

Implications of using antiretroviral therapy on the life style of children with AIDS*

IMPLICAÇÕES DO USO DA TERAPIA ANTIRRETROVIRAL NO MODO DE VIVER DE CRIANÇAS COM AIDS

IMPLICANCIAS DEL USO DE LA TERAPIA ANTIRRETROVIRAL EN EL MODO DE VIDA DE NIÑOS CON AIDS

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ABSTRACT

This descriptive, exploratory study was performed using a qualitative approach with the purpose of learning about the life style of children with AIDS and the implications that following a antiretroviral therapy have on them. Participants were five children with ages between 10 and 12 years. Data collection took place after the study was approved by the Review Board and was performed using the Focal Group technique. Data analysis was performed using thematic analysis, from which three categories and respective subcategories emerged. This article addresses one of the categories: The child's involvement with the antiretroviral drugs. This category reveals how the children perceive and relate with the antiretroviral therapy. The study findings may serve as supporting information for health professionals, education programs about health care to children living with AIDS.

KEY WORDS

Acquired immunodeficiency syndrome.
Child.
Medication adherence.
Pediatric nursing.

RESUMO

Trata-se de estudo exploratório descritivo, com abordagem qualitativa, que objetivou conhecer o viver de crianças portadoras de aids e as implicações do uso da terapia antirretroviral. Participaram cinco crianças com idades entre 10 e 12 anos. A coleta de informação iniciou-se somente após aprovação em Comitê de Ética em Pesquisa e foi realizada por meio da técnica de Grupo Focal. Para análise das informações, utilizou-se a análise temática. Da análise surgiram três categorias e suas subcategorias. Neste artigo será abordada a categoria Envolvimento da criança com os antirretrovirais. Esta categoria revela como a criança percebe e se relaciona com a terapia antirretroviral. Considera-se que estes achados possam subsidiar profissionais da saúde e da educação na atenção e cuidado às crianças que vivem com aids.

DESCRIPTORIOS

Síndrome de imunodeficiência adquirida.
Criança.
Adesão à medicação.
Enfermagem pediátrica.

RESUMEN

Se trata de un estudio exploratorio descriptivo, con abordaje cualitativo, que objetivó conocer el modo de vida de niños portadores de AIDS y las implicancias del uso de la terapia antirretroviral. Participaron cinco niños con edades entre diez y doce años. La recolección de información se inició solamente con posterioridad a la aprobación del Comité de Ética en Investigación y fue efectuada a través de la técnica de Grupo Focal. Para el análisis de las informaciones, se utilizó el análisis temático. Del análisis surgieron tres categorías y cuatro subcategorías. En este artículo será abordada la categoría Involucración del niño con los antirretrovirales. Esta categoría revela el modo en que el niño percibe y se relaciona con la terapia antirretroviral. Se considera que estos hallazgos puedan ser de ayuda a profesionales de la salud y de la educación en la atención y cuidado a niños que viven con AIDS.

DESCRIPTORIOS

Síndrome de inmunodeficiencia adquirida.
Niño.
Cumplimiento de la medicación.
Enfermería pediátrica.

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INTRODUCTION

Near its outbreak in the beginning of the 80's, AIDS was more associated to the so called *risk groups*, however, as the epidemic advanced, the disease left this risk group concept behind and started reaching people in all age groups and belonging to different groups, including children. Nowadays, it is possible to find children and adolescents who have been living with AIDS since their birth, with all the repercussions of the disease, including the need for antiretroviral medication for long periods. According to the World Health Organization, there are approximately 17,000 children who need to use antiretroviral medication in Latin America⁽¹⁾.

The development of zidovudine (AZT), which represented a remarkable moment, was fundamental for increasing the current therapeutic plans used to treat AIDS⁽²⁾. Nowadays, the use of the antiretroviral therapy combined with three or more drugs may reduce significantly the mortality and morbidity of children and adults with AIDS, which leads AIDS to start presenting characteristics of a chronic disease and, as such, demanding from its carriers the maintenance of the antiretroviral therapy for increasingly longer periods. In face of this, it is important to consider the implications that AIDS and the antiretroviral therapy bring to the life of children. In order to have the disease controlled, it is vital that the patient follows his treatment correctly.

