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## Affectation Situation of HIV/AIDS in Colombian Children

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### 1. Introduction

Acquired immunodeficiency syndrome (AIDS) is a global emergency and one of the most formidable challenges to human life and human dignity. The Declaration of Commitment on HIV/AIDS, adopted unanimously by the member states of the United Nations at the Special Session of the General Assembly (UNGASS) in New York and the Millennium Declaration, adopted by 189 nations and signed by 147 heads of state and government called for global action to build a global response to HIV/AIDS. (United Nations General Assembly Special Session on HIV/AIDS [UNGASS], 2001).

Globally, the number of children under 15 living with HIV has increased from 1.6 million [1.4 million – 2,1 million] in 2001 to 2.0 million [1.9 million-2, 3 million] in 2007, while young people between 15 and 24 represent an estimated 45% of new HIV infections worldwide. (Joint United Nations Programme on HIV/AIDS [UNAIDS] & World Health Organization [WHO], 2007).

With an adjustment in early 2006, the National Institute of Health (NIH) reported 54,805 cases of Colombian HIV infection and AIDS. The general behavior of the notification has been toward increased, with the rate for the period 1983-2005 to 5.36 cases per 100,000 population and for the last decade 1995-2004 to 7.85 cases per 100,000 population. The reported annual incidence should be used with caution in response to underdiagnosis, the underreporting and delayed reporting that characterized the passive surveillance of HIV/AIDS in the country. (Programa Conjunto de las Naciones Unidas sobre el VIH/SIDA [ONUSIDA] Grupo Temático para Colombia & Ministerio de la Protección Social de Colombia Dirección General de Salud Pública, 2006).

This chapter aims to analyze the situation of involvement for HIV/AIDS in Colombian children based on a study conducted in five cities - Colombian regions: (1) Barranquilla, Santa Marta and Cartagena, (2) Cali and Buenaventura (Instituto Colombiano de Bienestar Familiar [ICBF], Save the Children, Unicef & Universidad del Norte, 2006). The study shows that the delivery of HIV/AIDS diagnosis in children affected is not an established practice in the Colombian context. The low rate of disclosure indicates that within the integrated health management is a priority to develop strategies or clinical models of revelation that support processes of professionals who provide health services to affected families.

This project arose from the need to understand the situation of involvement and quality of life of children and adolescents seropositive for HIV in five Colombian cities, to articulate and assess the scope of the public policies at the time. Our study included children under 18

years of age with three situations of HIV/AIDS affectation: (1) children seropositive or seronegative for HIV, orphans HIV/AIDS (father, mother or both who had died from the disease), (2) children seropositive for HIV and, (3) children seropositive or seronegative for HIV, having lived with HIV positive people.

In 2006, only (3.8%) for 11 children in five Colombian cities were aware of their diagnosis of HIV/AIDS seropositivity compared with [96.2% (n=275)] who were unaware of the situation of HIV/AIDS affectation. The reasons for delaying the delivery of diagnosis that were reported by health professionals and caregivers of affected children, are related to prevent psychological harm or emotional stress to the child; situations cause fear of stigmatization and discrimination against the inadvertent disclosure of the child to others, and lack training regarding the procedure and age to provide this information by professionals providing health services to these children.

Furthermore, due to the importance of quality of life related to health (HRQOL) of children and their caregivers affected in the diagnosis, care and treatment of HIV/AIDS, the chapter will also address the evaluation of the following dimensions of quality of life: (1) Mobility, (2) Personal Care, (3) Activities of Daily Living, (4) Pain/Discomfort and (5) Anxiety/Depression using EuroQol (EQ-5D) instrument, as necessary to make decisions regarding front the care of these children.

Although current antiretroviral treatments managed to increase survival and quality of life of people affected by HIV/AIDS, it is also true that as a chronic disease requiring ongoing treatment, not exempt of adverse effects, to which should be add an important psychosocial impact. Based on this, relevant psychosocial variables have been also analyzed, such as family function instrument employing the Family Apgar and the perception of social support both children and their caregivers using the instrument Social Support (MOS) and scan variables Clinic children were seropositive for HIV/AIDS, which are also explored throughout this chapter.

