
THE DAILY LIVING OF ADOLESCENTS WITH HIV/AIDS: IMPERSONALITY AND TENDENCY TO FEAR

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ABSTRACT: This phenomenological investigation aimed to understand the therapeutic routine of adolescents with HIV/AIDS. Sixteen adolescents between 13 and 19 years of age, assisted by the health service and aware of their diagnosis were interviewed, between December of 2009 and May of 2010, in the University Hospital of Santa Maria, Rio Grande do Sul, Brazil. Their statements, which were analyzed in the light of Heidegger, revealed that the being-adolescent is presented as a being-with-in-the-world through the impersonality of the characteristics of adolescence and the occupation with activities of the daily living. In face of having HIV/AIDS, they fear that, besides their family, other people might learn about their disease, due to prejudice. This comprehensive perspective allowed the possibility of a nursing care based on an attentive approach to the pluralities and singularities in the daily living, and mediated by the dialogue with the being-adolescent and its family, in order to make this being the leading figure in its permanent care.

DESCRIPTORS: Acquired Immunodeficiency Syndrome. Adolescent health. Pediatric nursing. Nursing care.

O COTIDIANO DO ADOLESCENTE QUE TEM HIV/AIDS: IMPESSOALIDADE E DISPOSIÇÃO AO TEMOR

RESUMO: Investigação fenomenológica com objetivo de compreender o cotidiano terapêutico do adolescente que tem HIV/aids. Foram entrevistados 16 adolescentes de 13 a 19 anos, assistidos pelo serviço de saúde, conhecedores de seu diagnóstico, de dezembro/2009 a maio/2010, no Hospital Universitário de Santa Maria, Rio Grande do Sul, Brasil. Os depoimentos, analisados à luz de Heidegger, revelaram que o ser-adolescente se mostra no modo de ser-com-no-mundo pela impessoalidade das características da adolescência e pela ocupação com as atividades cotidianas. Diante da facticidade de ter HIV/aids, temem que, além de sua família, outras pessoas saibam da doença, devido ao preconceito. A partir deste olhar compreensivo, emergiu a possibilidade do cuidado de enfermagem pautado em uma abordagem atenta às pluralidades e singularidade(s) no cotidiano, e mediado pela dialogicidade com o ser-adolescente e família, a fim torná-lo protagonista de seu cuidado permanente.

DESCRIPTORIOS: Síndrome de Imunodeficiência Adquirida. Saúde do adolescente. Enfermagem pediátrica. Cuidados de enfermagem.

EL COTIDIANO DEL ADOLESCENTE CON VIH/SIDA: IMPERSONALIDAD Y DISPOSICIÓN AL TEMOR

RESUMEN: Se trata de una investigación fenomenológica con el objetivo de comprender el cotidiano terapéutico del adolescente enfermo de VIH/SIDA. Desde diciembre 2009 hasta mayo 2010, en el Hospital Universitario de Santa Maria, Rio Grande do Sul, Brasil. Fueron entrevistados 16 adolescentes de 13 a 19 años, asistidos por el servicio de salud y que conocían su diagnóstico. Los testimonios fueron analizados a la luz del Heidegger, revelaron que el ser-adolescente se muestra, en la condición de ser-con-el-mundo, de modo impersonal considerándose las características de la adolescencia y la ocupación de actividades cotidianas. Ante el hecho de estar enfermo de VIH/SIDA y debido al prejuicio general sobre la enfermedad, él teme que, además de su familia, otras personas sepan de su enfermedad. A partir de esta mirada comprensiva, emergió la posibilidad del cuidado de Enfermería pautado en un abordaje atento a las pluralidades y singularidad(es) en el cotidiano y mediado por la dialógica con el ser-adolescente y la familia, a fin de tornarlo protagonista de su cuidado permanente.

DESCRIPTORIOS: Síndrome de Inmunodeficiencia Adquirida. Salud del adolescente. Enfermería pediátrica. Cuidados de enfermería.