In this context of AIDS, the compliance has been broadly studied. However, The compliance to the therapy remains a complex theme involving several factors that are still not well known⁽³⁾. Although this theme is rather explored with adults, it is still incipient when it comes to pediatric patients. There are currently few studies that deal specifically with the compliance among children and adolescents⁽⁴⁾.

Although the biological aspects of pediatric AIDS have been well studied, little attention is given to the subjective aspects, mainly concerning the caregiver, the professional and the child specifically⁽⁵⁾. This study proposed to represent children with AIDS and to disclose, based on their own experiences, their life with the disease and the therapy.

It is believed that the perception of the child regarding AIDS and the antiretroviral medication may be an important tool for the development and use of health strategies and approaches that serve mainly the children who live with AIDS.

Therefore, it is possible to perceive the need to study this population aimed at comprehending, based on their own point of view, their life experience with AIDS and their involvement with the antiretroviral therapy so that these speeches may enable a look oriented to their needs and to think of strategies aimed at providing a life with more quality for this part of the population.

OBJECTIVE

The objective of this study was to learn the way children with AIDS live and the implication of the use of the antiretroviral therapy.

METHOD

In order to reach the proposed objective, an exploratory descriptive study was developed, with qualitative approach. The qualitative approach was chosen in order to learn the way the child perceives and relates to the antiretroviral therapy, as it is believed that these inquietudes could only be apprehended through this approach.

The study was developed with the Non-Governmental Organization (NGO) Mais Criança. This NGO was chosen as field study because it represents an institution aimed at the support, preventive education, psychological and socioeconomic care to children and adolescents who live with AIDS and their respective families. The headquarters of the NGO

Mais Criança is in the municipality of Porto Alegre (RS), where its activities are developed. It is considered that this NGO represents a health extra-institution scenario, favorable to the development of the study. The NGO environment made the meetings more informal than they would be in health institutions like hospitals, health units, among others. It is believed that this relaxed environment may enable greater freedom of expression to the participants of the study. Another factor that determined the NGO choice was the fact that it is a place where the researchers develop other activities and get to know the children and their families.

The participants in the study were five children aged between 10 and 12 incomplete years old. The number of participants in focal groups with children must be more reduced than that in groups with adults, with an appropriate quantity considered from five to six children in order to facilitate the moderation⁽⁶⁾. The selection of the participants was intentional and performed with the social worker of the NGO, who indicated the possible participants. The study included children with AIDS who knew their diagnosis, who had been using antiretroviral medication for at least six months, who were associated to the NGO Mais Criança and authorized by their parents or legal guardians to take part in the group.

Data were collected through the focal group technique. After the group, an identification form was filled out with the caregiver and the child in order to characterize the informers. It is important to highlight that the data collection was only initiated after the project had been approved (no. 2007808) by the Committee of Ethics in Research of the Federal University of Rio Grande do Sul, aimed at com-

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plying with the resolution 196/96 of the National Health Council, and the signature of the Term of Free and Clarified Consent, which had the necessary information for the participant to understand the study objectives, procedures, risks and benefits, besides a space for the signature of the person in charge of the child and the child's consent, indicating he agreed to participate in the study.

The focal group was semi-structured, in other words, a structured guide of themes and open questions was presented, allowing the moderator to lead a flexible discussion among the participants. This collection technique may be very rich when it is intended to learn about how a group thinks about a certain subject⁽⁷⁾.

Regarding the number of meetings, two sessions were initially scheduled, however, in face of the material collected in the first two groups, it was perceived that more meetings were necessary in order to guarantee that the approached themes were completely used and contemplated the study objective, thus, a total of four focal groups were formed.

