

## Barriers in Health Care of Children with HIV

Alcides Troncoso<sup>1\*</sup> and Roberto Hirsch<sup>2</sup>

<sup>1</sup>Department of Infectious Diseases, Buenos Aires Medical University, Argentina

<sup>2</sup>Department of Infectious Diseases, Division of Pediatric Infectious Diseases and Global Health, Muniz Hospital, Buenos Aires State Department of Health, Argentina

\*Corresponding author: Alcides Troncoso, Department of Infectious Diseases, School of Medicine, University of Buenos Aires, Argentina, Tel: 5411 4861 1508; E-mail: [microbiologiayparasitologia@yahoo.com.ar](mailto:microbiologiayparasitologia@yahoo.com.ar)

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### Summary

This brief essay aims at identifying and analysing the barriers to adherence to treatment of children with HIV/AIDS in developing countries. The United Nations proposal and the perspective of human rights, especially the right to health, are the analytical framework to show the findings. From this perspective, the intrinsic relationship between health and the concept of well-being that includes individual and collective dimension of the right to health is recognized. No one is unaware that the right to timely and continuous treatment is a condition required for adhesion. This requires implementing a proper environment for adherence and successful treatment. Not always the barriers to the right to health of children with HIV infection are identified.

Half of the children with HIV in Argentina have lost one of their parents due to AIDS, and 25% have lost both parents. Currently, every year 140 new cases of HIV in children are reported, mainly by mother-child transmission, although current treatments can reduce this transmission to values close to zero. In Argentina, 5% of children under 5 years old are underweight, and 1.2% suffers from acute malnutrition (not including malnourished). Almost 50% of children live below the poverty threshold, and nearly half of them cannot meet their basic needs. A poor diet and sociocultural environment affect growth and intellectual development of children, reduce their resilience to disease, and aggravate social inequalities. As a result, it is found:

- A growing number of children with HIV/AIDS.
- It is a discriminated and marginalized population.
- Parents are often sick, with labour and social scarcity and a lot of them have already died.

Children have a weak support to keep their treatments over time, and therefore be able to live and grow with HIV infection [1]. Consequently, several inconsistencies can be mentioned: breach of basic human rights; insufficient food; and lack of confidence of children and their families with the health team and institutions that assist them [2]. Sometimes there is contempt and/or ignorance of most health professionals about the importance of an interdisciplinary and multidisciplinary approach, which has as its primary objective the respect for the basic rights of children to cope with treatments in a chronic disease that is not curable such as AIDS in childhood [3].

Care of children with HIV infection and their families has varied according to the implementation of new antiretroviral treatments and according to the processes promoted by the health team about the different ways of dealing with this problem. It is worth recalling that in the early onset of the disease, children lived a few years, and that is why professionals who were dedicated to their attention, mainly

doctors and psychologists, could only, at best, accompany them in this period, just trying to alleviate their pain [4]. The application of new treatments, apart from the permanent efforts to understand and accompany these families, turned the infection by HIV/AIDS into a chronic disease. The team was modifying a biologicistic way of attention, gradually strengthening a model aimed at the multi and interdisciplinary approach, increasingly focusing not only on how long the children lived, but also, and mainly, on how they lived. In this context, all disciplines are especially focused on a primary objective: the attempt to improve the quality of life of patients and their families, and, for this purpose, adherence to treatment [5].

Adherence to a treatment has been defined as "the degree to which patients take their medication as they were prescribed by the health care professional". The adherence rate for each individual patient is commonly defined as "the percentage of prescribed doses that are actually taken by the patient in a given period". Although adherence is, in general, considered exclusively as regards taking medication, adherence also takes into account other behaviours related to health care that go beyond the mere fact of consuming prescription medicines. Adherence to treatment in children is a great challenge in which factors related to patients, their caregivers and medicines must be considered. The formulation of an adherence plan and the possibility and desire of adherence of the child, the compliance strategy by their parents or caregivers, the commitment of the health team involved, as well as the monitoring as described, are essential steps for this adhesion [6,7].

The difference between the terms "adhesion" and "compliance" should be noted. The main difference is that adhesion requires patient compliance on the recommendations. In the term "compliance", which is focused on biomedical ideology, the patient is considered to be an achiever of the recommendations. Thus, in the traditional doctor-patient relationship, the child's behaviour is directed by the professional and does not presuppose an appropriate interaction and communication between them. Therefore, the concept does not take into account other important aspects such as the role of the family, representations of health, body and ailment of patients and their families, among others [8].

The term "compliance" was questioned because it involves pejorative judgments and emphasizes the failures of patients as regards medical indications. The term "adherence" seeks to highlight the patient's perspective, as a being able to make a conscious and responsible decision for treatment, which implies that he/she has the autonomy to accept or not medical advice [9].

Adherence is a primary determinant of the effectiveness of antiretroviral treatment. In transmissible chronic conditions such as HIV infection, good adherence to treatment was related to a slower clinical progression of the disease. One of the most important

consequences of poor adherence to treatment is the development of viral drug resistance. The emergence of resistance results, in terms of public health, in years of life lost by premature mortality and increased health care costs, which is attributable to preventable morbidity [10].

The initial approach covers basic information about HIV and its natural history, as well as the benefits and side effects of treatment. It is necessary to emphasize the difficulties in the ingestion of drugs, the importance of not omitting doses and the understanding and possibilities of commitment by the patient in relation to what was said before. It may be necessary in young children to use additional methods (for example: make them taste the medicine, train them in the intake of the tablets, teach caregivers to measure liquids, etc.). It is also important to adapt drugs to the lifestyle of the child and, if possible, harmonize drug regimens for children and adults of the same family [11].

