

THE KNOWLEDGE AND PERCEPTIONS OF HIV POSITIVE CHILDREN AND THEIR PARENTS OR RESPONSIBLES ABOUT AIDS

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ABSTRACT. In this study knowledge and perceptions of parents and/or responsables and of their HIV infected children and adolescents in a national health clinic of pediatric Aids were investigated. Observation techniques and semi-structured interviews were used before the installation of a playroom to investigate: the discovery of the HIV infection by the family, their social conditions, access to prevention and treatment and their perception of the disease. Results show that a significant number of relatives interviewed ($n=28$) realized that they were also HIV-carriers when their children's health deteriorated (14 or 50.0 %); the death of the spouse occurred (6 or 21.4%) and by the symptoms of the disease in themselves (8 or 28.6%). Among the 32 children interviewed, 28 (87.5%) were not aware of their diagnosis and 18 (56.3%) were not enrolled into school. Out of the 14 different schools frequented by 14 (43.8%) children, only 7 (50%) of these institutions knew about the children's diagnosis. Analysis of drawings and general playroom activities indicate that the playroom is a promising environment for the promotion of health information and continued dialog, stimulating adhesion to treatment.

Key words: Pediatric AIDS, playroom, health education.

OS CONHECIMENTOS E PERCEPÇÕES DE CRIANÇAS HIV POSITIVAS E DE SEUS PAIS OU RESPONSÁVEIS SOBRE AIDS

RESUMO. Este trabalho objetivou estudar os conhecimentos e percepções de pais/responsáveis e de suas crianças e adolescentes de um ambulatório de Aids pediátrica. Foi investigado: A descoberta do vírus pela família; as condições sociais, o acesso à prevenção e tratamento e a percepção da doença. Foram realizadas observações participantes e entrevistas semi-estruturadas, previamente à implantação de uma brinquedoteca. Os resultados revelam que 14 (50%) dos familiares entrevistados ($n=28$) toma consciência de que são portadores do HIV através do adoecimento das crianças, 6 (21,4%) pela morte de um dos cônjuges e 8 (28,6%) pelos sintomas da doença deles próprios. Das crianças entrevistadas ($n=32$), 28 (87,5%) não tinham conhecimento do diagnóstico, 18 (56,3%) não frequentavam escola. Das 14 (43,8%), crianças escolarizadas em 14 diferentes instituições, 7 das escolhas (50%) não tinham conhecimento do diagnóstico da criança. A análise das representações gráficas e atividades gerais na brinquedoteca indicam o seu potencial enquanto ambiente promissor para intervenção terapêutica, promoção do diálogo, podendo tornar-se estímulo à adesão ao tratamento.

Palavras-chave: Aids pediátrica, brinquedoteca, educação em saúde.

LOS CONOCIMIENTOS Y PERCEPCIONES DE LOS NIÑOS Y DE SUS PADRES/CUIDADORES ACERCA DE SIDA

RESUMEN. Este trabajo apuntó a estudiar los conocimientos y percepciones de los padres/cuidadores y de sus niños y adolescentes en un dispensario de sida pediátrico. Se investigaron: la descubierta del virus por la familia; las condiciones sociales; el acceso a la prevención, tratamiento y la percepción de la enfermedad. Los resultados muestran que el 14-50% de los familiares ($n=28$) descubre que son portadores del VIH a través de la enfermedad de los niños; el 6-21,4% por la muerte de uno de los cónyuges y el 8-28,6% por la enfermedad de los mismos. De los niños ($n=32$), 28 (87,5%) no tenían

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conocimiento de la diagnosis, 18 (56,3%) no frecuentaban la escuela. De los 14 (43,8%) que lo hacían, en diferentes escuelas, 7 (50%) de las instituciones no conocían su diagnosis. El análisis de las representaciones gráficas y actividades en la ludoteca permite caracterizarla como un ambiente prometedor a la intervención terapéutica, al diálogo y a la adherencia al tratamiento.

Palabras-clave: Sida pediátrico, ludoteca, educación de la salud.

UNAIDS estimates indicate that about 2.5 million children worldwide have been infected from the start of the epidemic in 1982 until December 2003, with about 500,000 deaths (UNAIDS, 2005).