Similarly results are displayed on the levels of information about the disease who have children who are aware of their diagnosis of HIV/AIDS seropositivity, as well as the caregivers of children who are still unaware of their situation involvement, which will allow to assess the degree of knowledge or misinformation that has this affected population and how can this affect or not confronting the diagnosis. In the same way, will address findings related to usage patterns and access to health services and education which will show that the health and education services in the Colombian context must overcome some obstacles in ensuring not only access to care but also increase the availability, fairness, integrity and quality from the perspective of rights and in order to benefit the child population under 18 years affected with HIV/AIDS.

This will be discussed by combining data from both quantitative and qualitative methodology, provided by the research tools employed and by the focus groups conducted with: (1) children who are aware of their diagnosis of HIV/AIDS, (2) caregivers of children who know their status of involvement for HIV/AIDS and (3) Professionals who provide health services to children affected population, which contain relevant evidence that allow further appreciation of the difficulties felt by the affected children in our country.

## **2. Illness status disclosure to children with HIV/AIDS**

One of the factors that most worries the caregivers of children with HIV and professionals who provide health services is the issue of who, when and how they will reveal to the child

that he/she has a chronic and stigmatizing disease that requires demanding treatment and involves the issue of death. (Nagler et al., 1995) explain that the HIV/AIDS carries stigma, which has profound psychological, social and emotional implications for the sufferer. For this reason, too many families make the decision to hide the child's HIV diagnosis, including members of the same family.

