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## Existential movement experienced by adolescents with acquired immunodeficiency syndrome: a phenomenological study

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### ABSTRACT

**Objective:** Human beings with vertical transmission HIV pass from childhood to adolescence, and little is known about how they care for themselves on a daily basis. The objective was to understand the quotidian life of adolescents with AIDS.

**Method:** The phenomenological interview of 11 boys/girls aged between 12-14 years with a disclosed diagnosis took place after ethical approval was obtained from the Institutional Review Board at Rio de Janeiro.

**Results:** The Heidegger comprehensive analysis approach shows that an adolescent's experience is an existential movement which is marked by childhood and adolescent moments. In childhood, there is a desire to play like other children. In adolescence, there is a desire to be like others in general (in terms of appearance, mood, attitudes, lifestyle, leisure and relationship). Their desire reveals the diagnosis, studying, working and parenting. They say that taking medication and going into hospital are part of their condition. In the double-*facticity* in their *inauthenticity*, they feel dominated by the depersonalization of appearing like other children/adolescents. In terms of their *authenticity*, the singularity of their feelings, difficulties and possibilities are revealed.

**Conclusion:** The existential movement experienced by them is not limited by age or by childhood/adolescence patterns, or by clinical fragility. The challenge is conjugating biological and existential dimensions to adolescent care.

**Keywords:** Adolescent Health; Child Health; Pediatric Nursing; Acquired Immunodeficiency Syndrome; Qualitative Research

## INTRODUCTION

In Brazil, 90% of reported cases of HIV/AIDS in children under 13 years of age were related to vertical transmission infection<sup>(1)</sup>. Among other reasons, this group of children has not tended to die due to the free access to antiretroviral treatment and prophylaxis of opportunistic infections provided by the National Healthcare System (NHS)<sup>(2)</sup>. As a result, an increasing number of children have been surviving, and many of them are moving forward to a new phase of human development beyond childhood. They are recognized as the first generation of HIV/aids individuals infected by vertical transmission<sup>(3-5)</sup>. Children with vertical transmission HIV pass from childhood to adolescence, and little is known about how they care for themselves on a daily basis in this process of becoming adolescents<sup>(6-7)</sup>. These problematic aspects show the necessity of understanding the daily life of adolescents with AIDS.

Furthermore, scientific publications about HIV/AIDS in children and adolescents is more focused on clinical-epidemiological and socio-cultural aspects than on an existential dimension of the individual person as a human being<sup>(6-8)</sup>. Moreover, there are a limited number of studies that discuss the vertical transmission of HIV/AIDS with regard to children who are in transition to adolescence<sup>(9-14)</sup>. Among the studies available, there is a lack of discussion about the existential dimension of this specific group in terms of being-adolescent.

Being-adolescent means the being of the human happening as a being-in-the-world, particularly during the transition from childhood to adolescence. In this sense, as a conceptual framework, we have adopted the analytics of existentialism of the human being from a Heideggerian perspective<sup>(15)</sup> which allows us to understand the ways of being in daily life. The phenomenological approach does not seek an explanation nor to universalize the phenomenon, but is concerned with its essence (meanings and senses) based on the uniqueness of the human being in the world she/he lives in and on her/his existential totality.

According to Heidegger, two concepts are basic to understanding the existential dimension of the human being: the daily life and existential movement. The daily life refers to the dimension of the facts of living and the behavior of human beings. In one's daily life, one points to one's significances in terms of what happens in one's life, in other words, as one comprehends what one lives and experiences as part of one's existence. The existential movement indicates that lived transience expresses that the human being acts as a discover-being that is in continuous coming-to-be<sup>(15)</sup>. Thus, on the movement of existing-being, it conserves what has been (in the past) and what will go on (into the future), that indicates the ontological constitution of the place itself, in other words, each individual's historicity.

## **METHOD**

The study was conducted through phenomenological interview. The researcher asked the adolescents: 'Tell me, how do you feel about becoming an adolescent?' They talked freely about their experience of becoming adolescents and what is going on during the transition time from childhood to adolescence. When the adolescent, in her/his answer, referred to the serological condition, another question was elicited: can you tell me about your everyday life, living with the disease?

The interview was conducted with 11 non-institutionalized boys and girls aged between 12 and 14 with a disclosed diagnosis. The selection of respondents happened during the development of data production. In other words, the health professional highlighted in the appointment book, those who were the possible respondents. Therefore, family members were contacted to confirm the diagnosis disclosure and to request consent, given that, in terms of them being children who knew about their disease, parental assent was required.

