

**CHILD WITH HIV/AIDS: PERCEPTION OF THE ANTIRETROVIRAL TREATMENT**

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**ABSTRACT**

This article presents a cutting from the multicentric study carried out in the municipalities of Porto Alegre and Santa Maria/ RS with the objective of unveiling the perception and the life experience of the child regarding the antiretroviral treatment. With qualitative approach, the study was carried out with seven children of five to ten years of age, in the period from 2006 to 2010, after approval by Committee National for Ethics in research and the Committees of Ethics in research. Based on the thematic analysis was obtained the results: the day-to-day life of the child with medicines; the family care upon the adhesion to the antiretroviral treatment; the professional care: perception of children with infection. Observation showed that the children face adversities, know and appreciate the treatment in spite of the paradoxical movement of rejection/acceptance expressed by the fight against the syndrome.

**Descriptors:** Acquired Immunodeficiency Syndrome. HIV. Child. Perception.

**RESUMO**

*Neste artigo, faz-se um recorte do estudo multicêntrico, realizado nos municípios de Porto Alegre e Santa Maria/RS, com o objetivo de desvelar a percepção e a vivência da criança quanto ao tratamento antirretroviral. Com abordagem qualitativa, o estudo foi realizado com sete crianças, com idade entre cinco e 10 anos de idade, no período de 2006 a 2010, após aprovação pela Comissão Nacional de Ética em Pesquisa e pelos Comitês de Ética em pesquisa. A partir da análise temática, foram obtidos os resultados: Cotidiano medicamentoso da criança; Cuidado familiar na adesão ao tratamento antirretroviral; Cuidado Profissional: percepção da criança com a infecção. Observou-se que as crianças enfrentam adversidades, conhecem e valorizam o tratamento apesar do movimento paradoxal de rejeição/aceitação manifestados pela luta contra a síndrome.*

**Descritores:** Síndrome de Imunodeficiência Adquirida. HIV. Criança. Percepção.

**Título:** Criança com HIV/AIDS: percepção do tratamento antirretroviral

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## RESUMEN

*En este artículo se hace un recorte del estudio multicéntrico realizado en las municipalidades de Porto Alegre y Santa Maria/RS con el objetivo de revelar la percepción y la experiencia del niño con respecto al tratamiento antirretroviral. Con abordaje cualitativo, se hizo el estudio con siete niños de edad entre cinco y 10 años, el período de 2006 hasta 2010, después de la aprobación por el Comité Nacional de Ética en Investigación y por los Comités de Ética en investigación. Se utilizó el análisis temático de las cuales se obtuvo los siguientes resultados: el diario medicamentoso del niño; la atención familiar en la adhesión al tratamiento antirretroviral; la atención profesional: la percepción de los niños con infección. Se observó que los niños enfrentan adversidades, conocen y valoran el tratamiento a pesar del movimiento paradójico de rechazo/aceptación manifestado por la lucha contra el síndrome.*

**Descriptor:** Síndrome de Inmunodeficiencia Adquirida. VIH. Niño. Percepción.

**Título:** Niño con HIV/SIDA: percepción del tratamiento antirretroviral.

## INTRODUCTION

With the emergence of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), the infected population was associated with risk behaviors and groups. However, from the 1990s, pediatric AIDS began presenting significant epidemiological data changing the HIV/Aids profile<sup>(1)</sup>.

In the period between 1980 and 2010, 14,926 cases of HIV-infected children aged between zero and twelve years of age were reported being 7,402 males and 7,524 females. It was observed that in recent years, there has been a decrease of infected children in 2009, 304 cases of AIDS in children were reported by Information System for Notifiable Diseases, and only 72 cases were reported in 2010. However, these data, associated with the feminization of the epidemic, are reflected in health practices related to prenatal care, which is central to reducing the incidence of diseases with vertical transmission, such as HIV, achieving an early diagnosis and appropriate treatment. It has been observed that in regions where the prenatal is effective, the transmission rates were reduced to less than 2%<sup>(2)</sup>.

Attentive to the children with HIV/AIDS, who experience their development associated with a disease with chronic features<sup>(3)</sup>, and that requires constant care. These children's experiences constitute a routine that requires clinical and laboratory permanent assistance, adherence to medication, added to the social issues that trigger the disease, including the orphanhood, prejudice and discrimination.