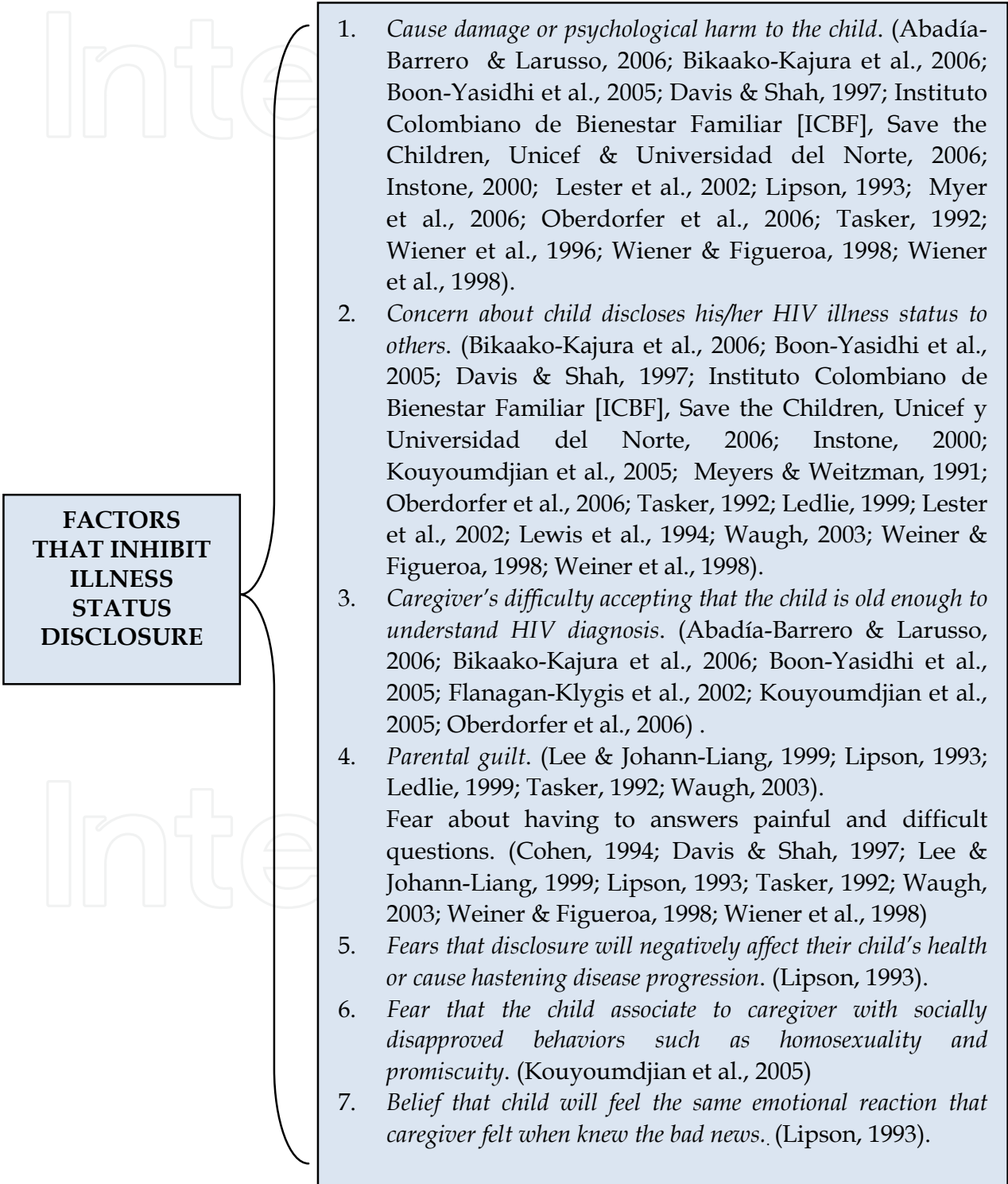


Fig. 1. Factors that inhibit illness status disclosure to children with HIV/ AIDS.

Colombian caregivers were afraid that the child would get depressed, be isolated, anxious or worried about having this chronic disease. Caregivers also fear that once the illness status is disclosed, the child will tell others, which will lead him and his family to situations of stigma and discrimination with potentially serious consequences such as expulsion from residence, school, and refusal to play with the child, among others. Similarly, professionals who provide health services to these children showed a lack of consensus on the procedure and age for disclosing illness status.

Researchers found that children were aware of their illness and impending death, despite their parent's stance of protective communication. (Hardy et al., 1994). Given the number of visits they make to the hospital or clinic and the acquaintances they meet, complete unawareness by a certain age is doubtful. Although kept in secrecy, children often showed curiosity or knowledge about their treatments (Lee & Johann-Liang, 1999). They may listen in on a conversation about AZT treatment between the doctor and their parent or ask other patients about their condition (Lipson, 1993). The stigma of HIV/AIDS leads families to keep the diagnosis secret from the child, other family members and schools.

The American Academy of Pediatrics guidelines for the illness status disclosure to children and adolescents with HIV infection says it is imperative that all adolescents have knowledge of their illness status and that disclosure should be considered for children under school age according to their level of cognitive development, age, family dynamics, psychosocial maturity and other clinical variables (Committee on Pediatric AIDS [COPA], 1999).

Disclosure of HIV diagnosis to children is becoming increasingly important because antiretroviral therapy becomes more widely available, however internationally rates of disclosure seem to be low. Some factors can inhibit and facilitate the decision making of caregivers to disclose illness status to their children with HIV/AIDS (See Figure 1).

Disclosure of HIV diagnosis should be viewed as a process, rather than an event, it is related to the child's cognitive development and aims to provide him/her with age appropriate information.

### **3. Health-Related Quality of Life (HRQOL) in children affected with HIV/AIDS**

Advances in HIV treatment have allowed that quality of life of people affected with HIV/AIDS increased. Quality of Life related to Health subscales provides an overall vision of health and allows make important decisions about patient care. To have a benchmark of the health status of the pediatric patient should be a priority for institutions that provide health services.

For this reason we use EuroQol (EQ-5D) to estimate how Colombian caregivers perceive the Health-Related Quality of Life of their children. EQ-5D is a standardized instrument for use as a measure of health outcome. Applicable to a wide range of health conditions and treatments, it provides information about mobility, self-care, usual activities, pain/discomfort and anxiety/depression.