Preparing children and/or caregivers for common side effects can facilitate a satisfactory adherence to treatment. During the first weeks of treatment, adherence may be essential for the long term success of an antiretroviral treatment, mainly in the case of some combinations that have a higher risk of generating resistance. Monitoring and constant support of adherence are vital components of an integrated approach to anti-retroviral treatment. The assessment of adherence should be performed in all controls and/or consultations, in order to identify children who need more help to achieve the best response to treatment. This is how adherence to antiretroviral treatment is a joint claim of all members of the health team to prevent some forms of resistance and preserving the effectiveness of the medication, and constitutes a factor of weakness in the administration and effects of antiretroviral drugs [7].

It is essential to distinguish early the factors that lead to poor adherence. In our experience, we have had to modify the significance we attach to the adhesion. At first, some years ago, the weight of adhesion was mainly related to families. Once the doctor had indicated treatment, what remained was to detect if the family did not cooperate, if so, he insisted with parents about it. The mission of the professional team was to prescribe. We wanted children to only open their mouth and assimilate well the drug [12].

Then it was time to assess the socioeconomic problems in which families were immersed, and give the growing material difficulties the importance of obstacle for continuing the treatment. It was no longer simply related to whether the child "takes or does not take" medicines, but if families had the resources to feed him and to fund the trips to the hospital for assistance, etc. This new vision required to build a link with other networks of support as neighbourhood centres or primary health care centres, near the patient's home. The life of children affected by the HIV virus, in very unfavourable family socio-economic conditions, entails innumerable efforts carried out by themselves and their families, who must overcome obstacles in their attempts to survive [13].

Finally, we decided that the conception of "adherence" not only involved the child as a subject of treatment, but, more critically, it made our work as a professional team problematic. There were two parallel processes. On the one hand, children made clear their desire to understand the nature of their illness, the reason of their hospitalization and/or the health status of their parents, and we received another horizon for the work of the health team. Moreover, it became imperative to rectify our simplistic approach as we found out that adherence is not simply the hand that gives a drug and the child's

mouth that swallows. A genuine adherence not only requires the understanding and trust of that child and his family.

Also, from the health team, we deepened our ability to detect the questions that the child may have [4,7,10]. That is, we have been transiting the passage from a traditional focus on doctor-patient relationship to another one involving a care for the respect of human rights of children and their families, and which forces the health team to have a different ethical position [14].

Taking into account certain characteristics in children and adolescents such as lack of psychic energy, lack of social integration, orphans, and foster families in poor living conditions led us to look for ways of increasing early intervention, and to analyse thoroughly the social determinants of adherence in this particularly vulnerable population. Furthermore, sometimes mothers delay entry into the educational system, contending fears: that their children infect others, discrimination or the fact of acquiring other diseases. We orient families to prevail the benefit that the law gives them about the anonymity of the disease. It is worth mentioning that families have no obligation to inform schools about the diagnosis, as in our environment it stigmatizes the child [2].

The identification of poor adherence helps to prevent unnecessary treatment changes. But this is not a simple task, especially when working with children. It is essential to make the children who are in "excellent" health aware of the need for compliance with a treatment in order not to "be sick". This paradoxical positioning, which is contradictory for children, requires good training of professionals to give solid answers [9].

It is necessary to advise mothers and other relatives who must cope, in most cases, with their own disease as well as with the demands for explanation from their children about their condition, about their continuous intake of medications and about not knowing the name of this disease. The interdisciplinary perspective allows us to understand that some confidence starts through making sense of the need for information. But lots of children avoid asking or are reluctant to dialogue. This position generally corresponds to families which keep the disease as an absolute secret. Anyway, the flow of information does not usually occur smoothly, and there is an attempt of concealment of the disease, even in the bosom of the family. In some cases, there are children who need to know about their illness and their parents do not allow them to be informed. On the contrary, it may happen that adults want to inform and children are not predisposed to know [14].

Always, in all cases, the interest and the benefit of the child are priorities. Information should be provided considering the uniqueness of the patient, modalities and cognitive resources. Children relate HIV infection to an immediate and specific disease that impacts their body. It is extremely difficult for them, as well as for adults, to imagine assumptions or representations of the virus.

In some families of children with HIV infection, economic and social difficulties are so severe, when it comes to survival, that even the HIV pathology is relativized [11]. All these difficult forms of interaction with the environment set up a path of social regression which, once it is settled, becomes very difficult to backtrack.

The socialization process is extremely important for all children, but it takes a special dimension in those who must add treatments throughout their lives. Undeniably, a person with an active social life will have motivations and resources that allow him to transform the condition of living taking medicines, as happened in the late 90s, into

taking medicines to stay alive and it is at this point that the fact of having an active social life becomes so important.

In several Latin American countries, the right to health is violated and the signing of several international agreements for the protection of the rights of children with HIV is breached. The defence of the right to health of children affected by the virus and creating conditions to facilitate adherence require to promote equity and better public health policies. It is necessary to increase their well-being and the economic independence of the families affected by the pandemic of HIV/AIDS, generate better income and defend their right to work for a decent life. Unfortunately, for more than two decades, Argentina is one of the countries of Latin America with the lowest scores in generating policies related to AIDS in childhood. In addition, it does not look acceptable that a public policy such as social security health is based on the market economy and nobody pays attention to social reality of thousands of people affected by the pandemic, including the children.

### Conflicts of Interest

None

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