

Vulnerability, Human Rights, and Comprehensive Health Care Needs of Young People Living With HIV/AIDS

We sought to identify and understand the health care needs of young people living with HIV/AIDS, particularly in terms of their psychosocial well-being. We conducted a qualitative analysis of HIV-positive young people and their caregivers, focusing on the implications of an HIV diagnosis for health care needs.

Stigma was a recurrent issue that arose in the interviews conducted with the respondents, and it was evident that youths had been denied many rights related to health. We concluded that young people living with HIV need comprehensive care based on a human rights approach. In this regard, we offer some practical recommendations for health programs. (*Am J Public Health*. 2006;96:1001–1006. doi:10.2105/AJPH.2004.060905)

José Ricardo de Carvalho Mesquita Ayres, MD, PhD, Vera Paiva, PhD, Ivan França Jr, MD, PhD, Neide Gravato, MS, Regina Lacerda, MS, Marinella Della Negra, MD, PhD, Heloisa Helena de Sousa Marques, MD, PhD, Eliana Galano, PhD, Pilar Lecussan, MD, Aluísio Cotrim Segurado, MD, PhD, and Mariliza Henrique Silva, MD

ADOLESCENTS AND YOUNG

people have specific needs with respect to their well-being, including issues related to their social integration, family life, education, and sexuality.^{1,2} Relatively few studies have focused on how adolescents living with HIV/AIDS deal with these needs, but there is evidence to suggest that these needs must be considered in providing care for this group.^{3–7}

Introduction of antiretroviral treatments and other types of resources, such as legal guarantees for access to treatment and protection against discrimination, can alter the way society deals with AIDS and its related stigma.⁸ In Brazil, both strategies have been used and have been shown to have significant effects on prevention, access to counseling, and treatment.^{9–12} The policy of universal and free access to antiretroviral treatments in Brazil has resulted in a large number of HIV-positive youngsters receiving these treatments through public health care services. In 2004, of the 18 430 reported Brazilian children and adolescents 18 years or younger who had been diagnosed with AIDS, almost half were undergoing antiretroviral treatment.¹³ In this context, comprehensive care of young people living with HIV poses a long-term challenge.

A group of health professionals, researchers, and activists working in the early stages of the national response to AIDS in the cities of São Paulo and Santos,

which were epicenters of the epidemic in Brazil, decided to address the emerging issue of caring for young people living with HIV/AIDS. These professionals shared the assumption that an effective response to these youths' care needs would demand a joint effort on the part of different disciplines and sectors. In 2001, they joined forces in the Enhancing Care Initiative, an international scientific and technical cooperation initiative coordinated by the Harvard AIDS Institute and the François-Xavier Bagnoud Center for Health and Human Rights.¹⁴

The Enhancing Care Initiative in Brazil involved a multidisciplinary team of health professionals, including specialists in the fields of public health, epidemiology, infectious diseases, and pediatrics, as well as psychologists and a social worker. These individuals were involved with diverse institutions and sectors, including universities, hospitals, basic health units, health offices, and non-governmental organizations.

The participants in the Enhancing Care Initiative recognized that the challenge was to achieve the highest attainable standard of health for young people living with HIV/AIDS; the focus was on provision of not only infection control but quality of life, with a particular emphasis on mental and social well-being. The objective of the study subsequently conducted by the initiative was to identify and

understand the health care needs of young people living with HIV/AIDS from their own and their caregivers' perspectives. Here we focus on HIV disclosure among young people from both of these perspectives and on challenges with respect to the socialization of these youths.

UNDERSTANDING THE NEEDS OF YOUTHS

We conducted interviews with people aged 10 to 20 years who were aware that they were HIV positive and with caregivers of other patients in the same age group who were not necessarily aware of their serological status. Participants were selected from 248 eligible patients from 5 HIV/AIDS service providers. Between September 2002 and March 2003, 35 interviews were conducted in a private setting in the health service once interviewees had agreed to participate (Table 1). The interviewers were physicians, psychologists, and social workers.

