risks of HIV infection); medical (inability to get optimal quality and level of care); human rights (exposure to discrimination); social (deprived of some or all social rights and services); economic (inability to offset risk of infection or access to care); and political (inability to get full representation or lacking political power). Plummer & Porter (28) write: “If people whose social practices are potentially harmful are also less powerful, they cannot be expected to take sole responsibility for their vulnerability. Their vulnerability is the result of a system constructed and regulated by the powerful. The powerful are invisible on the epidemiological map of HIV with our existing risk groups.”

Interventions based on the development paradigm therefore target communities, put emphasis on solidarity and empowerment, and try to improve the conditions in which people must survive. For instance, preventive interventions for injecting drug users should not be restricted to the development of harm reduction programmes but should focus also on pursuing an enabling environment, where harm reduction practices make sense. Another example is that programmes targeting sex workers should not only provide good STD services and condom promotion but also advocate for legislation that prevents harassment by clients and police, and focus on self-esteem and gender awareness of sex workers to give them more control over reproduction and sexuality. In the action research project CARAM-Asia (Co-ordination of Action Research on AIDS and Mobility), for instance, interventions focus on the vulnerability of documented as well as undocumented migrant workers. Their desire to adapt to another culture, their need to belong to new social networks, their loneliness, the exploitative situation in which many have to live (especially female migrants), and the lack of appropriate information in their own language make migrants vulnerable to STD and HIV infection, and they are often not in a situation to choose, as the biomedical paradigm assumes. Interventions based only on the decontextualizing medical paradigm may therefore not be very successful in developing countries.

The development paradigm has a broad scope, and its advocates argue that biomedical interventions should assume their proper place in the process of total development rather than make the development process subordinate to priorities identified by representatives of biomedicine.

An example: preventing perinatal HIV infection

That the two paradigms are in conflict with each other becomes clear when we look at programmes that try to provide zidovudine for HIV-infected pregnant women. Zidovudine is one of the few biomedical preventive interventions available, and programmes to distribute it are common in many developing countries. Treatment for an HIV-infected pregnant woman is something that can be financed in the framework of a donor-driven programme. Cheaper treatment with single-dose nevirapine has also become available (29, 30). An article published in the Lancet in 1999 reported data on the effectiveness of zidovudine in preventing perinatal HIV infection (31). The accompanying commentary (32) provided a list of requirements to implement effectively these regimens. Ironically, this list details everything we have not been able to realize in decades of development cooperation, including available and accessible antenatal care, a prerequisite for a successful programme to prevent perinatal HIV infection. It has proved practically impossible to reduce maternal mortality, provide full immunization coverage, abolish needless infant mortality due simply to dehydration from diarrhoea, and so on, armed only with biomedical interventions. Will it suddenly be different in the case of the HIV epidemic?

Apart from the obstacles to developing sustainable interventions because of the lack of infrastructure and financial resources, we are faced with other implications of preventing perinatal HIV infection with zidovudine. All pregnant women must be routinely tested to identify those whose offspring might benefit from zidovudine or nevirapine treatment. This involves more costs, but also skilled health care staff who can counsel pregnant women and take care of the psychological crisis that follows the instant a woman realizes she is HIV-infected. Knowing that she is HIV-infected is one stressor for a woman (33), but there is also a risk that as soon as the community finds out her HIV status, she will be discriminated against or even killed, as happened with Gugu Dlamani, the South African woman who
declared her status on World AIDS Day in December 1998. Such cases show that investment needs to be made in developing HIV/AIDS-tolerant societies, emphasizing that any member of the community can be infected, instead of isolating those who have been identified. Finally, the fact must also be taken into account that HIV infection may be prevented in the child, but the mother will probably die within a few years, and her husband as well. The child will become an orphan and thus a member of a group that is highly vulnerable to HIV infection owing to the lack of parental protection in societies with limited social support for the marginalized. Decosas has something to say about this: “Now that the big push is on to introduce short term antiretroviral therapy for pregnant women in Africa, we are suddenly seeing all the other missing bits of the response to AIDS. All the failures of health services to respond adequately to the epidemic are being exposed. Where are the counselling services? What happens to the mothers after they deliver? What about the fathers? What happens to the child once the mother dies? Where is the care for the sick and dying? etc.” (34)

What would be more fruitful would be to bring together the different stakeholders and to organize an open discussion about the conditions on which a programme to prevent perinatal HIV infection should be based. Women (both HIV-infected and noninfected), orphans, members of the community who care for orphans, local health care workers, and others at the grass-roots level should be invited to join in a priorities-setting process. That in itself is already a part of the methodology used in the development paradigm. The consensus statement on preventing perinatal HIV infection that was published in the Lancet (35) was drafted by 11 authors, only 1 of whom was from a developing country, during a workshop with 40 participants in attendance and only 7 from developing countries. Including only a few scientists from developing countries in a consensus meeting cannot be taken seriously as a process of equal dialogue and should not be seen as a credible voice (36).

