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## The life of the adolescent with HIV/AIDS and self-care: a descriptive study

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### ABSTRACT

**Aim:** to describe the relationship of adolescents that live with the Human Immunodeficiency Virus (HIV) and their self-care practices. **Method:** This is a descriptive study, based on the Orem's Self-care General Theory, performed with nine adolescents, patients of the Sexually Transmitted Diseases ward of a hospital located in the city of Fortaleza, Brazil. The interpretation of this study was based on the analysis of the content found. **Results:** Family support, health professionals and friends, mass media and intrinsic motivation were mentioned as self-care stimulus. The barriers found were prejudice and shame, ineffective adaptation and lack of information. **Discussion:** Through the education in health as assisting practice of this context, it is possible to promote strategies of specific self-care inside the sociocultural environment of the adolescents. **Conclusion:** It is a duty to health professionals, especially the nurses, to join efforts in order to improve the strategies that aim to engage HIV-positive adolescents in the use of self-care practices.

**Keywords:** Adolescent; HIV; Self Care; Nursing Care

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## **INTRODUCTION**

The Acquired Immunodeficiency Syndrome (AIDS) is one of the greatest public health issues worldwide. The United Nations (UN) points out that, in 2009, there were 2.7 million new cases of the disease throughout the world, and of the infected subjects, around 430,000 of them are 15 years-old or less<sup>(1)</sup>.

In the Brazilian scenario, according to reports issued by the Brazilian Ministry of Health, there were 66,698 cases of AIDS in young people between 15 and 24 in June 2011. This represents 10.9% of the AIDS cases notified in Brazil. At the same age, sexual transmission represents 68% of the notified cases, and blood transmissions are responsible for 23% of the notifications<sup>(2)</sup>.

Based on these facts, we observe that teenagers represent an important layer of the population that can be infected, thus it is fundamental that health services and professionals improve the healthcare policies in order to consider the specific particularities and necessities of this age group, adding the complex situations imposed by the seropositivity condition<sup>(3)</sup>.

In terms of seropositive youngsters, self-care is characterized as an assisting strategy that is able to answer the needs of this part of the population. To Orem<sup>(4)</sup>, self-care is the practice of activities the individual initiates and performs for his own benefit, to maintain life, health and well-being. The actions taken, according to a certain model, aim to contribute specifically to the integrity of the person, good performance in terms of how he functions, and human development.

Self-care is understood in the health literature as being fragmented and limited, specifically its use is studied with regard to patients with HIV/AIDS, being restricted in terms of access to antiretroviral treatment or, as a preventive measure of accession, stimulating the use of preservatives. The definition of self-care used in this study is based in a vast consciousness of the individual, which encompass the preservation of the self and the recognition of the patient as a subject of law.

Regarding adolescents, the amplified dimension of self-care incorporates aspects related to an adequate adherence to medication therapy, use of preservatives during sexual intercourse (for both seropositive and non-seropositive partners), proper nutrition, housing, an active search for a space for listening and understanding, the preservation of self image, among others<sup>(5)</sup>.

The professional practices destined to encourage the aim of self-care in order to empower the adolescent diagnosed with HIV, are characterized as a fundamental strategy to promote health, as they motivate the individual to adopt healthy and autonomous habits in order to establish and maintain his own health<sup>(6)</sup>.

The nurse, as part of the multidisciplinary team, through nursing consultations<sup>(5)</sup>, puts into place the conditions to improve the quality of life of the patient, as this professional can engage in a contextualized and participative approach to the adolescent. The consultation permits the nurse to engage in work regarding the promotion of health, and prepares the client for the practice of self-care<sup>(7)</sup>.

The importance of developing work that encompass self-care in the adolescent population is related to the identification of the tasks involved in this context. This generates understanding through a system of reflective attitudes by the adolescents themselves, in terms of the aspects that harm/facilitate the adherence to self-care practice, which contributes with an understanding regarding the behavior of the teenage HIV/AIDS bearer. Thus, the objective of this study is to describe the confrontation with HIV/AIDS in the bearer adolescent through a system of self-care practices.