We defined the total number of individuals to be interviewed according to sufficiency criteria, that is, on the basis of an appraisal that a comprehensive frame encompassing our primary research question (What are the health care needs of young people living with HIV/AIDS from their own and their caregivers' perspectives?) could be drawn from the data.¹⁵ The in-depth interviews focused on the following topics:

TABLE 1—Mode of Exposure, Adolescent Gender and Age at Interview, and Caregiver Relationship

| Mode of Exposure | Gender | Age, y | Caregiver |
|-----------------------------|--------|--------|--------------------------------------|
| Adolescents (n = 22) | | | |
| Mother to child | F | 13 | Father |
| Mother to child | F | 13 | Grandmother |
| Mother to child | F | 14 | Adoptive parents |
| Mother to child | F | 14 | Adoptive parents, brothers |
| Unknown | M | 14 | Uncles, grandparents, cousins |
| Mother to child | F | 14 | Institutional (with brother) |
| Mother to child | F | 15 | Grandparents, brothers |
| Unknown | M | 15 | Father and mother |
| Mother to child | F | 15 | Uncle and extended family members |
| Mother to child | F | 15 | Foster home |
| Mother to child | M | 16 | Foster home |
| Transfusion | F | 16 | Parents and sister |
| Unknown | M | 16 | Grandparents and aunt |
| Mother to child | M | 17 | Institutional |
| Sexual | F | 17 | Parents and brothers |
| Unknown | M | 17 | Father and brothers |
| Sexual | F | 18 | Mother, brother, and mother's child |
| Sexual | M | 18 | Father and brothers |
| Mother to child | M | 18 | Parents and brothers |
| Sexual | M | 19 | Parents and a brother |
| Sexual | F | 20 | Husband, mother-in-law and daughters |
| Unknown | M | 20 | Mother |
| Caregivers (n = 13) | | | |
| ... | ... | ... | Institutional |
| ... | ... | ... | Institutional |
| ... | F | 9 | Aunt |
| ... | F | 10 | HIV-positive mother |
| ... | F | 12 | Adoptive father |
| ... | F | 12 | Aunt |
| ... | M | 13 | Adoptive mother |
| ... | M | 14 | Paternal grandmother |
| ... | F | 15 | HIV-positive mother |
| ... | F | 15 | HIV-positive mother |
| ... | F | 16 | Paternal grandmother |
| ... | M | 17 | HIV-negative mother |
| ... | M | 17 | Adoptive mother |

Note. F = female; M = male.

school, friends, leisure time, the disclosure process, sexuality, plans for the future, and evaluation of health services. Given that such factors could potentially influence our findings, gender, age,

mode of infection, and whether parents or caregivers were HIV positive (or, alternatively, whether respondents were residing with foster families or in institutions) were taken into consideration

during the participant selection process.

The interviews were treated as *discourses*; that is, responses were interpreted in a nonformal way with the aim of identifying how the narratives were structured, the facts and actions concretely referred to, and the associated values, beliefs, and feelings.^{16,17} In our hermeneutic approach, we also assumed that interpretation is always part of a broader understanding process, and thus any interpretation is deeply dependent on practical interests and theoretical frameworks.

We were guided by a framework based on the concept of vulnerability and attention to human rights.^{18,19} The starting point of a vulnerability analysis is a particular health disorder, and the goal is to identify, as exhaustively as possible, the physical, mental, or behavioral factors that may expose an individual to that disorder through risk assessments and other approaches. The next analytical step focuses on the collective level, which comprises 2 components.

In the first component, the social dimension of vulnerability is considered, and the focus is on cultural, moral, political, economic, and institutional factors that may determine the means of exposure determined at the previous analytical level. The second component is program analysis, which examines the ways in which policies, programs, and services may interfere in these social and individual situations. A human rights perspective offers a solid reference for both of these components, in that it not only helps to identify situations involving social vulnerability to HIV/AIDS but also guides health service programming and evaluation toward these broader

dimensions of health care needs (Table 2).^{20–23}

YOUNG PEOPLE'S AND CAREGIVERS' COMMENTS

We summarize the data derived from our interviews in terms of 2 major themes. First, we focus on the process of disclosure from the perspectives of both young people and their caregivers, a crucial aspect of the narratives of each group in that it represents a meaningful connection between normality and “abnormality.” Second, we raise relevant issues related to the daily challenges of living with HIV, both for young people and their caregivers, pointing out the links between vulnerability, human rights, and health care needs.

