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Orphans and vulnerable children affected by HIV/ AIDS in Brazil: where do we stand and where are we heading?

ABSTRACT

This study aimed at identifying human rights' status and situation, as expressed in the United Nations General Assembly Special Session on HIV/AIDS, of children and adolescents living with HIV/AIDS, non-orphans and orphans affected by AIDS, based on local and international literature review. The main study findings did not allow to accurately estimating those children and adolescents living with HIV and non-orphans affected by HIV/AIDS but data was available on those living with AIDS and orphans. The limitations and possibilities of these estimates obtained from surveillance systems, mathematical models and surveys are discussed. Though studies in literature are still quite scarce, there is indication of compromise of several rights such as health, education, housing, nutrition, nondiscrimination, and physical and mental integrity. Brazil still needs to advance to meet further needs of those orphaned and vulnerable children. Its response so far has been limited to providing health care to those children and adolescents living with HIV/AIDS, preventing mother-to-child HIV transmission and financing the implementation and maintenance of support homes (shelters according to Child and Adolescent Bill of Rights) for those infected and affected by HIV/AIDS, either orphans or not. These actions are not enough to ensure a supportive environment for children and adolescents orphaned, infected or affected by HIV/AIDS. It is proposed ways for Brazil to develop and improve databases to respond to these challenges.

KEYWORDS: HIV. Acquired immunodeficiency syndrome. Child. Adolescent. Child advocacy. Human rights. United Nations. Vulnerability and health. Orphanages.

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Table 1 - UNGASS targets for orphans and other children made vulnerable by HIV/AIDS.

Target number	UNGASS targets
65	By 2003, develop and by 2005 implement national policies and strategies to: build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS including by providing appropriate counseling and psychosocial support; ensuring their enrollment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;
66	Ensure nondiscrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV/AIDS;
67	Urge the international community, particularly donor countries, civil society, as well as the private sector to complement effectively national programs to support programs for children orphaned or made vulnerable by HIV/AIDS in affected regions, in countries at high risk and to direct special assistance to sub-Saharan Africa.

INTRODUCTION

The AIDS epidemic has an impact on the quality of life of children and adolescents who can suffer successive losses and be deprived of their parents, occasionally of their relatives, and of their own health. AIDS orphans have increased risk of malnutrition when compared to those children living with their parents, and they can be stigmatized and discriminated because of their or their parents' HIV status, among other unfavorable events.[6,7,11,14,15,*]

As for June 2005, 371,827 AIDS cases have been reported in Brazil according to the National Program for STD/AIDS. AIDS cases and deaths still constitute serious social and health urgency as, since the beginning of the epidemic, about one in every two affected people (46.2%) died.[4] A household survey conducted in Porto Alegre, Southern Brazil, found in the population studied that, of every 10 people who died between 1998 and 2002, 8.8 were orphans.[2]

A study carried out in the cities of São Paulo and Santos among adolescents living with HIV/AIDS, some of them AIDS orphans, reported that, because of fear of stigma and discrimination, they put off knowing their HIV status and disclosing it to other people. These factors have an impact on their access to healthcare and on other spheres of their emotional, sexual, social, and educational lives, increasing their isolation and vulnerability to AIDS and violating other human rights[1] as well. Other studies in the city of São Paulo showed AIDS orphans, especially those living with HIV, have to live with several restrictions of their rights to health, education, nutrition, privacy, sexuality, and reproduction.* These all constitute violations of the rights established by Article 92 of the Child and Adolescent Bill of Rights.[3]

The United Nations has issued, in 2001, during the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), a Declaration of Commitment on HIV/AIDS defining targets and indicators for implementing national programs and establishing systematic evaluation and monitoring of HIV/AIDS epidemic.**,*** The UNGASS Declaration includes a special section on children and adolescents orphaned and those vulnerable by HIV/AIDS. Brazil has endorsed the UNGASS Declaration that same year.

Global human rights documents need to be examined as to whom are the *subjects of rights* they are referring to. Based on the definition of these subjects there will be drawn a set of rights and obligations for their relationship with the State and other social actors. It is understood that the UNGASS Declaration referred to any child and adolescent aged between zero and 18 years, in the terms of the UN Convention on the Rights of the Child,**** who has been affected, directly or indirectly through their parents or caretakers, by the epidemic at any of its stages: infection, disease, or death. According to UNGASS terminology, children and adolescents were grouped as: (1) *those living with HIV/AIDS* (infected or diseased), orphaned or not; (2) *affected non-orphans* (those living with and relying on adults, parents or caretakers infected by HIV or having AIDS disease); and (3) *affected orphans* (those who lost a parent affected by AIDS), infected or not.