After the stage of data collection, the information was organized and analyzed. As an alternative to facilitate the organization of the collected material, the software Qualitative Solutions Research (QSR) Nvivo 2.0 was used. This tool is exclusively used for data organization, not for its analysis, as this is an exclusive task of the researcher. After the organization of the information, the stage of analysis and interpretation was initiated. The thematic content analysis was used for the analysis of the material since it is a complex and delicate subject. The thematic analysis searches for the centers of meaning present in the material to be analyzed, whose presence or frequency may have meaning, in other words, which may contribute to achieve the study objectives⁽⁸⁾.

RESULTS AND DISCUSSION

The material analysis generated three categories. This article presents and discusses the category *Involvement of the child to antiretroviral drugs*.

Meeting the children

The participants were children from 10 to 12 years old, who attended 3rd and the 6th grade of elementary school. One of the children was only taken care by her mother and other by her grandmother due to the death of her biological mother, whereas the others were taken care by their mother and their father. The number of siblings was around five and one participant was an only child. The family income was approximately R\$ 800,00. The education level of the caregivers varied from incomplete elementary school to college graduation, as it follows: three had completed elementary school and one had not completed it, two had completed high school and two caregivers had a college graduation. Most of the caregivers worked as assistants of general services. Regarding the period of time

using the antiretroviral, two children had been using it since birth, two of them for six years, and one child for a year. The mean of pills used daily was around four. As for the revelation of the diagnosis, the children had their condition as HIV carriers informed by their parents at ages that varied from five to 10 years old. The children acquired HIV through vertical transmission.

Involvement of the child to antiretroviral drugs

This category explored the involvement of the child to the therapy and its repercussions in their daily lives. For a better comprehension of the phenomenon, this category is presented in two subcategories: *Administration* and *Perceptions about the antiretroviral drugs*.

Administration

Although all children could read, it was possible to observe that they use alternative ways to identify the medication, such as, mainly, the color and the size of the pills. When questioned about the name of the medication they used, no one could answer:

I don't remember (G1P2).

I know by the characteristic of the drug (G1P1)!

I know it, but I don't remember the name (G3P3).

I take that pill that has two colors (G3P4).

In the morning I take a white and a yellow one and at night a blue, a white and a yellow one (G2P5).

These alternatives to identify the medication were probably used because antiretroviral drugs present rather complex and long names, which are difficult to pronounce and memorize even for adults. Besides the characteristics, other alternatives were found to identify the medication such as the use of illustrative stickers:

His drugs have a sticker of the ninja turtles. And mine have a doll (G2P2)!

The one I take at night has Garfield (G2P3).

And who gave these stickers to you (RES)?

I got them at the health unit (G2P3).

It is important to highlight that these stickers were created and distributed by the professionals of the Specialized Care Service (SCS) in STD/AIDS of the Health Center Vila dos Comerciantes, which is a reference location in the municipality of Porto Alegre, for children with HIV/AIDS. This initiative of the health team towards the child with HIV/AIDS, targeted at helping them handle the medication, is a strategy used as a way to motivate children in their compliance to the treatment, since it may contribute to facilitate the ingestion of the medication. The relation established by the health professionals and the health service to HIV/AIDS carriers may favor the increase of the compliance⁽⁹⁾.

Other authors emphasize that this must be a relation of trust, in which the health team must be willing to instruct and clarify the patient's doubts in the most accessible language. Whenever there is a good relationship between professional and patient, both have conditions to think and find strategies aimed at facilitating the daily ingestion of the medication and improving the life quality of the patient⁽¹⁰⁾.

In this context, it is necessary to comment and highlight the strategies of this health service, in which the children make their treatment and find support, as well as their caregivers, regarding the antiretroviral drugs. One of them was the creation of these stickers that are placed on the labels or boxes of the medication aimed at facilitating the memorization and recognition of the antiretroviral drug by the child, as shown in some of the collected statements. These stickers are pictures of toys or animals. Besides this strategy, the SCS promotes the integration of the children, caregivers and team through parties on celebration days like the Children's Day, for instance. One of the authors participated in one of these meetings, in which, at the same time they were served with candies, snacks and soft drinks, they watched theatrical plays created and performed by the professionals (doctors, nurses, psychologists, social workers, nursing technicians and administrative technicians) with themes related to the compliance with the antiretroviral therapy. Gifts and symbolic medals were distributed for the children to offer to the person who helped them most in the maintenance of the antiretroviral therapy. The activity took the whole day and the environment was filled with harmony, enjoyment and satisfaction.

