

# HIV/AIDS in childhood and adolescence. Trends in Brazilian scientific production

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### Abstract

**Objective.** To analyze the theme HIV/AIDS in childhood and adolescence, its characteristics and trends, in Brazilian scientific production between 1983 and 2010. **Methodology.** Review of 121 quantitative and qualitative descriptive studies. **Results.** 81% of the production comes from the South-East/South of the country. In the 1980's, a balance is observed between experience reports (50%) and research (50%). Seventy percent of the papers were produced between 2003 and 2010. The most frequent theme analyzed with regard to childhood was care delivery (75%), against prevention in adolescence (72%). Studies related to HIV/AIDS in emphasized clinical-epidemiological aspects (70%), while sociocultural studies predominated for the adolescent period (90%), with a preventive trend. **Conclusion.** The scientific production under analysis is coherent with the Brazilian policy to cope with the epidemic and addresses all care levels related to this public health problem.

**Key words:** adolescent health; child health; acquired immunodeficiency syndrome.

## VIH/SIDA en la niñez y en la adolescencia. Tendencia de la producción científica brasileña

### Resumen

**Objetivo.** Analizar en la producción científica brasileña de 1983 a 2010, la temática VIH/sida en la niñez y adolescencia, sus naturalezas y tendencias. **Metodología.** Estudio de revisión de tema de 121 artículos con abordaje descriptivo cuantitativo y cualitativo. **Resultados.** El 81% es del eje sudeste-sur del país. En la década de 1980, hubo un equilibrio entre los informes de experiencias (50%) e investigaciones (50%). El 70% de toda la producción es del 2003 al 2010. La temática de investigación más frecuente para la infancia fue la asistencial (75%), mientras para los adolescentes fue la prevención (72%) Los estudios

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relacionados con VIH/SIDA en la niñez enfatizaron sobre aspectos clínico-epidemiológicos (70%) y en la adolescencia predominaron las investigaciones socioculturales (90%) con tendencia preventiva. **Conclusión.** La producción científica estudiada es coherente con la política brasileña de enfrentamiento de la epidemia y contempla todos los niveles de atención para este problema de salud pública.

**Palabras clave:** salud del adolescente; salud del niño; síndrome de la inmunodeficiencia adquirida.

## HIV/AIDS na infância e na adolescência. Tendência da produção científica brasileira

### ■ Resumo ■

**Objetivo.** Analisar na produção científica brasileira de 1983 a 2010, a temática HIV/aids na infância e adolescência, suas naturezas e tendências. **Metodologia.** Estudo de revisão de tema de 121 artigos com abordagem descritiva quantitativo e qualitativo. **Resultados.** 81% são do eixo sudeste-sul do país. Na década de 1980, teve um equilíbrio entre os relatórios de experiências (50%) e investigações (50%). 70% de toda a produção é de 2003 a 2010. A temática de investigação mais frequente para a infância foi a assistencial (75%) enquanto para os adolescentes foi a prevenção (72%) Os estudos relacionados com HIV/AIDS na infância enfatizaram sobre aspectos clínico-epidemiológicos (70%) e na adolescência predominaram as investigações socioculturais (90%) com tendência preventiva. **Conclusão.** A produção científica estudada é coerente com a política brasileira de confronto da epidemia e contempla todos os níveis de atendimento para este problema de saúde pública.

**Palavras chaves:** saúde do adolescente; saúde da criança; síndrome de imunodeficiência adquirida.

## Introduction

Infection by Human Immunodeficiency Virus (HIV) and illness from the Acquired Immunodeficiency Syndrome (AIDS) are contemporary issues in the health and social sciences, due to their clinical-epidemiological, sociological, political and economic nature. In Brazil, since the 1980's, the evolution of AIDS indicated the interface of the clinical-epidemiological issue with the socio-political one, as a reflection of the quantitative and qualitative changes in the epidemic's profile.<sup>1,2</sup> The infection with HIV of women of reproductive age resulted in an increase in the number of cases of children infected by vertical transmission.<sup>3</sup> Between 1980 and 2011, 608,230 cases of AIDS were notified, of which 19,518 fell in the age range 0 to 12 (infancy), and 12,891 from 13 to 19 years of age (adolescence). It stands out that 90% of the cases notified in infancy correspond to children below five years old

(vertical transmission).<sup>4</sup> The scale of this epidemic of AIDS in childhood and adolescence required the health services to provide actions directed at care, prevention, control of vertical transmission, and protection and surveillance of cases.<sup>5</sup> These actions were added to the implantation of the Prophylactic Therapy for Vertical Transmission (AIDS Clinical Trial Group-ACTG protocol 076/1997), and were reflected in the decline of infection from vertical transmission<sup>6,7</sup>.

