

THERAPEUTIC EVERYDAY OF ADOLESCENT WHO HAS HIV/AIDS: SELF-CARING OCCUPATION AND FAMILY SOLITUDE¹

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ABSTRACT

Phenomenological investigation aimed to comprehend the therapeutic everyday of adolescents who have HIV/aids. After Ethics Committee approval, interviews were developed, from December 2009 to May 2010, with 16 adolescents that have HIV/aids, with ages between 13 and 19 years old, assisted by the health service and that were aware of their diagnosis. The setting is a university hospital in southern Brazil, in three units: pediatric, adult and obstetric ambulatories. The statements, analyzed under heideggerian method, revealed that, on their therapeutic everyday, being-teenager: is determined by the fact of having HIV/aids; being able to take care of one self, taking medication, going to consults, eating well and exercising. Family solitude is on talking about adolescence and helping on treatment. From a comprehensive look, it emerges a nursing care possibility, based on dialogue with adolescent and his/her family, in order to make him/her protagonist on his/her permanent care.

Keywords: Acquired Immunodeficiency Syndrome. Adolescent Health. Family. Pediatric Nursing. Nursing Care.

INTRODUCTION

The form of acquisition of the Human Immunodeficiency Virus (HIV) among adolescents can be divided into two groups. The first group, due to the maternal serological condition, has the HIV infection through the vertical transmission of the virus. The second group was infected through sex or drug use, through horizontal transmission⁽¹⁾.

The first group, who were born with the virus which causes Acquired Immune Deficiency Syndrome (AIDS), and have not died, were children and passed through pre-adolescence. During the transition to adolescence, sometimes they want to be children and to be able to play as before, and in recognizing themselves to be adolescents consider that what is happening is the same as what happens to everybody⁽²⁾.

However, the monitoring of the adolescents who have HIV/AIDS requires specific attention

to their health needs, due to the phase of growth and changes in their metabolism and bodily composition. This monitoring is ongoing and provides information to the professionals for treatment choices, hence they attend outpatient appointments regularly and undergo routine laboratory and clinical tests. Thus, their serological and clinical condition of living with an incurable illness specifies special health needs – associated in particular with dependence on drug technology⁽¹⁻⁷⁾.

Thus, their clinical frailty because of the immunological compromise, their vulnerability to opportunistic infections, the need for ongoing clinical and laboratorial follow-up, compliance with treatment and the adverse effects and therapeutic failures which make up a therapeutic everyday are part of the experiences of the adolescents who have HIV/AIDS.

In this routine, most of the adolescents still need a responsible person to accompany them, as they are still passing through the infantile

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phase – in which there was dependence on family members – to a phase in which the autonomy is partial. This indicates not only the importance of a space for active listening for the family, but also of health actions which take into account the adolescents' creative and innovative potential⁽⁸⁾.

In the face of the complexity surrounding the issue of the adolescent with HIV/AIDS, this study had as its objective: to understand the therapeutic everyday of the adolescent with HIV/AIDS.

METHODOLOGY

This article is an extract from a dissertation written for a Master's degree in Nursing⁽⁹⁾, which was qualitative in nature, with a phenomenological approach and a philosophical theoretical-methodological framework⁽¹⁰⁾. This approach seeks to reveal in the object of the study the how it is in itself – how the therapeutic everyday is, through its meaning – that is, knowledge of a phenomenon, rather than only about it. To this end, the factual knowledge is suspended – what is already known about the facts – in search of an existential comprehension of the phenomenon. In this way, it is possible to view the adolescent with HIV/AIDS in his or her own existential world. This is possible through the intersubjectivity between the researcher and the research subject, in the search for the meanings which the adolescents themselves attribute to their survival, expressed in their own words, based on the world of everyday life, on their baggage of knowledge and their history.

The field research stage was developed and carried out in the Santa Maria University Hospital (HUSM), located in the Center-West region of Rio Grande do Sul in Brazil. This is a center of excellence in medium- and high-complexity care for the macro-region, and specializes in HIV/AIDS. Regarding the attendance in the service, some adolescents who have HIV/AIDS do the monitoring in the pediatric outpatient center, where they have maintained a link with the service's team since childhood. The other adolescents are attended in the adult outpatient center. When the adolescents are pregnant, they are attended in the obstetric outpatient center. This research's field work

stage was carried out in these three outpatient centers in the period December 2009 to May 2010.

