

# The voice of children who live with HIV on implications of the disease in their daily life

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## The voice of children who live with HIV on implications of the disease in their daily life

**Objective.** To determine the effects of HIV/AIDS on the daily lives of HIV-infected children, based on their responses to a semi-structured interview. **Methods.** This exploratory descriptive study with a qualitative approach was carried out from November 2012 to March 2013 among five children with HIV aged 11 to 12 years. The children were registered at the non-governmental organization “Mais Criança” in Porto Alegre/RS/Brazil. Data were collected using semi-structured interviews, and the results were submitted to thematic analysis. **Results.** The analysis of content identified two categories: *fears in daily life of the child with HIV* and *experiences: lived knowledge*. With regard to daily life, the children reported no difference in their lives compared with the lives of other children because they can take part in any activities they want if they are taking their medicines. They seemed to have positive expectations about the future. **Conclusion.** Children with HIV/AIDS live in a complex situation with severe conflicts. However, their childhood is similar to that of other children without the disease. Health professionals, especially nurses, need to develop strategies to strengthen the bond with these children and their families in order to give them the opportunity to express their feelings and to cope better with living with the disease.

**Key words:** child; acquired immunodeficiency syndrome; hiv; nursing.

## La voz del niño con VIH / SIDA sobre sus implicaciones en su vida cotidiana

**Objetivo.** Conocer a partir de la voz del niño con VIH/SIDA las implicaciones que esta presenta en su vida cotidiana. **Metodología.** Estudio exploratorio descriptivo con abordaje cualitativo, realizado de noviembre de 2012 a marzo de 2013 con la participación de cinco niños con VIH/SIDA, con edades entre 11 a 12 años, vinculados a la Organización No Gubernamental “Mais Criança” del municipio de Porto Alegre/RS/Brasil. La información se recolectó mediante una entrevista semiestructurada, la cual fue sometida a análisis temática de contenido. **Resultados.** Se

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evidenciaron dos categorías: *Temores cotidianos del niño con SIDA*, y *Experiencias: el conocimiento vivido*. En relación con lo cotidiano, los niños relataron que no tenían una vida diferente a la de los demás, no dejaron de hacer sus actividades diarias y, por supuesto, tuvieron que tomar la medicación. Manifestaron tener expectativas positivas para el futuro. **Conclusión.** Los niños con VIH/SIDA viven una situación compleja permeada con conflictos graves. Sin embargo, su infancia es similar a la de los demás niños. Los profesionales de la salud, y en especial enfermería, necesitan desarrollar estrategias para el fortalecimiento de un vínculo que posibilite al niño y a su familia la manifestación de sus sentimientos, que contribuya en la conducción del proceso de vivir con esta enfermedad.

**Palabras clave:** niño; síndrome de inmunodeficiencia adquirida; vih; enfermería.

### A Voz da criança que vive com o HIV / AIDS sobre as implicações na sua vida cotidiana

**Objetivo.** Conhecer a partir da voz da criança que vive com HIV/AIDS as implicações na sua vida cotidiana. **Metodologia.** Estudo exploratório descritivo com abordagem qualitativa, realizado entre novembro de 2012 a março de 2013 com a participação de cinco crianças com HIV/AIDS, com idades entre 11 a 12 anos, vinculados à Organização Não Governamental “Mais Criança” do município de Porto Alegre/RS/Brasil. A informação, coletada por meio de uma entrevista semiestruturada, foi submetida a análise temática de conteúdo. **Resultados.** Se evidenciaram duas categorias: Temores cotidianos da criança com AIDS, e Experiências: o conhecimento vivido. Em relação ao cotidiano as crianças relatam que não têm uma vida diferente aos demais; não deixam de fazer suas atividades diárias enquanto vivem com o HIV/AIDS e têm que tomar a medicação. Manifestar ter expectativas positivas para o futuro. **Conclusão.** As crianças com HIV/AIDS vivem uma situação complexa permeada com conflitos graves. No entanto, sua infância é similar aos de outras crianças sem a doença. Os profissionais da saúde, e em especial enfermagem, precisam desenvolver estratégias para o fortalecimento de um vínculo que possibilite à criança e a sua família a manifestação de seus sentimentos, que contribua na condução do processo de viver com esta doença.