The research project was developed at three healthcare facilities in Rio de Janeiro. Among the referral hospitals for the outpatient treatment of pediatric AIDS, and those which met the criteria for the homogeneity of institutions were university hospitals,

integrated within the NHS, which were pioneers with regard to assistance to children and adolescents infected by HIV / AIDS.

The data analysis was based on Heidegger's analysis<sup>(15-16)</sup>, which determines two comprehensive methodical moments: 1) vague and median understanding: Understanding is to raise the meanings (the existential, more evident in everyday life) which show how the human being expresses him/herself through speech, silence, behavior; 2) interpretive understanding: Interpreting is to unveil the sense (existential behind of) of the phenomenon in itself, through an understanding of the meanings.

The research project was approved by the three Ethics Institutional Review Boards at healthcare facilities in Rio de Janeiro where the fieldwork took place. These were, respectively, EEAN/UFRJ (096/06); IPPMG/UFRJ (09/07); HUGG/UNIRIO (36/07). The study followed Resolution 196/96 and, to ensure the anonymity of the deponents, interviews were codified with the letter C correspondent to children, followed by the numbers 1 to 11.

## RESULTS

The being-adolescent's experience represents an existential movement which is marked by childhood and adolescent moments.

In childhood, there is a wish to play like other children.

*I would like to be a child again [...] when I realized that I was getting older, I found it difficult to play [...] the others were teasing me all the time like: 'baby, baby' (C6)*

In adolescence, there is a wish to be like others in appearance, mood, attitudes, daily activities, lifestyle, leisure and relationship with family and friends.

*I am like everybody else... you know, I want to do what every girl does at my age... I want to go out at night, go to a party [...] every girl wants to wear mini-skirts, top and colorful clothes to draw attention to herself [laughter] (C3)*

In the transition between these two moments, a process of becoming adolescent is revealed.

*Sometimes I am mature, sometimes I am a child [...] not always do you feel pretty [...] but now I feel a little more [silence] neither Giselle Bündchen nor ugly-Betty. But now, I think I am more beautiful, more sensual [...] I am a lazy girl [...] sometimes I have a bad temper, which drives my mother crazy. (C3)*

Despite the limits of their condition, they wish to reveal the diagnosis, to date, to study, to work, to plan for the future.

*[...] once [pause] when I had a boyfriend [...] suddenly, one day ...I wanted to tell him... but, I thought: "what might his reaction be...?" It is not easy... I gave up. (C2)*

*[...] I want to study, to work, to help my family [...] I need to finish my studies. When I grow up [...] When I become an adult, I would like to be a fireman or a soccer player. I really would like to be a soccer player [silence] but I can't [silence and tears appeared in his eyes] I can't run because my heart beats too fast [silence] (C6)*

The individual recognizes himself/ herself as a being-adolescent who has AIDS by revealing that he/she knows they have a virus in the blood and discovers that he/she has the same illness as their mother.

*I got this disease from my mother. I have two brothers, but they did not get it.*

*Only me [...] When she became pregnant with me, and since she had taken the test before, and the result was negative, she did not want to take (the test) again. [...] But, then, my aunt talked to her and persuaded her to take it, because as the time went by she was losing weight and vomiting a lot [...] she did not want to accept it (the positive result) [silence] [...] She got it from my father [...] then I was born [...] (C2)*

To have relatives who have died is a reason for sadness. They do not like to speak or remember it. When someone asks, they invent some reason for the death and do not speak about HIV.

*It is that she (the mother) is sick [silence], she is in pain, she needs to take medication, go to the hospital [silence, looks up, looks down], and says: it is bad to have my mother sick (C1)*

*it has been six years since my mother died of HIV [...] [...] she got it from my father [...] My father also died [...] my friends asked me why she was [...] sick, thin ... [pause in speech] so I answered: 'I didn't know' [...] They also asked me: 'What did she die of?' so I [...] make*

*up something, sometimes I do not even like to remember [silence, looking down in tears] ( C2)*

The being-adolescent remembers how he/she was told about the diagnosis of the disease, when someone in the family with the help of a professional told him/her about it. It was explained that he/she has the same virus as their mother, then the need of going to the hospital and take the medicine.

