

Difficulties encountered by families in caring for children or adolescents with HIV

Dificuldades encontradas pela família no cuidado à criança/adolescente com HIV

Dificultades encontradas por la familia en el cuidado al niño/adolescente con VIH

*Aline Rodrigues Costa^I; Camila Magroski Goulart Nobre^{II}; Giovana Calcagno Gomes^{III};
Simone Quadros Alvarez^{IV}; Juliane Portella Ribeiro^V; Gabriela Silva Miranda Rosa^{VI}*

ABSTRACT

Objective: to learn the difficulties encountered by families in caring for children or adolescents with HIV. **Methodology:** this qualitative study was conducted at a day hospital in southern Brazil in 2018. The participants were 20 family caregivers of seropositive children or adolescents. Data were collected through interviews and subjected to Content Analysis. Ethical principles were respected. **Results:** the families claimed to have no care facilities. They reported difficulties in keeping the children's or adolescents' diagnosis confidential; securing adherence to medication and administration schedules; minimizing side effects; attending appointments; suffering prejudice and gaining social acceptance of the disease, which included concern for the children's or adolescents' futures. **Conclusion:** it was found to be important that health professionals' or nurses' invest in care focused on promoting the health of children and adolescents with HIV, furthering health education and managing the difficulties encountered in care.

Descriptors: Child; adolescent; family; HIV; nursing.

RESUMO

Objetivo: conhecer as dificuldades encontradas pela família para o cuidado à criança/adolescente com HIV. **Metodologia:** pesquisa qualitativa realizada em um Hospital Dia no sul do Brasil em 2018. Participaram 20 familiares cuidadores de crianças/adolescentes soropositivos. Os dados foram coletados por entrevistas e submetidos à Análise de Conteúdo. Respeitaram-se os princípios éticos. **Resultados:** as famílias afirmaram não ter facilidades no cuidado. Referiram dificuldades em manter o sigilo do diagnóstico para a criança/adolescente; na adesão desta à medicação e minimização dos seus efeitos colaterais, em seguir os horários de administração; na assiduidade às consultas; em sofrer preconceito e na aceitação da sociedade diante da doença, incluindo a preocupação com o futuro da criança/adolescente. **Conclusão:** verificou-se como importante a atuação dos profissionais da saúde/enfermeiros investindo em uma assistência voltada para a promoção de saúde de crianças e adolescentes com HIV, promovendo educação em saúde e o manejo das dificuldades enfrentadas com o cuidado.

Descritores: Criança; adolescente; família; HIV; enfermagem.

RESUMEN

Objetivo: conocer las dificultades encontradas por la familia para el cuidado al niño/adolescente con VIH. **Método:** investigación cualitativa realizada en un Hospital Día en el sur de Brasil en 2018. Participaron 20 familiares cuidadores de niños/adolescentes seropositivos. Los datos fueron recolectados por entrevistas y sometidos al Análisis de Contenido. Se respetaron los principios éticos. **Resultados:** las familias afirmaron no tener facilidades en el cuidado. Dijeron que tienen dificultades para mantener el secreto del diagnóstico junto al niño/adolescente, también para su adherencia a la medicación y minimización de sus efectos colaterales, para seguir los horarios correctos de administración; la asiduidad de las consultas; por sufrir con los prejuicios y la dificultad de aceptación social de la enfermedad y la preocupación por el futuro del niño/adolescente. **Conclusión:** se verificó que es muy importante la actuación de los profesionales de salud/enfermeros que invierten en una atención volcada a la promoción de salud de niños y adolescentes con VIH, promoviendo la educación sanitaria y la gestión de las dificultades enfrentadas con el cuidado.

Descriptores: Niño; adolescente; familia; HIV; enfermería.

INTRODUCTION

Care provided to children and adolescents diagnosed with HIV is varied and requires the attention and availability of family caregivers. It is the family that follows the child/adolescent throughout their growth and development, having experiences and perceptions that allow them to build care that help them live with quality. Therefore, it is important for the nursing team to be committed to providing care and staying with these families, acting and assisting them in the construction of care for children/adolescents so that they go through human dimensions according to their context and lifestyle¹.

^INursing PhD student at the Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. E-mail: aline.rodrigues.costa@hotmail.com.

^{II}Nursing PhD student at the Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. E-mail: kamy_magroski@yahoo.com.br.

^{III}PhD in Nursing. Professor at the Federal University of Rio Grande. Brazil. E-mail: giovanacalcagno@furg.br.

