

Disclosure of the HIV diagnosis to the teenager: ways of being everyday

Revelação do diagnóstico de HIV para o adolescente: modos de ser cotidiano
Revelación del diagnóstico de VIH para el adolescente: modos de ser en el cotidiano

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ABSTRACT

Objective: Understand the meaning of the disclosure of the diagnosis of the human immunodeficiency virus for the teenager. **Methods:** Phenomenological research with theoretical-methodological framework of Martin Heidegger. It was developed a phenomenological interview with twelve teenagers in a referral service in a teaching hospital in the South of Brazil, from november 2011 to february 2012. **Results:** Were set up two units of meaning: The unveiled that they already knew the diagnosis. Told them and they knew how the transmission happened; Known as the transmission of the virus and in need of treatment; Be a normal person, the different is the virus, have to take medicine and go to the hospital. These units of meaning were the thread of interpretation, which desvelaran way. **Conclusion:** The nurse has the possibility to promote the experience movement through consultations and groups with these teenagers.

Keywords: Nursing, Truth disclosure; Adolescent's health; Acquired immunodeficiency syndrome; HIV.

RESUMO

Objetivo: Compreender o significado da revelação do diagnóstico do Vírus da Imunodeficiência Humana para o adolescente. **Métodos:** Investigação fenomenológica fundamentada no referencial teórico-metodológico de Martin Heidegger. Desenvolveu-se uma entrevista fenomenológica com 12 adolescentes, em serviço especializado de um hospital universitário do Sul do Brasil, no período de novembro de 2011 a fevereiro de 2012. **Resultados:** Constituíram-se duas unidades de significação: Saber do diagnóstico antes de alguém lhe contar, mesmo sem entender, até a família e/ou profissionais da saúde explicar. Saber como ocorreu à transmissão do vírus e que precisa de tratamento; Ser uma pessoa normal, o diferente é o vírus, ter que tomar os remédios e ir ao hospital. Essas unidades de significação foram o fio condutor da interpretação, que desvelaram os sentidos. **Conclusão:** O enfermeiro tem a possibilidade de desencadear o movimento vivido por meio das consultas e grupos com esses adolescentes.

Palavras-chave: Enfermagem; Revelação da Verdade; Saúde do Adolescente; Síndrome de Imunodeficiência Adquirida; HIV.

RESUMEN

Objetivo: Comprender el significado de la revelación del diagnóstico del virus de la inmunodeficiencia humana para el adolescente. **Métodos:** Investigación fenomenológica sostenida por el referencial teórico-metodológico de Martin Heidegger. Participaron de la entrevista fenomenológica 12 adolescentes en servicio especializado de un hospital universitario del sur de Brasil, entre Noviembre de 2011 y Febrero de 2012. **Resultados:** Fueron construidas dos unidades de significación: saber del diagnóstico antes que la familia y/o los profesionales de salud les cuenten a ellos, aunque no se comprenda cómo ocurrió la transmisión y la necesidad de tratamiento; vivir como una persona común, puesto que diferente es el virus, y convivir con medicaciones y la rutina hospitalaria. Estas unidades de significación formaron el hilo conductor de la interpretación, la cual ha desnudado los sentidos. **Conclusión:** El enfermero tiene la posibilidad de promover el movimiento vivido a través de consultas y grupos con estos adolescentes.

Palabras clave: Enfermería; Revelación de la verdad; Salud del adolescente; Síndrome de la Inmunodeficiencia Adquirida; VIH.

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INTRODUCTION

In Brazil, reports of Human Immunodeficiency Virus (HIV) infection in adolescents indicate that in the period from 1980 to 2014, there were 13,010 cases with individuals aged between 13-19 years old¹. Considering such epidemiologic magnitude, specific policies were applied to this population, involving prevention, control and assistance. By chaining these actions, it was possible to contribute to the reduction of morbidity and mortality², so that children infected by vertical transmission of HIV may transpose the phase from childhood to adolescence, composing then the group of adolescents who have HIV³. Added to this group, there are also the teens who became HIV infected by horizontal transmission⁴.