INTRODUCTION

Adolescents who have the Human Immunodeficiency Virus (HIV) and consequently become sick due to the Acquired Immunodeficiency Syndrome (AIDS) require specialized care to their health needs regarding the phase of growth and development and the serologic condition of infection by HIV; need permanent monitoring, go to ambulatory visits regularly, are submitted to laboratory and clinical routine tests and comply with treatment conducts. The serologic and clinical condition of living with an incurable disease determine the special health need associated with the dependence on drug technology.¹⁻⁵

It is important to highlight the clinical frailty of an adolescent with HIV/AIDS, due to the compromised immune system and the vulnerability to opportunistic diseases, which indicates the need for permanent clinical and laboratory monitoring, in which the compliance with the treatment, adverse effects and therapeutic failures configure their therapeutic routine.¹

The experiences of the adolescent with HIV/AIDS show that he/she goes through this phase of development with common characteristics to adolescents who do not have the infection. In addition to the physical and psychosocial transformations, there are specific needs of their serologic condition – learning about the diagnosis, the consequences of the disease in their daily living due to the therapeutic routine and the situations of prejudice and discrimination.⁶⁻¹¹

It is important to reinforce, thus, the relevance of producing this knowledge regarding the therapeutic routine of adolescents with HIV/AIDS, since the fact of having the virus generates singular situations in their lives – the continuous clinical treatment that goes through questions of prejudice and discrimination, which, somehow, make their treatment and social relationships frail.^{1-2,7} In consonance with the theme, the authors aimed to have an existential perspective regarding the demands experienced by the adolescent with HIV/AIDS and other possibilities of interpreting their daily living, in the intention of revealing aspects of what is hidden in their therapeutic routine. The intention, thus, is to produce certain knowledge that implicates contributions to the intervention practices mediated by care actions, centered in health promotion and education aimed at the development of care.

Hence, the adolescent with HIV/AIDS relates with family members and friends and keeps leisure and daily living activities, a normal attitude even for those who have the virus. Taking care of themselves is something they must do and they need to be willing to do so.² However, there are difficulties involving the treatment, related with the stigma and the discrimination towards the disease, which may often make their health condition more fragile. Hence, this study aimed to understand the therapeutic routine of the adolescent with HIV/AIDS.

METHOD

This qualitative study, with phenomenological approach and theoretical-philosophical framework,¹² aims to uncover the study object for what it is – the therapeutic routine and its meaning – that is, to produce knowledge of the phenomenon, not only about it. In this context, the factual knowledge is suspended – what is already known regarding the facts – in order to achieve the existential comprehension of the phenomenon. Thus, it allows to have a perspective of the adolescent with HIV/AIDS in his/her own existential world, through the intersubjectivity between the researcher and the study subject, in the search for meanings attributed by these adolescents to their experiences, expressed in their own words, based on the world of the daily living, their knowledge and historicity.

The phase of field study was developed at the University Hospital of Santa Maria (HUSM), located in the midwest region of the state of Rio Grande do Sul, Brazil. This hospital provides reference service of medium and high complexity for the macroregion and is specialized in HIV/AIDS. Regarding the service to the patients, some adolescents who have HIV/AIDS are monitored in the pediatric ambulatory, where they have bonds to the service team since their childhood. Others are assisted in the adult ambulatory and pregnant adolescents are assisted in the obstetric ambulatory. Field work was developed in these three ambulatories, in the period between December of 2009 and May of 2010.

The study participants were adolescents with HIV/AIDS, aged between 13 and 19 years, who were followed up in the studied health service and knew their infection diagnosis. The exclusion criterion was applied to adolescents who were not aware of their condition, due to the risk of breaking the confidentiality of the diagnosis, which could

result in harm to the participants. The selection of the adolescents who could participate in the study was initially performed by contacting the service professionals in order to clarify the criterion of diagnosis disclosure, and, later, their participation was confirmed with the family members/caregivers responsible for the adolescents. Finally, the authors contacted those who were aware of the diagnosis of infection by HIV or AIDS.

The number of participants was not predetermined, since the phase of field work, which was developed concomitantly with the analysis, showed the number of interviews necessary to meet the study purpose, pointing out the sufficiency of meanings expressed in the speeches of the adolescents.¹³ Data were produced by means of a phenomenological interview with the adolescents, who were located based on the schedule of appointments of the sectors and their medical records, totaling 16 participants. This modality of access to the participants allowed to consider the experience of the human being, by means of a movement of comprehension. As a means of access to the being, the interview was developed as a meeting, individually established between the researcher and each participant. The meeting was mediated by the empathy and intersubjectivity, based on the reduction of presuppositions,¹⁴ which required from the researcher an attitude of self de-centralization, in order to lead, intentionally, to the understanding of the adolescents.