## **METHOD**

This is a descriptive study, which adopts a qualitative approach. It uses the Orem's Self-care General Theory<sup>(4)</sup> as the main theoretical reference, as this conceptual model enables a great applicability of nursing assistance to the adolescent bearers of HIV/AIDS, and identifies the demands for self-care, permitting the adolescent and the relatives to have an active role in ensuring compliance with the described self-care practices. The

basic principle of self-care theory put forward by Dorothea E. Orem is that every human being has congenital abilities to take care of himself. The author defends the point of view that people have the capacity to regulate external and internal factors that can interfere in their functioning and development. Such regulatory actions and capacities are called self-care.

This research was performed in a Sexually Transmitted Diseases (STD) ward of a hospital in the city of Fortaleza, Brazil. Nine adolescents participated in this study (five males and four females), from 16 to 19 years old, bearers of HIV that were present in the ward from March 31<sup>st</sup> to April 30<sup>th</sup> 2010. Of these adolescents, five received the virus through Mother-to-Child Transmission (MTCT), and four by sexual intercourse transmission. All of them acknowledge the diagnosis. As criteria for inclusion, we decided to add: adolescents between the ages of 12 and 19, from both sexes, that came to the ward during the period of study; that, at the moment of the interview, had the psychological strength to participate in this study and that they had the authorization of their parents and/or guardians.

During the study, 13 adolescents attended the STD ward. Of these, four could not participate because they did not have the authorization from their families.

To collect the information, we used free observations and individual, semi-structured interviews. These proceedings were performed in a private room at the hospital, in order to guarantee the secrecy and confidentiality of the interview. At this moment, we presented the Free and Clear Consent Agreement (FCCA), which was filled at the site if the parents/guardians were present, or scheduled to be done at a later moment to both collect the information and to sign the FCCA.

The collection instrument had five open questions: the first question tried to ascertain the concept of the adolescents regarding self-care; the second mentioned the information linked to the actions of self-care done by the patients; the third and fourth investigated the ease and the barriers to exercising self-care, and finally, a question was designed to collect suggestions of strategies that could be used by the health professionals in order to stimulate self-care.

The analysis of the data was done through an analysis of the content<sup>(8)</sup> using systematic proceedings and objectives to describe the content of the messages. This analysis presents three fundamental phases: pre-analysis, material exploration, and the treatment of results. The analysis of the data allowed the researchers to identify the conceptual categories: *self-care as seen by the adolescents* and *factors that promote or impede self-care practices*.

The development of the study followed the ethical precepts under Resolution 196/96 of the Brazilian National Health Council<sup>(9)</sup>, later approved by the Ethics in Research Committee of the institution where we developed this research (Protocol 03/2010).

## RESULTS

The analysis of the data allowed the identification of conceptual categories: *self-care as seen by the adolescent* and *Factors that promote or impede self-care practices*. Such categories were presented and illustrated with examples extracted from the interviews with the patients of the studied ward.

### Self-care as seen by the adolescent

The concept of self-care built by the majority of the patients includes aspects related to quality of life, nutrition and prevention, and the typical roles of teenagers, such as reading, studying and dating.

*Self-care is doing things that keep me healthy [...]. I take my medication at the right time, drink a lot of liquids, eat well, use condoms, and don't smoke.*  
(P<sub>6</sub>)

The views of self-care was permeated by aspects linked to self-preservation, to the consciousness of a self-existence and to the value as a human being. It observed the feeling of satisfaction at being able to experiment with regard to the control over their bodies, their own life.