Conclusion

Some of these practical and ethical issues may lead us to wonder what investment of funds, human resources, and time is most likely to yield a sustainable and long-term impact. This is especially important because biomedical interventions can be very costly, leaving little room for substantial funding of other preventive activities. All this is interesting in the light of the continuous lobbying by pharmaceutical companies and high-ranking US politicians in (for instance) South Africa to protest the decision by South Africa’s health minister not to administer zidovudine to pregnant women infected with HIV, owing to a lack of funds to support the programme at the provincial level (37). As a result, some US scientists were planning to boycott the Thirteenth World AIDS Conference, in Durban (South Africa), in 2000, a step HIV/AIDS researchers from developing countries viewed as arrogant, as indicated by their reactions expressed in Internet AIDS discussion networks.

In the meanwhile, the conflict appears to have been resolved. But it was a prime example of people locked up in their own paradigms, unable to look outside the world they know. In a market-oriented individualist culture where consumer choice is not a fiction and combination therapy is available, basing AIDS policies on the biomedical paradigm does not seem all that strange. However, in the context of the developing world the development paradigm merits more support from donors, international organizations, and researchers.

In that sense, experience in dealing with other health problems is a good teacher. Marshall & Hunt (38) write: “As with other development issues, HIV is about people’s control over their lives. Ultimately, it relies on people realising that their future lies in their own hands.” It would be worth while to consider ways of ensuring that people have control and then allowing them to choose among the options for dealing with the AIDS threat — condoms, abstinence, HIV tests, and zidovudine — instead of the other way around. Only then will they believe that their lives are valuable enough to make such choices.

Résumé

Paradigme biomédical et paradigme du développement dans la prévention du SIDA

Dans la lutte contre le virus de l’immunodéficience humaine/syndrome d’immunodéficience acquise (VIH/SIDA), on peut distinguer plusieurs approches reflétant des horizons professionnels, visions du monde et intérêts politiques différents. Il existe notamment une différence importante entre le paradigme biomédical et le paradigme du développement. Le paradigme biomédical se caractérise par l’accent mis sur l’individu et par la notion de « risque ». Cette dernière est liée à la notion de marché, selon laquelle la santé est un produit de services et le progrès une série de découvertes qui peuvent faire l’objet d’une promotion. Le paradigme biomédical privilégie l’individu par rapport à son contexte : famille, communauté, environnement et culture. La personne infectée par le VIH l’est devenue de par son comportement, et par conséquent la notion de comportement à risque ou de groupes à haut risque est très importante. Selon cette approche, l’individu peut influer sur son comportement en faisant des choix adéquats. En donnant une éducation sanitaire correcte, on fera changer les comportements.

Le paradigme du développement se caractérise par la participation de l’ensemble des partenaires et par le travail communautaire. Contrairement au paradigme
Resumen

Paradigmas biomédico y de desarrollo en la prevención del SIDA

En la lucha contra el virus de la inmunodeficiencia humana/síndrome de inmunodeficiencia adquirida (VIH/SIDA), se distinguen diferentes planteamientos que reflejan experiencias profesionales, cosmisiones e intereses políticos de diverso tipo. Es importante diferenciar el paradigma biomédico y el paradigma de desarrollo. El primero se caracteriza por la individualización y el concepto de «riesgo» y, a su vez, está relacionado con el concepto de mercado, ente en el que la salud es un producto de servicios, y el progreso una serie de nuevos descubrimientos que cabe impulsar. El paradigma biomédico concede mayor importancia a las personas que al contexto en el que viven: familia, comunidad, medio ambiente y cultura. Las personas infectadas por el VIH se han contagiado a causa de su comportamiento, por lo que el concepto de comportamiento de alto riesgo o de grupos de alto riesgo reviste gran importancia. En el paradigma biomédico las personas pueden influir en su comportamiento tomando las decisiones idóneas. Impartiendo a las personas la educación sanitaria apropiada se logrará que cambien de actitud.