Considering that such therapy is long term, possibly many children have suffered changes in antiretroviral therapy (ART) for multiple causes that

affect and are affected by adherence, for instance, to medicinal products (size, taste and smell); the difficulties of adaptation prescription (time, dosage and frequency); for personal/social routine; by adverse effects of medications in addition to treatment failure<sup>(4-7)</sup>. It appears, then, that children with HIV/AIDS fit into the group of children with special health care needs, demanding<sup>(8)</sup> medical care and health service dependency.

It is worth mentioning the role of the family caregiver that is essential in the care of health needs, growth and development of children. The family caregiver seeks a routine that allows the naturalization of antiretrovirals, and often hides the disease, stimulating the child's imagination from the perspective of making the intake of medicine inherent in the family's daily and normal life<sup>(1)</sup>.

Given the complexity involved in the experiences of children with HIV/AIDS in relation to ART, we performed a multicenter study entitled Impact of Adherence to antiretroviral therapy in children and adolescents, from the family, child and adolescent perspective, in the municipalities of Porto Alegre and Santa Maria/RS, under contract No.: ED03756/2006 (UNESCO); TRPJ No. As -3833/2006, funded by the Department of HIV/AIDS and Viral Hepatitis of the Ministry of Health, the United Nations Educational, Scientific and Cultural Organization<sup>(10)</sup>. One of the motivating factors of the study was the high rate of disease, detecting that Porto Alegre ranks first and Santa Maria the twenty-seventh in cases of HIV/AIDS in children<sup>(9)</sup>.

The survey was conducted using quantitative and qualitative approaches, with the theme of the ART adherence by children and adolescents in the family, children and adolescents perspective.

In this article, we present an outline of the qualitative phase which focused on the child, and aimed to unveil the perception and experience of the child to the antiretroviral treatment.

## METHOD

The research is qualitative in nature, using the Sensitive and Creative Method as a strategy to collect information for the production of data. The qualitative approach seeks holistic understanding of the phenomena, describes and explains the research question, delving into the world of meanings<sup>(10)</sup>.

The steps of the research field have been developed in specialized STD and AIDS (SAE), Therapeutic Care Service of Hospital Parthenon, and Pediatric AIDS care group of Pediatrics Ambulatory at Children's Hospital Conceição (GAAP) in Porto Alegre, and the Pediatric Infectious Diseases Ambulatory at the Teaching Hospital of Santa Maria (HUSM).

Study participants were seven children with HIV / AIDS whose age group ranges from five to ten years old. Inclusion criteria defined in the study were age between zero and twelve years old, according to criteria of the STD/AIDS and Viral Hepatitis of the Ministry of Health, diagnosed with AIDS, and antiretroviral therapy for at least three months.

The data collection occurred through the development of Dynamics of Creativity and Sensibility (DCS) proposed by Sensible Creative Method which values the uniqueness of each member of the group, and through the collectivization of the experiences<sup>(11)</sup>.

The MCS occurred in five stages: in the first one, there was the presentation of each group member through integration and interaction among participants and researchers, explaining how the activities would be developed. In the second stage, the materials were made available to carry out the dynamics: kraft paper, colored pencils, plasticine, games, among others. The questions prepared in order to generate the necessary data for this study were: facilities and difficulties in relation to Antiretroviral Treatment (ART); what was used to overcome them, starting from the guiding question: How is it for you to always take medicine every day, all day long?

In the third stage, participants presented their individual or collective artistic productions, socializing them. The coded generating themes were negotiated with the participants that in the fourth stage, decoded them into subthemes during

the collective analysis and the group discussion. Finally, in the fifth stage there was the thematic synthesis of the themes and subthemes, and the data validation<sup>(11)</sup>.

The two dynamics developed with the children were: Modeling and Free to Create, which aimed to unveil the children's experience in relation to the use of antiretroviral in their daily lives. Regarding the logistics of research, the meetings were previously planned, considering the choice of an appropriate place and prediction of materials to be made available to the participants. Three workshops were held, with an approximate duration between fifty minutes and one hour and thirty minutes, and the DCS were coordinated by one of the researchers responsible for the project, and relied on undergraduates and graduate in the role of research assistants.