**Palavras chave:** criança; síndrome de imunodeficiência adquirida; hiv; enfermagem.

## Introduction

The human immunodeficiency virus (HIV) represents a huge health problem. Each day more and more people are infected by the virus, despite a large number of media campaigns in Brazil that publicize preventive strategies and institutional policies providing guidance about HIV. In 2011, the number of persons living with HIV in the world reached 34 million. Of these, 3.4 million are children younger than 15 years of age.<sup>1</sup> In Brazil, between 1980 and 2012, 656 701 cases of HIV were reported, and roughly 15 000 cases (14,807) were in children younger than 3 years.<sup>2</sup> The HIV/AIDS epidemic constitutes one of the most serious public health problems; it poses a high degree of morbidity and mortality, and

continues to grow and spread in all continents. The possibility of controlling this pandemic still seems remote, despite the development of new therapies and a worldwide effort to develop a vaccine against the infection.<sup>3</sup>

Children living with HIV/AIDS make up a heterogeneous population in terms of manner with which and age at which viral transmission occurred. Those factors have consequences on clinical, immunological, psychosocial, and cultural conditions and pathway for treatment. We are witnessing the first generation of children and adolescents living with HIV/AIDS since birth, along with the repercussions of the disease (including the

continuous use of medicines). In such situations, it is fundamental to consider the implications for the daily life of these children.<sup>4</sup> Children living with HIV/AIDS establish a long-term bond with healthcare professionals and health services. This long relationship is marked by periods of stability, fear, anxiety, and uncertainty for the child, his/her family, and the healthcare team.

A study of the experience of children with HIV and their families found that visits to a health unit provide an opportunity for assessment of well-being; during these visits, the children and families can talk about the disease frankly with professionals, without feeling embarrassment and prejudice.<sup>5</sup> These visits can help to clarify doubts, but they can also generate other fears and anxieties. Nonetheless, settings are needed in which these children can report on their efforts to have a better life despite all problems associated with HIV infection. It is understood that relationships with family, feelings, perceptions of fears, and fantasies can influence children's daily life. Thus, listening to them and observing their perceptions can help create and advance nursing knowledge at the national and international level.

This study sought to answer the following question: What does a child who lives with HIV/AIDS report on implications of his/her condition in daily life? The aim, based on interviews with children living with HIV/AIDS, was to determine implications in their daily lives. There is a need to study this population in order to understand how children with HIV experience life with the disease and to create strategies to improve their quality of life.<sup>6</sup>

## Methodology

This was an exploratory descriptive study with a qualitative approach conducted at the headquarters of a non-governmental organization (NGO) called "Mais Criança." This site was chosen because of the recognition for the work developed with an HIV-infected population in the municipality of Porto Alegre/RS/Brazil, and also

because this NGO is an institution that provides support, preventive education, and psychological and socioeconomic assistance for children and adolescents living with HIV and their families. Currently, Mais Criança develops activities with 78 families and follows, roughly, 100 children and adolescents with HIV/AIDS aged 0 to 19 years. This institution was not part of the traditional health care system, a fact that favored the conducting of our study. The NGO assists children and families from several health services of the municipality of Porto Alegre; therefore, their constituents are quite diverse and representative of the surrounding area. The population comes from different care institutions, social classes, and neighborhoods in Porto Alegre.<sup>7</sup>

The study population was composed of five children aged 11 to 12 years (one boy and four girls); they were able to provide information independently without the support of a caregiver. The sample size was small because of the difficulty in arranging arrange days and times with the children's mothers (the study took place in the summer with extremely hot days), the other children in the family, and the lack of commitment to the study. Another limitation was related to the age group served by the NGO; many children were too young to participate. In addition, because data collection was scheduled to occur during school holidays, we believed that the probability of children visiting the NGO would be higher; however, the opposite occurred. Nonetheless, data collected during the interviews, transcribed, and submitted for analysis showed that the children included in the study fulfilled the objective of this study. It is well known that during interviews with children, the particularities in their testimonials must be considered.

Participants were selected intentionally, and the NGO president was responsible for identifying the children who met the inclusion criteria: i.e., children who were aware of their HIV-positive status, had used antiretroviral drugs for at least six months, were registered at Mais Criança, and agreed to participate in the study after their parents or legal guardians gave authorization.

Data were collected using semi-structured interviews. In this study the interviews were called “chats” because children often like to talk and share their daily life experience in an informal way. The approach of the interview considered the age of the child, characteristics of his/her age group, questions related to antiretroviral therapy and the implications of the disease in his/her life. To the best of our ability, during the interview we used language that could be easily understood by the child.