The UNGASS Declaration defines several building blocks of a supportive environment for children and adolescents (Table 1).

The present study had the purpose of describing the magnitude and status, as expressed in the UNGASS Declaration, of several human rights of children and adolescents living with HIV/AIDS, affected non-or-

*Dados inéditos.
**United Nations (UN). Declaração de compromisso sobre o VIH/SIDA. Sessão extraordinária da Assembléia Geral das Nações Unidas, 25-27 de junho de 2001. Disponível em: http://data.unAids.org/publications/irc-pub03/Aidsdeclaration_pt.pdf [acesso em 1 mar 2006]
***United Nations (UN). Monitoring the declaration of commitment on HIV/AIDS - Guidelines on construction of core indicators, 2005. Disponível em: http://data.unAids.org/publications/irc-pub06/jc1126-constrcoreindic-ungass_en.pdf [acesso em 1 mar 2006]
****United Nations. Convention on the Rights of the Child. Washington (DC): 1990. Disponível em: http://www.unhchr.ch/html/menu3/b/k2crc.htm [acesso em 1 mar 2006]

Table 2 - Supportive environment and human rights of orphaned and other children made vulnerable by HIV/AIDS.

tems for a supportive environment	Constitutional rights
Psychosocial counseling and support,	Right to health*
Ensure enrollment in school,	Right to education**
Access to shelter,	Right to housing***
Good nutrition and	Right to nutrition****
Nondiscriminative access of those infected and affected to social services,	Right to nondiscrimination*****
Protection of orphaned and children made vulnerable to all forms of abuse, violence, exploitation, trafficking	Right to physical and mental integrity******
Loss of succession rights	Right to inheritance*******

*Article 196 of the Brazilian Constitution
**Article 205 of the Brazilian Constitution
***Article 6 of the Brazilian Constitution
****Article 227 of the Brazilian Constitution
*****Article 3 of the Brazilian Constitution
******Article 227 of the Brazilian Constitution
*******Article 5 of the Brazilian Constitution

phans and AIDS orphans in Brazil based on local and international literature review.

METHODOLOGICAL PROCEEDINGS

Data was obtained from MEDLINE and Scholar Google databases. Although searches were not conducted for specific time periods, publications starting from 1980, in any language, were included in the study. Other texts, abstracts and articles from sources other than these databases were included based on the authors' expertise.

From studies estimating the size of these populations, it was sought to concisely reconstruct their methods and results to assess their feasibility and limitations. In regard to rights, studies identifying human rights established in the 1988 Brazilian Constitution and the Child and Adolescent Bill of Rights (ECA),[3] related to paragraphs 65 and 66 of UNGASS Declaration (Table 2), were examined.

RIGHTS OF CHILDREN AND ADOLESCENTS LIVING WITH HIV

How many are there in Brazil living with HIV, affected non-orphans, and orphans by AIDS? And what is their human rights status?

These are the questions still need to be answered.

For those living with HIV/AIDS, data is available on AIDS cases but not on HIV-infected individuals.

The latest issue of the National Program for STD/AIDS Bulletin reported that, in the period 1980–2005, 10,404 AIDS cases were notified in children under five, 3,905 cases in those aged five to 12 years, and 8,075 in those aged 13 to 19 years.[4] Since the disease peaked in 1997 (926 cases) and 1998 (943 cases), there has been fewer case reports of children under five. However, a growing number of cases of children (5-12 years) and adolescents (13-19 years) have been reported since 2002. Incidence rates show similar trends to those of absolute cases. The reduction of cases in children under five is mostly due to advances in prevention of mother-to-child HIV transmission[12] while declining absolute cases can be explained by more children and adolescents surviving HIV/AIDS as a result of universal free access to antiretroviral therapy.[12]

Qualitative studies have brought to light accounts of adolescents living with AIDS and caretakers on their troublesome condition regarding their rights to health, education, and physical and mental integrity, all included in the UNGASS Declaration and documented by Ayres et al[1] (2006). The right to nutrition has been denied to some orphans infected and affected by AIDS. Their realities are pervaded by stigma and discrimination.

