

# Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil

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Available online 15 August 2005

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## Abstract

This study describes and conceptualizes the experiences of stigma in a group of children living with HIV in São Paulo, Brazil, and evaluates the impact of access to highly active antiretroviral therapy (HAART) over the social course of AIDS and over the children's experiences of stigma. Through ethnographic research in São Paulo from 1999 to 2001, the life trajectories of 50 children ages 1–15 living with or affected by HIV were studied. Data were collected via participant observation and semi-structured informal interviews and analyzed using social theories on illness experience and social inequality. Our results demonstrate that AIDS-related stigma occurs within complex discrimination processes that change as children reach adolescence. We found that structural violence in the forms of poverty, racism, and inequalities in social status, gender, and age fuels children's experiences of stigma. We also describe how access to HAART changes the lived experience of children, reduces stigma, and brings new challenges in AIDS care such as adolescents' sexuality and treatment adherence. Based on these results, we propose structural violence as the framework to study stigma and argue that interventions to reduce stigma that solely target the perception and attitudes toward people living with HIV are limited. In contrast universal access to HAART in Brazil is a powerful intervention that reduces stigma, in that it transforms AIDS from a debilitating and fatal disease to a chronic and manageable one, belongs to a broader mechanism to assure citizens' rights, and reduces social inequalities in access to health care.

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*Keywords:* Brazil; HIV/AIDS; Stigma; HAART; Structural violence; Children and adolescents

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## Introduction

Despite global efforts to reduce and eliminate AIDS-related stigma and discrimination (UNAIDS, 2002a), stigma continues to be extremely common around the world with an increasing number of countries reporting discrimination against people living with HIV (de Bruyn, 2002). It has been argued that AIDS-related stigma and discrimination substantially interfere with

prevention efforts and discourage people from safe sex practices, care-seeking behavior, or finding a diagnosis (Brown, Macintyre, & Trujillo, 2003; de Bruyn, 2002; Fortenberry et al., 2002; Herek, Capitano, & Widaman, 2002; Herek et al., 1998; Valdiserri, 2002); or that stigma compromises the quality of care provided to people living with HIV, their partners, and communities (Brown et al., 2003; Herek et al., 1998). Via larger discriminatory processes, AIDS-related stigma results in negative outcomes in the forms of violations of social, economic, and political rights, including access to health care (de Bruyn, 2002; Herek et al., 1998; Malcolm et al., 1998; Parker & Aggleton, 2003).

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Interventions to reduce AIDS-related stigma have produced mixed results, ranging from seemingly successful strategies that increase people's tolerance toward people living with HIV to short term effects on people's attitudes and ineffective strategies (Brown et al., 2003). One study even reported how an educational program that reduced negative attitudes toward people living with HIV in a South African high school also led to the rumor that the students and teachers at that school had AIDS, causing much distress (Kuhn, Steinberg, & Mathews, 1994). The conflicting results of that study might indicate that some interventions can both reduce and enhance stigma. New theories and research that help us understand the complex individual and social interrelatedness of stigma are desperately needed.

Research on AIDS-related stigma in Brazil is of particular relevance given that its response to its large AIDS epidemic is a leading world example that integrates prevention with comprehensive treatment (Parker, Galvão, & Bessa, 1999; Piot & Coll Seck, 2001; Reardon, 2002). During the 1995–2000 period, Brazil prevented around 600,000 new infections and stabilized the rate of infection at a 0.7 percent level contrary to mid-1990s predictions (Ministério da Saúde, 2001; Ministry of Health of Brazil, 2002; Piot & Coll Seck, 2001; Reardon, 2002; UNAIDS, 2002b). At the clinical level, Brazil's largest success is its AIDS drug policy, which provides universal and free access to medications and medical care within the public health system (Galvão, 2001, 2002; Ministry of Health of Brazil, 2001, 2002). Since 1996, when highly active antiretroviral therapy (HAART) was first introduced in Brazil, mortality rates dropped by 50 percent, hospital admissions by AIDS patients by 80 percent, and treatment of opportunistic infections by 60–80 percent (Ministry of Health of Brazil, 2002). As a result, Brazil has replaced more expensive hospital-based care with less expensive ambulatory-based care, further improving survival and quality of life and saving millions of dollars in projected health care expenditures (Ministry of Health of Brazil, 2001, 2002; Piot & Coll Seck, 2001; Reardon, 2002). Largely due to the successful Brazilian experience, universal access to HAART is considered essential for scaling up health-care systems in Latin America and the Caribbean (Castro et al., 2003).