During the meeting, the researcher had to be attentive to the manners of the adolescents interviewed; to capture what was said and unsaid; to observe the other forms of discourse – silence, gestures, reservedness and pauses; and to respect the space and timing of the other. This open position of the researcher towards the other allows to improve, progressively, the conduction of the interview. The interview was initiated with the guiding question: what is your health care daily routine like? In order to keep the anonymity of the interviewees, their names were coded with the letter a, as in adolescent, followed by a numbers between 1 and 16.

The analysis, as per Heidegger's method, was developed in two phases: comprehensive analysis and interpretative analysis.¹² The vague and average understanding – first moment – consisted of the suspension of presuppositions of the researcher, by attentively listening and reading the interviews, aimed to understand the meaning of the therapeutic routine of the adolescent with

HIV/AIDS, without imposing predetermined categories to them through the theoretical/practical knowledge. Essential structures were highlighted in the transcriptions, forming an analysis framework, from which the meaning units and the phenomenological discourse were constituted, in order to build the concept experienced that is the common thread of hermeneutics – second methodological moment.¹²

The research proposal was approved by the Research Ethics Committee (CEP-UFSM/RS), by means of the Certificate of Submission for Ethical Appreciation no. 0213.0.243.000-09. As per the guidelines for researches involving human beings, recommended by the resolution 196/96¹⁵ of the National Health Council, two free and informed consent forms were developed, one for the legal guardian of the adolescent, and the other for the adolescent, aged 18 years or older, emancipated or pregnant.

At this moment, two mMeaning Units (MU) are presented, showing the experience of the therapeutic routine of the adolescent with HIV/AIDS: 1) In the daily living, as he/she goes to school, to parties, plays videogame, talks to friends; and 2) Only the family and no one else knows about the disease, due to prejudice.

RESULTS

The study sample consisted of adolescents aged between 13 and 19 years, who had children, were pregnant, orphans, adopted or those whose parents were separated. The adolescents lived with their partners, biological parents, grandparents, mother, siblings. They used TARV and relied on the help of family members for the treatment. Most of them were coursing the elementary education.

The study results indicate that the daily living of the adolescent with HIV/AIDS is permeated with activities: going to school, playing, going to parties, talking to friends, using the computer, and talking about dating and their bodily image.

I play with friends, play soccer [...] go to school (a2).

I have the opportunity to live, go out, go to parties, then I feel fine [...] (a5).

I like playing soccer [...] using the computer (a6).

I even put on some weight [...] I want to grow up some more, because I am a little short (a8).

[...] everyone has a boyfriend, someone by their side, and we don't. Am I that ugly? I don't know (a15).

Due to the prejudice against AIDS, adolescents do not want anyone to know they have HIV. The diagnosis is only shared with the family, to whom they can talk about it with parents, uncles, aunts, grandparents, and sometimes even with a boyfriend. Friends do not know, since they are not aware of what the disease is. The adolescents state people look at them differently and make questions regarding their low weight, but they know that once they tell people about their disease they will be rejected, so they are careful not to let anyone see them taking the medications.

[...] *I am careful so that anyone sees [the medications] [...] it is because they are all prejudiced there, right? Against AIDS (a1).*

[...] *only my family knows [...] no one else, no one talks to anyone, because I don't want anyone to know (a11).*

[...] *my parents, my aunts and uncles, and grandparents know. My friends don't know [...] (a12).*

[...] *we talk [friends], but they don't know about my condition, only people from my family and my boyfriend do (a14).*

[...] *people look at you [...]. There are people who come, look at me and say, 'you are so thin, you are different, strange', and it is hard. I know that once I tell them [...] no one is going to be by my side [silence] [...] so I don't say anything to my friends (a15).*

DISCUSSION

In the present study, adolescents with HIV/AIDS described their routine in the family and school world. Hence, the way they are presented in the daily living takes place in a spatiality – in the world, which indicates the “[...] context in which dasein lives”,^{12:105} as this dasein “[...] does not only reside in the world, but also relates with it”.^{12:164} This routine is configured in the relationships of the adolescent with peers, manifested in the exchanges and sharing with the world.