In parallel, the situation of AIDS in the country has mobilized the researchers to investigate its transformations and demands.<sup>8</sup> While scientific production has shown itself to be consistent with the advances of Brazilian policies for confronting the epidemic, the issue of AIDS points to the need for health care which contributes to the improvement in quality of life of children and

adolescents who have AIDS or who are vulnerable to infection. Within the group of these productions, one can find studies on the tendency of the issue of HIV/AIDS in different human groups, there being a need for broadening studies on the group made up of children and adolescents/young people.<sup>9-11</sup> In this regard, the research question – what are the tendencies of Brazilian scientific production on HIV/AIDS in childhood and adolescence? – is conducted with the objective of analyzing the specific characteristics, nature and tendency of Brazilian scientific production, from 1983 to 2010, on the issue of HIV/AIDS in childhood and adolescence.

The study's relevance lies in the search for scientific evidence in the directives of the knowledge on the matter, which may confer visibility on new questions which are necessary for the development of scientific investigations, filling gaps existing in the knowledge in this area. The actions of protection, prevention, assistance and epidemiological surveillance, which are inherent to the issue of HIV/AIDS in childhood and adolescence and are revealed in the tendency of the studies can demonstrate the consistency between Brazilian scientific production and public policies.

## Methodology

This is a literature review study with an analytical, critical and reflective approach, whose source of data was large databases of the health sciences, in particular Medical line (MEDLINE) and Latin-American and Caribbean Health Sciences Literature Database (LILACS). This search was undertaken in the second semester of 2011, based on the descriptors: [HIV *or* Acquired Immunodeficiency Syndrome] *and* [child *or* adolescent]. The cut-off point for starting was 1983, when the first case of AIDS in a child in Brazil was diagnosed.<sup>4</sup> The inclusion criteria were: article on the issue of HIV/AIDS in childhood and/or adolescence, published in the period 1983 – 2010, with the full text available electronically. When linked to more than

one database, the article was considered a single version for analysis. The exclusion criteria were: articles that were not authored by Brazilians, and abstracts with the text incomplete.

The scientific productions were selected based on readings of the titles and the abstracts. A documental analysis record was developed, made up of the following items: year of publication, data-base linked, region of origin of production and specifics (origin: South, South-East, Center-West, North, North-East: sub-area of knowledge – medicine, nursing, dentistry, pharmacy, psychology, nutrition, biology, education, social services, anthropology, communication, multi-professional, speech therapy, physiotherapy: type – review, reflection, experience reports, research: nature – clinical-epidemiological, socio-cultural, political: and tendency – care, prevention, protection, epidemiological surveillance), based on a model of systematization of academic and scientific production adopted by the Coordination for the Improvement of Higher Education Personnel (CAPES).

To identify the specific nature of the scientific productions, key words were used, based on the MEDLINE descriptors: a) *clinical-epidemiological*: viral load, opportunist infection, co-infection, diagnosis, treatment, therapy, immunology, prevalence, epidemiological index, epidemiology; b) *socio-cultural*: relations, social support, legislation, human rights, prejudice, discrimination, attitudes and practices in health, knowledge, perception, behavior; c) *policy*: evaluation of results, evaluation of programs and projects in health, health services, health education, and health promotion.

With the data obtained, comparison was made with the productions' periods of publication, thus producing a five-yearly distribution. The results are presented in the form of absolute and relative frequencies, illustrated in tables and graphs. The determination of the nature and tendency are grounded in the assumptions of thematic content analysis.<sup>12</sup>

## Results

The corpus of the analysis was 121 articles. The specificity of the productions was analyzed by origin, sub-area and type. It was ascertained that the area of Brazil standing out in terms of

originating these productions was the South-East (60.3%). Regarding the sub-areas of knowledge, a concentration of studies in medicine was observed (32.2%). (Table 1).