Fundamental to these results has been a large social movement (Abadía-Barrero, 2003) characterized by a strong public political commitment through its AIDS National Program (Ministry of Health of Brazil, 2002) and by the many partnerships and social support networks for people living with or affected by HIV (Galvão, 1997, 2000, 2001; Ministry of Health of Brazil, 2002; Paiva, Ayres, Buchalla, & Hearst, 2002; Parker, 1997; Parker et al., 1999; Teixeira, Paiva, & Shimma, 2000). Brazil demonstrated that a universal and comprehensive prevention and treatment approach is the

only adequate strategy to face the epidemic in humanitarian and economic terms, and that the high pricing of the life-saving antiretrovirals set by private pharmaceutical companies is the greatest threat to successful local and global responses to AIDS (Abadía-Barrero, 2003).

Studies in Haiti reported that access to HAART led to more people seeking medical care, all of which has decreased AIDS-related stigma (Castro & Farmer, 2005; Castro, Léandre, Raymonville, & Farmer, 2004; Farmer et al., 2001). After the introduction of HAART in Brazil in 1996, a 40 percent increase in newly reported AIDS cases was noted, due to both improvements in the notification system and people seeking medical care once therapy became available (Galvão, 2001). However, while access to HAART reduces care-seeking related stigma, other sources of stigma, associated mostly with poverty, sexism, and racism, limit some of the scope of both treatment and prevention of HIV.

It has been documented that the lived experience of Brazilian women living with HIV is filled with multiple sources of distress that are not limited to sickness episodes, AIDS treatment, or AIDS-related discrimination (Tunala, 2002). Even though Brazilian women who live with AIDS have their right to health care respected, they still face important discrimination when it comes to negotiate their sexuality, find and keep a job, and care for their family members (Barbosa & Parker, 1999). In one study, 46 percent of the interviewed women were unemployed and their lack of resources impeded them from obtaining good nutrition, pay their bills, and care for their families (Tunala, 2002). These studies show how power—through a complex amalgam of emotional, economic, and illness-related factors—plays a role in the women's experiences of distress and discrimination (Barbosa & Parker, 1999; Tunala, 2002).

Notwithstanding, Brazilian men living with HIV may experience more discrimination from providers than women when expressing their desires to become parents. One study conducted in São Paulo showed that men living with HIV report how providers either pay little attention or do not support their wish to become fathers and offer them considerably less information about treatment options on how to protect their future children from HIV than what is offered to women living with HIV who express their desire to become mothers (Paiva, Filipe, Santos, Lima, & Segurado, 2003). The study concludes that even though providers have ethical and legal responsibilities to promote and protect reproductive rights of both men and women, providers are more sympathetic to women's desires to become mothers even though men in this study report to have more sexual relationships and more desires to have children than women. Thus, the study exhibits a kind of AIDS-related discrimination coming from the providers and targeting men. Studies such as these not only underline the importance of gender in the different

experiences of stigma in Brazil, but they also suggest that stigma comprises a complex web of affective, institutional, and social forces that produce distress and other consequences detrimental to the person's well-being.