Belo Horizonte, with 6.601 notified cases of AIDS, has the 4th highest number of cases, representing 2.7% of total cases in Brazil. Epidemic behavior pattern follows others already reported in the twenty-seven states of Brazil e.g. epidemic poverty and an increase in the importance of heterosexual transmission category (Boletim epidemiológico, 2004). A consequence of the latter results in an increase in the number of children born to infected mothers, reflected in the number of patients assisted at "Centro de Treinamento e Referência em Doenças Infecciosas e Parasitárias" (CTR/DIP) (Training and Reference Center for Infectious and Parasitic Diseases), Belo Horizonte MG Brazil, where the playroom, object of current research, has been established.

The assistance of children infected by HIV and of their relatives is, as a rule, centered on medical treatment with emphasis on the clinical and laboratory diagnosis and on therapeutic treatment. Since children attending the health care centers often experience long waiting periods before seeing a doctor, it seemed possible that this waiting time could be put to better use by extending medical assistance, improving relationships with the medical staff and, consequently, improving attendance at the centers.

This is actually the experience of a laboratory team (Laboratory of Environmental and Health Education (LEAS/IOC/FIOCRUZ), under the coordination of Schall (1991) who conceived and implemented a playroom in "Hospital Fernandes Figueira" (IFF – FIOCRUZ, Rio de Janeiro RJ Brazil), where HIV-infected children could play together whilst waiting for the doctor's assistance or for their parents and/or for those responsible for them. They take part in in-group activities, lectures and exchange experiences with a multi-professional team (Silva, 2000).

Playing is revealed to be an effective pediatric nursing intervention strategy in helping the child to overcome assistance-imposed barriers. The strategy favors the communication process among children, companions and professionals and, thus, greatly

contributes to improve care delivery (Pedro et al., 2007).

The ludic activity may act as a marker to gauge the children's experience of life whilst living with AIDS. Play has an ontological dimension in the subjects' well-being during which they may express how they feel the milieu around them.

A review of the national and international literature revealed that this topic is an important part of studies on hospitalization, especially issues related to the humanization of hospital assistance. Starting from the late 1980s, an increase in publications on the issue by Sherlock (1988), Chiattonne, (1984), Duarte, Meirelles, Bruno and Duarte (1987), Guimarães (1988) has been reported. Further, Lindquist (1996), Pinheiro and Lopes (1993), Junqueira, (1999), Melo e Valle (2003), Herdy et al. (2003), Motta and Enumo (2004); Mitre and Gomes (2004); Pedrosa, Monteiro, Lins, Pedrosa, and Melo (2007) have been recently added.

HIV-infected children require regular medical care, with frequent visits to the health care unit. Since many undergo prolonged hospitalization or have to attend the hospital regularly to receive parenteral medication, much time is spent in a hospital-medical environment. The playroom implementation is an important therapeutic resource to facilitate a quicker and less traumatic recovery of the child, both as an in-patient and as an out-patient. Although they may feel ill and experience difficult moments, children still maintain a ludic potential which must be further explored (Tosta, 1997).

Current research assesses the representation of the disease in the family environment and investigates a) how and when they discovered they were infected, b) the social conditions of this population and c) what kind of access they had for its prevention and treatment so that the development of activities in the playroom, integrated with medical care in the ambulatory, may be improved.

Guidelines for the follow-up of the families may be developed, aiming at a greater adherence to the treatment and to an improvement in the quality of ambulatory assistance. The children's access to a place which allows them to express their distress, sorrows, happiness and curiosity regarding their illness should be guaranteed (Winnicott, 1975).

MATERIALS AND METHODS

Place and sample of study

This study was being carried out at the Playroom Hortênsia de Hollanda, a playroom located in the front yard of the Training and Reference Center for Infectious and Parasitic Diseases of the Federal University of Minas Gerais (UFMG), Belo Horizonte MG Brazil and of the Municipal Secretariat for Health of the Belo Horizonte Town Hall, CTR/DIP/PBH/UFMG (Figure 1). Room space, measuring 16 m², is lined with colored plastic, allowing flexibility and communication with the public. Several toys, tables, chairs, pedagogical material and audiovisual resources occupy the space.