**Table 1.** Distribution of the issues of AIDS in childhood (AC) and AIDS in adolescence (AA), by region of origin and sub-area of knowledge of the scientific production. Brazil, 1983-2010

Variables	Issues		
	% AC (n=71)	% AA (n=50)	% Total (n=121)
Region of origin of Scientific Production			
South-East	67.6	50.0	60.3
South	25.4	14.0	20.7
North-East	5.6	22.0	12.4
Center-West	1.4	12.0	5.8
North	0.0	2.0	0.8
Sub-area of knowledge			
Medicine	42.3	18.0	32.2
Nursing	11.3	36.0	21.5
Psychology	7.0	22.0	13.2
Dentistry	18.3	0.0	10.7
Multiprofessional	18.3	22.0	19.8
Communication	0.0	2.0	0.8
Speech therapy	1.4	0.0	0.8
Physiotherapy	1.4	0.0	0.8

The scientific production's distribution, in line with the variable 'type of study', shows that in the decade of the 1980's there was a balance between the experience reports (50.0%) and research studies (50.0%). From the decade of the 1990's onward, research increasingly stood out (98%). The productions' five-yearly distribution shows significant growth: 1983-1987 (0.8%), 1988-1992 (0.0%), 1993-1997 (7.5%), 1998-2002 (19.1%), 2003-2007 (42.5%), 2008-2010 (30.0%).

Regarding the nature, it was ascertained that in the clinical-epidemiological nature the studies covered the diagnostic, therapeutic and prognostic

issues of morbidity and mortality; in the socio-cultural nature, they involved historical, social and cultural questions relevant to the information and interventions; and in the political nature, they included aspects inherent to planning, implantation, implementation and evaluation of the health actions. In the productions' distribution in the sub-areas of knowledge, it was observed that texts originating from medicine and dentistry were characterized, essentially, as clinical-epidemiological, while those from nursing and psychology were characterized as socio-cultural. The studies analyzed that covered the age range of childhood indicated a tendency of care, and

a clinical-epidemiological nature (Table 2). The studies carried out in the age range of adolescence

indicated a preventive tendency and a socio-cultural nature (Table 3).

**Table 2.** Distribution of the issue of AIDS in childhood and in adolescence, according to productions' tendency, by period of publication. Brazil, 1983-2010

Issue	% 1983- 1987	% 1988- 1992	% 1993- 1997	% 1998- 2002	% 2003- 2007	% 2008- 2010	% Total
Childhood (n=71)							
Care	2.8	0.0	8.5	12.7	29.6	21.1	74.7
Prevention	0.0	0.0	0.0	0.0	0.0	1.4	1.4
Protection	0.0	0.0	1.4	2.8	7.0	12.7	23.9
Epidemiological surveillance	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Total	2.8	0.0	9.9	15.5	36.6	35.2	100.0
Adolescence (n=50)							
Care	0.0	0.0	0.0	6.0	10.0	10.0	26.0
Prevention	0.0	0.0	4.0	18.0	40.0	10.0	72.0
Protection	0.0	0.0	0.0	0.0	0.0	2.0	2.0
Epidemiological surveillance	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Total	0.0	0.0	4.0	24.0	50.0	22.0	100.0

**Table 3.** Distribution of the issue of AIDS in childhood and in adolescence according to the scientific productions' nature, by period of publication. Brazil, 1983-2010

Issue	% 1983- 1987	% 1988- 1992	% 1993- 1997	% 1998- 2002	% 2003- 2007	% 2008- 2010	% Total
Childhood (n=71)							
Clinical-epidemiological	2.8	0.0	8.5	15.5	21.1	22.5	70.4
Socio-cultural	0.0	0.0	1.4	0.0	14.1	12.7	28.2
Political	0.0	0.0	0.0	0.0	1.4	0.0	1.4
Total	2.8	0.0	9.9	15.5	36.6	35.2	100.0
Adolescence (n=50)							
Clinical-epidemiological	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Socio-cultural	0.0	0.0	4.0	22.0	42.0	22.0	90.0
Political	0.0	0.0	0.0	2.0	8.0	0.0	10.0
Total	0.0	0.0	4.0	24.0	50.0	22.0	100.0