Disclosure and “Being Normal”

Most of the young people living with HIV who were interviewed had contracted the infection from their mothers and had reached adolescence because they were able to obtain medication through the country's policy of universal access. (In the passages to follow, respondents had contracted the infection from their mothers unless otherwise indicated.) In many cases, they grew to adolescence without being aware that they were HIV positive. For example:

I took medications and I associated them with the ads I saw on TV. I found out by myself, asking the woman who took care of us at the foster home. (16-year-old girl)

I discovered when I overheard the doctor talking to my aunt. (15-year-old girl)

The caregivers' narratives indicated that delaying disclosure of infection was a common measure

TABLE 2—Dimensions and Relevant Aspects of HIV/AIDS Vulnerability Analyses

| Individual Dimension | Collective Dimension | |
|---------------------------|-------------------------------------------------------|--------------------------------------------------------------------------|
| | Social | Programmatic |
| Values | Social norms | Government commitment to HIV/AIDS responses |
| Interests | Cultural references | Definition of HIV/AIDS policy |
| Beliefs | Gender relations | Planning and evaluation of HIV/AIDS policy |
| Desires | Racial relations | Social participation in planning and evaluation processes |
| Knowledge | Generational relations | Material and human resources related to HIV/AIDS policy |
| Attitudes | Religious beliefs and norms | Political governance of HIV/AIDS policy |
| Behaviors | Stigma and discrimination | Public control of HIV/AIDS policy |
| Networking and friendship | Social welfare | Political, institutional, and material sustainability of HIV/AIDS policy |
| Conjugal relations | Employment | Multisectoral connections |
| Familial relations | Income | Intersectoral activities |
| Social networks | Social support | Health sector organization |
| Mental health | Access to health care | Health service access |
| Physical constitution | Access to education | Quality of health services |
| | Access to culture, leisure, and sports | Multidisciplinary teams |
| | Access to media | Interdisciplinary approaches |
| | Freedom of thought and expression | Prevention and care integration |
| | Political participation | Team technical-scientific background |
| | Citizenship entitlements | Team human rights awareness and sensitivity |
| | Public and private sector accountability | Public control of and participation in health services |
| | Access to legal system | Accountability of health services |
| | Government commitment to health and social well-being | Planning and evaluation of health services |

infected occurred between the ages of 11 and 14 years. The aspects these adolescents valued most were the possibility of relying on their family’s support and being informed in a clear and appropriate manner.

You have to talk about it correctly, go to the doctor together. . . . Hiding things makes things worse. At least I think so. Because I wouldn’t like anybody to hide anything from me. If you have to say something, no matter how bad it is, say it now. (14-year-old girl)

The most difficult disclosure scenes, those involving the least support and the most negative effects, occurred among sexually infected participants in the oldest age group. For example:

I opened the envelope and took a look at the results . . . as soon as I opened the envelope I saw that I was HIV positive. . . . I went into a state of shock in the middle of the street. I was alone on the curb, with nothing on my mind. And then I passed out. . . . When I woke up, I started crying. I was desperate. (19-year-old boy, sexual transmission)

Some girls who had contracted HIV via sexual transmission were diagnosed during antenatal care. In such contexts, carelessness regarding the form of disclosure may occur, resulting in serious consequences.

Then she asked me to call my mother. . . . I took a seat, and she said [to my mother], “Well, your daughter is infected with the virus.” “Who, me?” She said, “Yes, but you already knew.” [I said] “I already knew?! How did I already know?” She said, “Oh, that’s why you were taking so long to do the tests.” That’s how it happened. . . . Then I became desperate, I started crying, and she said, “It’s no use crying now.” (18-year-old girl)

Becoming aware of their diagnosis places young people in a situation in which they must face the issue of whether to keep the

taken to protect adolescents. Most caregivers interviewed believed that mischaracterization of the “abnormality” represented by HIV infection might result in disclosure bringing more benefits than harm.

In my prayers I would tell God that I wanted there to be a person He had chosen, that would be the right person [to disclose to my son]. . . . I hadn’t the faintest idea where I would find this person. . . . I thought that, at that moment, if I had told him the truth, he wouldn’t have resisted, because he was well . . . and he was a child, right? He had just turned 11 a little while ago. (HIV-negative mother of male adolescent infected via blood transfusion)

When we asked the adolescents what life was like for a young person living with HIV, the most frequent (and significant) reply was “I am normal.” This was not merely an expression but a narrative axis that

served as a structure for all of the interviews.