To our knowledge, no study has examined the relationship between access to HAART and the experiences of stigma in children. Brazilian children have also suffered from AIDS-related stigma, such as being denied their right to education (Galvão, 2000; Tunala, 2002). We believe, however, that their experiences of stigma and discrimination have been transformed by Brazil's extensive social support networks. When children are abandoned or become orphaned by AIDS, non-governmental organizations (NGOs) not only bring them to medical visits for comprehensive medical care, which includes HAART, but also provide shelter, food, and out of hospital medical care (Abadía-Barrero, 2002a). Nonetheless, considering the profound levels of poverty and inequalities in which the Brazilian AIDS epidemic takes place (Bastos & Szwarcwald, 2000; Parker & Rochel, 2000), having AIDS and being an orphan can become desirable life conditions for Brazilian children given that the "AIDS and orphan" category brings social advantages out of reach for the majority of their peers who live in poverty (Abadía-Barrero, 2002b, 2004).

#### *Background: the social construction of stigma*

The leading social theory of the association between stigma and disease is that developed by Goffman. He postulated that stigma occurs when the construction of categories is linked to socially stereotyped beliefs that label some people as acceptable and others as carriers of discrediting differences. As a result, individual and social identities are spoiled and the stigmatized person incorporates a negative view of the self (Goffman, 1963). Even though Goffman emphasized that it is through interactions and relations of power that labeling and stereotyping lead to the construction of "spoiled identities," many interpretations of AIDS-related stigma focus on the individual level (Brown et al., 2003; Herek, 1990; Herek et al., 2002).

However, conceptualizing stigma solely as the labeling of stereotyped attributes that establishes differences between "self/normal" and "other/abnormal" leads to shallow interpretations. Such binary oppositions analyze human relationships as independent of larger cultural, socio-economic, and political processes (Fabian, 1983, pp. 154–155). Thus, individual explanations of stigma fail to recognize that stigma changes over the course of AIDS (Alonzo & Reynolds, 1995; Castro & Farmer, 2005; Farmer & Good, 1991) and is a socially constructed process that results in "separation, status loss and discrimination" (Link & Phelan, 2001).

Through social interactions, cultural contexts, and relations of power, stigma leads to discriminatory processes with harmful consequences to the person's well-being.

The social construction of AIDS-related stigma has been nurtured by historical components including social fear, ignorance, anxiety, lack of knowledge, denial, shame, taboo, racism, xenophobia, and moral judgments (Malcolm et al., 1998; UNAIDS, 2002a), and by misleading metaphors like death, punishment, crime, war, horror, otherness, and shame (Sontag, 1990). De Bruyn (2002) proposes a helpful framework to study three different dimensions of AIDS-related stigma and discrimination. Structural discrimination refers to "inequalities in both institutional and non-institutional spheres of society related to gender, ethnic identity, socio-economic status, and the like." Institutional discrimination includes the spheres where "legislations, regulations, policies and procedures can include discriminatory or anti-discrimination provisions and practices." Non-institutional discrimination refers specifically to relations between individuals, within families and within communities (de Bruyn, 2002, pp. 9–10).

Hence, we define stigma as a contextual, historical, and strategically deployed social process that produces and reproduces social inequalities and functions at the point of intersection between culture, power, and difference (Parker & Aggleton, 2003). Parker and Aggleton (2003) proposed a new research and action agenda on AIDS-related stigma that goes beyond the behavioral and psychological models that dominate research, policy, and interventions to new approaches that take seriously "the social processes linked to the reproduction of inequality and exclusion."

We argue that the association between AIDS-related stigma and power differentials is enabled by structural inequality (Castro & Farmer, 2005; Link & Phelan, 2001; Malcolm et al., 1998; Parker & Aggleton, 2003; UNAIDS, 2002a). Furthermore, our theoretical framework maintains that the links between stigma and structural inequality reinforce marginalization and social exclusion of already stigmatized groups (Castro & Farmer, 2005; Parker & Aggleton, 2003). Our main objectives are to describe and conceptualize the experiences of stigma in a group of children living with HIV in São Paulo, Brazil, and to assess the role of HAART over the social course of AIDS and its impact in the experiences of stigma.