The research project was approved by the National Research Ethics (CONEP) and Research Ethics Committees (CEP) of the institutions involved: CEP/UFRGS, under number 2005446; CEP/UFSM, under number 23081.017341/2006-61; CEP/SMS/POA, under number 001014268.07.8; CEP/GHC, under number 113/08. It was guaranteed the protection of the participants regarding the principles of the Resolution 196/96<sup>(12)</sup>. To ensure their anonymity, the children's names were replaced by Cr coding, plus an ordinal number, regardless of the order of the DCS execution.

To the research corpus, consisting of the transcripts of the dynamics associated with artistic productions (drawings), was applied to thematic analysis as a strategy for interpreting information. This type of analysis included three stages: pre-analysis, the material exploration and processing, and interpretation of results<sup>(10)</sup>. In the pre-analysis the pieces of information were organized through exhaustive reading of the dynamics report. From the exploration of the material, they looked up the meanings and groupings of information, obtaining the themes or categories. The last stage consisted of analyzing and interpreting the multiple facets of meaning that emerged from the perceptions and experiences of children based on the theoretical.

## RESULTS

Analyzing the results, the following categories occurred: The daily life of medicated child; family

care in the adherence to the antiretroviral treatment; Professional Care: perception of children with HIV/AIDS.

### The daily life of medicated child

The drug in the world of children living with HIV/AIDS takes up a space with multiple meanings, representing a key element in maintaining the quality of life. The daily life of the child is between the limits of schedules of drugs associated with family care and silences preservers of prejudice and discrimination.

In treatment, the drug assumes centrality in their daily routine, and the child becomes aware of the physical space for the storage, regarding the quantity, frequency and timetable for the drug administration.

*My mom gives me (medicine) [...] The medicine is on beside the sink which is the table (Cr1).*

*There's one that is indeed bad, the 11 o'clock one, it seems to be the Kaletra or the AZT, it is liquid, and it tastes bad [...]. The 12 o'clock one is sweet and the 9 o'clock one tastes like strawberry (Cr2).*

*There are three ones in the morning, on fast, you know? Afterwards, two ones after breakfast and four ones in the evening (Cr6).*

*I take them in the morning and twice in the evening (Cr9).*

Adverse effects are also present in the speech of children who make correlations of the type of medication with the administration forms and their effects.

*The first time I took that bad medicine and I took without anything to drink, because I did not know, so I took it with water, on the other days I took. I used to vomit, now I'm not vomiting anymore (Cr2).*

*No, not the Kaletra, it only burned my mouth. It burns the mouth with Kaletra. My mouth hurt because it is very strong (Cr1).*

Even with the difficulties to meet the treatment, the children consider it to be good and positive to their health.

*It is that I do not want to stay in hospital [...] we have to take them to be good (Cr2).*

*The remedy is good [...] It's good for our health, otherwise we get bad (Cr1).*

*Yes (they like taking medicine). Because our health is 'more good' [...] I think it's good [...] It's cool (Cr1).*

*I drew a landscape with a lot of life. Because when I take the medicine, I feel better (Cr6).*

*I feel good (I drew) a girl smiling because she is feeling good with the medicine (Cr9).*

### Family care in the adherence to antiretroviral treatment

In the process of taking care of children with HIV/AIDS, the participation of family caregivers constitutes a key factor. To this demand it is possible to add social issues of stigma, discrimination and prejudice related to this syndrome which is full of peculiar myths and taboos. The family care treatment appears in the participants' speech:

*The grandmother and, sometimes, the grandfather. The grandfather stays up until midnight (to give the medication) [...] Sometimes I'm playing and my grandmother calls me (to taking medication) (Cr2).*

*Sometimes I'm playing and my mom goes there and call me (taking medication) (Cr1).*

The family/caregivers, organize the schedules of medication so that it is not necessary for children to take them outside the home or at school. Agreements are also established between the family members in order to protect the child from prejudice and discrimination that accompany the syndrome.