The transition from childhood to adolescence results in challenges for the health service⁵, among which there is the moment of disclosure of the diagnosis to teens. The disclosure is understood as a process, i.e., it does not qualify as a unique moment. This process should be linked to the cognitive development of children in accordance with their age. It should be started in stages, as a strategy in which parents provide children with information about their disease, without naming it specifically. The family and professional support are essential while at the beginning of the disclosure about the diagnosis and in order to keep monitoring the process. In addition, specific strategies to choose the best way to reveal the diagnosis to children or adolescents are relevant⁶⁻⁸.

It is evident that HIV studies in childhood tend to focus on the care and have clinical-epidemiological characteristics when compared to those focused on adolescents that usually aim at preventive and sociocultural scopes⁹. This article focuses on the moment of the HIV diagnosis disclosure, which constitutes an existential opportunity, due to the discovery or confirmation of the diagnosis by the teenager who, until then, remained silent.

Thus, the following research question was brought up: How is/was the diagnosis disclosure for the teenager who has HIV? The study aimed at understanding the meaning of the HIV diagnosis disclosure to adolescents.

METHODS

It is a phenomenological qualitative research, sustained in the theoretical and methodological framework of Martin Heidegger¹⁰. Phenomenology focuses on the understanding of the subjects about what they experience and live in their daily lives in order to enlighten subjects themselves to what/how they are like.

Data production was developed from November 2011 to February 2012 at the Infectious Disease Department at the Pediatric Ambulatory from the Hospital Universitário Santa Maria, Rio Grande do Sul, Brazil (HUSM).

The subjects were 12 adolescents who have HIV/AIDS. This quantity was not previously determined. The field research stage, however, concomitant to the analysis, indicated the time to end the interviews when there was sufficiency of the

meanings expressed in the discourse that met the objective of the research^{11,12}. The subjects were coded as A, referring to adolescent, then numbered from 1 to 12.

As inclusion criteria were elected: teenagers who have HIV/AIDS, aged between 13-19¹ years old, in attendance in that service, and that were aware of their diagnosis. In order to meet this last criterion, it was also requested information from professionals and family members and/or caregivers. The exclusion criteria were: present cognitive and mental limitations (that made verbal expression difficult), those who were fulfilling legal socio-educational measures and individuals above 18 years old who were in the prison situation, once during consultations they are escorted by police officers, fact that does not meet the principle of privacy.

The phenomenological interview^{13,14} was developed in individual meetings, uniquely established between the teenager and the researcher. It was demanded from the researcher a decentralization movement from herself, to be intentionally directed to the significance provided by the adolescents. The meeting enabled by the interview lasted 30 minutes. The adolescents who were above 18 years old signed the Informed Consent term (IC), and the minors, after having the Informed Consent signed by their parents and/or guardians also participated by signing of the Informed Consent Term (IC).

The guiding question of the interview was: How was it for you to get to know about your diagnosis? The way teenagers referred or silenced serological condition was respected: *this, thing, disease or virus*. The researcher had to be attentive to the ways the speeches were made, considering gestures, pauses and silences in order to apprehend what was said and what was not said. During the conduction of the interview, empathic questions were formulated, highlighting the words expressed by the adolescents themselves, in regards to what needed to be deepened to a better comprehension of the study object. The interview was concluded with a feedback, when the researcher made a summary of what had been understood in the interview and then the teenagers were questioned whether they would like to add anything. The audio of the interviews were recorded with consent and then transcribed.

