







Being a teenager with Human Immunodeficiency Virus: meanings of daily living

Ser adolescente com Vírus da Imunodeficiência Humana: significados do viver cotidiano

Ser un adolescente con el virus de la inmunodeficiencia humana: significados de la vida diaria

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ABSTRACT

Objective: to understand the meaning of being a teenager living with the Human Immunodeficiency Virus. **Method:** qualitative study using Martin Heidegger's theoretical-philosophical-methodological framework for analysis and interpretation of the experience of nine HIV-positive adolescents assisted in the Specialized Assistance Service of the city of Juiz de Fora, during 2016. **Results:** most of the time, participants only know about their diagnosis sometime after treatment, they have the same routine of activities as adolescents who do not live with HIV, they value good relationships with peers, but only family or few friends know about their HIV status. **Conclusion:** HIV-positive adolescents experience an ex-sis equal to others of their age, understand that they need to maintain adherence to drug treatment, routine laboratory tests and a lifestyle that includes a healthy diet and exercise.

Descriptors: Nursing; Adolescent; HIV; Quality of Life.

RESUMO

Objetivo: compreender o sentido de ser adolescente vivendo com o Vírus da Imunodeficiência Humana. **Método:** estudo qualitativo utilizando o referencial teórico-filosófico-metodológico de Martin Heidegger para análise e interpretação do vivido de nove adolescentes soropositivos assistidos no Serviço de Assistência Especializada da cidade de Juiz de Fora, durante o ano de 2016. **Resultados:** na maioria das vezes, os participantes sabem de seu diagnóstico somente algum tempo após o tratamento, possuem a mesma rotina de atividades dos adolescentes que não convivem com HIV, valorizam o bom relacionamento com os colegas, mas somente a família ou poucos amigos sabem de sua condição de soropositividade. **Conclusão:** adolescentes soropositivos vivenciam um ex-sistir igual aos demais de sua idade, compreendem que precisam manter a adesão ao tratamento medicamentoso, à rotina de exames laboratoriais e ao estilo de vida que inclui dieta saudável e prática de exercícios.

Descritores: Enfermagem; Adolescente; HIV; Qualidade de Vida.

RESUMEN

Objetivo: comprender el significado de ser un adolescente que convive con el Virus de la Inmunodeficiencia Humana. **Método:** estudio cualitativo que utiliza el marco teórico-filosófico-metodológico de Martin Heidegger para análisis e interpretación de la experiencia de nueve adolescentes VIH positivos atendidos en el Servicio de Atención Especializada de la ciudad de Juiz de Fora, durante 2016. **Resultados:** la mayoría de las veces, los participantes solo conocen su diagnóstico algún tiempo después del tratamiento, tienen la misma rutina de actividades que los adolescentes que no tienen el VIH, valoran las buenas relaciones con sus compañeros, pero solo la familia o pocos amigos conocen su condición de seropositividad. **Conclusión:** los adolescentes seropositivos experimentan un ex-sistir igual a los otros de su edad, entienden que necesitan mantener el tratamiento farmacológico, la rutina de pruebas de laboratorio y un estilo de vida que incluye una dieta saludable y la práctica de ejercicios.

Descritores: Enfermería; Adolescente; VIH; Calidad de Vida.

INTRODUCTION

Adolescence is characterized as a transition phase from childhood to adulthood. It is a chronological period that comprises the age group from 10 to 19 years old, according to the World Health Organization¹, varying according to the subject's social context. In this sense, as they are influenced by their social environment, adolescents are subjected to factors related to their health, including early initiation of their sexual life, which makes them vulnerable to Sexually Transmitted Infections (STIs) and to Acquired Immune Deficiency Syndrome (AIDS)^{2,3}.

In Brazil, the HIV/AIDS epidemic has prevailed, throughout the history of the infection, in certain population segments, concentrated among adolescents during some periods of time. Data from the Ministry of Health (*Ministerio da Saúde*, MS) evidenced that growth of HIV/AIDS will occur in line with the trends regarding evolution of the disease in the country, going through internalization, feminization and impoverishment, with impacts on the young population⁴.

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Adolescents are subjected to social, economic and cultural conditions that, in turn, increase their vulnerability to the unfavorable evolution of their clinical condition. Vulnerability is an interdisciplinary term, applicable in different thematic fields, referring to the sense of weaknesses in individual, social and programmatic perspectives. Individual vulnerability is related to aspects linked to individual actions, such as the subjects' behavior and attitudes, based on certain degree of awareness that they manifest; social vulnerability is based on the economic, political and social context; and programmatic vulnerability refers to actions led by the government, private initiative and civil society agencies^{5,6}.