*It is a way to live the best way possible, even knowing my disease. It is because even if I am HIV-positive, this does not mean I don't care about*

*myself anymore and that I don't have to worry about myself. I think about myself and the others around me. (P<sub>4</sub>)*

*For me, self-care is everything I have to do to protect my health, and besides taking care of myself, I have to take care of other people. For example, I cannot let people touch me when I'm bleeding, and explain about my sickness to my partners. (P<sub>1</sub>)*

On the other hand, the understanding of self-care based on the words of two adolescents is restricted to medication.

*When I think about self-care, the image of my cocktails comes right to my mind. They are fundamental to me. (P<sub>8</sub>)*

## **Factors that promote or impede self-care practices**

### **Family and health professionals**

The adolescents involved in this study mentioned that they have, as fundamental support for their self-care practices, the presence of the family, health professionals and of other people near them, such as their friends. The family support is expressed especially in terms of the constant presence of the partner for those adolescents who are in a relationship. In the case of the adolescents who still live with their parents, such individuals are partners in the caring process of the HIV-positive patient, as the health condition seemed to be an element of approximation. In all cases, the mothers were the "anchors" of this caring practice, as they accompanied their children to medical appointments.

*My mother knows I have HIV, [...] she doesn't come to the appointments with me, but just because she didn't stop talking with me or even kicked me out of my home, is the best support she can give me now. I wouldn't be coming here if she hadn't made the first move. (P<sub>3</sub>)*

Health professionals are mentioned as a source of support during the process that develops self-care, offering, besides information and knowledge, a certain emotional support.

*People here listen to us, and answers all our questions. But when they have to be tough, they are really hard on us. They always remind us of the caring we must do all the time. (P<sub>7</sub>)*

Regarding the support of health professionals, it is important to say that the most mentioned professional by the teenage patients was the doctor, which calls attention to a possible question as to how do nurses participate in the caring process of these individuals.

### **Mass media**

For the participants in this study, having information regarding HIV/AIDS, its complications and treatments, positively influences self-care practices. According to them, the sources of information are mainly found on the Internet and on TV. The comments mention that the Internet provides information about the need for self-care, and motivates the use of professional guidance.

*... another thing I think is important is when you have any doubt about the disease, what you can or cannot do, you have the Internet. And you can always ask the doctors, too, of course. (P<sub>7</sub>)*

TV also presents a strong cultural influence in developing understanding about HIV/AIDS. It seems that there is a relationship in the form of specific knowledge transfer from TV programs regarding self-care practices. These have an influence on the teenage HIV/AIDS bearer, as described at the following comment:

*I try to read books, magazines, to watch the news and the new things on TV. I try to know everything about AIDS. (P<sub>9</sub>)*

### **Intrinsic motivation**

Believing in the possibility of having a better life, or even to find a cure, is a factor that contributes to self-care, and this consciousness is present in three comments reported in this study. The adolescents have a certain hope in terms of a better future as a source of motivation. They believe that, based on faith, time and patience, they will have a better quality of life.

*One thing that makes things easy is my own desire to live better. I have my whole life ahead of me, and I have to try to make it the best possible. (P<sub>4</sub>)*

Another aspect that emerged favorably to aid self-care practice was the manifestation of spirituality. We believe that perhaps the patient, as a way of feeling supported in an unknown environment, uses this spirituality, particularly in moments of extreme fragility, as for them, belief, faith and protection can lead to cure, comfort and salvation. This is clearly shown by sentences such as:

*...my willpower, because if it was another person that had gone through what I had gone through, this person would have probably given up living. But I believe in God, and thanks to Him that I have never felt anything related to my sickness. (P<sub>6</sub>)*

### **Prejudice and shame**

Because of the illness, adolescents feel discriminated against by family members and by those people who are part of their social environment. As was said by one adolescent:

*It is really bad to hide myself, and my family isolate me, and they don't talk to me anymore. (P<sub>3</sub>)*

Family members living with a teenage HIV bearer may be forced many times to adopt attitudes that aim to protect the youngster, and also to protect the family itself, against prejudice and feelings about AIDS of society as a whole. Families believe that the best thing to be done was to hide the teenager's diagnosis from other people. However, this is not always the attitude of the adolescent.