*There was a time when I wanted to know more about it, so I asked my mother what I had [...] and she began to cry and I did not understand anything, I was so surprised [. ..]Then she explained to me what was going on! [...] (C3)*

*I was told this year, here in the hospital, by the psychologist [silence] It is that my mother could not tell me, then I guess that the psychologist helped her (C11)*

When they were told about the disease, the being-adolescent had feelings of sadness, rejection and shame. However, even before the family had told them about the diagnosis, the being-adolescent already knew of it because he/she had heard at school, on television, at the appointments or read the consultation papers from the hospital.

*How did I find out? Ah, it was at school. We study many things, study this, that; listening here and there... finally, a person grasps the whole idea and understands!(C9)*

*I already knew it because I paid attention to the hospital papers, to the appointments, the information; I heard things on television, at school. [Silence] She (the mother) never talked about it, but I knew. She can't do it, then we don't talk about it. I never said anything; neither has she spoken about it [silence] (C11)*

Only a few people in the family knew about the diagnosis, the professionals from the hospital and, in some situations, the school principal and/or the teacher. The

family says he/she should not tell anyone about the disease, so they do not tell anyone.

*I was told not to tell anyone, so I did not tell [pause in speech, looking down] just my mother, my sister, my grandma knew [pause in speech, look out of the window] and here in the hospital [pause speech]. At school, no one knows about it (C1)*

*My family tell me not to say anything to anyone, truly, not a word, only when I'm already married, before making love [...] (C2)*

*My grandmother talked to the Principal about the diagnosis, so she knows why I have to come here, but only the Principal knows (C5)*

They understand that, even having this disease, they are surviving and have rights and needs. They reflect on the importance of thinking about themselves and getting to know who they are.

*I figured out if I want to see my family well, I also have to wish all the best for me. Otherwise, how could I live with them? This is the way I know I am okay! (C3)*

*It is life, isn't it? It is still life! The person may have many things, but he or she is a human being. He or she has a life and cannot be shaken by what other people think. First you have to think: who am I? [...] If you don't think about yourself, it's over! (C9)*

Due to having been infected by the vertical transmission of HIV, they had gone to hospital ever since their birth or since they were little.

*I have come here since I was little child [silence] I always come here! (C1)*

*I have come here (to the hospital) since I was born. (C6)*

Taking care of himself/herself is a synonym for going to hospital to check on their health status.

*Aah, I have to come to (the hospital), to check my test results and my prescriptions [...] It is just that, because I'm okay! (C5)*



*Sometimes I have to come here, to the hospital [...] I only speak with the doctors, have the tests done, check the medicines I have to take, or whatever they ask me, and schedule the next appointment, that's it! (C10)*

The being-adolescent realizes that with the treatment at the hospital, his/her health improves, but that this care has to be continuous.

*I realize that I have no difficulty at all with the disease [pause in speech] I haven't had any symptoms that might make me stay in hospital. (C3)*

*When I had started the treatment at the hospital, I got better.(C9)*

Due to the fact that they are going into adolescence, they will have more responsibilities, including caring for themselves.

*I come alone to the consultation with the doctor, because my aunt and my cousin work. They can't come with me. So, I must be more responsible for with my appointments. To come alone [silence, looks around] I think it's not too bad, nor is it nice. (C2)*

Taking care of himself/herself includes taking the medication. The being-adolescent remembers that he/she has undergone the treatment since the disease was discovered. It has been a long time.

*It's been a long time (that ... taken the medication), since they discovered it (the disease). Since then, I have been taking the medication everyday. I've never stopped (C9)*

Over time, the being-adolescent starts to understand that he/she really has to take the medicine to be healthy and continue living. He/she comprehends that if he/she does not undergo the treatment, he/she is not harming others, but himself/herself.

*After some time, I understood that it was up to me to take the*

*medicine [...] my life depends on the medicine, if I don't take it; my life is over (C2)*

The being-adolescent states that the course of treatment interferes with the routine, because he/she has to take them every day, several times a day and forever. The time for taking the medicine may be when they are in school, playing or doing some other activity, or while they are visiting friends or relatives who do not know about their diagnosis. If this happens, it may be a reason for not taking the medicine, or for them to not do what they want to do, or be where they would like to be. Therefore, the being-adolescent considers the treatment very difficult and wonder if they will be able stop it some day.

*Day to day is difficult because of the drugs [...] everyday I have to take medicines [...] will I stop taking medicine someday? [...] When you have to go to someone's house, then you have to take the medicine, then I don't go! [...] because they will ask you, 'why are you taking medicine?' then I'll have to give them some answer (C2)*

Some adolescents take the drugs by themselves since they knew about the disease, or the parents have given them this responsibility, or when there is not someone to give them the drugs.