#### **Methods**

During a 20-month fieldwork period (1999–2001), the first author collected data consisting of the life trajectories of 50 children and adolescents aged 1–15 living with HIV and/or orphaned by AIDS, who live in

Table 1  
Number of children at the two support houses researched (Ages as of October 2001)

Age (years)	Support house 1		Support house 2	
	HIV positive	HIV negative	HIV positive	HIV negative
	Total	Total	Total	Total
0 < 2	0	1 <sup>a</sup>	1	2 <sup>a</sup>
2–6	5	6	3	0
7–9	5	3	3	0
10–12	5	4	3	0
> 13	3	4	2	0
Total	18	18	12	2

<sup>a</sup>These children were younger than 18 months and had an inconclusive test result.

two *casas de apoio*—support houses, which here we call support house 1 and support house 2. In Brazil, support houses are NGOs that shelter both categories of children. Data collection relied on standard ethnographic methodologies: participant observation and semi-structured informal interviews. Table 1 shows the children included in the study at both support houses.

We present ethnographic data of personal accounts and social interactions and analyze the interplay between individual experiences, social inequality, and power differentials in relation to stigma. To examine these complex issues of childhood, AIDS-related stigma, and access to HAART in Brazil we relied on anthropological theories that connect AIDS illness experiences and social inequality, and on studies that demonstrate that effective therapy reduces stigma by reverting the logic of interpretation of the disease (Castro & Farmer, 2003, 2005; Kleinman et al., 1995) and that stigma varies over the social and biological course of AIDS (Alonzo & Reynolds, 1995; Farmer, 1994; Farmer & Good, 1991).

## Results

### *Case 1. AIDS-related stigma occurs within a context of structural violence*

When Jacqueline and Luisa's mother died of AIDS in 1988, Carmenza took her three- and five-year-old orphaned nieces home. Uneasy about the presence of AIDS in the little girls and being afraid of her father and brother—who were drug dealers in the region and about to complete their jail sentence—Carmenza decided to keep Jacqueline and Luisa away from her nine children and lock them up in a tiny space outside the house. She introduced food through a slot, but she never took the girls outside. Two years later, when authorities rescued Jacqueline and Luisa from the small, pestilent room in which they were incarcerated, they were cold and dirty, lying on

sheets on the floor, afraid of the light and of people. Vomit and excrement covered their chapped and injured skins.

This story was taken from the judiciary and social service reports of the São Paulo's state child protection service. This service mandated that Jacqueline and Luisa's custody be taken from their relatives and transferred to support house 1, where adequate care could be provided. When the girls were taken to the health care services to assess their health care needs, they were discovered to be HIV-negative. The many interviews and interactions with Jacqueline, Luisa, and their caretakers at the support house reflected that, over time, the girls stopped fearing adults and started to go to school. They grew up at the support house and when Jacqueline finished high school, she was struggling to find a job. Luisa had 1 more year of high school and expected to face a similar fate.

Their story is both unique and common: unique because each experience of suffering is personal and common because many other children face similar violent actions. Even though they tested negative for HIV, the violence they suffered relates not only to their aunt Carmenza's fear of their infection, but also it becomes evident, in other sections of the report, that Carmenza also feared how her father and brother were going to take the presence of two more kids in an already crowded dwelling. In addition, their current discrimination in the job market does not relate to the disease but to limited economic options to obtain good education and consequently a well-paid job.

At both support houses, the child protection service reports and the caretakers describe how the majority of the children's stories are characterized by different forms of physical and emotional violence, such as neglect, abuse, mistreatments, or abandonment, and how their families and communities struggle within the boundaries of legal and illegal actions, poverty and survival strategies. Jacqueline and Luisa's case exemplify how

close relatives or neighbors take care of children after they become orphaned or abandoned. Usually relatives or neighbors are overburdened themselves with poverty and end up contacting the health authorities or child protection services to transfer the custody of children to the support houses. In other cases, like in Jacqueline and Luisa's, parents, relatives or neighbors are reported to the authorities.