Meetings like this certainly strengthen the bond between the health professional and the children and their caregivers, being an example of involvement and interest of the health team to improve the compliance of their patients and representing models that could be followed. However, the availability of the team members to instruct and perform educational reinforcing activities with the child and the caregiver constitutes a great well-known challenge. Regarding the ingestion routine, even though they did not identify their medication by their respective name, the children were aware of which medication they should use, as well as they knew the number of pills and the time they should take them:

I take it in the morning and at night. I take it after breakfast, before I go to school and at night before I go to bed (G1P2).

I take four pills at night and two in the morning (G2P1)!

I take it in the morning after I am ready to go to school, and at night I take it when I go to bed (G2P3).

The statement of P3 showed some divergence and called attention to the matter of compliance as he stated having *no problem taking the drugs* and at the same time revealed *I sometimes forget to take it*. Besides P3, other two participants – P1 and P4 – mentioned they forget to take the antiretroviral drugs. How could the health team help in this

aspect? The information about what could happen, the implications in the treatment and the responsibility assumed by the child and the caregivers are aspects to consider:

I take it before I go to bed, and when I wake up. I have no problem taking the drugs (G1P3)!

What did you write there? (RES)?

[...] that I sometimes forget to take it (G1P3).

And do you always take it (RES)?

I sometimes forget (G2P1).

A few times (G4P4)!

I just forgot once, when I was at my grandmother's house (G4P1).

These statements called attention to a crucial point in the scope of HIV/AIDS and the antiretroviral therapy – the matter of the compliance with the treatment. In their statements, the children reveal they sometimes forget to take the medication.

In this perspective, a study developed in Porto Alegre about the prevalence of the non-compliance with the treatment among children who used antiretroviral therapy found 49.5% of prevalence of non-compliance with the treatment⁽³⁾. Aimed at reaching satisfactory levels of compliance of the children with the therapy, it is considered that the caregiver and the child need to be involved in multidisciplinary work counting on both health and educational professionals.

A more recent cross-sectional study, with 262 participants aged between one and 20 years old, evidenced that 54.6% of the informers revealed they forget taking the antiretroviral medication. In this study, the factors associated to the non-compliance were the fact of forgetting to take the doses, the fact of living with their grandparents and the difficulties to deal with the treatment⁽¹¹⁾.

These data about the compliance with the treatment generated concern, since the non-compliance or/and partial compliance with the therapeutic program may be harmful not only for the individual's but for the collectivity's health, since it enables the emergence of viral strains increasingly resistant to the therapies available⁽¹²⁾.

The compliance to the antiretroviral therapy finds several obstacles. Besides the difficulty to ingest several pills daily, there is still the question of the undesired effects caused by the daily and extended ingestion of drugs. It is unquestionable that the antiretroviral therapy brought huge advances towards the increase of life expectancy of AIDS carriers, reducing the viremia (quantity of present virus) and making the immune system more capable of defending itself from opportunist infections, but it also brought adverse effects associated to its ingestion. However, despite of the adverse effects and the difficulties related to the therapy, the compliance of the patients must be close to 100% of the doses so that the therapy is effective⁽¹³⁾.

In this study, opposed to the statements of *forgetfulness*, there were those of *non forgetfulness*. Two participants stated they never forget it, which may indicate an appropriate compliance, but it is not possible to state it really happens as reported, since there is not an appropriate instrument that allows to confirm the compliance among children:

I always take it, I never forget (G2P5)!

[...] I take two in the morning and three at night (G2P5).

I never forget it (G2P2).