*The fact that I don't have to mention that I am a bearer is also hard for me. In my case, I would say it to anyone, but I can't speak for my mother, as she doesn't want other people to know. (A<sub>4</sub>)*

Shame was a feeling mentioned by two teenagers and seen as a barrier to adopting or continuing self-care practices. Going to the hospital for scheduled appointments was seen



as a potential risk in terms of having their condition revealed to others. They consequently decided to hide the truth as a way of protecting themselves from this feeling.

*Prejudice, I never had it because no one knows I have this disease, you know? If someone knows, I don't know [...] I don't know how I would react [...] I think I'd be ashamed, I don't know. (P<sub>2</sub>)*

*I am very ashamed to be a bearer. For example, when I cut myself, I always try to justify why people cannot touch me [...] and coming to the hospital too; I come here like I am hiding from everybody, but of course I don't miss an appointment [...] but that's terrible.*

### **Self-acceptance, adaptation to a new lifestyle**

During the interviews, it was evident that the problems of self-acceptance and adaptation to the new lifestyle that HIV demands is an on-going task involving the effective engagement in self-care practices. The reports from the adolescents suggest that there is no full acceptance of the disease. There are moments when they understand the situation, when it seems that they understand all the conditions, but that is cyclical, because at other moments, they show that they cannot handle the fact they are HIV bearers well.

*The hardest was to accept I have the disease, and I used to cry my eyes out, hiding from everybody [...] I used to think about the worst [...] I didn't want to take care of myself [...]. (A<sub>8</sub>)*

This non-acceptance, or ineffective adaptation, is found not to be linked, in many cases, with the disease itself, but especially with the necessary caring practices. This occurs mainly when these caring practices demand the youngster abide by the common behavior of their age group.

*My biggest difficulty is me, because you know how teenagers are... Sometimes we exaggerate, sometimes I want to have a drink, you know? Going out with the guys... This is what I am mostly afraid of: because of the disease, I'll develop some side effects. (A<sub>7</sub>)*

In addition to this example, we identified a lack of understanding or the necessity for the guidance of participants in this study about the ways of HIV infection. It was seen that the lack of information developed as a restriction to effective practice of self-care in

terms of the adoption of excessive protection by a biased belief about HIV infection (infection of third parties only by skin contact and their infected blood, for example).

*I must take a maximum care to not cut myself and not let people touch that bleeding. (A<sub>1</sub>)*

The lack of information of the partner was also pointed out by a female adolescent, who expressed some sadness with the fact, by looking down, not making eye contact and having drooped shoulders when answering the question.

*He (the partner) really supports me, but I don't think he is 100% aware of the sickness, you know? Many things I think he needs to listen straight from the doctor, really. (A<sub>5</sub>)*

## **DISCUSSION**

One aspect that was brought to light in one of the discourses is the wider perception of the concept of health promotion, which sees self-care practices in a relational sense, or in other words, transcends the idea of "self" care, or a care "of the self", as from them, the concept also includes the caring of the people that live with them.

The systemic perception of self-care practices reported by the adolescents, added to the theory proposed in this study, reminds us that the previous experiences exemplified the beliefs and values that may influence the possibility to integral self-care procedures, aimed not only at the use of medication, but also at the practice of actions that contribute to the management of health<sup>(10)</sup>.

On the other hand, the understanding of what self-care practices would be for two adolescents was based on a narrow idea, directed to the use of medication. This action mobilized a commitment and ensured an effective effort by the teenager, who used to see the medication as the only and fundamental reason for staying healthy<sup>(11)</sup>. This mentality can promote the spread of the illness.