From 2007 to June 2020, 342,459 cases of HIV infection in Brazil were reported in the Notifiable Diseases Information System. Between 2015 and 2019, Minas Gerais ranked 27th among the states of the federation in terms of the AIDS incidence rate. At the local level, in the 1996-2021 period, the municipality of Juiz de Fora presented 6,312 notified cases of HIV, with a total number of registered children and, in the age group between 10 and 19 years old, 37 AIDS cases were notified^{7,8}.

Data from the 2020 Epidemiological Bulletin draw the attention to the incidence of young people aged between 13 and 19 years old, revealing a divergence in the number of reported cases between males and females. In this age group, there are 533 accumulated cases for males and 256 cases for females, showing a significant increase in cases among males⁷.

Considering the importance of unveiling the daily lives of adolescents living with HIV, monitored by public or private health services, especially regarding their living experiences, in environments where they are normally found, such as schools and health services, the following concerns emerged: How do these young individuals feel about their role as a member of a social group? What do they value as care and health practices, based on their HIV status? How do they experience their daily lives with the Acquired Immunodeficiency Virus?

Answers to these questions can certainly be found in the scientific literature; however, in the search to know how the topic of adolescents with HIV has been discussed, no papers from an existential perspective were identified that incorporate the singularities of living with HIV, including the approach of the commitments with themselves and with their social group in the broad sense of the "collective protection" term^{9,10}. Thus, this study aims at understanding the meaning of being an adolescent living with HIV.

METHOD

Phenomenology was chosen as the approach method for this research, as it allows showing, describing and understanding the phenomenon, as researchers come into contact with what has been lived, with human experiences and speech, which puts them in a position of *in-volving*, of sharing, through direct contact with the phenomenon studied, seeking to understand it from the experience described by the being-in-the-world¹¹.

In order to understand and reach the meaning of the phenomena, this research was based on Martin Heidegger's philosophical thinking, which considers phenomenology as the way to reach the meaning of being. Heidegger sought to understand the being of the man who presents himself for life in behaviors or own ways of being in the world concerned about something. Man is man because he is *being-there* [...] ^{12:157-158}, launched into the world, with the understanding of the relationships that occur in his existence being fundamental, where the other's *being-there* is part of his existence and, consequently, he lives his daily life in the sense of being-with-others-in-the-world¹²⁻¹⁴.

This study was carried out at the Specialized Assistance Service (*Serviço de Assistência Especializada*, SAE) located in the central region of the municipality of Juiz de Fora, which is a reference in screening, counseling for new cases and outpatient care for users who have acquired HIV and AIDS. The participants were 9 adolescents with HIV, who met the following inclusion criteria: aged between 13 and 19 years old; aware of their diagnosis as HIV-seropositive; living in Juiz de Fora; undergoing periodic outpatient treatment at the SAE; and presenting adequate cognitive conditions to participate in the interview. Adolescents with mental health problems were excluded.

The data collection stage or field stage was initiated with the analysis of the registration form in the SAE, using the self-report method through the phenomenological interview technique, guided by open questions aimed at greater interaction between the researchers and the adolescents living with HIV/AIDS and the description of their experiences, recognizing the other's otherness and seeking to capture how they see themselves and are in the world, that is, how they live their existential daily life¹¹.

A pilot test was carried out with three adolescents, who were not included in the study, as adaptations to the data collection instrument were necessary, such as inclusion of the following open questions: Can you tell me about your daily life as an adolescent who lives with HIV? How is it for you to undergo the treatment using antiretroviral medications? What is it like to have your treatment monitored by the Specialized Assistance Service?

The interviews took place from November 2015 to March 2016 and were conducted by the main researcher, in an office that ensured privacy. They lasted a mean of 40 minutes, were recorded on MP4 and transcribed at the end, with no losses or refusals during the collection process. After reading the transcribed material, essential structures responsive to the study objective emerged and, by adding new ideas, the data collection stage was concluded.

Analysis of the testimonies aimed at understanding the meaning that grounds the existential analysis of being-in-the-world, which is characteristic of the phenomenological method, being the most suitable for the search of the meaning that bases all human experiences¹⁴. Thus, it was initiated with the transcription of the situation experienced by the interviewee, without worrying about the truth or falsehood of the experiences that were being described, but trying to understand the phenomenon, that is, what was shown as the interviewee's way of being¹³.

The hermeneutical analytical movement was focused on showing the experience of adolescents living with HIV. In the first phase, five Units of Meaning (UMs) emerged, namely: UM1 - Adolescents' knowledge about the disease; UM2 - Therapeutic routine; UM3 - Strategies to avoid discrimination; UM4 - Awareness of the effects of non-adherence to the treatment; and UM5 - Recognition of the importance of monitoring in the Specialized Assistance Service.