As for those affected non-orphans, there is a single study conducted by the Global Orphan Project/ Instituto Promundo, supported by the United Nations Children's Fund (UNICEF).[5] A mathematical model was applied at three different stages of risk (children living with AIDS mothers, children living with HIV mothers and AIDS orphans). The following variables were used for AIDS mothers: number of women living with AIDS, number of children of mothers living with AIDS and adjusted to AIDS infant and child mortality. As of August 1997, there were 57,600 children of mothers living with AIDS.

At the second stage of the model, the following variables were used for women living with HIV: number of women living with HIV, estimated number of asymptomatic women living with HIV, number of children of asymptomatic mothers living with HIV and adjusted to overall infant and child AIDS mortality. A total of 136,650 children of HIV-infected mothers[5] were estimated.

Although this model included several correction factors, such as delays in case reporting and underreporting, there are limitations in the study. The potential biases are attributable to the fact that this study was carried out before antiretroviral therapy was avail-

able when little was known on the reproductive life of those women infected. The two major limitations were that those women deceased were not subtracted from the study population and the use of fecundity rates similar to the general female population. Both biases would imply in overestimation of the number of children affected by their mothers' HIV status and clinical condition.

There were not found studies considering the rights of affected non-orphans.

RIGHTS OF CHILDREN AND ADOLESCENTS ORPHANED BY AIDS

In regard to *AIDS orphans* in Brazil, there are available three estimates based on mathematical models and a household survey carried out in a state capital.

To evaluate the impacts of orphanhood, a first study was developed by Global Orphan Project/*Instituto Promundo*.[5] The variables used to estimate the number of orphans were number of women who died from AIDS and number of children born to mothers who died from AIDS adjusted to infant and child AIDS mortality. It was estimated 15,900 children under 15 of mothers who died from AIDS as of August 1997. It was also predicted there would be 27,000 orphans by the year 2002[4]. While Fontes et al[5] (1998) corrected death underreporting in their study modeling, potential overestimation occurred because fecundity rates were assumed to be similar to the general female population.[9]

Two years later, Szwarcwald et al[16] (2000), also using a mathematical model, estimated that 30,000 Brazilian children under 15 would have been orphaned by their mothers dying from AIDS in the period 1987 to 1999. Their model was based on multiplying the accumulated fecundity rate for the study period by the number of deaths from AIDS among women aged 15 to 49 years, corrected by the likelihood of child survival between five and nine years of age. This study estimated that, in 1999, 5,500 children would have been orphaned by their mothers dying from AIDS.

There are two potential biases in this model: use of uncorrected fecundity rates of general female population and use of expected perinatal mortality of 90% of HIV-infected children. This expected mortality was already declining as a result of universal access to antiretrovirals since 1996. It should be noted that these factors take effect in opposite directions but key factors for estimating the number of orphans are the number of women who died and their fecundity rates.[8] Thus potential overestimation was likely in this model.

The third model studied was developed by the Jointed United Nations Programme on HIV/AIDS (UNAIDS), UNICEF and the United States Agency for International Development (USAID).* On the first edition of Children on the Brink (2002), 127,000 AIDS orphans were estimated in Brazil in 2001, where 34,000 would be maternal and 100,000 paternal orphans. This estimate is slightly higher than those previously projected. A more complex model was used including the following variables: estimated AIDS mortality based on the North Princeton mortality charts, fecundity rates adjusted to less than 20% of the original rates for female population and the likelihood of those HIV-infected children surviving up to 15 years of age.[8]

This model has also potential biases. The number of deaths was obtained from an estimate assuming a median survival time of nine years (8.6 years for men and 9.4 for women) after clinically diagnosing AIDS. In Brazil, the estimate of 9-year survival seems to be very short. It is well documented the dissociation between AIDS prevalence and mortality rates attributed to a government program of universal free access to medical care.[10] The number of orphans declines as women survival increases so their children are able to live beyond 15 years of age.