Self-care practice that is reported almost exclusively as medication usage is a reduced view of the studied practice. Medication represents the possibility of constructing a future life project: the possibility to graduate, to work and to generate a family. Erdmann<sup>(12)</sup>

says that a life project is a symptom of "normality" or, in other words, to live "normally". It is necessary to have projects and, to do that, you must deny death, which in the cases studied here, the adolescents see HIV as the sense of death permanently present in their lives.

The integration and development of the individual as a subject is conditioned by the presence of meaningful people that aid these processes<sup>(12)</sup>. In this sense, the relational view of self-care practice as an extension of the systemic perception of the self is characterized mainly as a benefit rather than a loss to the teenager.

Based on the discourses and the importance of the nursing professional assisting the HIV-seropositive adolescent, it is necessary to say that this professional assumes a worrying coadjutant position in this assistance, which was not even mentioned by the participants. The health professional is the one who must guide the self-care practices that can guarantee the efficiency of adherence to the treatment, and among the specialists, the nurse is the most indicated, because of that person's familiarity with the conducting of strategies to promote health, as present in the nurse's academic background<sup>(3)</sup>. The relationship between the nurse and the patient offers fertile soil to develop life-changing educational practices, as caring is the basis of all nursing practice<sup>(13)</sup>.

We know that education in health is one of the fundamental bases to support the HIV-seropositive individual, as it contributes to the development of the ability to change habits and to motivate the individual to a better understanding of new information regarding self-care, in a critical and reflexive format<sup>(11)</sup>. This is of even greater importance when the virus bearer is in his adolescence. We suppose that the process of instruction that the health professionals have developed with the members of this study may have helped to build a systemic view of self-care, also influenced by the beliefs and intrinsic values to these youngsters.

The educational process must promote the idea that the use of new technologies are to be used, as they are fundamental elements of self-care. Authors reinforce that the understanding of HIV/AIDS and other chronic diseases, as well the way to control them,

are important aspects of their treatment, prevention and maintenance. The mass media today is one of the main forms of access to information<sup>(14)</sup>. Despite that, the information needs to be refined to become the knowledge that allows people to make decisions favorable to their health and well-being, so that they can take control of their own self-care practices.

The health professional, through the use of education in health, must be aware of the information sent out in the media, to be able to develop a selective process to distinguish between the useful and the useless to the patient. Once more, we highlight the importance of the nurse in this context, who could use pedagogic and educational moments as a way to facilitate the access to information about the health condition of the adolescent.

The information, when transmitted in a correct format and balanced in terms of social and cultural necessities, promotes the development of abilities, and helps to foster feeling of self-confidence in the family and in the seropositive adolescents with regard to self-care practices. It is seen that the mass media are capable of influencing the practice of self-care in the subjects when using the information destined to "educate" people, teaching them ways to perceive the reality in which they live<sup>(13)</sup>.

We reinforce the idea that beliefs and values are factors that influence the views with regard to health and self-care that will develop throughout the life of the individuals. The construction of such beliefs is strongly influenced by familiar contexts, on which the individual is inserted.

We see that hope, as a reflex of intrinsic motivation, contributes to improving the state of the individuals, and also helps them look for alternatives to face adversities, allowing them to believe in a positive outcome for their lives<sup>(14)</sup>. This is a component that needs to be considered as relevant, because it mobilizes the adolescent to search for an integral self-care practice, even when facing the circumstances imposed by HIV.

There is also the recognition of spirituality, by the interviewed teenagers, as a motivating factor when it comes to self-care. Culturally, the Brazilian people are filled by spirituality, independently from the religious, and in the most difficult times, the majority search for

their faith. It is understood that in a situation of serious illness, the patient recovers his moral and spiritual values as a way to ask God for his health and for a cure<sup>(14)</sup>.

In reflection over the word 'prejudice', we can observe that it is linked to an opinion of belief to be taken without further discussion or examination, internalized by the individuals without their awareness, and influencing their way of living and how they consider the lived reality. It is generated by a naïve view of the world that is transmitted culturally and which reflects beliefs, values and interests of society or a social group<sup>(15)</sup>.