^{IV}PhD in Nursing, Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. E-mail: alvarez.sqa@gmail.com.

^VPhD in Nursing, Federal University of Rio Grande. Adjunct Professor at the Federal University of Pelotas. Brazil. E-mail: ju_ribeiro1985@hotmail.com.

^{VI}Nursing undergraduate student at the Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. E-mail: gabrielasilva.enf@outlook.com.

Over time, families observe, discover, and learn to develop and provide care. They need to be attentive when facing the needs and things that happen to adapt to care of a child/adolescent. They are calm when the child/adolescent accepts the drugs, then the child/adolescent learns that he/she has to take the medication, remember the times, request the medication, and begin to take them alone, and participate in his/her own care².

It is the family that usually cares for and provides most of the support needed by a child/adolescent during their development. However, on this journey there may be difficulties that interfere with their lives. Difficulties leading to problems in the periodic follow-up of the child/adolescent to the Specialized Assistance Service (SAE)³ were observed. The main difficulty was access to the SAE from the patient's home, because the family caregivers relied on instrumental support and resources to pay for transportation. The same difficulty was also mentioned in other countries. In Uganda, Africa, lack of transportation to health services was also cited as a hindering barrier⁴. In addition, they also report difficulty in scheduling appointments due to the types of referrals required for scheduling, which take a longer period of time³.

The lack of a stable income, and the vulnerability that many families face affects the way their care is provided. In Uganda, the lack of financial support to fund adequate and nutritious food for the children/adolescents was mentioned as a difficulty that interferes with its quality. In addition, they reported having difficulties in care when the children/adolescents were ill⁴.

Given the multiple difficulties faced by the families, the figure of a professional who is present and assists them throughout this process of adaptation of the child/adolescent is essential. The nurse is the first professional who comes into contact with HIV patients and their families, so it is important that they use the knowledge learned during their practice to create strategies that minimize the difficulties and weaknesses that may appear. In addition, bonding with the children/adolescents is essential for trust, intimacy, empathy and affection to be established, and for nurses to guide them⁵.

Thus, the objective of this study is to learn the difficulties faced by families to care for children/adolescents with HIV. This study is expected to broaden the knowledge of health professionals regarding the theme, in order to assist in the creation of strategies to help families with the care of seropositive children/adolescents.

METHODOLOGY

A qualitative, descriptive study, with an exploratory approach, was developed. The study setting was the Pediatric Day Hospital of a teaching Hospital located in southern Brazil. The participants of this study were 20 family caregivers of children and adolescents followed at the Day Hospital, during the data collection period. The inclusion criteria were: being the main family caregiver of the child/adolescent with HIV at home, following the child/adolescent periodically in the treatment at the Day Hospital, and being at least 18 years old. The exclusion criterion was following the child/adolescent in the consultations only occasionally.

Data collection was performed in the first semester of 2018 through an individual interview with each family caregiver, held in an individual room at the day hospital after the medical consultation, or during waiting time. The number of study participants was defined by data saturation. They were asked about the difficulties faced in caring for the child/adolescent with HIV. The collected data were analyzed using the content analysis technique, which involves an analysis of "meanings", enriching the exploratory attempt, and increasing the propensity for discovery, thus being an empirical method⁶. This technique was implemented through three steps: in the pre-analysis, there was thorough reading of data, and the most significant statements that illustrated the content of the categories and the preparation of the material were chosen; the material was explored, with categories being defined; and during treatment and interpretation of the results obtained, data were discussed based on authors dedicated to the theme⁶.

Resolution 466/12 that governs research involving human subjects was followed. The research project was submitted to a health research ethics committee - and approved under number 29/2018. Participants signed an informed consent form, and were identified by the letter F for family member, followed by the interview number to ensure their anonymity.

RESULTS

Participant characterization

Twenty family caregivers, aged between 21 and 65 years, with a mean age of 37.9 years, participated in the study. They were related to the child's mother (nine), adoptive mother (four), father (two), stepmother (one), uncle (one) or

grandmother (three). Their level of education was: incomplete elementary school (ten), complete elementary school (four), complete high school (four), incomplete high school (one), and complete higher education (one). As for marital status, seven were single, eight were married, four were separated, and one was a widow. They lived with a family income between R\$ 187.00 and R\$10,000.00, with an average of R\$ 1,074.00, and two reported no income. The children were aged between nine months and 14 years, with a mean age of 7.08 years, and eleven being males and nine being females. All acquired the HIV virus by vertical transmission.