Relating is fundamental for the constitution of the world, since it does not correspond to an already given geometrical structure, in which the being is located. The world exists only in a system of relationships. It is only produced in the being-together, movement of the dasein (distancing/approaching) towards that (others or things) which meets the being. Hence, it denotes a “[...] fundamental structure in dasein: being-in-the-world”,^{12:52} which designates an articulated totality, since “[...] there is no world without being, as well as there is no being without world”.^{12:52} It is

important to highlight, thus, the adolescent and his/her relationships with the world, which are indissociable, and, regardless of being close to the other geographically, these relationships are made of meanings and senses in their experiences.

In the world, the being-adolescent establishes experiences and builds bonds, showing himself in the relationship with people: family, boyfriend/girlfriend, friends and colleagues. This relationship points to the meaning of being-with, since being-with indicates the human relational nature, demonstrating that “[...] every being is always being-with, even in solitude and isolation. Dasein is always co-presence, the world is always shared-world, and living is always co-existing”.^{12:319}

The being-adolescent is revealed as a being-in-the-world-with-others because he talks about himself, relating his being with-others. The being-in-the-world occurs together with other things in the surrounding world, moves through the daily living with the others, in which a leveling is convenient and the being is presented similar to the others.¹² These are ways for the adolescent to be in the world, that is, based on the relationships with peers they are found to be equal the others, which is often interesting, since they gain strength in the group.

Hence, the daily living of the being-adolescent is marked by typical characteristics of the adolescent phase: parties, school, conversations, games, dating. The fact of being equal their peers indicates the way of being of the impersonality, in which the being strives in the co-existence of the being-with-others, showing what everyone is like, not what he/she is.

In the daily experience, both what is accessible to everyone and what everyone may talk about comes equally to the being, thus, it is no longer possible to separate, in the authentic comprehension, what is and what is not open.¹² Based on relationships, the practices of the daily living are generalized in a movement of authenticity and unauthenticity, in which the adolescent often shows his/her authentic essence, however, it is often built and manifested in his/her experiences.

Therefore, the being grows-with-others in the way he/she relates-in-the-world, “[...] from which several possibilities emerge: ‘world’ may stand for the ‘public’ we-world, or one’s ‘own’ closest (domestic) environment”.^{12:105} In the light of these possibilities, “[...] dasein may behave differently [...] based on the possibility of being or not being itself”.^{12:39} The possibility of being oneself is

assumed in the singularity of the way of being of the authenticity; whereas not being oneself leads to getting lost in the impersonality of the way of being of the unauthenticity.

The being-adolescent expresses an impersonality in the way it is presented in the daily living: as ourselves and not only oneself. Thus, "[...] a depersonalization of people" takes place.^{12:319} In addition, in the daily living "[...] the dasein relates to the world as per a predominant way of being: the impersonal".^{12:164} This is often the way of being of the dasein, according to which "[...] everyone is the other and no one is himself".^{12:181} Hence, the being-adolescent, in the being-with-the-others in the public world, assumes this impersonal identity. The impersonality allows him not to differ from the others, since being considered different makes the co-existence difficult. Therefore, he is equalized in the form of what is common and expected by everyone. In the form of being-with, the dasein occurs essentially as a result of others.¹²

The being is often lost in this public character of the impersonal, which constitutes a way of being-in-the-world that is totally absorbed by this being and the co-presence of others, since the world is filled with absolute questions and associated to the influence of people in the daily living of the adolescent. Not being oneself is a possibility, since it approaches the beings to the occupations in the world,¹² as there is a prevalence of public interpretation, which makes "all of us no one",¹⁶ in which everyone is like the other.

The way of being of the daily living determines the impersonal, which is not predetermined, although everyone keeps this way of being. Distancing, commonness and leveling, constituted as public character, are ways of being of the impersonal. The impersonal removes all the responsibilities from the dasein, which allows its support. It is possible to say that the impersonal was who, however it was no one.¹²

In this context, the being-adolescent lives the facticity of having HIV or AIDS, that is, his health condition is established, a situation from which it is not possible to escape. Hence, the dasein is cast towards what is already determined and to which it is not possible to escape. "The expression being-cast must indicate the facticity of being subject to responsibility".^{12:189} The adolescent must continuously develop care towards his health, since he needs to keep his condition stable, as the result of a disease without cure up to the present date, which

leads to living with the virus, to the treatment and to stigmatizing situations permanently.