Measuring the compliance of children with the therapy is a challenge both for doctors and for researchers. It is known that some countries, like the United States, use a system of electronic monitoring to measure precisely the compliance in cases of diseases such as cystic fibrosis, tuberculosis and AIDS, mainly in the pediatric area. A monitoring system known as MEMS (Medication Event Monitoring System) is used in order to monitor the compliance to the antiretroviral drugs. The MEMS consists on a flask, whose lid is thicker than a usual lid and contains a software application that is capable of storing information about the time when the flask was opened. This information is stored for a maximum period of three years and may be transferred to a computer. When the patient goes to the appointment, he takes his MEMS and its information is analyzed by the professional and the patient. Nevertheless, despite of advances like these in the attempt to verify the compliance, these mechanisms do not offer the certainty that the medication was ingested. The compliance is presumed by the number of times the flask was opened, but the system does not let the professional know whether the medication was ingested, vomited or simply disposed. Therefore, even though these methods are efficient, only biochemical exams are capable of verifying whether the drug is really present in the blood⁽¹³⁾.

Another point that deserved to be highlighted was the family support. The children in the study had the support of relatives such as their father, mother, siblings or grandmother regarding the treatment:

My mother, my brother and my father help me (G1P1).

My mother and my father help me (G1P3).

My grandmother wakes me up and I take the medication, then I get dressed, have breakfast and go to school (G2P5)!

I always do it alone (G2P2).

I get up in the morning, get ready to go to school and my mother keeps annoying me all the time, then I forget to take the medication and I only take it at night, or at night I am on the street and my mother makes me take it (G4P4).

Despite of providing the children with some autonomy for the ingestion of the medication, these caregivers did not let them alone in this task. They were always supporting, checking and confirming whether the treatment was being followed. Whenever they were not around, some par-

ents would call or even text their children to remind them about the commitment to the medication.

When I go to a friend's house, my mother keeps annoying me not to forget, she even texts me on my cell phone [...](G4P1).

The network of family support represents an important factor of protection for the individual⁽¹⁴⁾. This support tends to acquire fundamental importance in delicate situations such as *being an HIV/AIDS carrier*.

Perceptions about the antiretroviral drugs

This subcategory evidenced the way the child perceives the antiretroviral medication, mainly regarding its palatability, as well as their perception about the reasons why they use the antiretroviral medication.

During the group discussions, the researchers tried to learn the opinion of the participants about the taste of the antiretroviral medication. At first, in the dialogues regarding the medication palatability, it was possible to observe speeches stating the medication did not have any taste:

It has no taste (G2P1)!

It does not have any taste (G2P2)!

But I would thank if it had a cherry or chocolate flavor (G2P1).

Nevertheless, during the groups, mainly in the third and fourth meetings, other opinions started to emerge, as perceived in the dialogues of the groups 3 and 4:

The drugs taste bad (G3P3)!

I think it doesn't have any taste (G3P1)!

It has no taste, only if you chew it (G3P2).

It's true, it has a bad taste if you chew it (G3P1).

I think it tastes really bad, but I don't have any problem taking it (G3P3).

But if you chew it, the taste is horrible (G4P2).

It also sticks to your throat and it burns (G4P3)!

But it only burns if you chew it (G4P1).

It burns and sticks to your throat (G4P3).

These speeches showed that some children qualified the medication as *bad*, *very bad* and *horrible* and they also said it *burns and sticks to the throat*. Reinforcing these findings, similar results were found in a study with children and adolescents in São Paulo, which evidenced that 60% of the informants presented problems with the taste of the medications⁽¹¹⁾. Other international study with children and their caregivers, aimed at studying the difficulties in the compliance to the therapy, revealed that the children and their caregiver found the medication taste unpleasant. Furthermore, the caregivers stated they used several types of food in order to make the medication more palatable to the child⁽¹⁵⁾.

Nevertheless, this strategy is not valid for all medications, since it may not be used for those that must be ingested with intervals between the meals, such as Didanosine (ddl), which must be administered either 1h before or 2h after eating⁽¹⁶⁾. Besides, there is a risk of making the child reject certain types of food as they are associated to unpleasant medications to the palate.