*I already take the medicines by myself. I have taken them by myself since last year. After, my mother told me about what I have; I had been doing everything (C4)*

*I already take the medicines by myself [silence] I don't always take them [silence] but I don't tell whether I take them or not. [Silence] (C11)*

The being-adolescent believes that maintaining the treatment is more difficult than any other thing in his/her daily life. Consequently, they need help from someone special, particularly a person who knows his/her condition, such as a family member.

*Sometimes [puts his hands on his face] I forget [looks at me smiling] [...] my mother says 'you have to take them', 'you have to do things right' [...] (C3)*

*It's bad to live with the virus inside me [...] I feel quite normal on my daily life. What is abnormal is the fact that I have to take the medicine everyday! (C10)*

## DISCUSSION

The ways of being-adolescent in their daily lives reveal an existential movement from inauthenticity to authenticity. Inauthenticity means the deviation on the part of each individual in terms of that individual's essential project in favor of daily occupations, confusing it with the collective mass, in which, being all, it is not oneself. The being in one's daily life is a public being (inauthentic), and not one's own being (authentic), reducing one's life with others and for others, alienating oneself from the main task, that would be becoming oneself. The Heideggerian meaning of inauthenticity doesn't refer to a value judgment, as something negative with regard to the behavior of human beings, but to the way of the daily being, in other words, how we behave most of the time<sup>(15)</sup>.

The inauthenticity is related to the double-facticity of being-adolescent and having AIDS; in other words, one cannot escape these facts, because they are inherent to one's human development situation and health/disease. Therefore, the being is launched in what is already determined and which cannot be escaped. The expression of being-launched must indicate the facticity of being delivered to adopting responsibility for a determined situation, indicating enforced connotation<sup>(15)</sup>.

The inauthenticity was evidenced in the impersonality, occupation and talk<sup>(15)</sup>. The meaning of impersonality indicated that the being-adolescents show themselves as any other teenager in terms of acting, behaving, appearance and mood. They does not say that they have the virus; they do not even name what

they know they have. This being-adolescent does not assume themselves in their singularity; they keep their adolescent identity and serological condition anonymous. The being-adolescent becomes equal in terms of what is common and expected by all, because to be considered different exposes themselves to labels, making living in the community difficult.

This impersonality is expressed in the way that the being presents himself like all in daily life, and does not express as himself. There is a "depersonalization of people"<sup>(15:319)</sup>. Therefore, in everyday life, "...the being is related to the world according to a way of being that predominates: the impersonal"<sup>(15:164)</sup>, according to which "everyone is another and no one is himself"<sup>(15:181)</sup>.

The meaning of occupation indicates that, in childhood, the individual kept himself/herself busy with what the professionals and family said that the being-adolescent should be doing (going to consultations, checkups, taking medication) and how to do it (behavior on the way to the hospital, coping with the results of tests and taking the treatment seriously). In this prescriptive way-of-being, the being-adolescent is almost always involved with the same routines as is his friends, as well as with the particular demands of AIDS.

Hence, according to "the occupations of our daily habits"<sup>(15:154)</sup>, the routine is familiar to the individual and in them is the routine. Therefore, "...his/her being to the world is essentially an occupation"<sup>(15:95)</sup>. This involvement with what has to be done, keeps the being-adolescent busy in dealing with AIDS in the face of the other tasks of adolescence.

The meaning of talk indicates that the being-adolescent repeats the biomedical discourse that he/she has heard since childhood, using an inherited speech to explain his/her needs and attitudes. Concerning the disease, they limit their knowledge to what people tell them. Each being-adolescent believes that by

repeating the information each one has heard, they have already understood everything. Each one is satisfied by repeating what has been said, believing that things are as they are, because it has been said so, which shows the lack of a true understanding, thus constituting the talking<sup>(15)</sup>. However, this attitude conceals the authentic understanding of the being that goes beyond listening, repeating and dealing with what has always been said, but passes through questioning and discussing.

The talk is constituted by daily understanding in that the being repeats (words) and passes on the news, not with the intention of saying things about the world, but only to circumvent the silence and merely to maintain communication<sup>(15)</sup>.