Results shows in Mobility subscale that 94.4% (N=269) of children with HIV/AIDS do not have trouble walking, 5.6% (N=17) have some problems or confined to bed. In Self-Care subscale, 96.1% (N=275) do not have problems bathing or dressing; 3.9% (N=11) of children have some problems or are unable to bathing or dressing. In Usual Activities subscale results shows that 96.1% (N=275) do not have problems to perform their usual activities, 3.9% (N=11) of children have some problems or are unable to perform their usual activities. In Pain/Discomfort subscale caregivers perceive that 84.6% (N=242) of their children do not



have pain or discomfort, however 15.4% (N= 44) of children have some problems or may be experiencing pain and discomfort. Finally, caregivers perceive that 90.2% (N=258) of their HIV-positive children do not have anxiety or depression while 9.8% (N=28) may be experiencing anxiety or depression according to caregiver’s report (See Table 1.)

Health-Related Quality of Life N=(286)	No Problems		Some Problems		Confined to bed/Unable to Perform	
	F	%	F	%	F	%
Mobility	269	94.4%	16	5.2%	1	0.4%
Self-Care	275	96.1%	7	2.5%	4	1.4%
Usual Activities	275	96.1%	8	2.9%	3	1%
Pain/Discomfort	242	84.6%	40	14%	4	1.4%
Anxiety/Depression	258	90.2%	25	8.7%	3	1.1%

Table 1. Health-Related Quality of Life (HRQOL) in Colombian children affected with HIV/ AIDS measured by their caregivers.

The above results indicate that Colombian children affected with HIV/ AIDS have a good level of health. Worth noting that all these children are affiliated to the social security health and are receiving Highly Active Antiretroviral Treatment (HAART). However, the highest percentage of problems found in Pain/Discomfort subscale with 15.4% of children who have some problems or may be experiencing pain and discomfort according to caregiver’s report. (The World Health Organization [WHO], 2003) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. It follows that measurement of health must not only include estimates of the frequency and severity of diseases, but also well-being and quality of life. This is particularly true for patients with HIV/AIDS because of the chronic and debilitating nature of the illness, stigma, and a high rise of premature death (Nojomi et al., 2008).

4. Family Functioning and social support in families affected with HIV/AIDS

Family Functioning play a very important role in coping with HIV illness. Understanding aspects of this interaction between children’s health and their family is important to keep and increase quality of life, coping and adherence to treatment, well-being and psychological adjustment for a HIV-positive child. A family with good parental relationships would mean the family members are willing to solve problems together, showing concern for each other, and there will be fewer quarrels. In this sense, it is necessary for a child with a chronic illness such as HIV could find in his/her family some solid foundations that allow him/her to deal with this diagnosis. For estimated this variable, we used Family Apgar to assess a family member’s perception of family functioning by examining his/her satisfaction with family relationships. 73.8% (N=211) of Colombian children are in a norm functionality family. This mean, responder’s perception about his/her family has the basic features to be functional and harmonic in the domains: adaptation, partnership, growth, affection and resolve. 18.2% (N=52) of families

affected with HIV/AIDS report moderate dysfunction while 8% (N=23) families report severe dysfunction (See Table 2).

In every family has a complex dynamic patterns governing their living and functioning. Of this dynamic is appropriate and flexible, in other words, functional, contribute to family harmony and provide its members the ability to develop strong feelings of identity, safety and welfare (Sherbourne & Stewart, 2003; Cohen et al., 1985).

Family Functioning N=(286)	F	%
Norm Functionality	211	73.8%
Moderate dysfunction	52	18.2%
Severe dysfunction	23	8%

Table 2. Family Functioning in families affected with HIV/AIDS.

Interest in the concept of social support has increased dramatically over the last few years, due to the belief that the availability of support may impact favorably on a person’s health and emotional well-being (Sherbourne, 1988). Consider the psychological impact of HIV/AIDS social support may play a small but potentially important role in helping HIV-positive people to cope with illness.