Difficulty keeping confidentiality about the diagnosis of the child/adolescent to the patient

Even though HIV is a disease in which patients can have the same life as anyone else, with the correct treatment, family caregivers said they did not see care provided as an easy task. They reported difficulties to keep confidentiality of the diagnosis of the children/adolescents, because they wanted to choose the appropriate time to reveal it.

There is nothing easy (F5).

There is no easiness at all. It is not easy (F11).

When she enters the office, the girls do not speak about HIV or what she has. I asked, because she's very smart, knows everything. I want to choose the best time to tell her what she has (F19).

Difficulties in compliance with the children/adolescents' therapy

One of the difficulties found was compliance with medication by the children/adolescents. They mentioned its bitter taste as a reason for their refusal to accept the medicine.

What I find difficult about medication is its bitter taste. He takes a little and spits the other half. The doctor told me today that I can mix it with some jelly or orange juice (F5).

At first, it was pretty hard because she couldn't swallow, and the taste was bad. But she has already adapted to it (F6).

It is a struggle for him to take the medicine because of its taste (F7).

In addition, they find it very difficult to administer antiretrovirals to the children/adolescents, because they are medications that usually cause gastric reactions such as stomach pain, nausea and vomiting, with difficult ingestion. Their major concern is that the medication shall be used for their whole lives.

Regarding medication, she had some reaction, stomachache and vomiting. I came to the doctor, I explained, and she gave me a drug for the stomach. She only takes the medication because she thinks it is to grow (F19).

Now reaching adolescence is kind of complicated for him. He has the side effects of medications, diarrhea, vomiting. It is complicated because it has to be taken forever not to get sick. He gets a little withdrawn, but I don't blame him for being that way (F17).

Another difficulty found was the drug administration schedule, which interferes with the sleep of the children/adolescents. In addition, two family caregivers reported having difficulties with food.

[...] is that sometimes she is sleeping and I have to wake her up to give the medication. Then it disturbs her sleep, because there are three medications. You give one medication and you wait to give the other one not to cause a stomach problem [...] It disturbs her sleep and even interferes with eating times (F8).

Now, he stopped eating. He doesn't want to eat. Then I make him eat even if it is a spoonful, because he can't stop eating (F3).

Difficulty in attending appointments

Attendance appointments was also reported as a difficulty, either due to forgetfulness or because the family caregiver lives in another city and has to travel to go to the consultation. They seek treatment in another city as a way to ensure confidentiality about the serology of the children/adolescents. One of the participants mentioned difficulty assuming the responsibility for care, because before the child/adolescent she did not need it or needed to take it over alone.

Sometimes I forget consultations. I've been forgetting sometimes. Today, for example, I only remembered when I was looking for something in my wallet and saw that it was today. Then I had to rush. (F3).

The most difficult is to come to the appointments, because I have to travel from my city to here [...] (F4).

The doctor, who was his doctor in our town, referred me to the doctor here. It's hard to come every month and sometimes I forget (F15).

At first, it was difficult because I wasn't used to it. I am a crack user, I am also HIV-positive, I support them alone. I'm a call girl [...] Then, I make a lot of effort. The first three, four months that were harsh, because, you see, there

is so much medicine, you have to give the inhaler, you have to take the child to the consultations. I was not used to so much responsibility. I always had a crazy life [...] (F4).

Experiencing prejudice and being accepted in society

Prejudice and acceptance by society were cited as difficulties experienced. Two participants mentioned that the reason for staying alive and strong is the presence of the child/adolescent, even mentioning suicide as an alternative if they were aware of the disease before the child's birth.

It is difficult because of prejudice. At school, nobody knows. When she doesn't go to school due to an exam, we say it is a routine exam. No one has to know (F9),

I feel the prejudice of others where I live. They say: The girl has HIV. His father's own relatives are prejudiced. Then I suffer and have depression because of it. I have to take some medicine. Sometimes it makes you want to sink into drugs and give up (F4).

[...] It's not everyone who will accept you the way you are. I know because after I had him I tried to have a partner and tried to explain it to him [...] Then he said he would not stay with me like that, because he did not want to risk getting it [...]. Since then I have not had anyone else. There are times when I think about just giving up and not living anymore because it is not everyone who accepts it. But then when I look at my son, I forget everything. But if I had found out before I had him I would have killed myself on the spot because I wouldn't have anything to live for anyway [...] I look at him and he is my joy in life, the one who gives me strength (F5).