We have to take care of the risks of getting hurt . . . not passing it on, you know. . . . But it’s totally normal. We have schedules for taking our pills, the responsibilities are greater, because [suppose] someone’s got a cold, if she or he is near us, it’s dangerous. . . . But aside from this, it’s absolutely normal. (15-year-old girl)

Disclosure was one of the most important moments in terms of realizing that “abnormality” was a possibility: being marked by a difference or by the possibility of segregation. However, a majority of the young people interviewed noted that the normalcy of their daily life depended on the strategies they used to protect their serological status. According to one respondent:

I lie so that I won’t lose a friendship . . . otherwise they’ll

harm me, then I won’t have any friends, I’ll get upset. . . . I’m a guy, someone . . . like any other guy. (16-year-old boy)

A typical HIV disclosure scenario among children born with HIV is one that includes family members or caregivers and a health professional, and the encounter typically involves receipt of already foreseen information.

[She] told me. But, you know, I already suspected that I had some disease . . . didn’t know the name of it. Then she told me the name of the disease I have, but then afterwards . . . it was OK. . . . She asked me, my sister, and my great-grandmother to come into her office for a conversation. . . . She said she wanted to talk to me about my disease because I wasn’t taking the medicine I had to take. (15-year-old girl)

In most of the cases considered here, disclosure among young people who had been vertically

diagnosis a secret from their friends. They face the dilemma of freeing themselves from this burden, coming to grips with the risk of possible rejection, or sustaining the burden and dealing with the losses this choice implies.

For me, telling someone brings . . . great relief. . . . But when I told some friends of mine, they asked me if my blood was another color, if I felt the virus inside me. (15-year-old girl)

That's why I don't make friends anymore . . . they say if they know someone in the group is infected, they won't even come near that person. (18-year-old girl, sexual transmission)

Living With HIV: Life Horizons and Challenges

The life horizons of these HIV-positive children and young people were, in many cases, unnecessarily and involuntarily restricted, especially before anti-retroviral treatments became available in 1996. Negligence concerning material provisions is but one of many forms of discrimination that may affect young people's social, psychological, and physical well-being.

I opened a bank account for my son and I didn't open one for [my seropositive daughter]. I thought, "She will die, why should I open an account for her?" . . . There was nothing but death ahead of me. . . . I didn't think that she would live . . . long. (HIV-positive mother of girl infected via mother-to-child transmission)

In terms of these young people's sexuality, conflicts were evident between what would be technically adequate in terms of prevention and the fear, expressed by caregivers and health professionals, that dealing with sexual matters could be harmful to young people's psychosocial development. Frequently, the consequences were stigmatization and lack of clear information.

Then we said, "You are conscious of the fact that you're seropositive, you are aware of all of the difficulties that you face in life because you are seropositive. If you contaminate someone and don't tell this person . . . you will be prosecuted, you may even be arrested." So it isn't cruel to say this. . . . This is . . . reality. (foster home caregiver)

There are medications for not transmitting HIV. . . . The medication is something that the women take, I think they're pills, so she won't become pregnant.

[What else? Do you know how to use it?]

I don't know. I know nothing about it. (16-year-old boy)

Often, these young men and women reported that they chose not to disclose their diagnosis to their relationship partners, indicating that they needed to trust people before they could disclose to them.

You gotta trust the person. . . . I thought it was better not to tell any of the girls. . . . For me to tell someone, I would have to be certain that I was going to spend the rest of my life with that person. (16-year-old boy)

Although surrounded by ambiguities and fears, the desire to start a family and raise children was often noted in the interviews.

Well, I would like to have a child of my own. But it's . . . not even because of the HIV. . . . I'm afraid. If you have HIV, you have to do a C-section and so on, and I'm very scared of that. I prefer adopting a child. . . . I would like to have my own; really, I would love to have my own child. (15-year-old girl)

The prejudice encountered by the respondents, including their experiences at school, and concerns about their professional future frightened them and caused suffering. When confronted with inequity and discrimination, they tended to limit their plans for the future.

What I really like is computers. I was going to [take] computer

sciences at college. Oh, I think I'll have to . . . I don't know . . . if they ask, for instance, they may even ask my blood type, I'll have to tell, of course. (14-year-old boy)

I'm scared I won't have friends; they will put me aside, isolate me. (15-year-old boy)

Concerns in the areas of discrimination at school and educational achievement were also in evidence in the comments of caregivers or guardians, from a very objective as well as symbolic point of view.

