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Brazilian psychosocial and operational research vis-à-vis the UNGASS targets

ABSTRACT

Items from the UNGASS Draft Declaration of Commitment on HIV/AIDS (2001) are analyzed. The Brazilian experience of new methods for testing and counseling among vulnerable populations, preventive methods controlled by women, prevention, psychosocial support for people living with HIV/AIDS, and mother-child transmission, is discussed. These items were put into operation in the form of keywords, in systematic searches within the standard biomedicine databases, also including the subdivisions of the Web of Science relating to natural and social sciences. The Brazilian experience relating to testing and counseling strategies has been consolidated through the utilization of algorithms aimed at estimating incidence rates and identifying recently infected individuals, testing and counseling for pregnant women, and application of quick tests. The introduction of alternative methods and new technologies for collecting data from vulnerable populations has been allowing speedy monitoring of the epidemic. Psychosocial support assessments for people living with HIV/AIDS have gained impetus in Brazil, probably as a result of increased survival and quality of life among these individuals. Substantial advances in controlling mother-child transmission have been observed. This is one of the most important victories within the field of HIV/AIDS in Brazil, but deficiencies in prenatal care still constitute a challenge. With regard to prevention methods for women, Brazil has only shown a shy response. Widespread implementation of new technologies for data gathering and management depends on investments in infrastructure and professional skills acquisition.

KEYWORDS: Acquired immunodeficiency syndrome, prevention & control. Disease transmission, vertical. AIDS serodiagnosis, trends. Condoms. Condoms, females. Health education.

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INTRODUCTION

The present work complements the approach developed in a previous paper⁷ that analyzed certain items from the base document of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) giving targets for Science, Technology and Innovation relating to HIV/AIDS. The objective of the present paper was to discuss the Brazilian experience of new testing methods and counseling for particularly vulnerable populations (for instance, pregnant women); new technologies for data capture and management, especially regarding injectable drugs users; and multicenter studies. Publications on female preventive methods (microbicides and female condoms), prevention and psychosocial support for people living with HIV/AIDS and measures aimed at controlling mother-child HIV transmission were also assessed.

METHODOLOGICAL PROCEDURES

As detailed in the previous paper,⁷ the items listed were worked on as key words in systematic searches in standard biomedicine databases (MEDLINE and SciELO), and also included the Web of Science, in its subdivisions relating to Natural Sciences (SCI-Expanded) and Social Sciences (SSCI). Further details regarding the methodology and procedures utilized here can be found in the abovementioned article.

TESTING AND COUNSELING

Brazil has now accumulated wide-ranging experience in counseling and testing for HIV/AIDS, although very little of the knowledge initially acquired has been translated into *stricto sensu* papers. This is probably because of the pressure arising from the significant demand and the immediate need to provide an extensive infrastructure network of counseling and testing units. Professional training in the use of laboratory techniques was provided, as was training in the procedures needed for counseling, with capacitation relating to the ethical principles of respect for individuals' desire to be tested (or not) and protection of their confidentiality.

Nevertheless, over recent years, the Brazilian experience relating to new testing and counseling strategies has been consolidating in three areas: 1) use of testing algorithms with sensitive/less sensitive tests, with the aims of assessing the incidence of infection and identifying recently infected individuals; 2) testing and counseling for pregnant women; and 3) assessment and application of fast tests in different populations.

The Brazilian experience is very consistent with regard to estimating the incidence of infection and identifying recently infected individuals by means of testing algorithms that use sensitive and less sensitive tests. Originally called 'detuned assays' and more recently named the "STAHRS algorithm", this method has been applied to projects that recruit large samples coming from clinics^{1,24,34} or that form part of preparatory studies for behavioral and/or vaccinal interventions.⁶ Some studies have been using this methodology for dealing with more unapproachable populations, such as drug users.^{27,68,72}

In the light of the success of the protocol for the AIDS Clinical Trials Group, study 076 (ACTG 076), and subsequent developments in the prevention of mother-child HIV transmission, such prevention has today become an absolute priority in all countries. This protocol aims at making the strategies for testing, counseling and fast intervention as systematic and wide-ranging as possible. The objective is to reduce and, if possible, eliminate mother-child HIV transmission. From this perspective, it highlights the need to incorporate, maintain and test the greatest number of pregnant women possible within the context of regular antenatal care and, failing this, to use fast tests with the aim of providing backing for immediate intervention for women and babies around the time of birth.