The analysis was developed in two moments: comprehensive analysis and analogue interpretative analysis. The comprehensive analysis, also known as vague and average comprehension revealed the understanding of the research subjects through the meanings they assign to the object of study. It was developed from the suspension of the researcher's assumptions while at the attentive listening of the recording of the interviews and the reading of the transcripts, without imposing pre-established categories by theoretical/practical knowledge. In the interviews transcribed, the essential structures that indicated the meanings addressed by the objectives of the research were highlighted and thus, constituted the units of signification¹⁰. The speeches provided by the adolescents presented in the results of this paper were used as illustrations of the phenomenological discourse and are displayed below the vague and average comprehension. This

speech, written by the researcher, describes the understanding of the adolescent himself or herself about their diagnosis disclosure.

From the meanings expressed in the vague and average comprehension we have sought to, according to Heidegger's theoretical framework, achieve the interpretation of the unveiled senses. This interpretation is composed by the interpretative analysis, also called hermeneutics. Thus the hermeneutic understanding, according to Martin Heidegger's references, proposes to unveil the meanings expressed by the subjects themselves, in this study by adolescents, without pointing out the factual assumptions, i.e., the one described by scientific knowledge. Therefore, making comparisons with other references interfere in the analysis of the ontological dimension of the being as specified by the referential pointed out in this study¹⁰.

All the ethical principles of Resolution N. 196/1996 were respected, in force at the time of the survey. The project was approved by the Ethics Committee of the Universidade Federal de Santa Maria, under the certificate number 0321.0.243.000-11.

RESULTS

From the interviews, elements were searched to compose the adolescent's history. Thus, eight teenagers were female and four male. The age average ranged from 13 to 18 years old. The HIV infection occurred in 10 adolescents by vertical transmission and two by horizontal. Among these, 10 were undergoing antiretroviral therapy.

In the comprehensive analysis the following meaning units were formed: 1) Knowing the diagnosis before someone told you, even without understanding it, until family and/or health professionals explain it. Knowing about the transmission of the virus and the need for treatment; 2) Being a normal person, and that only the virus is different, and having to take drugs and besides going to the hospital. These signification units were the conducting thread for the interpretation, which unveiled the senses that will be subsequently discussed with Heidegger's framework.

The adolescents reported knowing the diagnosis since their childhood. They began to suspect that something was different when they started the consultations, examinations and treatment in hospital. They grew up knowing what they had, even without anyone telling them about this disease. Even when people spoke about the disease and treatment, they did not understand the reasons they had to go to hospital and take medications. They did not care about what they had and did not know what was happening, but suspected that something was not good.

When I learned these things, I was five, I was very little. She [the mother] told me but I did not quite understand what it was [pause], mom is the one who knows about these things. (A1)

I discovered this since I was little. I didn't care about it then, only later. At the time I was normal, I did not know what it was. (A3)

I knew what I had nobody told me, I started coming to the hospital I started suspecting [trembling voice] and I alone understood what it was [...] I was one year old and my mother already told me [...] she said that I had some bugs and that I had to take the medications. (A4)

I thought it was odd, I thought to myself, this isn't good. [Pause] I did not quite understand why I had to take medications. (A5)

They began to question the reasons to go to hospital and always take medications. So the family and/or caregivers explained, telling them they had some bugs in the blood, a difficult problem to heal, and that they needed to make the health monitoring and take the medicine.

They found out they got infected in their childhood because the mother had the same virus and that sometimes the father also had that virus. Some teenagers have found, also, that they were adopted, some even because their biological parents had already died from this disease. When they got infected in adolescence, it was because they did not use protection during sexual intercourse.

First, they told my parents and then they told me. Then I discovered I had the virus and that I was adopted. I got the virus from my birth mother, who had already died. (A2)

I asked when I went to the drugs and she [the mother] answered that one day I would know [silence] I learned about it when I came here for the treatment and the doctor told me straightaway. He said I was old enough to know, I was able to know what I had, because I needed to know how to make the right treatment, which it would depend on me. (A6)

My sister told me little by little [silence] that I have this [silence]. She explained that I got it from the father and mother when I was little, so then they died [silence] because of this the disease. (A7)