In many of the children's stories, their orphan status is clearly linked to the murder of the parents, usually because of drug trafficking, gang conflicts, or everyday violent crime, rather than to the parents dying because of AIDS. In many cases, a combination of AIDS-related poor health along with other health hazards such as alcoholism, drug use, malnutrition, or vulnerability to violence and other diseases due to prostitution is described as the reason for the parents' deaths. In cases of abandonment, many stories are about how dire poverty impedes parents from taking care of their children, or how illegal actions result in parents going to jail. Thus, the lived experiences of children affected by HIV are about a complex amalgam of social and family factors that relate to how the AIDS epidemic is part of the unequal and violent structure of the Brazilian society.

Isabella's story, also retrieved from the reports of the child protection service, supports the claim that a complex intermingle of violent physical, emotional, and economic factors affect the experiences of stigma in both groups of children studied: HIV-positive and -negative.

Isabella, diagnosed with AIDS at the age of five, arrived at the support house because of mistreatment and neglect in terms of schooling, food, and health care. It is unclear whether she was sexually abused. After her mother died, she had lived with her father in a run-down dwelling plagued by promiscuity and drug abuse. The police rescued Isabella when she was eight.

Isabella's story, also from support house 1, similarly reflects a complex blend of brutalities imposed on children. Even though AIDS-related stigma and discrimination is part of their suffering, their childhood and adolescent years have been not only about growing up at the support house as AIDS orphans, but also as poor and black girls (*morenas* or *pretas*).

As reflected through ethnographic research, Isabella also went into adolescence at this support house and, at the age of 16, shared Jacqueline and Luisa's worries about her future. Nonetheless, the fact that Isabella was infected with HIV has resulted in special repercussions for her experiences of stigma. While Jacqueline and Luisa are confronted with multiple stigmatizing labels—such as being AIDS orphans, coming from poor

families, being black girls, living at an institution, having inadequate education, and facing unemployment—which are relevant to their lived experience, Isabella has to face the additional stigma of living with AIDS. She has commented how growing up with AIDS complicates dating and the relationships with classmates at school, where she has engaged in fights. She remembers that, when she was 14, a classmate threatened to say “something” she was not going to like. She recalls challenging him: “*I asked him to say it, he didn't want to, so then I grabbed him and started to kick him. I said if you don't talk now, you will never talk again. I started to hit him... [w]ith one punch he went all the way to the end [of the classroom] until a boy stopped him with another punch. Then, a girlfriend of mine held me back [from hitting him again].*” She clarifies that although he did not say “the word”—AIDS—to be deserving of the punishment, his intention to use it was enough reason to trigger Isabella's reaction.

Regardless of whether the kid had said the word AIDS or not, Isabella was ready to fight off the intended stigmatization through physical means. AIDS, as a stigmatizing label, has been part of the history of support house 1, the neighborhood, the school, and hence of Isabella's life. To her advantage, Isabella is known to be very smart, to have many friends, to be self-confident, and to have a very strong body. At the support house, she is known to impose order and make sure that other housemates do not “mess around with her”. At school, even though she hardly ever had problems, she could defend herself when needed.

#### *Case 2. Access to HAART changes the social course of AIDS, reduces disease-related stigma, and brings on new challenges to the children's epidemic*

Before, it was very hard, César, we would have a child at the hospital all the time. Also, the children were not as cute as you see them now; they were sick—but *really* sick. It was crazy, one with vomiting, one with diarrhea, one with ear infection, one with skin injuries, one with fever...It seemed as if we couldn't think of anything else but sick children...

It was also horrible when they died. Once, we had hospitalized 12 children and we came back with 11, then, we hospitalized 3 and we returned with 2.... We kept on wondering who would be next.

Obá is the main caretaker at support house 1 and her memories of the early years of the epidemic, since the late 1980s until the introduction of HAART in 1996, represent the distressing reality that was thankfully changed with the advent of effective medications. Obá also recalls how Mariana was very sick before HAART became available and how the frequency of children becoming sick and dying made them buy a dress for her



funeral. Obá talks about this story in a guilt and embarrassed tone given that Mariana, now 13, looks far from dying. Her recovery is described by Obá as “miraculous”.