Another potential bias is the estimate of fecundity rates lower than 20% in local epidemics. Actual fecundity rates of Brazilian women living with HIV/AIDS are unknown. Grassly et al[8] (2004) state that 50% decrease in fecundity rates would dramatically reduce the estimated number of orphans. These factors suggest an overestimated number of orphans. At last, adjusting child mortality in a scenario of free access to AIDS therapy should be reviewed because it points out to the opposite direction showing an increased number of orphans living with AIDS.[13]

In fact, on the second edition of Children on the Brink (2004), UNAIDS, UNICEF and USAID stated there would be no estimates of AIDS orphans in Brazil, among others.* They first alleged that these would be low prevalence epidemics and a significant number of cases would come from groups such as intravenous drug users and men having sex with men with unknown fecundity rates, resulting in a low accuracy model.

While these estimates have been obtained using different methodology at different time periods, they

*UNAIDS, UNICEF & USAID. Children on the Brink 2004: A Joint Reporter on Orphan Estimates and Program Strategies. New York: UNICEF, July 2004. Disponível em http://www.unicef.org/publications/index_22212.html [acesso em 1 mar 2006]

seem to be consistent ranging from 30,000 (1999),[16] 34,000 (2001)* to 27,000 (2002)[5] maternal orphans.

All indications are that to know the number of orphans in Brazil hereafter estimates should be based on more updated and refined mathematical models including data on adult and child mortality and fecundity rates or actual population counts through surveys. Surveys are explicitly recommended in the UNGASS report on indicators.**

Doring et al[2] (2005) conducted the first population-based survey on AIDS orphanhood in the city of Porto Alegre, Southern Brazil, and were able to locate the address of 80% of all deceased (n=1,616) between 1998 and 2001. Of 1,294 people found, 43.4% (n=562) were survived by 1,131 children under 15 years. For every group of 10 deceased found in the study there were about 8.8 orphans.

Population-based surveys in Brazil based on mortality data have major limitations: differential underreporting of AIDS deaths; great geographical mobility, especially of poor families affected by AIDS deaths; and difficulty in localizing children sheltered in institutions or living on the streets.

By extrapolating Doring et al[2] (2005) findings, 42,876 deaths reported in Brazil between 1998 and 2001 would have resulted in 37,474 children orphaned by AIDS, about 50% (18,846) of them maternal orphans. This extrapolation should be carefully considered since different Brazilian regions have distinctive demographic characteristics and HIV/AIDS epidemic profile.

With regard to human rights, Doring et al[2] (2005) have interestingly found relatively low institutionalization rate of orphans (5%) (in opposition to the rights to shelter and family life) in Porto Alegre. But the associated factors identified (HIV-infected 4.6 x; maternal loss 5.9 x; or both 3.7 x; child born to a non-white mother 4 x) show persisting stigma and discrimination associated to HIV status, gender, and race.

Marques et al*** (2004) evaluated income transfer programs and general aid to those living with HIV/AIDS and their orphans in three Brazilian municipalities. They identified isolated initiatives for improving life conditions of those at risk or vulnerable, especially those below the line of poverty, that could be extended to those living with HIV/AIDS. But they would need to be adjusted to this population and they lie far from reaching all those affected. Income can be either a facilitating or hindering factor of access to rights such as education, shelter, and nutrition.

FINAL CONSIDERATIONS

As mentioned before, studies in the literature on children and adolescents infected and affected by HIV/AIDS disease or death are still scarce and studies on human rights are even rarer. Global consensus as expressed in the UNGASS allow investigators to focus their research in collaboration with local and international scientific communities and consistent with potential public programs.

There is thus a need to develop initiatives that will help to build up in the coming years a monitoring system of children and adolescents infected and affected by HIV/AIDS epidemic.

Hence it would be valuable *to adjust* and/or *create* information systems to provide data on those infected and affected (orphaned or not) by the epidemic and their social condition. Information confidentiality should be further reassured since AIDS deaths are a sensitive issue and could give rise to violations of rights such as privacy and dignity among others.

With respect to *adjusting*, epidemiological reporting forms and death certificates, which are filled out in health services, could be redesigned to include other information fields such as number, age, and degree of kinship of children and adolescents related to the index-case (who is either infected, diseased or died). This will require convincing health information system managers on the usefulness of monitoring those affected (orphaned or not) by the epidemic.

Within the National Program for STD/AIDS, orphanhood-related concerns could be included in standard studies on draftees and sexual behavior.**** Ethical concerns should be reinforced in these initiatives.