A study by Marques et al⁴¹ (2002) identified deficiencies in the field of testing for HIV and counseling of pregnant women in reference centers in São Paulo. Subsequent studies, such as the study by Goldani et al²⁶ (2003), carried out in Porto Alegre, showed improvements in the patterns of testing and counseling in antenatal services, though there were differences between social classes, to the detriment of the less favored segments of the population. Further assessments, like the nationwide study by Souza Jr. et al⁶⁶ (2004), corroborated the regional findings of Goldani et al.²⁶ Both of these studies indicated class-related differences, with deficient coverage for the detection of HIV infection in women from poorer backgrounds, in addition to the regional differential, to the detriment of the poorer and less industrialized regions of the country.

Because of the deficiencies in testing and counseling for HIV/AIDS among pregnant women, different clinics have been implementing the strategy of using fast tests and immediate intervention among women who do not know their serological status until just before labor and delivery. The study by Nogueira et al⁵⁰ (2001) documents the successful implementation of a strategy consisting of fast testing, immediate coun-

seling and intervention in a reference maternity hospital in Rio de Janeiro.

More recently, systematic assessments of different types of fast tests²¹ have been started, with the aim of subsequent application not only to pregnant women but also to a variety of vulnerable and/or unapproachable populations.

METHODS CONTROLLED BY WOMEN AND MICROBICIDES

The use of vaginal microbicides for preventing the transmission of HIV and other STDs received a hard blow with the publication⁷³ of results from a clinical trial that assessed COL-1492, a gel based on nonoxynol-9. There have only been a few times in the history of interventions against HIV/AIDS that a strategy has been shown not only to be ineffective but also harmful if used improperly. Unfortunately, such improper conditions were very similar to the usual conditions observed in female populations under particular risk, such as sex professionals. Such findings drew attention to the possible harmful consequences of interventions in the field of microbicides and started a series of debates on the ethics of certain field studies on HIV/AIDS. In a particularly unfortunate coincidence, these findings came to light at the same time as some studies on mother-child HIV transmission in the sub-Saharan region of Africa with questionable ethical standards were being implemented.

Thus, the recent history of studies on microbicides has gone through its days of purgatory and, since then, there has been an oscillation between the essential need for such development and the difficulties in practical evaluation of such strategies through protocols that combine scientific consistency with respect for ethical principles.

There is a lack of Brazilian indexed literature in the international databases, with regard to new perspectives for substantial intervention using microbicides in human populations. The exception to this is in articles within the field of chemistry giving *in vitro* assessments of substance with antiretroviral and microbicide properties,^{4,55} and a series of papers on behavioral characteristics that are potentially linked to the adoption of vaginal microbicides for preventing HIV/AIDS and other STDs.^{28,29}

Brazil urgently needs to participate in the present debate on new alternatives for microbicides, and the good intentions of activists and researchers need to be transformed into effective protocols.

Brazilian publications on the female condom are equally rare in the indexed literature, although published data is frequently found in leaflets such as those issued by Family Health International, and therefore outside of the scope of the present review.

A study by Warren & Philpott⁷⁵ (2003) reviewed the inclusion of female condoms in the public policies of a large number of countries, including Brazil. A recent paper by Vieira et al⁷⁴ (2004) assessed the acceptability of male and female condoms according to women living with HIV/AIDS who were participating in an intervention project. This paper identified levels of acceptance of female condoms among women living with HIV/AIDS that were all in respects similar to their acceptance among women who were not infected by HIV.

A community intervention with the objective of reducing the vulnerability of women to STD/AIDS in São Paulo showed good acceptance and demand for female condoms in the community.²²

Despite the abovementioned publications, Brazil's participation in the world debate on the role of female condoms for the prevention of HIV/AIDS is still modest, in the context of indexed publications.

DATA CAPTURE AND MANAGEMENT REGARDING HIV/AIDS

Brazil's introduction into international protocols with wide coverage and complexity has led some centers of excellence to successfully implement modern methods of data collection, entry and management, instead of the traditional methods of manual digitization and assessment of the information collected.

Basically, the gains obtained can be divided along three lines. Firstly, some clinics have introduced strategies for data capture from visual information and analog-digital processing, followed by assessment and entry of the information into standard format digital databases. For example, this has been done through bringing into operation systems that utilize analog-digital conversion and are capable of processing immense volumes of data quickly, with small margins of error. In some data processing centers, such operations run in real time: the effective data entry in the database occurs practically simultaneously with its collection. This allows for almost immediate generation (via programming tools) of procedures and/or assessment reports on the digitized data. Likewise, other strategies for non-visual data capture have also been shown to be useful within systems with fast entry and immediate assessment of the information col-

lected, such as the use of web-based resources like “remote capture” systems, for example.