Obá’s recollection indicates that the perception of how children with AIDS should look has been transformed by HAART. For example, Jennifer (HIV-negative, orphan, and 11) admitted that she did not think that children at the support house who were on HAART had AIDS. In one of the interviews, she expressed that her confusion related to the fact that even though she has heard that the children at the house who take medications have AIDS, their physical appearances do not match with the knowledge she has obtained at school about AIDS. According to her knowledge, people who have AIDS should look “sick and debilitated” and this was not the reality of her housemates. In addition, the fact that some HIV-positive and some HIV-negative children have required hospitalizations adds to her confusion given that sickness seems not to be exclusively the experience of children who take medications.

Pitanguinha (HIV-positive, orphan, and 14) would confess that he was somehow reluctant to return to living with his older siblings, because he feared they could not provide as good care as the support house’s. Challenged by the question about what was special regarding the care provided at support house 1, Pitanguinha answered, laughing: “They don’t do anything special. They just take you to the hospital and give [you] the medication....”

When Pitanguinha was 5, his mother died of AIDS and his 14-year-old sister became his main care-taker. Months later, he developed pneumonia and was diagnosed with AIDS—he then suffered from repeated respiratory and skin infections. When his family—which lived in a *favela* (city slum)—realized the specialized care that Pitanguinha needed, they decided to transfer his care and custody to support house 1 in 1993, when he was 7. Pitanguinha lived several years with ups and downs under the supervision of the support house’s personnel. Yet, once he was started on HAART, his care demands changed. Even though the new medications required strict adherence, the extenuating care needs associated with opportunistic infections and a debilitated body reduced dramatically. Because he feels very well overall, he defies the practices of care for sick children with AIDS by playing soccer in the rain and, at times, by not taking his medications.

In a joined interview, Pitanguinha and Mariana, both exhibiting treatment adherence problems, explained why they delay their morning dosage of medication until the afternoon. They argued: “[the schedule] doesn’t matter; you can take them anytime, as long as you take them.” Pitanguinha also revealed a lack of understanding regarding how living with AIDS affects his sexuality.

When questioned about whether he needed to use condoms if he were to engage in sexual encounters, he answered in a joking tone and cited the warnings given at school: he would use condoms so as “not to get diseases from ... whores ... [laughing].” He did not acknowledge the need to practice safer sex to protect others from HIV and, on another occasion at the hospital, he even expressed his desires to donate blood to “help others.”

Mariana and Pitanguinha’s adherence problems and Pitanguinha’s lack of understanding of how AIDS affects his sexuality and impedes him from donating blood both relate to the general feeling of wellness that they experience and to the way in which the institutions handle communication about HIV/AIDS and the children’s illness experiences (for a larger discussion about HIV/AIDS communication inside the support houses, see Abadía-Barrero & LaRusso, in press).

In fact, in support house 2, a more open communication about HIV/AIDS translated into less adherence problems and a better orientation toward their health care needs and sexuality. For example, Rogério (12, white, who lost his mother to AIDS and lived with two of his sisters and father in a rundown dwelling until he abandoned them) would agree with Pitanguinha when he considers that AIDS care is not very demanding. In his words “you don’t feel anything special... you only need to take the medications and eat well.” Nonetheless, as a difference from the children of support house 1, Rogério and his housemates acknowledge the importance to adhere with the schedules of the medications and would even follow the results of their CD4 and viral load tests.

Regarding sexuality, differences were evident between the two studied support houses. At support house 2, Bruno (HIV-positive, 14, black, and whose parents had been drug users) and Rogério wondered at some point how they would be able to have children if they had to use condoms “all the time.” Bruno, who was seemingly closer to engaging in sexual encounters, would ask more specific questions about HIV transmission and sexuality and wonder if “playing around” was safe or if he also needed to use condoms all the time even if there was not penetration. In terms of education, children at support house 2 had access to a private school affiliated with the religious community. Their future job opportunities, even though also unclear in terms of being able to afford higher education, seemed more promising than those of the children at the other house (Jacqueline, Luisa, Isabella, Pitanguinha, Jennifer and Mariana) given that their better education could result in higher chances to pass the required entry exams for public universities.