The participants, according to the inclusion criteria, were: adolescents in the age range between 13 and 19 years of age, who have HIV/AIDS, who were being monitored in the health service and who were aware of their diagnosis of infection. The exclusion criteria: the adolescent not knowing their diagnosis, as there was a risk of breaking the confidentiality of the diagnosis, which could result in harm to the participants. For selecting the adolescents who could participate in the research, firstly, professionals in the health service were accessed for clarification on the criteria of revelation of the diagnosis. Later, confirmation was sought from the family members/carers responsible for the adolescents. Finally, those who knew about their diagnosis of infection with HIV/AIDS were accessed.

The number of participants was not pre-determined, given that the field work stage, carried out at the same time as the analysis, showed the quantity of interviews necessary to respond to the research's objective, in indicating the sufficiency of the meanings expressed in the adolescents' accounts⁽¹¹⁾. There was a total of 16 participants.

Phenomenological interviews were held for the production of data. This mode of accessing the participants made it possible to take account of the experience of the human being, as presented in his or her experience, through a movement of comprehension. As a way of accessing the being, the interview is developed as a casual meeting, uniquely established between the researcher and each participant. The meeting was mediated by empathy and intersubjectivity, through the reduction of presuppositions⁽¹²⁾. This required of the researcher a positioning of de-centralization of oneself, so as to direct oneself intentionally toward understanding the adolescents.

During the meeting, the researcher needed: to be attent to how the adolescent being interviewed showed herself or himself; to capture what was said and left unsaid; to observe the other forms of discourse: hushes, the gestures, the reticence, and the pauses; and to respect the other's space and time. This position

of open-ness to the other on the part of the researcher made it possible to progressively improve the conducting of the interview, which began with the guiding question: how is your everyday of care for your health? As the interview progressed, the researcher formulated empathetic questions, so as to induce responses, while emphasizing questions expressed by the adolescents themselves, which needed to be extended for better comprehension of the possible meanings indicated. The interviews were wound up with feedback, asking if the adolescent would like to add anything, and thanking them for their willingness to meet up.

The statements were recorded, following consent to this, and the transcription of the interviews followed the original speech, in which the researcher indicated the silences and the bodily expressions observed during the meeting.

The analysis, following the Heideggerian method, was developed and carried out in two methodical periods: comprehensive analysis and interpretive analysis⁽¹⁰⁾. The vague and average comprehension – the first methodical period – involved the suspension of the researcher's presuppositions, in carrying out the attentive listening and reading of the interviews. This was done with a view to comprehending the meaning of the therapeutic everyday of the adolescent with HIV/AIDS, without imposing on him or her any categories which were predetermined by the theoretical or practical knowledge. In the transcriptions, the essential structures were highlighted, forming an analytical framework. From this picture, the units of meaning and the phenomenological discourse were constituted, so as to construct the experienced concept, which is the leitmotif of the hermeneutic – the second methodical moment⁽¹⁰⁾.

The research project, approved by the Ethics Committee under decision 23081.012612/2009-34, complied with the protection of the participants regarding the principles of: voluntariness, anonymity, confidentiality of the information in the research, justice, fairness, reduction of the risks and maximization of the benefits, safeguarding their physical-mental-social integrity from temporary and permanent damage. Due to the adolescents being considered to be a vulnerable group by the

National Research Ethics Commission⁽¹³⁾ (CONEP), it was necessary to ensure Terms of Free and Informed Consent (TFIC) to the legal guardian and a consent document for the adolescent. In the case of adolescents aged 18 or over, emancipated (Declared legally self-responsible by those legally responsible for the adolescent. Translator's note) or pregnant, another TFIC was elaborated. In the results, the participants were identified with the letter A for adolescent, followed by the number 1 to 16.

RESULTS AND DISCUSSION

Two units of meaning (UM) are presented here, which show the experience of the therapeutic everyday of the adolescent who has HIV/AIDS, these being: 1) having to care for oneself because of the virus in the blood; 2) needing to tell somebody, principally the mother, to converse and to help in the treatment. In the first, the adolescent-being's feeling of occupation was revealed, and in the second, the feeling of solicitude from the family.