Technicalities aside, such modern resources for data management have been making it possible to answer basic questions within the field of multicenter studies that form part of regional and national databases. At the same time, access to antiretroviral drugs has been substantially expanding in developing countries. Although the expansion has been much less than foreseen by the World Health Organization/United Nations Joint Programme on HIV/AIDS (OMS/UNAIDS) (as stated in the aims of the “3 by 5” program*), it is relevant in that detailed and continuous monitoring has been required on a large scale and over a short timeframe. A recent study from an international research group that includes researchers from two Brazilian centers, attests to the need and factorability of such initiatives.¹⁴

Finally, alternative methods for data collection are being introduced among particularly vulnerable populations such as injectable drug users, among whom technical questions and the ethics of collecting and managing potentially embarrassing, stigmatizing and even incriminating questions are a challenge.⁶³ Recently, with support from the Ministry of Health and international institutes, projects using computerized data collection techniques were implemented, with integrated use of visual information (specially designed screens for interactive data collection) and auditive information. This is the Audio-Computer Assisted Interview (ACASI) method, which has been shown to be extremely useful, with good acceptance and consistent results.⁶²

The central question is no longer whether or not the implementation of these methods is feasible. Practical experience has shown that it is, even in non-academic units, as is the case with the introduction of the ACASI method into treatment centers for drug users. The question today is a matter of progressively integrating the country into international initiatives for expanding the access to antiretroviral medications and for quickly and accurately monitoring side effects and resistance (if possible, in real time). The utilization of such techniques needs to be disseminated among health units, whether they have academic links or not.

There are also immense challenges regarding funding, installation/renovation of infrastructure, and capacitation and training for health professionals. However, there is no other route towards modernity, qual-

ity and equality of access to preventive methods and excellence in treatment.

PREVENTION AND PSYCHOSOCIAL SUPPORT

The success of the so-called “Brazilian model” for HIV/AIDS obviously does not solely consist of its innovatory program for universal access to antiretroviral drugs. As correctly pointed out by Berkman et al⁸ (2005), one fundamental dimension of the Brazilian model is its commitment to prevention. These efforts have been especially successful because of their wide-ranging and diversified nature with regard to application proposals and strategies, and also because of the integrated nature of the model, in terms of dialogue and joint action between the State and civil society and between prevention and treatment.

To learn more from the analyses, the offer of psychosocial support for people living with HIV/AIDS and prevention that is said to be primary were analyzed separately. The offer of psychosocial support is a fundamental strategy for secondary prevention that gives rise to individual and collective results. On the other hand, primary prevention is directed towards uninfected people, with the aim of avoiding subsequent infection.

The question of evaluating the psychosocial support has become more prominent in recent Brazilian production, probably due to the significant increases in the length of survival and quality of life of people living with HIV/AIDS. Moreover, there has been pressure from funding bodies and regulatory agencies for all the practical experiences (so far, these have been dispersed) to be systematized. Even so, Brazilian production continues to be erratic, with predominance of small-scale interventions that are dispersed among different clinics and inadequately assessed.

With this aim in mind, one of the lines being explored is to assess the discordance between effective risk (translated as high prevalence of risky behavior and/or high rates of HIV infection) and (low) self-perception of the risk and delay (or even absence) of demand for specific care. In these circumstances, the opportunity to implement secondary preventive actions does not materialize, since the individuals at effective risk and/or already infected do not recognize that they are in this situation and do not demand preventive actions, support and specific care.^{23,65}

Insofar as people with HIV/AIDS live longer and enjoy better quality of life, questions arise that, although

*World Health Organization. The 3 by 5 initiative: treat three million people living with HIV/AIDS by 2005. Disponível em <http://www.who.int/3by5/en/> [acesso em 20 jan 2006]

not new, are presented in a complex and challenging manner. For example, there is the question of people living with HIV/AIDS adopting and maintaining protected sexual practices when their partners are serodiscordant, and also analysis of reproductive decisions by men, women and couples. The pioneering work on this subject was by Santos et al⁵⁸ (2002), which assessed the sexual practices and reproductive decisions of women living with HIV/AIDS. Following this work, other papers dealt with different aspects of the sexual and reproductive health of these people, such as the recent paper on paternity among men living with HIV/AIDS.⁵² There has also been a study dealing with women's decisions in relation to their history of contraception and interaction with their sexual partners,¹³ and another paper analyzing the influence of contextual variables (the predominant medical culture in different localities) on the reproductive decisions made by women living with HIV/AIDS.⁵ This last question was taken up again in a recent study from a complementary viewpoint.³¹