(Leserman et al., 1992) found that subjects primarily coped with the threat of AIDS by adopting a fighting spirit, reframing stress to maximize personal growth, planning a course of action, and seeking social support; satisfaction with one's social support networks and participation in the AIDS community were related to more healthy coping strategies (e.g., fighting spirit, personal growth). These results suggest that health professionals should encourage more adaptive coping strategies, help the patients to use existing sources of positive social support, and assist patients in finding community support networks.

The availability of someone to provide help or emotional support may protect individuals from some of the negative consequences of major illness or stressful situations (Barrera, 1981).

Investigators (Brandt & Weinert, 1981; Brown & Brady, 1987; Broadhead et al, 1988; Cohen & Syme, 1985; Cohen & Wills, 1985; Duncan-Jones, 1981; House & Kahn, 1985; Norbeck et al., 1981; Reis, 1988; Sarason et al., 1983) have attempted to measure the functional components of social support under the belief that the most essential aspect of social support is the perceived availability of functional support. (Cohen & Hoberman, 1983; House & Work, 1981; Wills, 1985). Functional support refers to the degree to which interpersonal relationships serve particular functions.

The functions most often cited are (1) emotional support which involves caring, love and empathy, (2) instrumental support (referred to by many as tangible support), (3) information, guidance or feedback that can provide a solution to a problem, (4) appraisal support which involves information relevant to self-evaluation and, (5) social companionship, which involves spending time with others in leisure and recreational activities. (Ahumada et al., 2005; Fleming et al., 2004; Gill et al., 2002; Sherbourne, 1988).

A 20-item MOS questionnaire was administered to all participants. This questionnaire limits the evaluation scale of the entire network of the interview subjects; participants performed their social support excluding people that do not have a good relationship. Four degrees of functional social support (Call et al., 2000): An emotional/informational, tangible, affectionate, and positive social interaction were administered and shows a Global Index of

families affected with HIV/ AIDS. 74.1% of families have a maximum social support, 22.7% have a medium social support and 3.1% have a minimum social support (See Table 3).

Social Support N=(286)	F	%
Maximum	212	74.1%
Medium	65	22.7%
Minimum	9	3.1%

Table 3. Social Support in families affected with HIV/ AIDS.

5. Clinical status of children with HIV/AIDS

Health-related quality of life (HRQOL) is increasingly recognized as an important measure for assessing the burden of chronic diseases (Hays et al., 2000). HIV-specific parameters, such as low CD4 cell count and high virus load, have previously been shown to adversely affect HRQOL in some studies of HIV-infected patients (Casado et al., 2011; Niuwerk et al., 2001). Other studies show weak HRQOL associations with disease stage and CD4 cell count (Niuwerk et al., 2001). Similarly, the effect of HAART on HRQOL has been assessed with some studies (Call et al., 2000).

According to international definitions on the concept of childhood affected by HIV/ AIDS, participating minors must comply with the following affectation categories as criteria of population inclusion, nonexcluding amongst themselves: 1. HIV/ AIDS seropositive and/or seronegative children, and adolescents, orphaned by HIV/ AIDS (father, mother, or both deceased because of the disease). 2. HIV seropositive children and adolescents. 3. HIV seropositive and/or seronegative children and adolescents, cohabitating with HIV seropositive individuals.

80 children were HIV-positive in five Colombia cities. 80% (N=64) were receiving antiretroviral therapy and most 34.9% (N=30) had HIV load undetectable or low 20% (N=15) (See Table 4). As we mentioned earlier, Colombian children affected with HIV/ AIDS have a good level of health because all these children are affiliated to the social security health and are receiving Highly Active Antiretroviral Treatment (HAART); 80% (N=64) children are receiving HAART (See Table 4).

Viral Load N=(80)	F	%
High	10	13.8%
Medium	8	10%
Low	15	20%
Undetectable	30	34.9%
Unclassified	17	21.3%
Antirretroviral Therapy (N=80)	F	%
YES	64	80%
NO	14	17.5%
Unknown	2	2.5%

Table 4. Viral Load and Antiretroviral Therapy in HIV-positive children.