Nowadays, considering the scientific advances, wouldn't it be possible to make the medication more pleasant to its users? A participant, P1, in a previous dialogue, reported *I would thank if it had a cherry or chocolate flavor. Would it be possible to see a child choosing the flavor of his AZT, for instance? In this scenario, what would be the compliance to the therapy like? Wouldn't the question cost/benefit be rewarding not only individually, but also collectively?*

Besides, the study explored the child's perception about the reasons why they believe they use the medication. The result was that the main reason of the antiretroviral use seems to be associated to the fear of death. When questioned about the reason why they take the antiretroviral, the participants answered:

Because it is good for our health. My mother died because she didn't take the medication (G1P5)!

I love taking the medication, because it is very good for our health! [...] It is like our heart is thanking (G1P2).

In order to avoid dying so quickly (G1P1).

In order not to die (G2P2)!

In one of the groups the participant P2 reported he does not need help and he never forgets it, as stated in previous speeches. The participant in question seems to be engaged in his treatment showing commitment to the antiretroviral therapy. The interest in complying completely with the proposed treatment is supposedly motivated by the belief that, if he does not ingest the medication he will die.

My aunt didn't take it and thought she didn't have to, but she went to the hospital feeling sick and died (G4P2).

If I take it, I am not going to die and I am happy (G2P2).

During the groups, this participant reinforced the relation between compliance/life and non-compliance/death.

The good things (in life) are taking the medication to make my life last longer! I take it, I don't care (G3P2)!

The speeches of the participants reveal the association of not using the antiretroviral to death. The anxiety and the fear of death are multiplied in children when they have already had negative experiences⁽¹⁷⁾. Children with AIDS who are periodically monitored in the health service frequently meet and whenever one of them *disappears*, that it, dies, the others question what happened because they know they may share the same outcome⁽¹⁸⁾.

In face of diseases like AIDS, cancer and some types of cardiac problems, for instance, the presence of death is a

factor that may happen and limits life⁽¹⁷⁾. Although AIDS is currently considered a disease with chronicity characteristics, it is still seen by many people as a limiting disease that is responsible for shortening life. The extracts of the speeches allow to infer that the condition of having HIV/AIDS shows the disease as a fatality and a death sentence. During the groups, the discussions revealed the idea of an early death. The fear and the experience of witnessing the death of relatives or people close to them were also mentioned by the participants as an example of what could happen to them in case they did not take the medication.

These feelings of fear in face of death are inherent to the human condition, since the conscious of finitude is what differs human beings from animals⁽¹⁷⁾. The way death is perceived modifies according to the stage of life in which the person is. Pre-school children believe death is a temporary process that may be reverted, as it happens with characters from cartoons. During the school age, however, between five and nine years old, they understand death as a reversible phenomenon, but not natural and which does not affect all living beings. In this age, death is seen as something that is not capable of affecting someone close, only distant people. This idea changes when death reaches someone from the child's social circle. It is only between nine and ten years old that the child starts comprehending death like adults, as the discontinuance of the vital activities of the organism in an irreversible way and a phenomenon that affects all living beings, including those who we hold in high estimation⁽¹⁹⁾.

It is important to highlight that the participants of the present study were between 10 and 12 years old, so the conception of death possibly shared by them was about finitude, irreversibility and universality⁽¹⁹⁾. In face of the certainty that death is universal and the fact that it has affected people in similar conditions to theirs (HIV/AIDS carriers), like uncles or aunts, fathers or mothers, it is possible to comprehend better the fear of death present in some speeches. The speech of P4 shows the way the mother uses the daughter's fear of death to facilitate the ingestion of the antiretroviral medication:

Because our body starts drying up inside. My mother said that if I didn't take it I would go to the hospital, I would dry up and die (G4P4).