Additionally, it could be suggested to the Brazilian Institute of Statistics and Geography (IBGE) the inclusion of specific information fields to identify deaths occurring at home (name, date of birth, date and cause of death) and any related children and ado-

*UNAIDS, UNICEF & USAID. Children on the Brink 2002: A Joint Reporter on Orphan Estimates and Program Strategies. New York: UNICEF, 2002. disponível em http://www.unicef.org/publications/index_4378.html [acesso em 1 mar 2006]
**United Nations (UN). Monitoring the declaration of commitment on HIV/AIDS - Guidelines on construction of core indicators, 2005. Disponível em http://data.unaids.org/publications/irc-pub06/jc1126-constrcoreindic-ungass_en.pdf [acesso em 1 mar 2006]
***Marques RM, Mendes A, Maksud I, Hutz A. Pensando propostas de extensão às pessoas que vivem com HIV/AIDS e seus órfãos. 2004. Disponível em http://www.aids.gov.br/final/dh/extencao_servico.doc [acesso em 1 mar 2006].
****Ministério da Saúde. Relatório: conscritos do exército do Brasil, 2002. Elaborado por Célia Landmann Szwarcwald. Brasília (DF); 2003.

lescents (number, age, and degree of kinship with the deceased, covering the previous 12 months). IBGE census, population counts and surveys, such as the National Household Sample Survey (PNAD), can all be potential sources of information on orphanhood magnitude and profile. This will definitely require even more exhaustive discussions and technical definitions. Another proposal is to draw on school census but being careful for not exposing school children and adolescents orphaned by AIDS to further stigma and discrimination.

As for *creating* new sources of information, the Ministry of Health, via National Program for STD/AIDS, could reasonably implement a compulsory reporting system of HIV infection, which can provide data to assess the magnitude of HIV infection among children and adolescents. This new system could also provide information on any children and adolescents related to HIV-infected adults (number, age, and degree of kinship with those living with HIV). This has been considered a controversial proposal in collective health. The United States has adopted a confidential name-based HIV infection reporting system since 1994, and valuable lessons can be learned from the American experience.*

Civil registries, where death certificates are registered, are another potential source of information on orphanhood since surviving children are inventoried for testamentary purposes. Regretfully this information has not been much used as these registries are hardly accessible in Brazil due to scattered notary offices controlled by judiciary authorities. These obstacles can be overcome unless other social actors, such as judges, notaries, among others, would be involved.

Creating new or adjusting existing information sources could offer data on the magnitude of children and adolescents affected, directly or indirectly, by HIV/AIDS infection, disease or death in Brazil. However, there is a need of further information to evaluate whether specific targets, as listed in Table 2, are being achieved or not. For that, periodical population-based surveys to thoroughly measure life conditions and human rights status of those infected and affected would be paramount. These initiatives could develop by the Brazilian Ministry of Health in collaboration with research support agencies.

With respect to the paucity of data on human rights of those children orphaned or affected by HIV, the Brazilian government recognizes the limited outreach of public policies on this matter. The answer given by the Brazilian government in a 2002 report in reply to the UNGASS proposed question, "Are there any programs or strategies targeting the additional needs of those orphaned and other vulnerable children?" corroborates this finding: "Support homes for those children affected by HIV/AIDS; availability of milk formula to those children exposed to mother-to-child HIV transmission; intervention programs targeting children living on the streets and imprisoned adolescents".**

In conclusion, despite its limitations, the present study indicates the need for creating mechanisms for more properly assessing the magnitude of children orphaned or affected by HIV/AIDS epidemic and relevant conditions for their adequate care. On the other hand, it should be noted an existing concern for promoting, protecting, and respecting human rights although actions taken to control the impact of the epidemic on children and adolescents are to date limited.

The agenda on human rights proposed by UNGASS for creating a supportive environment is extensive (Table 2). Overall, the literature review made possible to document the existing wide gap. The required programs and strategies to actually exercise the concerned rights and monitor their status have not been implemented yet. There is still more to know and much to do in Brazil.

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*Center for Disease Control and Prevention. Statistics and Surveillance, 2006. Disponível em http://www.cdc.gov/hiv/topics/surveillance/index.htm [acesso em 1 mar 2006]

**Brasil. Follow-up to the Declaration of Commitment on HIV/AIDS (UNGASS) Brazil Reporting period: January-December 2002. Disponível em http://data.unaids.org/Topics/UNGASS2003/Americas/Brazil_UNGASSreport_2003-2_en.pdf [acesso em 1 mar 2006]

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