*No, I just take (to school) the 3 o'clock (medicine) to cough (Cr2).*

*There is no need to take at school (Cr6 and Cr8).*

*No (friends will not sleep in your house) (Cr9).*

*No (I do not take drugs) in front (of friends) no (Cr6).*

### Professional Care: child with HIV/AIDS perception

The professional care takes up a privileged space for its prominent position, mediating the scientific knowledge with the relatives/caregivers,

which pervades the world of the child and family/caregiver that experiences a chronic disease. Considering this factor, the professional responsibility extends to the care process.

(the doctor asks) *About the treatment, if I have a fever (Cr2).*

*He (the doctor) talks about the medicine. Only (Cr1).*

(the doctor asks) *if we're taking (the medicine) (Cr1 and Cr2).*

*The doctor said that I should take it with condensed milk, but I take it with juice (Cr2).*

## DISCUSSION

The drug daily life of the child permeates the peculiarities of the antiretroviral treatment (ART) considering its limitations, potentialities, and the participation of family members and health professionals.

In this daily life, it is possible to notice that even the children who do not know their diagnosis, denote knowledge regarding the treatment, the peculiarities of each of the medications they use; for example, the taste and the way they present themselves. Thus, among the factors that either contribute or not to the treatment adherence, it is important to emphasize the amount of drugs, the number of pills, number of doses per day, the duration of the proposed scheme, the interference in the activities and patient's lifestyle<sup>(13)</sup>.

Among the factors considered contributors to the treatment non-adherence, we can still highlight the privacy or fear of the treatment disclosure, forgetfulness of taking medication, the frequency in attending the health service, the size of the tablets or capsules by difficulty in swallowing them, bad taste of liquid antiretrovirals (ARV), and adverse effects<sup>(14)</sup>.

Despite the adverse effects immanent to ARV medications, children are aware of their need, and face their adverse effects in a paradoxical movement of rejection/acceptance. The adverse effects may mean a barrier, because taking medication can trigger unpleasant symptoms such as nausea, dizziness, malaise, added to the difficulties of communication between patients, and health professionals<sup>(15)</sup>.

However, it is observed that children face adversity and claim to know and value the importance

of continuing treatment. Even with the difficulties of adherence during the treatment, partly due to the complexity of ART, some medications must be taken on fast, or with some food, which requires a therapeutic plan developed from a restructuring and patient involvement in their treatment<sup>(15)</sup>. Thus, we highlight how complex it is to implement the ART to patients in general, which widens when it comes to children in a sensitive stage of growth and development.

The attitude towards the disease may favor or disfavor the treatment adherence. Some situations make it easier, for example, as the perception of the medicine as allies to improve and prolong life<sup>(16)</sup>, i.e., feeling better with the use of drugs enhances motivation to continue with treatment.

It is important to highlight the need for three levels of commitment to the success of adherence: those related to the service (laboratory tests, specialties, facilitated schedules, bonding and host), the quality of care provided by health professionals (listen, interact, educate, adjust your language, among others); and finally, the engagement of the child and family acceptance of the treatment using strategies to take care of themselves and the other<sup>(13)</sup>. From the perspective of future life and with quality to these children, it is considered that maintaining the conduct of treatment adherence<sup>(15)</sup>, it is essential to obtain good therapeutic results.

In the daily life of the medicated child, it is emphasized that the children in the study reported that their friends do not usually stay for long time in the children's home or the children in the friends' house. Secrecy about the condition of the child or adolescent with HIV/AIDS presents itself as a concern on the part of their caregivers, so not disclosing the diagnosis can lead to treatment limitations and reflect negatively on ART adherence<sup>(14)</sup>. Furthermore, taking the medicine at work or school can set up barriers and limitations in the child or adolescents<sup>(14)</sup>, considering that the prejudice that still surrounds the disease and the need for the child to be accepted by the group. Thus, the use of medication in social space can influence the behavior of children in relation to treatment.

It appears that the child's medicated daily life often becomes a challenge for the family, which implies difficulties for changes in the child and family's day-to-day life: therapeutic adherence, diagnosis disclosure, which adds to the care of growth and

development of children. And in the family and HIV child's daily lives still pervade feelings of fear and discrimination<sup>(15,17)</sup>.