Another type of dialogue and attitude would be necessary. However, blaming the caregiver does not guarantee any positive effect in these cases, since due to the complexity of the factors involved and implicated in the progress of the disease and the therapy, it is not possible to expect that only the relative takes the responsibility for the events related to them. Undoubtedly, situations like these demand special attention from the health team in order to offer the appropriate support both for the family and the HIV/AIDS carrier. Another question becomes necessary: has the health team provided or enabled an environment where the caregiver and the child feel comfortable to speak and to be heard, to question and to clarify doubts about the disease and the treatment? Where do they find clarification about the antiretroviral drugs and their disease?

The speeches revealed that the children in the study presented superficial knowledge about the action of the antiretroviral drugs in the organism. The following speech reveals uncertainty about the action of the medication in the disease control, as it may be observed:

And do you know what the antiretroviral drugs are used for? (RES).

Not to let the disease evolve (G3P1).

Not to let it evolve (G3P2).

I don't know, I think it improves the disease we have (G3P3).

It is possible to observe that these extracts present simple answers to define the function of the antiretroviral medication. However, they seem to relate, in a vague way though, the use of the antiretroviral to the evolution of the disease. It is important to remember that all of them knew their diagnosis, attended school, were looked after by their parents or grandparents and monitored regularly at a health service. In this scenario, there is a question: how did they receive the information about the disease/virus that affects them? Who gave and give them information about the treatment and the disease?

It is believed that the organization of the knowledge about HIV/AIDS, or about any other subject, is generally mediated by means of mass communication, through the interaction with other people and through the school environment. A recent study about the knowledge of young people about HIV/AIDS revealed that young people present superficial, fragmented and little specific knowledge, reflecting the information contained in prevention campaigns broadcast by the media⁽²⁰⁾.

This types of knowledge apprehension, however, are often not enough to fill in the gaps of knowledge of both people who live with HIV/AIDS, and the society in general, maybe due to the type of messages they sent, which are sometimes little clarifying, and other times terrifying, superficial or suppressing. In this context, the activity of the health team becomes important in order to meet the needs presented by the system user, either to clarify their doubts, questions, or to provide them with a space to talk about the disease and its difficulties.

CONCLUSION

The study revealed that the children have knowledge about the routine of their treatment and recognize their

medication through its physical characteristics. The speeches showed they receive help from relatives in the administration of the medication, taking partial responsibility for its ingestion. They also revealed episodes in which the children forgot doses of the medication, which calls certain attention to the compliance matter.

The speeches were similar regarding the fear of death as the main motivator for the ingestion of the antiretroviral medication. The fear of death – inherent to human beings – was present in these children as one of the most evident aspects in their daily life, either because they had already experienced the death of relatives due to AIDS, or because of their own condition.

Regarding the palatability of the antiretroviral medication, the participants presented dubious opinions, since, while they stated the medication *was not bad* and that it *was good for their health*, they also stated it *was unpleasant, would burn and stick to their throat, and had a horrible taste*.

Another information that called the attention was regarding the little knowledge about the medication, since these are children in school age, HIV/AIDS carriers since birth, associated to a health service and to the NGO. In these conditions, they were expected to be more clarified about the aspects of the antiretroviral therapy. However, despite of their involvement and attitude in the focal groups, it is believed that feelings and verbal manifestations about their realities may have been omitted.

The development of a study of this nature involves many factors, mainly when the thematic is complex and difficult to approach, such as in the case of AIDS in children. It is important to highlight that there were several limitations, but the most remarkable and difficult to avoid concerned the selection of participants and the commitment of the children's caregivers to the study. After the project approval and the selection itself, the contact to the caregivers involved many telephone calls, exhausting possibilities of dates, shifts and times for the meetings, besides the waiting and disagreement to carry out the groups.

The authors hope these findings may contribute to the advance of the knowledge about this theme, aimed at making the childhood and adolescence of HIV/AIDS carriers less difficult. It is also believed that they may contribute to the elaboration of programs and strategies in order to improve not only the compliance to the therapy – necessary fact to guarantee the health quality –, but also the daily living of this part of the population.

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