6. Health service utilization and barriers to health services in children with HIV/AIDS

The results of this investigation shows the dynamics of the demand of services by children affected with HIV/ AIDS, and the information will be useful in planning and organizing care for families with HIV. We found in Colombian families affected with HIV/ AIDS a pattern of frequent use (50.8% N=145) of the health service (See Table 5).

Health Services Utilization (N=286)	F	%
Frequent	145	50.8 %
Regular	74	25.9 %
Occasional	37	12.9 %
Sporadic	30	10.4 %

Table 5. Health Services Utilization in Colombian families affected with HIV/ AIDS.

Families affected with HIV have to face some barriers in health service provision such as: Arrival Time to heath service (half hour to an hour or more than an hour) 60.4% (N=138); Waiting Time exceeding 30 minutes in 53.8% (N=154) and 85.7% (N=245) of the children affected are not receiving Home Care even though they needed it; Health professional argue against this latter finding that caregivers do not provide personal information for fear of discrimination (See Table 6).

No significant results were found for other barriers explored: Respectful and Friendly Service; Discretion and Confidentiality Service; Subsidizes Antiretroviral Therapy; Acquisition of Antiretroviral Therapy with own money and Transportation, however many of the families reported in the focus groups did not have resources for transportation to health service (See Table 6).

Barriers to Health Services	Category	N	%
Arrival Time (N=286)	Less than half an hour	148	51.7%
	Half hour to an Hour	102	35.7%
	More than an Hour	36	12.6%
Transportation (N=286)	One Bus	127	43.6%
	More than one Bus	25	9.1%
	Mototaxi	35	12.5%
	Particular Transport	29	10.5 %
	Other: (walking; bike)	70	24.3%
Waiting Time in Service (N=286)	Immediately (15')	39	13.6%
	Family should wait (15' A 30')	93	32.6%
	More than 30'	154	53.8%
Respectful and Friendly Service (N=286)	Yes	259	70.6%
	No	26	29.1%
	Sometimes	1	0.3%

Barriers to Health Services	Category	N	%
Discretion and Confidentiality Service (N=286)	Yes	265	92.7%
	No	20	7%
	Sometimes	1	0.3%
Home Care (N=286)	Monthly	4	1.4%
	2 to 3 months	14	4.9%
	Every 6 months	7	2.4%
	1 time per year	16	5.6%
	Never	245	85.7%
Entity that subsidizes Antiretroviral Therapy (N=64)	Subsidized by the foundation	4	6.5%
	Subsidized by the health lender (EPS)	6	10.4%
	Subsidized insurance scheme (ARS)	33	50.6%
	Subsidized by distrital or departamental health secretary	21	32.5%
Acquisition of Antiretroviral Therapy with own money (N=64)	Yes	4	6.7%
	No	60	93.3%

Table 6. Barriers of Health Services in Colombian families affected with HIV/ AIDS.

87.4% of Families affected with HIV reports that health attention has not been denied (See Table 7).

Denial of Health Services (N=286)	F	%
YES	36	12.6 %
NO	250	87.4 %

Table 7. Denial of Health Services in Colombian families affected with HIV/ AIDS.

7. Conclusion

The low rate of disclosure of HIV status to children found in the study indicates that it is a priority to develop disclosure clinical model in the Colombian context. For this reason since 2008 our institution is conducting the investigation: “Evaluation of the effects of a disclosure clinical model in HIV-positive children 7 - 18 years old in adherence to treatment and psychological adjustment”. Research Project awarded with the Fellowship for Research from the Department of Research and Projects. Awarded in the 2008 Call for Proposals for Doctorate Programs at Universidad del Norte

This research aims to provide a clinical model to help affected families overcome fears that lead them to delay the delivery of HIV diagnosis. Mainly, caregivers want to avoid psychological or emotional harm to child and they fear that child tell the diagnosis to others and be discriminated against.