Then I started coming to hospital and they told me what it was. It was at the ED [emergency department], dad took my exams and went home, and he came crying and told mom. Dad said that I had [pause] HIV [put down the cap over his face] I did not know what it was, and then he explained it to me [silence]. I was dating a girl I met on the internet, we did it without a condom, and a week later I found some spots on my skin. (A8)

I wanted to know why I had to come here, so she [the mother] told me. I once saw on the television the dr. [name of the doctor] that coordinates here! I was about four years old when they explained it to me that I had been in the hospital to do the monitoring with the medical team here in the pediatric ID [infectious disease]. They explained that I was taking the medications to control [pause] increase defenses, the immunity and how the platelets were, the leukocytes, the complete hemogram. (A12)

They could see themselves as equal to others and expressed themselves as normal. They accepted the disease and moved on with their lives as they always have, having fun, doing leisure activities and playing sports.

They consider that the different is having the disease and needing medicines, then they feel different among the other teenagers. Before the medications, they believed they had a normal life. They did not like when professionals say it is normal having this disease.

They know they have to take medicine, because healthcare workers control the treatment based on the test results. They do everything they need to avoid hospitalization.

I am a normal person just like the others, I mean, I am a normal person, but with a problem, you know? I am a normal person even there, even to have fun, to laugh, to walk, to run [pause] up to that point I'm normal, but [silence] there is that part of me that wanted to be normal, not having to come to hospital. It isn't normal having to take medications all the time. These medications have to be controlled, if I do not take them, they control [the doctors] the blood results [silence]. I'm not happy for having this. (A5)

There are people who say: "I do not accept myself with this problem," I'm moving on as normal, I am a normal person like everyone else, it's all normal, I'm moving on with my life as I always have. (A9)

You have a normal life, you keep on living, but for me it isn't like that. I feel disgusted when the professionals say it is normal. If you have the disease, I know that it is not normal. Because you have to be different! I feel different in the midst of strangers. I know I'm not like everyone else. Maybe if I did not have this disease I would be a normal person. (A10)

I live well, but not that well. I wish I could to be like everyone else. Because I already have to take medicines and that to me is bad [silence]. because I did not expect I would have to take medications. (A11)

DISCUSSION

The adolescents have unveiled as being-adolescent who experienced the disclosure of the HIV diagnosis. They were announced in their own existing world, by the comprehension of the world and themselves. They reported that they had the opportunity to hear about the disease, even without understanding it, but suspected by the frequent visits to hospitals and learned about the diagnosis before anyone telling them.

Guided by their experiences and the need to feel part of that world, they repeat what they heard from others and seen in the media, even without understanding it. Thus, the being-teenager shows up in the middle of being a subject for talks, comments and chatter¹⁰.

Chattering is a way of the everyday comprehension in which the being seems to have understood everything without even having appropriated what is being said. Things are as they are, since that is how they are carried out¹⁰. The truth means the unveiling, that is, enlightening, whereas someone who simply accepts and transmits the chatter has not released their inherent light, it reproduces what others say and do. They do not present as themselves, but as the others expect them to be. That of which it is spoken in chatter is inert and authoritarian, as it takes us, through the tranquility, to assume that things are fully resolved¹⁰, snatching the possibility of coming-to-be.

The adolescents report the various times they need to go to hospital and ingest the medications because they repeat what they have heard from family members and healthcare workers, who explained to them how the treatment should be followed. They continue to do it even without understanding what is happening.

They state that, even without understanding it, they try to learn more about what is happening and seek information by asking family members and health professionals. They question the relevance of having to take the medicine and the need to maintain continuous monitoring in the health service. Therefore, they are kept in and guided by their curiosity¹⁰.

Curiosity is always behind the latest news and presents an uneasiness before the changes without establishing any commitment, only trying to be updated from what others have seen and read. Curiosity, which is comparable to chattering, offers to the individual the security of a supposedly authentic life, however inauthentic. These two ways of living the everyday life are not simply expressed alongside, in their trend for impersonality, but they drag one along with the other. Chattering and curiosity originate the way of living from ambiguity¹⁰.