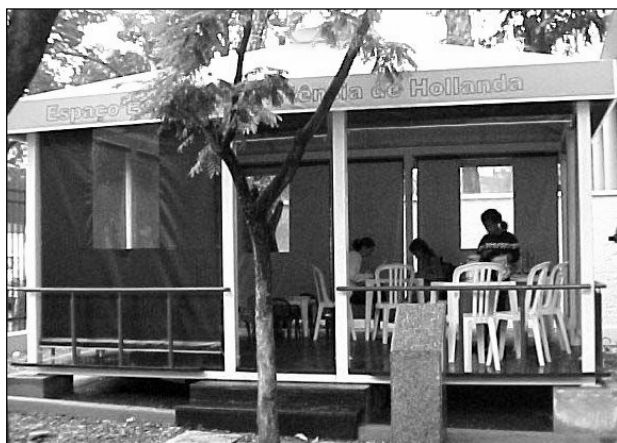


Figure 1. An outpatient clinic playroom for HIV-infected children in Belo Horizonte, MG, Brazil

Through the initiative of the Laboratory for Health Education, the Rene Rachou Research Center and the Pediatric Department of the Faculty of Medicine of the Federal University of Minas Gerais, and with a financial support of National Program for STD/AIDS of the Health Ministry, a playroom has been established. It enables communication between relatives or those responsible for the children; where HIV/AIDS-positive children may talk amongst themselves and both groups may communicate with the health team of the ambulatory care center.

Established in 1988, the AIDS Pediatrics Service of CTR/DIP is a reference service which assists the pediatric and adolescent populations of the metropolitan region of Belo Horizonte MG Brazil and other cases from counties in the state of Minas Gerais. This service has already assisted around 1,500 children and adolescents with a history of exposure to HIV until 2005. Two hundred and seventy-six have a positive serological diagnosis and 195 have been

undergoing anti-retroviral treatment. Thirty-one are adolescents, aged 11 - 17 years old; 13 are males and 18 females.

An average of 20 new infant cases per month, average age of 2 months, born to infected mothers, have been assisted. With the expansion of anti-HIV testing in prenatal visits, results show an increase in admissions at this age.

In the first phase of the study, before the implementation of the playroom, 32 children from 2.8 to 14 years old (15 males and 17 females) were interviewed. Choice was based on their frequency at the ambulatory center (the most present) and on their age bracket.

Most patients are from the metropolitan region of Belo Horizonte. A smaller group came from other towns in the state of Minas Gerais. The greatest number is composed of families from very low social-economical level.

The group was composed of children in the 1 to 5-year bracket (56.3%), 6 to 10-year bracket (31.3%) and 10 to 15-year bracket (12.5 %).

Definition of the methods used in study

Current investigation is characterized by a qualitative research (case study) to elucidate single aspects and general trends in the participants' statements and to understand the latter's perspective whilst taking part in the research. Interviews were carried out in an environment favoring free and spontaneous discussion, as suggested by Bromley (1986) and Minayo, Assis and Souza (2005).

First, data and opinions were collected on how HIV/AIDS-positive children and their families perceived the ambulatory care center; second, how they were related to the disease; third, the commitment of their respective families to treatment.

In order to achieve the proposed goal, the case study and the participants' observations are methodological approaches which offer the possibility of a deeper understanding of conceptions about the children's and their relatives' health and how they are related to the fact that they are sick.

The present investigation registers their life history and their concepts so that subjects could be understood in the therapeutic and ludic situation. Analysis of children's language is of paramount importance so that the relationship of their own notion of health, disease, experience and perceptions about themselves may be understood. This may be fundamental in introducing new strategies or even new viewpoints for the prevention process within the health area.

Measurement Methods

Two semi-structured interviews were used, one directed to the children and the other to the parents or those responsible for the children, for background information on the population studied.

The higher age group children and adolescents' interviews consisted of 15 questions with several themes, such as school, family, friends, favorite games, social life, health / disease, fears, dreams and history of the time spent in the hospital.

The collection of data with the 6-year-old smaller children was adapted to the age group and each child's understanding. Drawing and ludic strategies were employed since they were more appropriate to data collection at their cognitive stage and current language development.

The interviews prepared for parents and for those responsible for the children consisted of 8 questions, with themes related to the reason and the duration the children have been treated, family, number of times hospitalized, positive and negative points on the assistance they received and on the children's day-to-day experience.

The information from the interviews was analyzed by the content analysis method and enabled the authors to reach a greater understanding of the children's and their families' concerns (Bardin, 1986; Minayo, 2000).