Another dimension of primary and secondary prevention that has still not been explored much in this country is the optimism associated with the use of the powerful therapy of Highly Active Antiretroviral Therapy (HAART). This optimism may be translated in carelessness in relation to personal risks (when the individual trivializes the HIV/AIDS question from information that is excessively optimistic regarding AIDS prognoses in the post-HAART era). It may also lead to collective risk, when individuals living with HIV/AIDS conclude that, because they feel physically and/or psychologically well or have obtained favorable results from laboratory tests, they do not have the potential for transmitting HIV to their partners. Such optimism causes substantial difficulties for prevention, because such individuals would be impervious to preventive measures, which they think of as old-fashioned and even useless. A research group at Fiocruz, in Rio de Janeiro, has been exploring these question in partnership with colleagues from international institutions, both from a qualitative perspective,³⁵ and with regard to the relativistic role of such optimism, by means of conceptual and mathematical modeling.^{9,10}

A recent paper has documented the influence of optimistic perceptions about AIDS on risky sexual practices among men who have sex with men (MSM), in São Paulo.¹² It is recommended that such pioneering studies are extended to other populations and contexts, given the central importance of this question for prevention in the post-HAART era.

Brazilian scientific production is consistent with regard to *stricto sensu* primary prevention of HIV in-

fection, even though it does not reflect the variety of preventive interventions that have been developed in the country over the last 25 years, in response to the epidemic. The reason why the interventions that have been brought into effect have not been mirrored in the number of publications seems to be the existence of significant barriers between the formulation and implementation of projects and the writing of scientific papers. This question has recently been discussed in an editorial in the Brazilian supplement of the journal *AIDS*.¹¹ On the other hand, it needs to be emphasized that Brazil lacks a culture of assessment in practically all fields of health interventions, and the research on HIV/AIDS is therefore no exception.

Albeit limited in extent, in relation to all other interventions carried out, it can be highlighted that some papers in the literature have reported on successful systematized interventions among specific populations like drug users,^{38,54} migrants,³⁶ prison populations,⁵⁶ female sex workers⁶⁴ and dock workers.³⁰

Several papers have dealt with prevention among young people, giving emphasis to interventions implemented in schools,^{2,3,17,39} using play-based teaching resources.^{59,61}

One question that Brazilian research has barely systematized is the role of violence as a barrier to the implementation of preventive interventions. Despite a large number of non-systematic reports on this question, only two papers dealing with this subject within the specific field of HIV/AIDS were located.^{57,67}

More recent papers have been focusing on post-exposure prophylaxis^{25,60} as a fundamental question. However, these contain controversial points regarding the side effects of the medications and their possible adverse impact on the adoption and maintenance of safer practices. The adverse impact arises because, in theory, individuals could always fall back on such emergence resources, meaning that even if they were not using regular protection, they would not be at the mercy of circumstances.

A vigorous conceptual discussion has supported the need to develop interventions beyond the individual and small group level, incorporating the contextual dimension and an attempt to transform risk contexts in a structured manner. The American anthropologist Richard Parker is one of the proponents of this set of strategies.⁵³

Some initiatives based upon concepts of structural and/or community intervention have been systematized in the recent Brazilian literature. The work by

Paiva et al⁵¹ (2002) documents the establishment of a cooperative network between non-governmental organizations and the academic community in São Paulo. Community interventions developed in shantytowns in São Paulo²² and Rio de Janeiro¹⁹ can also be highlighted.

MOTHER-CHILD TRANSMISSION

No field of HIV/AIDS research and intervention can be compared with the control of mother-child transmission in terms of its efficacy and effectiveness for avoiding HIV dissemination. In the vast majority of countries, including Brazil, the risk of HIV transmission secondary to blood transfusion has been reduced to nearly zero. Thus, pediatric AIDS has become practically synonymous with mother-child transmission, with the exception of rare cases resulting from sexual abuse of children by infected adults, for example.

Starting with the ACTG 076 protocol and its successive refinements and adaptations to specific contexts,⁷¹ mother-child transmission has ceased to be a strictly technical problem. It is more related to the availability of financial resources, infrastructure, ready offer of antiretroviral drugs and capacitation of health professionals. In contexts where such limitations do not exist, mother-child transmission is nearly nonexistent, like in Europe and the United States, except in a few specific subgroups such as women belonging to minority groups.⁴⁵

Brazil has advanced greatly in controlling mother-child transmission, but there is still much to be done, since this is an immense country with clear regional, social and health infrastructure inequalities. While avoiding repetition of what was stated earlier regarding the use of fast tests within the field of mother-child transmission, the main Brazilian studies in this field have been reviewed.