By seeing themselves as normal, like other teenagers, and feeling different for having the virus, the being-adolescent is caught in the ambiguity. They report living daily experiences that are common to any adolescence, but they know they have restrictions due to the treatment, which cause to feel different among their equals and wanting to be like all those who do not have this disease.

Ambiguity predisposes the alleged fact of knowing what will happen and that one will do, when it seems that everything is understood when actually it was not. Ambiguity's way of being are both shown in the relationships with others and with themselves¹⁰.

The being-adolescent seems to have apprehended, questioned and understood everything about what they have, how was the transmission of the virus was done and the reason for carrying out the treatment, while in fact none of it was understood. They reveal that they accept what they have and move on with their everyday activities. However, they express that having the virus and needing to do the treatment is what makes them different.

Thus, the being-adolescent is absorbed by the living and fall in the impersonality of acting as everyone acts in their daily

life, that is, they do not reveal themselves in their singularity, as they are, but as everyone else is. Keeping themselves in the impersonality indicates their commitment to the living, even if that is conducted by the ways of being subject of chatter, curiosity and ambiguity, which, together, characterize the everyday life's predominant way of being: the decadence. That does not translate any negative evaluation, but suggests how the human beings usually shown themselves in their daily lives: impersonally¹⁰.

By wishing to be like everyone else, the being-adolescent reports wanting to be seen by their peers and other people of their context as normal. The world of this being is essentially a public world, accessible both to others as to themselves¹⁰. For being public, they go through what is expected from them to do: going to hospital and take the medicine to avoid getting sick. Most of the time, they can not get away from that to examine themselves. By the public expectation, the being-adolescent remains stuck to their everyday tasks such as leisure and sport, and their obligations.

Decadence's way of being is, in itself, tempting and tranquilizing. It is tempting because it allows the individual to be and do only what is expected from their daily lives, refuting what appears as novelty or possibility. This tranquility does not entails inertia and idleness; on the contrary, it keeps them busy. Thus, the decadence moves to being to an alienation once it prevents the inner-self of coming forth, and therefore voids the possibilities of the being to be what and who they really are¹⁰.

By sharing a living that is mediated by everyday relationships, the being-adolescent demands to be like everyone else is and how they are expected to be, they keep themselves alienated in their daily lives. That enables to get used to and to accept what they have. It tranquilizes them and let them move on with their lives.

CONCLUSION

The being-adolescent who has experienced the HIV diagnosis disclosure expresses themselves equally to all adolescents and acts according to what is expected from them. They do not show themselves as they really are in their uniqueness and keep themselves in the impersonal way of being. Trapped in the chatter of the information received and passed on about their HIV status, curious to know about their health status, and ambiguous between understanding themselves as normal and yet feeling different.

The adolescents' living expresses that the diagnosis disclosure enables the acknowledgement or confirmation of their HIV status. Thus, the study results indicate the need for the disclosure be understood beyond a single moment, but as a movement towards the announcement of the diagnosis to the adolescent, either by the family or by the health care professional.

Considering that at some point the family reveals the diagnosis, it is recommended to join the family in the adolescent's health monitoring, and it should built with the time and respect

to the willingness of each person to be open for this time of disclosure. For such, the family needs to be encouraged to disclose the diagnosis with the support of the health professionals once being with the family and the teenager, may present the benefits of the revelation.

The being-adolescent point out they knew their diagnosis even before anyone told them. The nurse, along with other members of the health team, has the ability to promote the dialogue in the care of a teenager, and to enable them to show how they are. This care can be developed in the consultation and in groups with teens. These care strategies, such as the consultation and the group, allow the nurse to make a connection between the health service and adolescents.

Such a move, powered by the nurse, will enable an existential journey in the means of moving from the impersonality to the uniqueness of showing up as they really are, to allow them to discover, within their potential and the limits of everyday life. They will contribute to the construction of autonomy for self-care.

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