Vague and average understanding is what the *person* thinks and speaks of being, but it is not yet the interpretation, which was achieved by means of hermeneutics at the second moment. Therefore, starting from the UMs, and using the intuition movement, which is characteristic of the researcher and, based on Martin Heidegger's Ontology in his work "Being and Time", the meaning of the experience underwent by the subject was sought, unveiling what is veiled: hermeneutics¹³.

The activities at the research locus were initiated after approval by the Research Ethics Committee, following the recommendations set forth in Resolution No. 466/12¹⁵. The adolescents' participation was voluntary, with written assent and formal consent from their legal guardians. It is noteworthy that the participants' names were kept anonymous, coded as follows: the letter E, identifying the interview ("Entrevista" in Portuguese), accompanied by its order number and the letter M or F, indicating Male and Female gender.

RESULTS

The participants in this study are aged between 13 and 18 years old: six females and three males. Of the total, four declared themselves black-skinned, three brown-skinned and two white-skinned. Regarding religion, most of them stated being Evangelical, two Catholics and only one Spiritist. Schooling ranged from sixth grade of Elementary School to third year of High School. In general, they live with their parents or with one of them, uncles or aunts, grandparents, cousins and only one lives in a Spiritist institution. Family income varied from one to three minimum wages and one declared having no income. Regarding the time since diagnosis, the most recent diagnosis was one year ago and the most distant in time, seven years ago.

Announcing the possibilities of being and living with HIV, the adolescents' routine is filled with school, home and other activities common to their age, according to the narratives:

I play, study, play soccer, everything is normal. In the morning I go to school, in the afternoon I study, I watch TV. I usually stay at home on the weekends or go out to play soccer, I don't go out at night. (E3F)

I wake up, go to school, then come home [...] I go out sometimes. At night, sometimes, I go out with my aunt. Most of the time, I stay at home. (E4M)

The adolescents maintain good relationships with their peers, but keep their condition of living with HIV as a secret:

My relationship is normal, I talk, sometimes we quarrel a little, that's it [...] if I tell, no one else will be my friend! [...] They will be scared, right? Because there, at school, everyone is prejudiced [...] (E5M)

Ah, I do play with them anyway. But they don't know. If I tell, it'll be worse for me [...] I think that they'll be scared [...] there's a friend of mine who knows [...], she doesn't have it, but she has two brothers who have it, and then I also have it. [...] she knows, so she stays close to us, talks, she knows everything that happens [...] (E9F)

Most of the time, the participants know about their diagnosis only some time after the treatment, through a specific family member or professional of the specialized service, as shown in the following speeches:

[...] my grandmother told me and later, in the consultation at the SAE, Dr. X told me and then I really found out. I was 13. (E6M)

[...] I knew since I was little [...] when I was 9. My mother told me, but I already used to come here, so I already knew it [...]. (E8F)

Although they recognize the ways in which viral load is controlled, the adolescents showed superficial knowledge about the ways in which HIV is transmitted, as can be seen in the following statements:

It's a contagious disease caused by sex, transmitted by sex when not using a condom, sharing a syringe. (E1M)
I know that it transmits through sexual intercourse, if I cut my finger and someone cuts it too, then if I touch it, it transmits. Yeah, I don't remember any other, no. I got it from my mother's belly. [...] this is the other way it transmits. [...] I don't know how my father didn't get it. My father doesn't have it, my brother doesn't have it, my other brother doesn't have it, my other sister doesn't have it. Just me, just me. (E2M)

On the other hand, they point out that, in order to lead a healthy life, it is necessary to eat well, practice physical activity, perform laboratory tests and use the medication daily. However, they need to be reminded to take the medication; otherwise they will suffer the effects of non-adherence to maintain the treatment.

I draw blood, take a vaccine [...] it (the medication) is to treat HIV, to prevent it. (E1M)
Eating well, taking medications and doing sports. I really like sports [...]. The treatment is very good to fight against HIV. (E5M)
I use Kaletra, AZT and the others I don't remember [...] one I take in the morning, when I wake up, fasting, and after I have lunch, I take another two, [...] after dinner, I take yet another two [...]. There are times when I get late, my aunt comes and asks if I've already taken it, then I say no and take it. (E7M)
[...] the medication is to keep my antibodies stronger because of the disease [...]. I think that I went a month without taking the medication, because I got sick. Then I got sick, I was hospitalized. [...] I started taking it. (E10M)

DISCUSSION

By capturing the singularities of being an adolescent with HIV, it was evidenced that their routine living with the virus is underwent with diversified experiences with their family members, schoolmates or neighborhood friends. They experience adolescence as a phase of transition from childhood to the adult world; in this movement, they are open to the possibilities that life offers them as students, children and playmates, experiencing activities specific to their age^{16,17}.