The interviews were conducted informally and were intercalated by activities chosen by the child. We tried to engage the child in an informal conversation about his/her daily routine, preferred sports, favorite soccer team, favorite games, and things he/she expected to do during school holidays, among other topics.

This study followed the ethical principles stated by Resolution no. 196-96 of the Brazilian National Health Council.<sup>8</sup> A consent form given to parents or legal guardians elaborated on the rights to information about the research, voluntary participation, and authorization for publication of data. All responsible parties signed two copies of the consent form; one copy was given to the participant and the other was kept with the researcher. To guarantee confidentiality, participants are identified by the letter S (for “subject”) and an identifier number according to the order of interviews (i.e., S1, S2, S3, S4, and S5). This project was analyzed and approved by the Ethical and Research Committee of the Universidade Federal do Rio Grande do Sul (no, 109.049). The authors of this study declare no conflicts of interest.

## Results

The analysis of contents identified two categories: fears in the child’s daily life and experiences: lived knowledge,

### Fears in daily life of the child with HIV

In testimonials, the fears reported by children as part of their life were related mainly to prejudice

and discrimination, confidentiality, and hiding negative feelings concerning the disease or the use of antiretroviral drugs. These feelings affected their day-to-day life and were sometimes not considered positive. The children sometimes had hidden their condition from friends and family or wound up denying their disease upon having to explain the use of the antiretroviral drugs. Children often used other diseases, considered less aggressive, to justify the use of medicine. This situation is observed in the following testimonials: *They know my condition, but when they asked what I had, I told them I had Asthma (S1); No, nobody knows. I don’t tell anyone (S2); I don’t tell anyone (S5).* Other subjects related to fear were prejudice and discrimination, which remain a part of the daily life of children with HIV/AIDS, as observed in the following statements: *They called me **AIDS carrier** and it is quite bad...(S4); Everybody calls me “the thing” in school (S5).*

The expressions “AIDS carrier” and “the thing,” even though expressed by other children (schoolmates and children around them), had been initially spoken (even if unconsciously) by adults to whom those children listened and then repeated. The attempt to find substitutes for AIDS in other diseases, such as tuberculosis, shows that HIV-infected patients may attempt to seek refuge in a disease that they do not have but is less socially objectionable; thus, they can say to others that their disease is not so bad, as expressed by S3: *(...) they leave people alone. Because, in fact, it is like you really have tuberculosis. It’s not a big deal (...) There is too much prejudice (S3).*

The use of the medicine is associated with well-being, sadness, not getting sick, and avoiding the risk for dying, as observed in the following testimonials: *I know it is a bad thing and I have to take the medicine or I go to the hospital and it’s not cool (...) When people talk about my father. Because he died recently and he also had this disease, and it makes me sad (S3).* The children noted how the use of medicine can interfere in their daily activities, such as *(...) when I had to stop everything to take them [Medicines] (S2).* In

other words, the children mentioned that having to stop playing and interrupt what they were doing as something that affects their daily life. These statements show the dual interpretations that children are able to experience. They must take the medicines, but at the same time interruptions for medication presents a limitation; some interruptions have an expressive meaning in a child's life, such as having to stop playing.

### **Experiences: lived knowledge**

This category consists of situations in children's daily lives that have implications in their way of life: for example, the regular use of medicines, expectations concerning the future, routines such as going to school, games, and other experiences that are integral to the children's lives and are relevant for coping with the disease and the circumstances that affect them.

With regard to use of medicines, it was evident that the presentation of drugs, palatability, and interruption of the children's routine remain the most predominant factors for these children, as observed in following testimonials: *Before I had to take Kaletra, that liquid, and it tasted horrible so I end up vomiting everything (S1); I hid the medicines under my mother's washing machine, because I didn't like to take them (...) because the taste was so horrible and I felt like gagging (S1); I don't feel very well! It seems that it [medicine] closes my throat. And I felt uncomfortable (...) (S2); the taste stays in your throat and it tastes horrible (S3).*

The testimonials of the children indicate that the taste of the medicine is still an obstacle to improving the adherence to antiretrovirals and, as a result, to increasing survival and quality of life. Nonadherence due to lack of medication palatability, adverse effects of medication, opportunistic infections, and clinical worsening interfere in the development of children's activities by removing the child from his/her environment for hospitalization or interruption of daily life, such as going to school, playing, and participating in leisure activities. In testimonials we also observed

that the taste of medicine turns the fact of taking the medicine, at least twice a day, into a huge problem for the children. It generates a bad feeling and sometimes nonadherence. This was clear in the testimonials of S1, who affirmed hiding the medicine in order to avoid taking it.