I had problems within a school, where the director knew [that my daughter was HIV positive], but not the teachers. Then, when that director left the school [she had also been in charge of administering the daughter's medication], the teachers found out about the medication and pressured the [new] director, saying "If the girl stays in school we're leaving." (stepfather of girl infected via mother-to-child transmission)

Most of our children are not doing well at school. I don't know if it is because they are seropositive. Maybe it's because they were abandoned, maybe it's because of the situation they face, maybe it's because their mothers and/or fathers were drug users. (foster home caregiver)

In general, young people indicated that their relationships with health service providers and health professionals were positive, but some described situations in which they were stigmatized. The lengths to which this violation may extend are illustrated by the following narrative, in which a child was denied surgery on a discriminatory basis.

My son had a problem . . . his testes were inside his belly. . . . So he needed the surgery, to put his testes in place. . . . Then the doctor said "It's no use doing the surgery, he won't last that long." (adoptive mother of boy infected via mother-to-child transmission)

VULNERABILITY, HUMAN RIGHTS, AND CARE

The vulnerability and human rights approach we took here made it possible to search for and attempt to understand the effects of living with HIV on different aspects of young people's personal and social well-being, as well as the effects on their caregivers. We were able to identify key issues in the areas of policy and health care practice, especially policies and practices oriented toward psychosocial attention (Table 3).

Stigma was a recurrent issue in participants' narratives, and types of stigma could be grouped into 2 categories: felt and enacted stigma. *Felt stigma* was characterized by subjective feelings of embarrassment associated with social discrimination and internalized as part of young people's identity. *Enacted stigma*, on the other hand, occurred when young people's rights were actively denied.²⁴ In both cases, the difficulties and challenges related to stigma provided an understanding of why, as discussed elsewhere,²⁵⁻²⁹ the interviewees defined their lives according to the predisclosure and postdisclosure periods.

Felt stigma was evident in caregivers' narratives in terms of their fears concerning young people's postdisclosure reactions: mismanagement of information, exposure to situations of discrimination, and placement of blame on parents, for example. In the young people's narratives, felt stigma was apparent in their fear that disclosure to friends or relationship partners would lead to isolation.

The power of enacted stigma was obvious in the accounts describing careless, untimely disclosures to young people who had contracted HIV via sexual transmission or through drug use. In

TABLE 3—Associations of Present Findings With Vulnerability Dimensions and Relevant Human Rights

| Fieldwork Findings | Vulnerability Aspects | Human Rights Aspects ^a |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Negligence regarding material provisions | Social: income, social welfare | Benefits from social security, including social insurance (26) Standard of living adequate for physical, mental, spiritual, moral, and social development (27) |
| Exclusion from school | Social: access to education | Access to high-quality education (28; 29) |
| Exclusion from health service access | Social: access to health care Programmatic: quality of care; human rights awareness/sensitivity of health care teams | Highest attainable standard of health and facilities for treatment (24) |
| Inadequate disclosure process (carelessness or postponement) | Programmatic: interdisciplinary approach; human rights awareness/sensitivity of health care teams | No arbitrary interference with individual privacy (16) Highest attainable standard of health and facilities for treatment (24) No inhumane or degrading treatment or punishment (37) |
| Lack of information or public debate on physical, psychological, and social aspects of HIV infection, sexuality, prevention, reproductive matters, and rights of children and youths | Social: access to health services; access to culture, leisure, and sports; access to media; cultural references Programmatic: interdisciplinary approach; human rights awareness/sensitivity of health care teams | Seeking, receiving, and imparting information and ideas of all kinds (13) Respecting the right to freedom of thought and conscience (14) Recognizing the important function of the mass media (17) |
| Conflicts and limitations regarding social integration, plans for future, family constitution, employment, etc.; fear of discrimination; isolation | Social: stigma and discrimination Programmatic: multisectoral connections; intersectoral activities; multidisciplinary teams; interdisciplinary approaches; prevention and care integration; human rights awareness/sensitivity of health care teams | Preservation of identity (8) Protection against all forms of physical and mental violence, including negligent treatment (19) Education directed toward personal and social development (29) |

^aBased on the Convention on the Rights of the Child, adopted by the United Nations General Assembly on November 20, 1989, and enforced on September 2, 1990. Numbers in parentheses refer to the articles of the convention related to each human rights issue.

elsewhere reinforce the assumption that the associations involving vulnerability, human rights, and health care needs observed here are comparable to those in other national contexts. In addition, studies have shown that although antiretroviral treatments are a necessary component of the care needs of young people living with HIV, their needs are by no means restricted to these treatments. On the basis of our observations, we offer the following recommendations for services and programs directed toward young people living with HIV/AIDS³⁰:

1. Inform and raise young people's, caregivers', and professionals' awareness concerning children's and youths' rights, as established in local and international conventions.
2. Expand the debate in relevant sectors regarding AIDS-related stigma and discrimination, actively discouraging and repressing any exclusion or restriction of young people's horizons and projects based on serological status.
3. Provide young people with complete information and access to the most accurate information on sexuality and HIV prevention, as well as counseling. This approach requires dialogical education components linked to diversified support systems that are related to all aspects of care.
4. Develop local guidelines supporting careful management of disclosure of HIV infection to young people and their families.
5. Promote and stimulate multisectoral activities and support for community groups working with children and young people living with HIV, particularly those working with

addition, disclosure was typically postponed among children born with HIV, and thus these children and the older adolescent participants often were informed of their infection during approximately the same age range. Such findings highlight the fact that HIV-positive youths experience different forms of discrimination that have differing effects on their rights to health and quality health care.

Another aspect of negligence curtailing young people's rights is lack of social inclusion. Questions that need to be answered in relation to this issue include the following: When and how should

young people reveal their HIV-positive status? To whom should they reveal it? What kind of support do they need in making this decision and following through? What resources are available to protect them against discrimination at school, in their neighborhood, or in their family? Where can they seek support? Who will identify and discuss with them unnecessary restrictions in their plans for the future?

With respect to sexuality, there was very little frank, objective, or practical discussion, and misinformation was even in evidence regarding fundamental aspects of prevention and reproductive life.

Most of our young interviewees reported planning to have children and families of their own, although none of them had had the opportunity to openly discuss these plans at home or with their health care providers.

TOWARD COMPREHENSIVE CARE

Some of the situations described here are certainly associated with the specific environment from which we gathered our data. However, the similarities between the difficulties and challenges reported by our respondents and those described

socially excluded segments such as homeless individuals and incarcerated youth.

Further research on multidisciplinary and multisectoral perspectives is required for a broader understanding of these needs and the efficacy and effectiveness of interventions, particularly intersectoral joint initiatives. In Brazil, the results of the Enhancing Care Initiative were presented for debate in an open seminar in July 2004 that involved health care professionals, AIDS activists, policymakers, and AIDS programs managers. In addition, these results have been disseminated in a special issue of an AIDS magazine³¹ and have been distributed at no charge to health services and non-governmental organizations throughout the country. We hope this initiative will inspire other similar efforts and contribute to enhancing the health care provided for young people living with HIV/AIDS in other countries. ■

About the Authors

José Ricardo de Carvalho Mesquita Ayres is with the Department of Preventive Medicine, School of Medicine, University of São Paulo, São Paulo, Brazil. Vera Paiva is with the Department of Social Psychology, School of Psychology, University of São Paulo. Ivan França Jr is with the Department of Maternal and Child Health, School of Public Health, University of São Paulo. Neide Gravato and Regina Lacerda are with the Santos STD/AIDS Program, Santos, Brazil. Marinella Della Negra is with the Emílio Ribas Institute of Infectious Diseases, São Paulo. Heloisa Helena de Sousa Marques and Pilar Lecussan are with the Child's Institute, Clinics Hospital of the School of Medicine, University of São Paulo. Eliana Galano and Mariliza Henrique Silva are with the São Paulo State STD/AIDS Program, São Paulo. Aluísio Cotrim Segurado is with the Department of Infectious Diseases, School of Medicine, University of São Paulo.

Requests for reprints should be sent to José Ricardo de Carvalho Mesquita Ayres, Avenida Doutor Arnaldo 455, sala 2222, 01246-903, São Paulo/SP, Brazil (e-mail: jrcayres@usp.br).

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Contributors

J.R.C.M. Ayres led the writing of the article. V. Paiva and I. França Jr contributed to the writing and revision of the article. N. Gravato, R. Lacerda, M. Della Negra, H.H.S. Marques, E. Galano, P. Lecussan, A.C. Segurado, and M.H. Silva contributed to revisions of the article. All of the authors contributed to formulation of the study aims and design and to data collection and interpretation.

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Human Participant Protection

This study was approved by the institutional review board of Hospital das Clínicas e Faculdade de Medicina da Universidade de São Paulo. Also, the protocol was approved by the ethics committees of the institutions involved in the study. All interviewees voluntarily agreed to take part in the study after reading and signing an informed consent form.

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