Nonetheless, there are many similarities in the children’s experiences at both support houses, including the routines around health care practices, the monthly visits to the doctor, and AIDS-related stigma. Rogério also recalls that he was involved in a school fight when a

girl “insulted him” by calling him “son of an AIDS.” “Then I got mad and kicked the girl in the face. She also got mad and started to cry.” His fight at school, similar to Isabella’s, relates to how a long history of AIDS-related stigma has been present in his family, the support house, the school, and the neighborhood, and hence is part of his lived experience.

## Discussion

Our results support the idea that a complex interplay of cultural practices, structural inequality, and power differentials produce stigma (Castro & Farmer, 2005; de Bruyn, 2002; Link & Phelan, 2001; Parker & Aggleton, 2003). We believe that the social construction of stigma is a reflection of structural violence—the ways in which history and political economy perpetuate and enhance social inequalities and power imbalances producing human suffering (Castro & Farmer, 2003, 2005; Farmer, 1992, 2003; Farmer, Connors, & Simmons, 1996). We recommend structural violence as the framework to study AIDS-related stigma and refer to the forces emerging from the relationship between structural violence and AIDS-related suffering as *structural sources of stigma*.

By studying this group of children over time we see a broad spectrum in personal experiences, from suffering multiple and strong dimensions of stigma to suffering from low intensity stigma—going beyond the superfluous assumption that conceptualizes the experience of stigma as a binary concept. For example, in Jacqueline, Luisa, and Isabella’s stories, their difficulties in finding a job relate to the high unemployment rate of the city (close to 18 percent at that time) and to the financial impossibility of continuing with college education. Even though Brazil offers free education from kindergarten to university, there is a sharp difference in quality between the public and private primary and secondary school systems. Often, children who attend primary and secondary private schools greatly outperform those who attend public schools and pass the tests required to attend public universities—decreasing the chances of poor children to achieve higher education. For the job market, Jacqueline, Luisa and Isabella might not be discriminated against only because of AIDS, but mostly because they are poor and black women with inadequate education.

In the experience of the children at support house 1, stigma is a social force that started with human rights violations related to child abuse and neglect and has continued as an excluding force that has deprived them from proper education and job opportunities. Thus the stigma they have experienced has changed over the years and, as much as it relates to the presence of HIV in their lives and the categories “orphans” for Jacqueline and

Luisa and “adolescent living with AIDS” for Isabella, it relates importantly to how dire poverty and Brazilian social inequality abate their expectations and harm their life outcomes. These stories show that even though AIDS is the main cause of stigma and suffering at different moments, there is a legacy of racism and economic and gender-based discrimination that influenced their first years of life and continues to impact their lives.

The lived experiences of Bruno, Rogério and their housemates at support house 2, just like children at support house 1, are marked by histories of AIDS and structural violence in their families, by being cared for at institutions, and by receiving the benefits of having universal access to HAART. In contrast with children from support house 1, however, they have the advantage of receiving better education and a more open communication about HIV/AIDS that allows them to resolve some of their questions regarding health care and sexuality. Nonetheless, the stigma that surrounds their orphan status, living at an institution, living with HIV/AIDS, being black in the case of Bruno, and coming from poor families are also part of their lived experiences of stigma and discrimination.

We conclude that several discriminatory processes, rather than isolated forces, act in synchronicity and are larger than the presence of AIDS in the children’s lives. In our study, children’s experiences of stigma are linked to AIDS, poverty, social inequality, racism, orphan status, access to resources, institutional characteristics, and inequalities in gender, age or geographic region. Our data shows that a child’s experience of stigma may be that of being a poor, black, orphan, pre-adolescent girl coming from poor northeastern Brazil and living with HIV in a specific support house and not only about being a “child living with HIV.” Our results are in agreement with previous studies that show that the cultural interpretations of AIDS and the illness experiences of people living with HIV are context dependent and change according to different social responses and biological outcomes (Alonzo & Reynolds, 1995; Farmer, 1994; Farmer & Good, 1991). We found that even though poverty and social inequalities continue to dominate the lives of these children, access to HAART and the presence of shelter institutions have assured survival and improved quality of life. However, differences among institutions and access to support networks are crucial for shaping the children’s lived experiences.