Concerning the daily lives of the children, we observed in their testimonial that all things were reported as normal situations. When the children were questioned about their routines and daily lives, they claimed that living with HIV/AIDS or taking medicines does not interfere with their activities: *Everything is normal (...) (S2); Everything is normal (...) I'm a quite calm person (S5).*

These responses were seen when the child was asked about his/her routine of going to school, with the aim of understanding which activities could cause physical fatigue, such as games during recess, running, playing, and going up the stairs. We verified that these activities did not harm the children because they continued to follow their physical routine without interference and without the perception that the disease or medicines changed their disposition: *I don't feel tired with anything (...) (S1); When I go to the park. I ran a lot there and played on the swings (...) (S2); I like to play (...) At school things are fairly calm, it's good (S3).* Children mentioned that they like to play like any other children, and the fact of living with HIV does not prevent them from having a normal life. This can be seen in the testimonial of S2, who, when questioned about what pleases her, answered that she liked to go to the park and run a lot.

Although the children said that their day-to-day lives were normal, the fact that they needed to stop an activity to take medicine is considered something bad that directly interferes with their daily life: *I feel uncomfortable (...) because I had to stop everything to take the medicine and it's bad (S2); It's bad because I don't like to take the medicine every day (S3); I had to stop everything to take the medicine (S5).* As observed in the following testimonials, children who live with HIV/AIDS mentioned willingness to engage in a wide

range of activities regarding work, without any differentiation. When asked what they would like to do when they grow up, the children provided answers that were similar to children without any disease: *A soccer player (S1); A waitress, at a market, organizing things (S2); Teacher or doctor (S4)*. Children with HIV/AIDS strive to not be seen as different. They are able to adapt their way of life so that they are accepted by others.

## Discussion

### Fears in daily lives of children with HIV

The term “quality of life” connotes comfort and well-being. This term has several meanings reflecting knowledge, individual or group experiences, and considerations for social and cultural scenarios.<sup>9</sup> In this study, assessment of quality of life showed the children’s perceptions on objectives, expectations, standards, and worries (i.e., their daily lives).

The silence regarding their HIV health status and the repercussions in the children’s lives — mainly at school (the most visited place for most of the children) — should be a point of reflection. The need for actions to promote a better life at school for HIV-infected children is clear, especially those who fear discrimination and being labeled.<sup>10</sup> Despite extensive efforts to reduce the stigma of AIDS, it is still associated with behaviors not accepted by society.<sup>11</sup>

Still, in this regard, the omission of HIV seropositivity status, for example, may serve as a strategy to avoid discrimination and stigmatization that devalue patients, produce social inequities, and reinforce those that already exist. Living with HIV positivity leads infected children and their caregivers to avoid circumstances that could further stigmatize them.<sup>12</sup>

Ill treatment of HIV-infected children by their peers is considered bullying and should be investigated

and discussed in any environment or group with which these children interact, including school, family, and friends. The response of the children in our study shows that they were still embarrassed by their illness even when they did not say a word about it. It is clear that the social and familiar context has an important role in transmitting values to children. Prejudice has pejorative connotations, in which one person has an opinion about another person or topic that can be both openly expressed and assumed. For this reason, an opinion is culturally transmitted and, consequently, internalized by persons whose behavior is susceptible to influence.<sup>13</sup>

The children expressed sadness and fear of becoming sick at any time, thereby revealing their condition to family members and their larger social group, with particular fear of judgments. In addition, there is also the prejudice related to a disease that remains associated with and marked by stigmas and stereotypes.<sup>14</sup>

When the children reported being left alone in a group of their peers, they noted becoming fearful of being different from the rest of the group and of not being accepted. Therefore, they found an alternate explanation for their illness. They believed that telling people they have tuberculosis (a widely known disease that in the past was severe and incurable) would allow them to escape others’ judgment because this alternate disease was not severe and or even a problem.