According to the above, health professionals do not know for sure at what age a child should know their HIV diagnosis. Some believe that at 10 years a child is old enough to manage this information. Some believe that children should learn about biosecurity practices and adherence to treatment without knowing the diagnosis in a playful way, through stories, comics and other fun techniques. Health professionals recognize that children perceive that something happens with his/her bodies by going through periods of illness and drugs.

Caregivers and health professionals explain to children that drugs are for flu, pneumonia, heart problems, fever and other low-impact diseases, but do not tell the child that he/she has HIV/AIDS.

Colombian families interviewed showed a positive degree of satisfaction with Family Functioning and Social Support. Children have good quality of life, low virus load and have access to Antiretroviral Treatment. Some barriers were identified in health services utilization.

On the other hand, we consider important to offer some recommendations to access to Colombian children affected with HIV/AIDS. Not all health services in the Colombia cities have pediatrics patients with HIV. Once identified health services, health teams evaluate the research protocol, this assessment could take 2 or 3 months. Also, it is important to know that caregivers take children to health services once a month and informed consent must be obtained through a detailed explanation of the research and get his/her signature as the child's legal representative.

Health services should provide to researches a private place for interviews. Many health services were not including in this study for lack of such space.

This type of researches must have a budget to be allocated to pay transportation costs of caregivers and HIV-positive children. These families have economic limitations to move to health services.

Another recommendation is to consider extending the running time for such studies because of the difficulties identified in the location and recruitment of subjects.

## 8. Acknowledgment

The authors acknowledge the support of the financial organizations and especially the willingness of those who made this study possible: children and adolescents affected by HIV/AIDS and caregivers of the five cities: Cali, Buenaventura, Barranquilla, Santa Marta y Cartagena.

Moreover, we extend our heartfelt thanks to all institution that offer services to families affected with HIV/AIDS, especially those who were agreed to cooperate with aims of this research:

In Cali city: Emsanar, Lila Mujer, Fundamor and Casa Gami.

In Buenaventura city: Fundación Si Buenaventura.

In Barranquilla city: Fundación François Xavier Bagnoud, Fundación Esperanza por la Vida, Susalud EPS, Fundación Grupo Estudio Barranquilla and Unidad Especial de Salud y Ambiente (UESA).

In Santa Marta city: Heres Salud E.U., Fundación Luz de Esperanza and Sistemas Integrales de Salud de Colombia (SISCO).

In Cartagena city: Unidad Médico Quirúrgica, Fundación Amigos Positivos, Sistemas Integrales de Salud de Colombia (SISCO) and Vivir Bien.

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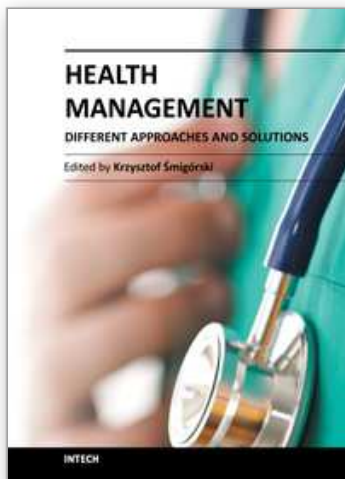
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Edited by Dr. Krzysztof Smigorski

ISBN 978-953-307-296-8

Hard cover, 498 pages

**Publisher** InTech

**Published online** 14, December, 2011

**Published in print edition** December, 2011

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### **How to reference**

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Ana María Trejos Herrera, Jorge Palacio Sañudo Mario Mosquera Vásquez and Rafael Tuesca Molina (2011). Affection Situation of HIV/AIDS in Colombian Children, Health Management - Different Approaches and Solutions, Dr. Krzysztof Smigorski (Ed.), ISBN: 978-953-307-296-8, InTech, Available from: <http://www.intechopen.com/books/health-management-different-approaches-and-solutions/affection-situation-of-hiv-aids-in-colombian-children>

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