The study also included data collected from HIV/AIDS-positive children after the establishment of the playroom. Information was collected by the following inter-related tools: 1) ludic activities with drawing exercises; 2) interviews / dialogue; 3) observation of the activities developed in the playroom (free and controlled activities), 4) observation reports of children's responsables and those of the health team during medical examinations. The graphic analysis was used with children as a form of assessment since they express themselves better when drawing.

Children's interviews

The children were also been asked to sign the consent term. In case they did not know how to write their names, signature was reserved only for the parents or the children's responsables.

Interviews with parents and children's proxies

Parents who were in the ambulatory care center's waiting room were invited to take part in an interview. Research purpose and objective were explained to them in detail. When approach has been established prior to the interview and the research's purpose explained, it was then verified

whether or not they were willing to take part in the project. If they agreed, they were asked to sign a free and clear consent form, which would then be signed by the children who are literate. This consent form is in agreement with the regulations of the Ethics Committee in Research with human beings of CPqRR/FIOCRUZ and of UFMG, who analyzed and approved the project.

Interviews were carried out in a psychology office, arranged by the Center's board of directors. So that interviews could be undertaken with the least interruption possible, it was suggested that interviewed would leave the children with a Psychology student who was also a partner in the project.

Children's interviews

After the parents' interview, the children were also invited to participate in an interview. Before each interview, a rapport was established in which the implementation of the playroom was addressed and each child's capacity of response was evaluated, which would in turn direct the critical questions as recommended (Arfouilloux, 1976).

The children were also been asked to sign the consent term. In case they did not know how to write their names, signature was reserved only for the parents or the children's proxy.

When the interviews were completed, the children were asked to make a drawing of the ambulatory care center. The drawings would later be used for comparative analysis with those made after the playroom's inauguration.

After the playroom's inauguration, children were also stimulated to draw each section. Most of the time, the drawings were done without any theme restrictions and, when necessary, the children were asked to draw a pre-determined theme according to the guidance of the projective techniques. Preliminary analyses were based on the criteria by Machover (1967), Van Kolck (1967, 1981), Hammer (1991) and Wechsler (2000).

Method of analyses

Interviews with parents or relatives were analyzed in such a way as to enable a better understanding of the disease's influence within the family circle. The identification data included name, age, kinship with the child, profession, serum positiveness, parents' death and origin. Complementary data were analyzed through listed and quantified contents' categories (Bardin, 1986; Minayo, 2000) which were analyzed

independently by two researchers to guarantee accuracy (Drummond and Schall).

The children's interviews also included the following identification data: name, age, sex, school life, last hospitalization, awareness of the disease, whether or not they were adopted, school's awareness of the disease and whether or not they were orphans.

The children's graphic productions during the interview and the activities in the playroom were also analyzed.

Drawing activities were undertaken from January 2002 to March 2003 by children and adolescents, within the 2 – 16 years bracket, who regularly attended the ambulatory care center, before and after the establishment of the playroom.

The 187 drawings were classified into categories whilst still in the analysis's initial phase. In this phase, categories were divided into sub-groups according to studies by Machover as cited in Van Kolck, Machover (1967) and Van Kolck (1967, 1981).

Various drawing techniques are known, but especially the Machover human figure test (1967 and 1969) showed to be a very useful tool. Machover states that people submitted to draw a person test necessarily refer to internalized images of themselves and of others, projecting in this way their corporal image.

Consequently, the drawing technique is of paramount importance, especially for children suffering from a disease affecting the body image, as is the case of HIV/Aids.

Categories were defined by the health team according to the themes which appeared with greater frequency, i.e. drawings of houses, human figures, the ambulatory care center, the playroom, landscapes and scribbles (Machover, 1967; Van Kolck, 1967, 1981).

RESULTS

Family awareness of the disease

Acknowledging the importance of the family during the progression of the disease and its treatment, the period and the manner the families became aware of being carriers of the virus were also investigated.

In the context of the 32 children interviewed, it was possible to talk with 28 adults who were responsible for them. The four remaining adults were the directors from support homes and have not yet been contacted. Amongst the first group were 18 parents, one grandmother, five aunts, one stepfather and one stepmother.