As observed in the children’s testimonials about living with HIV/AIDS, they feel they need to keep their situation hidden by claiming other diseases. In this way they avoid morally undesirable situations and justify the long-term use of medicines.<sup>15</sup>

It is well known that each day people living with HIV/AIDS have to deal with the fear of getting sick from a complication of disease or even dying. This fear is understandable because of the mortality associated with HIV/AIDS. Although today HIV/AIDS is considered a chronic disease, it is limiting for many patients and responsible for many early deaths.<sup>16</sup>

## **Experiences: lived knowledge**

The taste of medications is without doubt a huge factor posing difficulties with drug adherence. The pharmaceutical industry has been showing its concern by developing medications more specific and adaptable to children in terms of, for example, the size of the pill and type of formula. Recently, the Brazilian Health Surveillance Agency (ANVISA) approved a new formulation of the antiretroviral agent raltegravir—chewable 25-mg and 100-mg tablets—whose aim is to ease the treatment of HIV-infected children aged 2 to 12 years.<sup>17</sup>

It's well known that some individuals living with HIV/AIDS hide bottles with antiretroviral agents, change the packages, tell others that the infection is a different disease, or attempt to hide their treatment so as to not be recognized as someone with HIV/AIDS.<sup>18</sup>

The children in the current study claimed that HIV does not influence their day-to-day routines, such as going to school, playing with friends, and engaging in activities that could generate physical or psychological fatigue.

For children with HIV/AIDS, the perception of normality can influence adherence to medicine; if they do not feel sick, they may not take their medication. This shows that they live in a dual reality: They live with a disease and they live normally. The lack of symptoms can affect the perception of the disease severity and, as a consequence, be a factor in their feeling normal.<sup>19</sup>

The testimonials showed that the children have a different perception of their condition than do adults living in the same situation. Interviews with adults might identify more reports of discouragement or even complaints of depression and lack of willingness to continue with treatment. We know that children with chronic or severe disease become mature early. The chronic disease imposes changes in children and their family life, requiring reallocation concerning new situation and strategies for coping. This process depends

on the complexity and severity of the disease, the disease stage, and structures available to satisfy their needs and reacquire balance.<sup>20</sup>

Expectations are important issues related to children's lives and development. HIV-infected children, like other children, have hopes and aspirations for the future. They do not consider the fact that having an incurable disease might affect their aspirations.

This issue also includes children's resilience, especially when facing challenges, threats, and, in this case, a situation considered unfavorable by many persons; the child simply can develop a basic and positive resolution to adapt himself/herself to this condition, seeking good results even though several factors threaten their development.<sup>21,22</sup> Resilience in persons with HIV/AIDS has helped to reduce the stigma and prejudice associated with this disease and to refute the claim that well-being and good quality of life are contradictory and incompatible with HIV.<sup>23</sup> Living with HIV/AIDS presents an extreme adversity, mainly for adults; however, for children, life with HIV could be interpreted as a potential source for change and for new opportunities in life.<sup>24</sup>

This study showed that according to the children's perspective they had a life similar to that of other children; they participate in the same activities despite their HIV/AIDS status or the routine of taking medications. The children maintained this perspective even when noting that these issues affected their lives. The interruption in or even the impossibility of doing an activity in order to take an antiretroviral medication has become a part of their lives, and they deal well with it. The children who participated in the study reported facing prejudices and discrimination at school, with friends, and even in the family environment; these issues that interfere with their daily life. Negative feelings generated by these fears could compromise their daily life and lead them to reject the treatment or not adhere effectively to it, thereby compromising their health or even worsening their symptoms. These issues were evident when the children affirmed to hiding

their seropositive status to others. They did this to avoid the negative feelings associated with AIDS because of its relation to death. For these children, hiding their condition in order to distance themselves from prejudice and discrimination is also a way to avoid dealing with the fact that they will live with an incurable disease for the rest of their lives, even when they witness persons they know, including family members, dying of HIV complications.

Health professionals, primarily nurses, have an important role in caring for HIV-infected children, and they should make efforts to understand, support, and give voice to these children. Nurses usually serve as a reference to the child both for type of relationship they create with them and their families and for the availability to listen, help, and not criticize or judge the situation in which they live. This study is not a definitive assessment of this subject, but it does facilitate other questions for further investigations and implementation of care actions involving large samples at health and education institutions.

Limitations of this study mostly concern the small sample size; however, we verified that the number of patients would be sufficient to analyze the content and achieve the study objective. The question posed by this study enabled us to determine, on the basis of responses from children living with HIV/AIDS, the effects of the disease on their daily lives, as related to their well-being, concerns, and health expectations. Studies in childhood tend to be of assistance in origin and clinical-epidemiological in nature,<sup>25</sup> with little emphasis on sociocultural, behavioral, and emotional implications for the children.

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