In the light of the facticity of having HIV/AIDS, the being-adolescent is involved in circumstances of prejudice, discrimination, evaluations regarding their physical appearance, which cause modes of state-of-mind. The modes of state-of-mind are the ways people establish relationships with the world, the different ways of being and feeling human. "The state-of-mind reveals what someone is like and what he becomes".^{12:193} The state-of-mind occurs in the situations of life, in the relationships with people, and in this movement there are situations of life that determine how people feel and are built. It is latent, evoked by the circumstances of the daily living. Adolescents with HIV/AIDS reveal themselves in the modes of state-of-mind, which must be seen as a fundamental existential, and although these phenomena go unnoticed, the dasein will always be in tune with a state-of-mind.¹² The state-of-mind are ways of being of the adolescent, which exist in greater or lower intensity, and this intensity is determined by the meanings of the situations in his life.

The being-adolescent is afraid of other people learning about his disease, and that this revelation may trigger a set of situations in his life, such as prejudice and discrimination. Hence, the fear is instituted in his daily living, given by the facticity of having the virus.

One of the ways of state-of-mind is the fear of "[...] the character of threat".^{12:200} The being-adolescent is threatened by the disclosure of the disease to other people, so only their family know about the diagnosis, since they fear people will change their behavior, reject them, spread the information to others and point to them publicly, leading to them feeling lonely in face of the fact.

The phenomenon of fear may be considered in three perspectives: that in the face of which we fear, fearing and that about which we fear. "That in the face of which we fear, the 'fearsome', is in every case something which we encounter within-the-world"^{12:200} and is simply given. The being-adolescent fears that someone will learn about his disease, and for this reason they take their medication in secret or associate it with other disease.

Fearing is associated with the discrimination, that is, with situations that may be triggered in case the disease is revealed. The fact of fearing opens this being to the context of his dangers, to

the abandonment to himself, and represents the realization of what the disease triggers in his life. Fearing does not involve feelings, but modes of existential states-of-mind.

Therefore, fear is instituted in the daily living of the being-adolescent, hiding their existence, and, often, clouding possible ways of becoming and building in the world, which will affect the maintenance of their health, their development and emotional relationships.

FINAL CONSIDERATIONS

The adolescent lives in the facticity of having the virus or the disease, and reveals himself, in his existence, through relationships in the world and characteristics pertinent to the adolescence, occupied with what is common among adolescents, regardless of his serologic condition. The impersonality of presenting himself like everyone else, rather than like himself, marks the way of being of the being-adolescent's daily living, in which he does not differ from others in order to maintain his co-existence in the public world.

He fears that his disease is going to be disclosed at any time. Thus, he is hunted by the prejudice, which reinforces the silence of the diagnosis. Only the family knows and participates in their therapeutic routine. In the light of this experienced situation, the disease is closed in the primary network, since the being-adolescent fears that, if his disease is revealed, his social cycle and acceptance by the other are going to be modified. Thus, his support network is restricted to the family, which constantly pushes him away from being able to open himself to the world of possibilities, in which he may be able to be himself for a few moments.

Based on this comprehensive look at the therapeutic routine of the being-adolescent with HIV/AIDS, there was the need for nursing care outlined in an attentive approach to the pluralities of the facticity of the adolescence and the serologic condition, but especially to the singularities of the experience of each being. This care may be mediated by the dialogue with the being-adolescent and his family, so as to listen, guide and share strategies and decisions aimed at health promotion, based on his daily living.

By means of this interaction - adolescent, family and health professional - it is possible to make the adolescent the leading figure of his permanent care. There is also the possibility

that, through this establishment of bond(s), the adolescent has the possibility of moving from the impersonal to revealing himself in the singularity of being-himself. Therefore, the purpose is for care to strengthen an existential movement from the unauthenticity to the authenticity of understanding the facticity he has to face, aimed at his possibilities of coming-to-be-in-the-world.

The present study presents limitations of a qualitative study, regarding the location and the period in which it was developed. However, the study purpose was not to generalize results, but to broaden the analysis regarding the theme. News studies are recommended on the theme of adolescents with HIV/AIDS, contemplating other regions of the country. In this sense, it is important to develop studies approaching the experience of the adolescents, subsidized by references that allow an existential look at these subjects.

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