Time and how to explain to the children/adolescents about their diagnosis were mentioned as difficulties. They said they had not yet thought about it because of the children's age, and fear of their reaction, and of being blamed for the transmission of the disease. In addition, they are often asked by the children/adolescents about the reason for the continued use of medication.

He is growing. He understands things better. So how will he accept that he has the disease? It's difficult. I didn't tell him exactly what it is. Sometimes he asks if he will have to take the medicine forever and I say I don't know, let's see (F1).

[...] I wonder every day how I will explain to him in the future what happened. Because [...] There is a friend of mine that her mother did not follow the treatment and she has it too, and she is very crazy, angry. She says she's sick because of her mother, it's her fault. I see this and keep thinking that my son may be disgusted with me for transmitting the virus to him (F5).

Questions related to the development of the children/adolescents and future dating were referred to as worrying, being mentioned as difficulties to be faced. They are concerned with its conduct so that the disease is not transmitted to others. In addition, one of the interviewees reported concern about guiding her daughter on prenatal care as an adult so she does not do to her son what they did to her.

I worry about his growth, about dating, because nowadays it's all so fast (F1).

I hope he will be honest with people, that he will not do what they did to me, and tell the truth. If he doesn't want to say, that he takes care not to transmit to someone else (F7).

She will be a citizen like any other, she will work, and God willing, she can be a mother. She'll undergo prenatal care so she won't do to her son what they did to her. So, this is what I will try to pass on to my daughter, that the disease doesn't mean the end of the world (F19).

DISCUSSION

Family members who care for children/adolescents diagnosed with HIV daily do not find it easy to care for them, as they face a number of barriers that affect the way this care is exercised, especially in view of the disclosure of the diagnosis⁸. This moment leads to a series of changes that interfere with family life, with their choice, being a difficult decision to make. It was found that in many cases the omission of the disease occurs due to the young age and lack of maturity of the children/adolescents to understand their serology. They also choose to wait for them to gain responsibility for their self-care and emotional maturity to deal with HIV issues⁷.

Family members choose to keep confidentiality about the diagnosis for the children/adolescents, because they want to choose the appropriate moment for its disclosure⁸. Thus, for this moment not to be hard, it shall involve health professionals, becoming a shared and continuous decision. In addition, some aspects shall be taken into account, such as the particularities of social context, age and cognitive maturity⁹.

Another reason why family caregivers postpone the disclosure of the diagnosis to the children/adolescents is that during childhood children do not understand, do not ask and do not refuse treatment. However, when children get into adolescence, new questions begin to emerge demanding answers and changes in the attitude of the family caregivers¹⁰. Moreover, the stigma of the disease, even with all existing information, interferes with the disclosure of the diagnosis,

which can lead to the disclosure most often occurring during adolescence, which is considered a special and delicate moment in a person's life. This is a very common factor, because family caregivers believe they are protecting the children/adolescents¹¹. According to a study analyzed, it was observed that from the age of 11 on, the children/adolescents interviewed reported starting to understand a little better about their serology¹¹.

The disclosure of the diagnosis is an initial milestone for the construction of the children/adolescents' life history. However, this time, although necessary in their life and in their care, leads to a number of reactions and feelings, often negative, as it is a disease that interferes with several aspects, such as social and emotional ones, due to the stigma still existent in society¹².

The perception of the world is different and expanded in adolescence and therefore, the disclosure of the diagnosis is necessary and essential for the success of the antiretroviral treatment (ART). Adolescents with HIV need to know and participate in decisions related to their health-disease process in a unique and comprehensive way¹². Thus, there is the need for the presence of a health professional who welcomes and cares for them, as well as their family caregivers in their uniqueness, going beyond the disease to find each one's particularities¹⁰.

Because HIV is difficult to understand in childhood, leading to many doubts and questions to the children/adolescents, families and health professionals must be prepared to act on the theme. Nurses must encourage caregivers' communication and recognition of the children's/adolescents' efforts to learn how to manage information about their condition.

Regarding antiretroviral medication, under the eyes of the children/adolescents, especially during early childhood, it can negatively influence treatment adherence. They find it very difficult to administer antiretrovirals to the children/adolescents, because they are medications that usually cause gastric reactions such as stomach pain, nausea, and vomiting, with difficult ingestion. Their major concern is that the medication shall be used all for their whole lives. Undesirable effects, such as nausea, stomach pain, and malaise, were also observed as barriers to good adherence to therapy¹³.

One of the obstacles hindering adherence to antiretroviral therapy is the time of administration, which can interrupt the sleep cycle, as well as the need to get up early or sleep late to take the medicines. In addition, it was found that medications may impose some restrictions, making adherence difficult, especially in adolescence, in which adolescents often deprive themselves of activities such as trips or parties with friends¹³.