Many times, the being-adolescent shows himself/herself in the form of fleeting and rare movement of authenticity. This authenticity was evidenced in the anguish and pre-occupation felt by the individual when he/she comes face to face with himself/herself. In this sense, the being-adolescents look at themselves, in terms of their history and their wishes, needs and possibilities. They understand themselves as humans being who still has a life beyond the illness, who need to think of themselves, get to know who they are and wishes themselves well. They reflect that if one has a careless attitude about oneself, it will not affect other people, but only oneself. Anguish becomes the being singular in one's own being-in-the-world, who projects oneself, essentially, as a being of possibilities<sup>(15)</sup>.

Moving from childhood to adolescence, the individual starts to become pre-occupied with themselves, with their health and their relationships. In this pre-occupation, they become free; the possibility of anticipatory-freedom is open<sup>(15)</sup>. It happens in the relation of being with somebody (a person, either with the other or with him/herself) and not with a what (the disease). It allows the being-

adolescent to turn to his/her inner self and understand himself/herself with the possibility to be and to take care of him/herself.

Then, the movement of care is, at first, and for most of the time, dependent on the professionals and on family, a care shared with others. Regarding the modalities of care, during childhood, the caregivers were family members and professionals from the hospital. During the transition to adolescence, the individual starts taking responsibility for their own health care by going to the hospital on their own and assuming their treatment. They show themselves in a care-with, in which they need family and professional help. These methods of care highlight the transition between cared-by and cared-with. Thus, they reveal a movement of occupation with what they say one should do before the pre-occupation with one's self-care.

## **CONCLUSION**

It is understood that being-adolescents who have AIDS projects themselves as beings of possibilities. They have the possibility to be free from impersonality, being like others in the public world, discovering themselves as being unique, being-themselves in their own world.

The understanding of being-adolescents with HIV/aids is that the movement of life must be continued. They think about the future, and life is the way it is (facticity), without looking back. Thus, they are open to the possibilities of what they want (e.g. dating, studying and choice of profession), of what they need (such as taking medication and going to the hospital because of their illness). This set of findings revealed such individuals as beings of possibilities.

Respect for temporality of the being-adolescent implies the need for nurses to be aware of each adolescent's own singularity. When considering the transitional age from childhood to adolescence, the healthcare facility should provide a proper environment for welcoming adolescents with HIV/aids during their follow-

up consultations. Strategies to join peers, either with the same condition or not, can be applied. This should be a place where they can share experiences, knowledge, have fun, laugh, build together ways to cope with the difficulties of being-adolescence and being-ill. Respect for history involves identifying the landmarks of HIV/aids in the individual's own family, by considering the family system and the dynamics involved.

Faced with this and with daily self care, the contributions of the professional nursing staff in healthcare are shown as opportunities for assistance, research and teaching with regard to children with AIDS through vertical transmission, during the transition to adolescence.

In terms of assistance, there is a need to re-organize the health services in such a way as to attend to these people who have AIDS, ensuring a place for them as a group, considering their particularities and their special health needs. In such a situation, each group member is recognized, neither as children nor as adults. Rather, they are able to continue their treatment in terms of the specificities of transition from childhood to adolescence.

Among the health actions, it is necessary to ensure diagnosis as a right for children and adolescents, and for the need to continue the treatment. Awareness and knowledge of the disease they have is important so that, gradually, they can assume their own care.

In this sense, health education can contribute to the prevention, promotion, restoration, maintenance and protection of health. Prevention, especially with regard to re-infection and HIV transmission, should be performed without limiting it to discovering sexuality. Health promotion can be done through support groups to broaden the discussion beyond AIDS itself, incorporating themes of diet and physical activity among others, that are necessary to the development of adolescents.

The recovery of the health of children and adolescents affected by non-compliance with treatment can be accomplished through strategies that incorporate possible treatment, and help the individuals concerned to commit to taking care of themselves.

Health maintenance can be done through follow-up involving regular consultation. Consultations can be individual, shared with the family, in a group with peers, or in the form of multi-listening.

Health protection refers to the guarantee of the rights of children and adolescents in the Statute of Child and Adolescent (ECA, in portuguese), and countersigned by the national public policy for AIDS. It involves such aspects as access to health services, free treatment by the NHS, inclusion in the different social spaces in terms of family, school and work, among others.

In education, it is essential to incorporate into the training of health professionals the importance of care for those children who have AIDS through vertical transmission, and are transitioning to adolescence. It is crucial to discuss, experience and expand strategies to promote family and self care, as well as to recognize the need to build a space for this group within the health services, where it will be possible to give them a voice and build with them a care which considers their options in terms of the challenges of daily life.

In the field of research, much more can and must be investigated in order to contribute to the construction of knowledge about these patients in Brazil.

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