## Discussion

The findings related to the specific characteristics of the publications indicate a significant level of scientific production in the South-East region of Brazil, compared to the other regions of the country. The sub-areas of medicine, nursing, psychology and dentistry stood out among publications in health. The linking of these productions to the Post-Graduate Programs and to the Research Groups, of each sub-area, is explained by the interest and motivation of the researchers. The issues located the issue of AIDS in childhood and in adolescence in the clinical-epidemiological sense as part of the general context of the epidemic, in addition to responding to its socio-cultural and political demands. The greater systematization of those productions is owed to the fact that the states of São Paulo and Rio de Janeiro possess a higher concentration of research institutes and universities, these being recognized as centers for production of knowledge;<sup>13</sup> they developed partnerships and agreements with foreign institutions;<sup>14</sup> and, historically, they have responded to the influences of social movements and non-governmental organizations (NGO).<sup>15</sup> The higher concentration of research institutes and universities may be visualized by the distribution of the 434 *stricto sensu* Post-Graduate programs of the sub-areas of knowledge in the area of health in the South-East region (63%), followed by the South (17%), North-East (13%), Center-West (4%) and North (3%).<sup>16</sup>

In relation to the South-East region's recognition as a center of knowledge production, exploratory studies on scientific production in HIV/AIDS with other human groups have associated this phenomenon with the excellence of post-graduate courses and research centers of Brazil.<sup>17,18</sup> In these programs, the research groups can rely on a contingent of researchers and financial resources for this end, with a predominance of the clinical-epidemiological areas.<sup>19</sup> This explains, in part, why productions originating from medicine and dentistry are characterized as clinical-epidemiological. It stands out that productions

from nursing and psychology are characterized as socio-cultural, as some of their study objects are located in the social and human sciences. The consolidation of partnerships and agreements with foreign institutions is associated with the public competition for solicitation notices for financing research, published by international promotion bodies.<sup>20,21</sup>

One can add to this matter the Brazilian solicitation notices published by the National STD/AIDS Program, which formulates and fosters public policies on the issue. These grants were significantly characterized by support for research projects in the South-East region, implemented by Groups and Centers consolidated in the South-East region.<sup>22</sup>

The influence of the social movements and NGO's, through actions confronting the epidemic, made it possible to confer social visibility, initially, on the group of people who have HIV/AIDS and, later, on the group composed of children and adolescents.<sup>23,24</sup> The social mobilization and the greater presence of NGO's in the South-East region had a strong impact on the production of studies with investment and financing from federal bodies. Thus, the concentration of production in the South-East region strengthens the development of policies for the prevention of infection, for protection, and for health care for children and adolescents.<sup>25</sup> The implantation of strategies and actions organized in the form of projects, policies and programs took place first in the state ambit, later extending to the national plane.<sup>26</sup>

In the chronology of Brazilian scientific production, the first two publications in the decade of the 1980's were convergent with the beginning of the epidemic and the first cases of transmission of HIV through the bloodstream or by vertical transmission. In 1987, a clinical case study article was published on a hemophilic child, revealing the risk in blood transfusions and the need for controls in the blood banks. In the same



year, an article was also published regarding the prevalence of HIV antibodies in street children in the city of São Paulo. The first study found relating to AIDS in adolescence dates from 1995, and deals with the extent of information, attitudes and representations on the risk, and prevention of, AIDS in low-income adolescents in Rio de Janeiro. Only in 1997 does one find a study including the HIV sero-positive adolescent. Thus, in the epidemic's second decade, there is an emphasis on field research, possibly because the increased growth in production can be related to the implementation of the Post-Graduate Programs and the financing of research by national and international bodies.<sup>27,28</sup>

In relation to the study's natures and tendencies, the results showed the productions' consonance with the quantitative and qualitative evolution of the epidemic in Brazil.<sup>29</sup> In this regard, those productions followed the children's and adolescents' health needs and contributed to the creation of responses to the care requirements at a primary and secondary level.<sup>30</sup>

The issues of HIV/AIDS, investigated in the age range of childhood, indicated a care tendency, with a clinical-epidemiological nature, showing the importance and the link with the historical and epidemiological context of pediatric AIDS in Brazil.<sup>31</sup> These characteristics revealed the concern with the risk factors for infection with HIV in children and sought to estimate across Brazil the dimension of the cases of infection in minors below 13 years of age.<sup>32</sup> There followed investments in the development of a specific protocol for prophylaxis against vertical transmission; diagnostic methods; laboratory studies of co-infections; clinical-laboratorial parameters; medications for ARVT; and prophylaxis of opportunistic infections.<sup>33</sup>