El paradigma de desarrollo se caracteriza por la participación de las diferentes partes interesadas y el trabajo de la comunidad. A diferencia del paradigma biomédico, que considera a la persona responsable de su infección por su comportamiento de alto riesgo, el paradigma de desarrollo emplea el concepto de «vulnerabilidad». Algunas personas son más vulnerables que otras a la infección por el VIH debido a su situación desfavorable en la sociedad o comunidad a la que pertenecen, por problemas de acceso a la atención sanitaria preventiva, discriminación, aislamiento, imposibilidad de hablar sobre el uso de preservativos, etc. Se hace más énfasis en las iniciativas emprendidas para reducir esta vulnerabilidad, de diversas maneras sostenibles. La tecnología biomédica, por ejemplo el desarrollo de vacunas y medicinas, es sólo uno de los instrumentos de esas iniciativas.

Al comienzo de la pandemia de VIH/SIDA, el enfoque biomédico fue fundamental para descubrir el VIH y comprender su epidemiología. Debido a la falta de tratamiento o de vacunas, el paradigma de desarrollo adquirió más importancia y se alcanzó un mayor equilibrio entre los dos enfoques. Sin embargo, desde las primeras noticias sobre la eficacia de las terapias combinadas y las esperanzas de obtener una vacuna, el paradigma biomédico ha vuelto a reclamar su protagonismo en muchos de los programas de prevención del VIH/SIDA. Un ejemplo de este desplazamiento de un enfoque equilibrado a un enfoque principalmente biomédico es la reciente atención prestada a la prevención de la transmisión perinatal. La transmisión del VIH de madre a hijo puede evitarse en gran parte mediante un tratamiento relativamente breve. El ejemplo del suministro de zidovudina a las mujeres embarazadas infectadas por el VIH demuestra que los paradigmas de la biomedicina y el desarrollo pueden entrar en conflicto. La zidovudina es muy costosa y su empleo en el tratamiento de mujeres embarazadas infectadas por el VIH mengua los recursos que podrían invertirse en otras formas más económicas de tratamiento de relativamente breve duración permite d’empêcher dans de nombreux cas la transmission du VIH de la mère à l’enfant. L’exemple de la fourniture de zidovudine aux femmes enceintes infectées par le VIH montre que le paradigme biomédical et le paradigme du développement peuvent s’opposer. La zidovudine est très coûteuse et son utilisation chez les femmes enceintes infectées par le VIH consomme des ressources qui pourraient être utilisées pour d’autres formes de prévention du SIDA ayant un meilleur rapport coût/efficacité. De plus, elle exige un dépistage de masse des femmes enceintes, ce qui souleve par ailleurs des problemes pratiques et ethiques quant au conseil avant et après dépistage et au soutien aux familles infectees par le VIH. Le traitement par la zidovudine peut empêcher l’infection à VIH chez l’enfant, mais il y a de fortes chances que cet enfant devienne orphelin au bout de quelques années car le traitement est inaccessible, financièrement et pratique-ment, pour les parents.

Cet exemple montre la nécessité de trouver un meilleur équilibre entre ces deux paradigmes. Dans les pays en développement surtout, où il n’est pas réaliste de penser que des interventions biomédicales durables puissent être organisées à brève échéance, il serait contre-productif de fonder la lutte contre le VIH/SIDA exclusivement sur l’approche biomédicale.
prevención del SIDA. Por otra parte, requiere la realización masiva de pruebas entre las mujeres embarazadas, lo que también crea problemas prácticos y éticos en relación con el apoyo psicológico antes y después de la prueba, así como con el apoyo debido a las familias infectadas por el VIH. El tratamiento con zidovudina puede prevenir la infección por el VIH en los niños, pero es muy probable que estos niños queden huérfanos al cabo de algunos años, al no poder los padres conseguir o costearse el tratamiento contra el virus.

Este ejemplo demuestra que es preciso lograr un mayor equilibrio entre los dos paradigmas considerados. Sería contraproducente concentrar nuestros esfuerzos en hacer frente al VIH/SIDA empleando exclusivamente el enfoque biomédico, sobre todo en los países en desarrollo, donde la organización a corto plazo de intervenciones biomédicas sostenibles es impensable.

References