A significant number of interviewed family members stated they became aware of being HIV carriers through the children's deterioration in health (14 or 50.0%), through the death of one of the spouses (6 or 21.4%), or through the parent's disease (8 or 28.6%), which makes us conclude that diagnosis and preventive methods were late and ineffective.

In the family statements, it was possible to observe how they became aware of the disease. Some statements registered in the interviews are given below:

"We found W. in a terrible situation, as he already had pneumonia 8 times and was almost dead. His biological mother lives on the streets and didn't take care for him and that's why we decided to adopt him. After a while we found out he had the virus. The social assistant said that if we wanted to give him back, we could and he would be sent to a support house, but we didn't have courage to do that and he is very well today" (male, 25).

"She got sick very easily when she was adopted and that's how we found out about the virus" (female, 50).

"She is a carrier of HIV, as well as her father and I. We found out why she was hospitalized so often and had pneumonia 12 times. The physician had already given up when they found the virus and I was examined and found out about it. At first the father didn't want to undergo the examination as he did not believe AIDS existed, then he did it and it was confirmed. I wanted to be sure of when I got infected but I don't know" (female, 32).

"When I was breastfeeding I found out I had a sarcoma and then HIV" (female, 29).

"She was hospitalized very often, a week at home and the rest in hospital, then they examined her and found out about it" (female, 40).

"The father got sick and died very quickly, then we underwent the examination and found out about it." (female, 27)

"He was just decaying and almost died, here in BH. HIV was figured out" (female, 45).

"He was always hospitalized and then came back but he was never well, so they asked for an examination and found the virus. I was very scared and surprised because I have never imagined that. That is how I found out that I also have AIDS. Now I take medication but he still does not

need to take it. His father underwent the examination only once and says he does not have the virus, I don't know how because I had sexual relationships only with him" (female, 25).

Children's perception of the disease

Out of the 32 children interviewed, 17 (53.0 %) were females and 15 (47.0 %) males. Eighteen (56.3 %) were between 1 and 5 years; 10 (31.3%) were between 6 and 10; and 4 (12.5%) were over 10 years old. Seven were orphans, nine were adopted and they lived with their parents, uncles, aunts, grandparents, cousins or people legally responsible for them. Five of the children had not been hospitalized, whilst 27 had been hospitalized on one or more occasions.

Analysis of the children's statements showed that they have no real idea of the disease. This is due to the fact that the family tries to keep HIV a secret and avoids giving the children any correct information about the pathology.

From the interviewed sample ($n=32$), 28 (87.5%) of the children were not aware of the illness and 4 (12.5%) were aware of being carriers of HIV. This last group came from support houses.

The drawings and statements displayed below illustrate how the children perceive the disease in their world.

"I undergo a treatment here, I don't know what it is for" (male, 6)

"Once I was hospitalized because I was thin and I had dysentery, then I came here and the doctor prescribed me a medicine. I don't know what I have; my mother doesn't like to talk about it. I know I can't run because I get tired, and I can't get hurt so I won't bleed" (female, 10).

"To be examined and then get the medicine" (female, 5).

"I have to see the doctor, right? I don't know why" (female, 9).

"I have been sad since I was little, I was born like this. I am sick, that's what the doctors say, but I don't believe it" (male, 13).

"I come here because I have HIV virus. I got it from my mother when I was born. My dream is to get rid of the virus" (male, 14).

"The doctors say I am sick, but I don't believe it. My mother tells me not to believe it" (male, 13).

"I ask my mother but she doesn't answer me and keeps silent, she must know

something because she takes the medicine, too" (female, 7).

"I know I have to undergo a treatment because of the problem, the HIV" (female, 9).

"I have a little bug in my blood which is always sleeping, if I don't take medicine it wakes up and destroys the soldiers who take care of my body" (male, 12).

"I don't know why I come here, sometimes I get sick, and when I am not sick I come here anyway. Sometimes I have a fever and stomachache" (female, 13).

Influence of the disease in the children's life: School Environment

In the statements of families assisted at the Center, many mothers admit they are still afraid of exposing the children's disease to the school directors. Others say they do not send the children to school because of the medication and also because they are afraid that people discover that they are virus carriers.

In fact, out of the 32 children interviewed, 18 (56.3 %) did not go to school and 14 (43.8 %) were regular students. In the case of the 14 children who frequented school (each one in a different school, totalling 14 schools), seven schools (50.0%) knew that they were HIV virus carriers, whereas seven did not.