The promising results in the clinical-epidemiological areas of the health of the children who have HIV/AIDS evidenced the need for investigation of the cultural diversities, social conditions and the evaluation of the actions carried out.<sup>34</sup> Consequently, from the second decade on, an increase in socio-cultural and political studies was observed. The care tendency reveals the

commitment to the search, initially, for the clinical comprehension of the infection and the illness, and its implications in childhood.<sup>35</sup> The care tendency and the clinical-epidemiological nature entailed in these productions situate the matter of the child with HIV/AIDS in the theoretical-analytical category of clinical weakness, due to her immunodeficiency and the higher risk of illness.<sup>36</sup> From the very beginning of their lives, these children have special health needs, with multiple care demands on the health services and their family caregivers, and in particular for permanent multiprofessional monitoring in a specialized health service and dependence on medications.<sup>37</sup> In Brazil, these health factors include these children in the group of children with special health needs (CRIANES).<sup>38-40</sup> These children's childhood is experienced in the midst of the challenges of the exposure to the infection by HIV, of the immunodeficiency, of the illness' symptomatic manifestations, of the morbidity and mortality from AIDS or co-infections, and of (re-) hospitalization.<sup>41</sup> To the other questions associated with the disease, one can add the necessity of a routine of drug therapy, in which compliance with the treatment is imperative for it to be effective, and which has consequences of side effects and therapeutic limits.<sup>42</sup>

Concerning the issue of HIV/AIDS in the age range of adolescence, the preventive tendency of the socio-cultural nature shows consistency with the context in which the epidemic is inserted in this segment of the population. These specifications revealed the concern with the carrying-out of preventive actions regarding the main categories of exposure within this population – sex and the use of injected drugs. Investments in preventive policies in high-risk populations followed, along with harm-reduction policies, and educational actions related to safe sex, so as to reduce the rates of morbidity and mortality. The studies seek to understand the representations, the behaviors, the feelings, the relationships, and the information on the adolescents, so as to propose strategies for preventing the transmission of HIV.<sup>43,44</sup> Among the adolescents, the discussion is grounded in their vulnerability, in particular regarding sexuality,

drug use and violence.<sup>45</sup> These situations of risk characterize this phase in human development.<sup>46</sup> The preventive tendency of socio-cultural nature involved in these productions places the issue of adolescents with HIV/AIDS in the theoretical-analytical category of social vulnerability.<sup>47</sup> This populational segment's needs encompass the requirements of the phase of transition in human development;<sup>48</sup> a broadening of the environment of interpersonal relationships from the family circle to peer groups;<sup>49</sup> the access to health services;<sup>50</sup> access to information on sexuality, and means of preventing HIV/AIDS, among others.<sup>51</sup>

## Conclusions

The results evidenced that the studies on childhood are of the care tendency and of clinical-epidemiological nature, as opposed to those describing adolescence, which are of the preventive tendency and socio-cultural nature. The analysis of the specificities of Brazilian scientific production on HIV/AIDS in childhood and adolescence, published between 1983 and 2010 indicated that some articles dialogued with public policies on protective, preventive, care, and epidemiological surveillance actions. The directive on knowledge gave visibility to new questions necessary to the development of scientific investigations, extending this area's set of knowledge.

The influence of Brazilian public policy is the expression of partnership established between the government and civil society in confronting the syndrome. The broadening of prevention and care allowed the facility of access to health, the guarantee of access to preventive materials and the efficiency in the approaching of specific populations and minorities. These results of Brazilian policy are evident in the scientific productions on the issue of HIV/AIDS in childhood and adolescence. In relation to the directive on knowledge, the set of productions investigated infected children and exposed adolescents and indicated the possibility of rethinking the children

and adolescents who have HIV/AIDS as part of the CRIANES group due to their clinical weakness and social vulnerability. The studies' epistemological recurrence reflected advances and widened knowledge regarding the clinical-epidemiological, socio-cultural and political dimensions, without, however, encompassing the existential dimension of the child-being and the adolescent-being who has HIV/AIDS. In this regard, the need was evidenced to continue carrying out investigations relating to the phase of childhood and adolescence, as much of those who have HIV/AIDS as of those who are vulnerable to infection in their multiple dimensions. In addition to continuing with studies which investigate compliance with treatment and the diagnostic disclosure in this study population, the need is stressed to give visibility to the other questions: the presence and influence of the NGOs in health care and in the rights of children and adolescents who have HIV/AIDS; the epidemiological surveillance of AIDS in children and adolescents; already-infected or ill adolescents, and the children who have AIDS through vertical transmission and who are in the transition from infancy to adolescence.

The study's limitations refer to the use of two databases, and to the search strategy that provided a view of the field, which converges with the cut-off point and the analysis of Brazilian production.

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