The revelation of an HIV diagnosis in familiar and social circles is also seen as being discriminatory, as reported implicitly by the comments collected in this research, as it is supposed that both family and the social environment do not understand AIDS as a chronic illness that permits a fearless coexistence. In fact, it is the opposite: because of its history, AIDS still generates symbols of prejudice, such as shame and social isolation, which are extended to the family network when one member is an HIV bearer<sup>(16)</sup>.

With regard to HIV/AIDS, shame was reported as another feeling on the part of the bearers who, through their behavior, demonstrated a fragile aspect in terms of confronting the disease and its impositions. Similar to what happened with the fear of prejudice, the hiding of the illness by the teenagers is motivated by the shame of being an HIV bearer. Silence, even being filled with dilemmas, is understood by these adolescents as a necessity to protect themselves, creating an aura of normality around themselves.

Accepting is to face the circumstances of life. To be accepted, it is necessary that the person admits the reality of the facts, evaluates the situation and promotes the necessary changes, as this is the only way to achieve their personal objectives<sup>(14,15)</sup>. In conclusion, it is necessary to stimulate their abilities to adapt to a new lifestyle and make these adolescents become involved with the self-care practices that this health condition requires, so they can assume full control of their treatment for longer periods.

As well as the already mentioned elements, there is the importance of the multi-professional health team when it comes to promoting the self-acceptance of the seropositive adolescent, especially the nurse who works at identifying the limitations and,

together with the adolescent, seeks ways to perform self-care practices and strategies of adaptation to a chronic health condition<sup>(16)</sup>.

Self-care practices require more than just the apprehension of a technical and normative understanding. This understanding of the whole dimension of self-care embraces more complex issues and needs to build up the competencies related to the professionals involved<sup>(7)</sup>.

Therefore, to learn new things and acquire more understanding and experience makes the individual to cope with the negative aspects of the change in lifestyle and start to adapt himself better and safer to a new routine, valorizing the limits in order to perform, by himself, all the self-care proceedings needed to his survival<sup>(17)</sup>.

## **CONCLUSION**

It is necessary to emphasize the meaning of studying a topic as challenging as HIV/AIDS, based on the concepts of Orem's Self-care Theory. In the area related to STD/HIV prevention, this experience with the disease is still surrounded by stigmas and prejudice that demonstrate how important it is to deepen this understanding.

Orem's Self-care Theory allowed us to identify the situations experienced by the adolescents, and to confirm the assumption and application of assisting care. It also permits us to identify the demands of specific self-care practices, as well as the limitations associated with insertion in a self-care routine, or the dependent caring demonstrated in the context of this study.

In this research, it was possible to better visualize the universe of HIV/AIDS adolescent bearers in Fortaleza, based on self-care practices, identifying and understanding the perception of health and self-care from the comments of these youngsters, factors that contributed to their engagement and those that generate barriers. Beyond the results, we cannot make any generalizations, as the adolescents of other sociocultural backgrounds may behave differently. However, we can, based on this study, clarify a little of the reality that exists in the capital city of the Brazilian Northeast region, which concentrates a great number of cases in this age group.

Health professionals, especially nurses, are essential when it comes to merging efforts to acquire better strategies to engage HIV/AIDS bearing adolescents in self-care, as being in a vital situation with regard to recognizing the cultural and individual aspects of their clients, reevaluating concepts and conduct and perceiving the barriers to self-care in each individual.

Nursing assistance to teenagers that live with HIV/AIDS is quite important, and it must also work in a sense to help these patients to overcome their fears, doubts and future worries. In order to do this, the nurse must come up with a set of strategies to promote

health that can be used in this environment, education in health being just one these strategies.

From the moment the nurse incorporates this idea into caregiving practices, especially in the hospital environment, this professional will be contributing to improving the quality of life of these adolescents. It is necessary to understand that, through education, we can enable the client to promote his own care, as an expression of his autonomy.

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