It is worth mentioning that there is a facilitating factor in the treatment adherence, the social support<sup>(18)</sup>, with which the child can count: the practical or emotional support provided by the family, friends and people who maintain ties with the child, which may ease the negative consequences of stressful events, supporting the maintenance of the basic conditions for the treatment continuity.

It is clear, thus, that the movement of the child in the world is mediated by the family/caregiver, besides caring, dedicate them support and affective support<sup>(16)</sup>. This care is revealed in the attitude of protection, when they create strategies regarding the time and place of medication. It is noteworthy that the family/caregiver revealed to be a being of concern, which assumes the responsibility to preserve the child's life, unfolding in care actions for the maintenance of their life. Health professionals, besides providing subsidies to family/caregiver regarding the use of ARVs, the way to take the drugs, may also offer strategies to minimize the adverse effects.

So the family/caregiver regarding the treatment appears as a being of concern, particularly with regard to medication. In the child-centered care, the family/caregiver inclusion in the care and therapeutic plan is essential to the therapy encouragement and maintenance. From this perspective, the family is considered as allied to the health team, which must also be identified as the unit of care and the attention focus of health professionals<sup>(16)</sup>.

It is necessary, therefore, that the health professional is theoretically grounded in the disease process and treatment for HIV/AIDS to equip the family/caregiver. Moreover, this knowledge must assist the family/caregiver and child to find a way to live and coexist with the disease. It is still possible to highlight the importance of this knowledge acquisition by the children as a first step toward self-care<sup>(19)</sup>. This information can be useful as tools for transitivity of consciousness, causing them to become aware of their health condition and subsequently individual empowerment<sup>(20)</sup> to continue the treatment during adolescence and adulthood.

The ability of cooperation between professionals and users reflects the quality of the interaction between both. The communication and

interaction between the child, family and health professional are essential for a successful adherence. Therefore, it is necessary to use a language adapted to the cultural context in which the customer is located in order to comply with the therapeutic treatment plan<sup>(13)</sup>.

The treatment of children with HIV/AIDS and multiple associated factors – socioeconomic and cultural conditions, changed family dynamics, the stigma associated with the disease - require planning and execution of appropriate care to the uniqueness of each child, family/caregiver. Therefore, it is essential to have knowledge and practice an interdisciplinary view to the children considering their integrity, seeking to break the paradigm of fragmentation of care.

## FINAL CONSIDERATIONS

The realization of the qualitative stage of the study provided an approach to children with HIV/AIDS in order to know and understand their daily life experience with the use of ART, their involvement and their perceptions regarding the treatment. The Dynamics of Creativity and Sensitivity shape a strategy that favors the playful dialogue and listening, providing enriching moments among them in order to know each other and realize that the treatment goes beyond the use of medication, and the routine of appointments and tests. It was observed that the daily life of children with HIV/AIDS focuses on three essential dimensions: the size of the drug, the family care and the professional care. Added to these factors, the demands of specific health care of children living with HIV/AIDS especially medical care.

The size of the drug, in turn, is part of the children's world, and they need to deal with the adversities of a complex treatment, considering the amount and frequency of medication, the bad taste, the size of the capsules, the compliance with the time, side effects, resulting in a change in their routine according to the schema and format of therapeutic drugs.

It is noteworthy the silence regarding his health condition that pervaded the testimonies, often characterized by the social isolation of the child as a protection strategy of family/caregivers against the prejudice that accompanies the syndrome.

The proportion of the family care focuses on the responsibility of the treatment maintenance as preserver of the children's lives, emphasized in the children's speeches. In this sense, the family takes the position of the concerned caregiver who is worried with the care and conscious to prepare the children for their own care.

In the dimension of the professional caregiver, we can highlight the importance of the adherence process to the treatment of children who have HIV/AIDS, considering that their word has a direct effect on the care of the family/caregiver and the children in the care of themselves.

Finally, we conclude that these three dimensions must act in an integrated manner, combining up efforts to ensure adherence to child treatment, considering the characteristics of the disease and the social issues involved.

It can also be perceived the need for health actions that go beyond therapy, focusing on the stages of growth and development. The health professional, to approach the world of the child and his family, can use ludic games as a strategy for health education as part of the playful children life. It is the bridge between your inner and outer world, and it is essential to the understanding of self and the other.

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