Data show how the illness affects the normal development of the children, many times depriving them of healthy interaction with other children and of a regular and productive school life. This evidence suggests the need of guidelines and support for family members in such a way as to guarantee the children a better quality of life and the right to attend school.

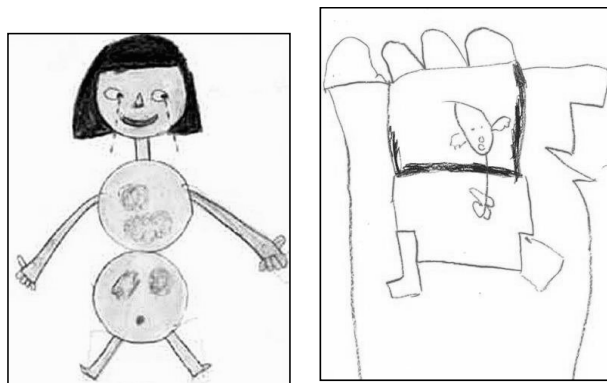
Manifestations of the disease: symptoms, complications and hospitalization

During the interviews and observations made in the ambulatory care center it was possible to see the diversity of symptoms and manifestations of the disease in the children. Twenty-seven (84.4%) had already been hospitalized one or more times and only 5 (15.6%) had not been hospitalized. In the context of symptoms and disease opportunists described by the family members and by the children themselves, we noted frequent bouts of pneumonia and other respiratory manifestations, diarrheas, tumors, high fever, pain in different parts of the body and

dermatological eruptions. It was easy to perceive the consequences of the disease in the behavior of some of the older children and in the adolescents through conversations and observations in the playroom. Scars on the body or the face, pain, relapse of symptoms which cause suffering and changes in their self-esteem may even lead them to lose confidence in the treatment which affects their attendance at the health care center.

The graphic analysis as an initial idea of each child's perception of reality

A group of 187 drawings was classified by categories which are represented in Figure 2. The largest category (20.9%) consisted of scribbling; the second one consisted of drawings of houses (19.3%); the third and fourth ones consisted of drawings of landscapes and animals (both with 12.8%); and the fifth and the sixth ones were composed of drawings of human figures and of the ambulatory care center/playroom (both with 12.8%). The largest number in the scribble category reflects the greater number of patients in the youngest age bracket, which corresponds to 56.3% of under 5-year-old children.

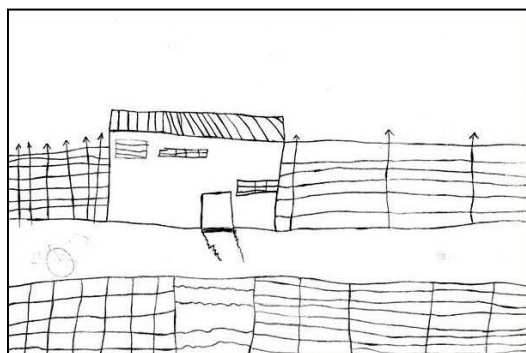


Drawing 1

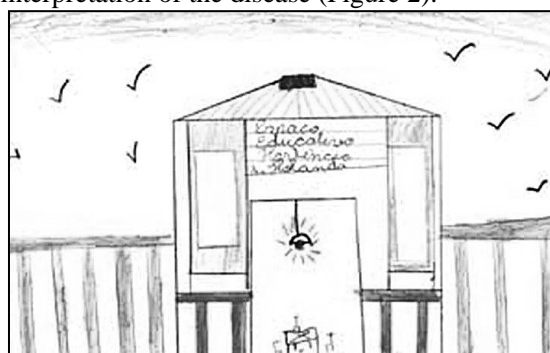
Drawing 2

Figure 2. An outpatient clinic playroom for HIV-infected children in Belo Horizonte, MG, Brazil

The drawings of human figures (Figure 3) were classified in category A for those with a negative view of the body (62.5%) and in category B for those with a positive view (37.5%). Drawings 1 and 2 of Figure 3 were considered to present a negative view of the body since they indicated apparent symptoms, pain or sadness, lying down and with a black color around the bed. Both the black outline and the expression in the drawing are highly symbolic within the children's interpretation of the disease (Figure 2).