Low medication adherence occurs due to low educational level, lack or little family and social support, alcohol and illicit drug consumption, in addition to the side effects of medication use. Thus, it is clear that the nursing staff can work with the community and support institutions to guide and work with people who need assistance, either in their activities of daily living or in the distribution or administration of ART¹⁴.

The support and assistance provided to families who have children/adolescents with HIV are essential for this group to be able to organize and meet the needs of the children/adolescents with quality, especially regarding drug routine. The presence of a professional who assists with appropriate interventions, who is present and provides support, is important for the family member to be able to go through this process.

A study conducted with children in an outpatient clinic specialized in sexually transmitted infections found that participants revealed restrictive eating habits, which inhibits the intake of food that is essential for good development¹⁵. In addition, the amount of medications that are ingested also interferes with the eating habits of the children/adolescents, causing great concern to the family caregivers⁸.

It was also observed that even though eating is important to assist in the quality of life of patients with HIV, HIV-positive adolescents have an eating pattern that is similar to that of adolescents without the disease. This is a worrying factor, because most HIV-positive adolescents are more likely to develop chronic diseases. Thus, they need to maintain a nutritious and healthy diet for their age group, as well as periodic follow-up at health services and consultations with the multidisciplinary team¹⁶.

The nurse is an important figure, and during consultations with the families and the children/adolescents shall encourage healthy eating habits, and create strategies that encourage the implementation of proper nutrition, within the conditions and individuality of each family. Health education, guidance, promotion, and prevention are actions that are part of nursing care and need to reach these groups in order to help them.

When caring for a child/adolescent, his/her guardian needs to take care of him/her, especially when the child has a disease that requires specific care. Adherence to drug therapy depends not only on the child/adolescent, but also on the responsibility and care provided by the family caregiver¹⁷. Therefore, caregivers need to adapt their routines, and use the strategies learned as a way of helping to solve the difficulties faced.

The need to acquire responsibilities and perform appropriate care to ensure a successful treatment is essential for the children/adolescents to have quality of life. Thus, family caregivers need to understand the importance of their role within the life of the children/adolescents with HIV, and take responsibility for the demands that will arise. Therefore, the presence of a nurse who listens and understands the reality of these families is essential to help them understand their importance in caring for the children/adolescents.

Situations related to prejudice and acceptance can occur within the school environment of the children/adolescents, often leading to the omission of the diagnosis due to fear that they will experience humiliation and prejudice by the teachers. Another problem faced by family caregivers is due to the fear that people have to get the disease when contacting someone with HIV; this leads to difficulties to find help in the care of the children/adolescents¹⁸.

The disease may reflect negatively on the life of the children/adolescents due to stigmas and prejudice. Due to people's lack of knowledge about the disease, family caregivers mentioned that the children/adolescents face rejection by peers, and do not participate in games at school¹⁹. This lack of knowledge often causes the patient to be silent about the disease, and make him/her face discrimination that can occur even within their own family, neighbors and health professionals. This type of situation can affect the individual's self-esteem, interfering with their self-care¹². Therefore, the inclusion of the individual with HIV should imply the production of care that deconstructs prejudice and offers a better life and future perspective¹².

In addition, health professionals and government agencies need to invest in campaigns and practices that stimulate people's awareness of HIV so that HIV-positive individuals live like any other citizen. Moreover, nurses shall act to promote critical thinking of these patients in the face of potentialities and weaknesses, so that they feel strengthened and confident to face the difficulties, and the still existing misunderstanding of society.

CONCLUSION

There are many difficulties presented and which interfere with the life and routine of both the families and the children/adolescents with HIV. They reported difficulties in keeping confidentiality about the diagnosis for the children/adolescents; adhering to the medication and minimizing its side effects; following the administration schedules; attending consultations; facing prejudice and acceptance of society in the face of the disease; they also mentioned concern with the future of the children/adolescents.

Data allowed us to detect the importance of the nursing team as an active and comprehensive part of the multidisciplinary team, since they are the ones who first come into contact with these patients and their families, both at primary health care and specialized services. The nurse is present when providing guidelines, health education and the humanization of care, aiming at the promotion and quality of life of children/adolescents with HIV and their families. This care will enable the creation of strategies, according to the individuality and experience of each family, so that they can provide quality care to children/adolescents, minimizing the difficulties experienced in their daily lives.

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