From this data it becomes evident that HAART changes the social course of AIDS and the experience of stigma when children reach adolescence. While access to HAART means improved survival and quality of life, it also means that healthy-looking adolescents contest adult power and health care practices. They progress from being perceived as sick and innocently infected victims during their childhood years to being feared as

potential victimizers as adolescent sexual subjects, which is perceived by the support houses as a new “problem.” Thus, healthy-looking adolescents challenge dichotomous perceptions of stigma such as victim–victimizer or normal–abnormal.

Obá’s memories of the years of the epidemic before HAART, Jennifer’s confusion about the change in stereotyped body image that people with AIDS should have, Pitanguinha’s fear of going back to living with his siblings, and the houses’ problems dealing with healthy-looking adolescents (school fights, communication about HIV/AIDS, adherence, and sexuality) point to significant changes brought about by HAART in the social course of AIDS in Brazilian children. First, children and adolescents’ health and their overall “normal” development contest the traditional, debilitated look associated with the presence of AIDS. Second, the fear of imminent death and serious illness decreases as children have access to HAART. Third, owing to access to comprehensive AIDS care, which includes HAART, children can develop a new sense of AIDS—a perception of AIDS as a disease “under control,” thereby erasing the idea that AIDS requires so many demanding health-care needs that make it impossible for families to care for relatives living with the disease. Fourth, as HAART allows children to become healthy adolescents, new challenges are created: treatment adherence and sexuality.

Furthermore, our data indicates that structural, institutional, and non-institutional discrimination (de Bruyn, 2002) are interconnected and interdependent. Therefore, approaches to change stigma “must be multifaceted and multileveled” (Link & Phelan, 2001, p. 11). Unfortunately, the majority of interventions to reduce stigma to date have focused exclusively on educational workshops, sensitivity and empathy training, or increasing tolerance through personal contacts with people living with HIV (Brown et al., 2003; Herek, 1990; Herek et al., 2002). These interventions are based on the assumption that a greater knowledge about AIDS and sensitivity towards people living with HIV alters the public perception of AIDS and reduces stigma. A recent review shows that these kinds of interventions produce mixed results, appear to work only in a small scale and in the short term, and do not guarantee that people will be tolerated in actual encounters (Brown et al., 2003). Based on our results, we argue that interventions that only tackle the perception of those unaffected by the disease without changing the experience of the stigmatized person or the structural sources of stigma are important, but have limited effects.

In contrast, our study indicates that access to HAART has been a powerful mechanism to reduce stigma in Brazil for three main reasons. First, it reverts the logic of interpretation of the disease by transforming AIDS from a fatal and incurable disease to a chronic

and manageable one. Thus, it improves the person’s well-being, changes the public perception of the disease, and allows people living with HIV to challenge and fight against stigmatization processes. Second, access to HAART in Brazil is part of its AIDS public health policy—a larger legislative effort to guarantee the rights of those living with HIV (Galvão, 2001, 2002; Ministry of Health of Brazil, 2001, 2002). Third, it redresses some of the structural forces that impede poor communities from having access to proper health care and reduces gender, age, and social inequality.

However, our study also indicates that other structural sources of discrimination continue to exist. We claim that even though access to HAART is the most important first step in reducing stigma, larger measures to fight poverty, racism, sexism, and social inequality are necessary to reduce AIDS-related stigma. Adopting structural violence as a model to understand the multiple sources of stigma in the experience of all people living with HIV will point to more promising interventions.

#### Acknowledgements

César Abadía-Barrero was funded by a doctoral grant from Colciencias and by a Richard Carley Hunt Fellowship from the Wenner-Gren Foundation for Anthropological Research. The authors would like to thank the children and adolescents who participated in the research.

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