Drawing 1



Drawing 2

Figure 3. An outpatient clinic playroom for HIV-infected children in Belo Horizonte, MG, Brazil

Drawings of houses: category A, with indications of conflict (55.6%); category B featuring well-structured houses (44.4%). Some drawings showed a well-structured house, indicating affection (hearts, sun and a colorful garden).

Other drawings represent the ambulatory care center and the playroom, landscapes or animals; all of them in prevailing sad colors, with sickly and scared expressions. One drawing of the playroom (Figure 3/drawing 2) includes a light bulb at its center (which does not exist) suggesting a positive view of the place. On the other hand, Figure 3/drawing 1 represents the view of the ambulatory care center before the

implementation of the playroom. The place looks like a prison.

The interpretation of the drawings and dialogues with the children on their drawings produced a better understanding of their health and helped address the disease in a milder and more constructive way. This is one of the alternatives by which the child establishes a link with places and with people who had previously seemed to be threatening, e.g. the hospital and the medical team. The children were then able to guarantee that they would continue the treatment. Further, the drawings would be used to develop educational materials directed towards methods of

prevention. The analyses presented were only a starting point for an in-depth study and further investigations.

DISCUSSION

Data collected from children's parents or proxies strongly indicate the ineffectiveness of prevention of the disease in the area studied. Previous studies confirm these data. Alves, Kovács, Stall and Paiva (2001) interviewed 26 infected women and 14 had the diagnostic test after their partner or child became ill. Vermelho, Barbosa and Nogueira (1999) reported that several women "received their diagnosis and initial medical care only after their partners' and/or children's illness or death." Herdy et al. (2003) presented a high percentage of the children who were index cases. Twenty-six patients (57.0%) out of 45 were index cases. The lack of knowledge of pregnant women with HIV was pointed out by Marques et al. (1998). The authors identified a lack of testing during pregnancy and inadequate information at the health care units, which are the most important health care sources for the population investigated. More recent data (Tomazelli, Czeresina & Barcellos, 2003), also confirmed a high proportion of unknown transmission category amongst the women investigated, revealing ignorance in such a high-risk situation.

All these results emphasize the risks to which some women are exposed and submitted and the failure of the health care system to provide them with information in a satisfactory manner. There is an urgent need to improve the prevention programs and to draw more attention to this situation.

Through prevention, any child of an HIV-infected mother may currently avoid being infected by HIV. In fact, there are a number of effective measures that may be employed to avoid the risk of transmission from mother to child. These comprise early diagnosis performed on the infected pregnant mother, the use of antiretroviral drugs, programmed caesarian birth and the suspension of maternal breastfeeding with the replacement by infant artificial milk and other foods, according to the age of the child. During prenatal examinations, all pregnant women in Brazil have the right to the HIV test and are encouraged to undertake it. The earlier the diagnosis of HIV infection in pregnant women, the greater are the chances in avoiding infected offspring. Treatment is free and available within the Brazilian Unified Health System (SUS) (Brasil, 2007).

Data collected reinforce the importance of the implementation of the method coupled to a new approach

of conducting and following the treatment of HIV-infected children and their families.

Since AIDS is a disease that involves the entire family, it is mandatory to reflect on its spread, its implications within the family circle and the physical and emotional effects on the children. The disease will affect their activities at home, with their siblings and friends, and also at school.

The way the children adapt themselves to the disease depends on their understanding and their relationship with others. Frequently when parents are facing the disease, they experience feelings of blame, fear, frustration, resentment, protection and indulgence. These feelings may or may not affect the children's way of dealing with the treatment. Since pediatric patients should be always seen as persons in their own right, they have a right to be respected in their individuality and should be listened to, whenever possible (Novaes, 1998).

Current paper points towards a positive perspective in the way the treatment of HIV-infected children and their families is conducted. It allows them to experience the implications of the disease in a place where they will be welcomed and listened to and where they can improve their self-esteem and their potential for the future.

Their perceptions about the illness reinforce the need for an integrated approach where the playroom can be a very important support.

COLLABORATORS

Drummond, I. worked on the conception, methodology, final version and bibliographical research; Schall, V. T. participated as supervisor in the theoretical section, data analysis and evaluation of the final version; Pinto, J. A. participated as research monitor and in the evaluation of the final version; Mesquita, J. D. collaborated in data collection and analysis.

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