The first Brazilian studies relating to mother-child transmission preceded the adoption of measures from the ACTG 076 protocol and were about the risk factors for mother-child transmission during pregnancy, delivery period and breast-feeding.^{69,70} They also dealt with mathematical modeling of the impact of the mother's infection on HIV transmission at different times during the pregnancy, delivery and breast-feeding.¹⁸ Recent studies¹⁶ have refined previous analyses with regard to the risk factors for mother-child HIV transmission, incorporating analyses of the mothers' genetic-immunological profile.

Since the favorable results from the ACTG 076 protocol in relation to prophylaxis for mother-child HIV

transmission were published, there has been a succession of papers documenting the ability of Brazilian institutions to implement prophylactic measures aimed at preventing mother-child transmission. Nogueira et al⁴⁹ (2001) evaluated the implementation of an integrated program for preventing mother-child transmission in Rio de Janeiro.

Over recent years, several successful experiences have been reported in the literature, in different localities and institutions. Nevertheless, structural problems and patient retention difficulties persisted in some of the localities and health units analyzed. By way of example, the experience obtained at reference centers in Rio de Janeiro (RJ)^{32,33} and Campo Grande (MS)¹⁵ can be cited; likewise, the gains and losses in the programs for preventing mother-child transmission in the municipalities of Goytacazes (RJ)²⁰ and Vitória (ES),⁴⁴ and the relative success of programs developed in Santos (SP)⁴⁸ and Porto Alegre (RS).³⁷

On the whole there have been significant gains, particularly in reference centers and local networks that have the infrastructure available and fast procedures for referral and counter-referral. This makes it possible to minimize the usual problems posed by demand surpassing the ideal for antenatal care, patient drop-out from these clinics, and delays and deficiencies in testing and counseling. On the other hand, when the scope of the analysis is expanded to include municipalities that have a precarious health structure, the deficiencies in assistance and prevention increase greatly, although this is not in any way exclusively in relation to HIV/AIDS control.

A recent update report on prevention activities developed in São Paulo was encouraging: this is the richest state in Brazil and contains the largest number of AIDS cases in the country.⁴²

One of the fundamental components in assessing mother-child transmission at its interface with child healthcare and pediatrics is the correct diagnostic evaluation of infected and non-infected children. Such evaluations cannot be done by means of the usual serological tests, because of the presence of maternal antibodies. Brazil has managed to successfully implement the polymerase chain reaction (PCR) diagnostic technique in its reference units. Work developed in São Paulo attests to the good results from this.^{46,47}

Despite the success of prevention initiatives in Brazil, the country still has significant numbers of children living with HIV/AIDS who need to have the benefit from recent research and treatment findings for this particular population. Recent studies have as-

sessed the clinical and genotype profiles of children followed at a reference center⁴⁰ and systematized the measures needed for providing these children with an increased survival rate and better quality of life.⁴³

CONCLUSIONS

The main challenge in using of new methods for testing and counseling among particularly vulnerable populations is the adoption of strategies for their use and for immediate interventions among pregnant women. This is due to deficiencies in antenatal care, which present clear differences between regions and social classes. Nonetheless, the reduction in mother-child transmission around the world and in Brazil today represents one of the most important victories among the initiatives within the field of HIV/AIDS research and prevention.

With regard to prevention methods controlled by women, such as female condoms and vaginal microbicides, Brazilian scientific production is still modest, judging by the production in indexed journals. This probably reflects, in the case of female condoms, questions relating to the cost of their adoption (and respective assessment) on a large scale; and in the case of microbicides, ethical dilemmas and operational difficulties, which have been observed all over the world.

New techniques for data capture and management

that are already in use in centers of excellence have enabled real-time monitoring of the epidemic (epidemiological surveillance and monitoring of viral resistance, among others). Nevertheless, this initiative depends on investments in infrastructure and professional capacitation.

The advances and innovations in science and technology in Brazil relating to the HIV/AIDS pandemic, as well as the scientific findings and the practical results, must be discussed within a global perspective. They must allow the establishment of parallels and contrasts in relation to initiatives being developed within other contexts, thus broadening the assessment of the UNGASS targets and forming the basis for comparative evaluations.

Apart from the obvious differences in scale and approach between science and technology in the United States and Europe and in developing countries, Brazilian production can be seen to be concentrated in "islands of excellence". There is an urgent need to minimize the asymmetries and inequalities between the economies and societies that are and are not players within the field of Science, Technology and Innovation, and between the many unequal "Brazils" that constitute our country. The objective is not only to bring science into step with the needs of a large proportion of the world's population, but to work towards a less unequal and unjust world.

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