In the current study, we identified a fragmented appropriation of development of the disease, of the reasons why it is necessary to take the medication and of monitoring disease evolution in the body by some adolescents. They repeat the technical speech with their words, they do not question the information received, whether from health professionals, the media or the school, which characterizes the chatter, in the ontic way of being.

In the chatter, speech is closed, preventing the truth from revealing itself to consciousness, blocking the interaction of one entity with another entity and with things. Regardless of their age, the adolescents did not appropriate the concepts. They got lost from the revealing language, which led them to an inadequate understanding of things since, on the cognitive level, they have an oscillating behavior between following the health professionals' guidelines all the time and doing what they think is appropriate for them, and sometimes choosing not to take the medications, especially when they interfere with programs with friends or with their participation in daily activities such as going to school¹³.

Adherence to the drug regimen is a dynamic process, sometimes subjective and objective, with alternating moments of greater or lesser interest. If, on the one hand, there is fatigue in the face of medications and the desire to interrupt the treatment due to strict schedules and side effects, there is another side, where most of the young individuals choose to follow the prescribed recommendations to achieve and maintain good quality of life^{18,19}.

A number of studies show that the participation of these adolescents is secondary to their own care decisions, generating a deficit of knowledge about their health condition, due to the way in which information reaches them with HIV, and they usually have support from family members or close people who know about their condition, for the necessary care for their physical well-being, which consequently undermines their autonomy^{19,20}. As identified in this study, in their daily health care routine, adolescents living with HIV seek help from others to remind them of the medication schedule. Thus, in the positive mode of care, the *person* endowed with being in the *pre-sence* is *being-there-with*, needs help and recognizes this need¹³.

In the daily life of adolescents living with HIV, fearing social pressure due to their clinically different condition from others, they get lost in the untruth, that is, in decay, occupying themselves and worrying about always being in good clinical condition. When they are driven by an impersonal, inappropriate and inauthentic way of being that disperses them, this makes them confused as to the path or decision they should take regarding, for example, disclosing their diagnosis. Keeping the condition of living with HIV veiled is a way of not suffering prejudice, especially in this time of transition, which is adolescence¹³.

The issue of *being-in-the-world* is constitutive of man, it is the *Dasein's* way of being. The word *Dasein* means here, now, that is, the place where the being manifests itself in the mode of understanding, that is, of opening to the future¹³.

Secrecy of the serological condition is something recurrent when it comes to the HIV virus. The participants identify the need for secrecy to avoid situations of prejudice, as in other studies^{10,19,20}.

Adolescents living with HIV rely on other young people, often different from them, who do not live with the virus. It is from the other that dimension is gained; thus, adolescents are dispersed from themselves, remaining in inauthenticity²¹. Prejudice makes it difficult for HIV-positive adolescents to experience bonds of friendship with confidence to share their experiences.

Adolescents living with HIV have differences in their daily lives, such as having to take medications and undergoing specialized follow-up, including laboratory tests, which bring fear of suffering a prejudice that deprives them of the naturalness of daily life. Fear is a mode of disposition, understood as a mood state in which the *Dasein* can be found¹³.

By understanding the adolescence period as being the time of conquests, of the search for independence, the fact of living with a chronic disease such as HIV, depending on physicians, medications and strict health controls could represent a threat to the achievement of independence and autonomy modifying their lives^{22,23}.

In an interprofessional approach, Nursing can make a difference in the care provided to adolescents, by adopting a dialogic stance that allows the other to break their silences, to seek information about the disease, to promote sexual education and to mobilize young people to participate in ethical and politic debates, so that knowledge makes them more secure in the present to fully live their possibilities²².

Therefore, it is necessary to go beyond technical assistance, valuing the other in its entirety and considering adolescents as individuals in the course of developing their human potential.

Study limitations

This study has limitations because its results are not generalizable, as they portray the experiences of a small number of adolescents living with HIV. In addition, recognition of the phenomenological qualitative methodology is still questioned by the scientific community.

CONCLUSION

The results corroborate the findings of other studies with adolescents living with HIV, indicating that this population may be more participative with its own care, in addition to the urgent need to fight against prejudice. Adolescents who live with HIV perform daily activities that are typical of their life cycle, but deal with the stigmatizing condition of the virus. Thus, it is recommended to carry out research studies that problematize common sense and strengthen the role of Nursing in this population group, given its ethical, humanized and emancipatory care.

The study also revealed possibilities for assistance and health promotion for these young people and for teaching and research in the different scenarios they frequent. Regarding the assistance offered in the SAE, the peer education strategy is suggested, opening spaces for young people to share experiences and reflect on the issues that permeate their daily lives, their doubts, their fears, their achievements and related practical aspects of STI/AIDS prevention.

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