The occupation of the adolescent-being who has HIV/AIDS, in his or her therapeutic everyday

In the experience of their therapeutic everyday, the adolescent-beings have to care for themselves because of the virus in their blood. So that the disease may not progress, they take medication at the correct time, eat properly, and take exercise. When they are pregnant, they take the medications for the sake of the baby. When they are mothers, they care for their child/children and take them to consultations so that they too can carry out the treatment.

[...] I just have a virus in my blood [...] all that changes is the cocktails. So you have to take everything just so [...] it's sad to know that a disease like this is there [...] I only take it because of him [baby] otherwise I wouldn't take it [...](A1).

[...] I take care of myself, you know, I eat little, I don't overdo it, I take my medication in the morning and at night [...] I take care not to cut myself, so that my disease won't progress [...]

I take the medication, nutrition [...] always taking care of myself, you know [...] ah, I mustn't hurt

myself [...] I take exercise, I stretch sometimes (A2)

[...] I eat properly, I don't eat much junk food [...] I take plenty of exercise [...] I always take care when the medicine is going to run out [...] I take care of my health (A3).

[...] we have to take care not to get ill, I worry, you know, about taking the medications, I take care about what I do, so as not to harm myself [...] I take care, caring for myself, trying so that nothing wrong happens to me [...] (A4).

[...] I take most care over food [...] I take care of myself, with colds, you know, because of this problem which I have with HIV (A8).

[...] taking all my medication, taking care of myself, eating properly [...] medications, it's something I think is great [...] I take care not to catch colds, things like that (A9)

[...] I know that, as I have this illness, I have to take the medication. I take it every day. (A11).

The adolescent-beings reveal that they have a virus, showing themselves in the facticity of AIDS, that is, that one cannot flee from this fact, as it is inherent to the situation of health/illness. What institutes the facticity is the concretization of the situations, the fact in itself, it being everything that one cannot escape, that which we were thrown, all that we experience between birth and dying⁽¹⁰⁾. Thus, AIDS is something in which he is thrown in the world. "The expression thrown-ness must indicate the facticity of being delivered to the responsibility"^(10:189). It is the connotation of imposition of the "being delivered to" which is expressed by the adolescent-being in the face of his or her illness.

Based on the facticity, as a condition of being-in-the-world, the adolescent-being who has HIV/AIDS occupies him-or her-self in his or her therapeutic everyday. The facticity determines the adolescent's occupations in his or her everyday, that which he or she has to do to care for him- or her-self and maintain his or her health. This is expressed by the having to take the medication on his or her own or because of the baby. The adolescent comes to do the things, to occupy him- or her-self with his or her health, and, when a mother, occupy herself in caring for her child/children.

In the everyday, "the everyday occupations of our habits"^(10:154) are known to the adolescents, who always repeat the same things. This involvement with that which has to be done keeps them occupied in a way of dealing with what they are facing. Therefore "their being in relation to the world is essentially occupation"^(10:95). They keep themselves occupied with that which the health professionals and family members say that they must do (go to consultations, do tests, take the medications, take care of their nutrition, undertake physical exercise) and how they must do them (when to go to hospital, the results expected in the tests, getting medication from the pharmacy so they won't run out before the next consultation, and the times specified for taking the medications).

It is understood that, in this way, the adolescent shows him- or her-self to be conformed to his or her therapeutic needs of having to care for him- or her-self, which refers to the circumstance of obligation to undertake the treatment and take the medication.

The facticity makes the adolescent occupy him- or her-self with his/her illness, with the mode of occupation being marked by the ongoing care. In this mode of existing in the world, the talk is present in the discourses. In scientific knowledge, maintaining physical activities and eating healthily are duties inserted in the concept of health and in the standards to have a healthy life. This knowledge is consolidated in the professional discourse. The adolescents infected with HIV through vertical transmission coexist with health professionals from birth. They hear, from an early age, this discourse and repeat it without necessarily understanding.

The talk, which happens in the public coexistence, is a specific concept of excess, superficiality and disengagement with what is said⁽¹⁰⁾, only reproducing what is already given as certain. The adolescent, in the day-to-day, cares for his or her health repeating what was given to him or her as certain, whether by the health professionals or by family members. Thus, the adolescent-being becomes closer to coexistence in the public world⁽¹⁰⁾.

The solicitude of the family in the therapeutic everyday of the adolescent-being who has HIV/AIDS

In his or her therapeutic everyday, the adolescent-being who has HIV/AIDS relies on his or her family members, the mother especially is his or her friend, on whom he or she can rely in difficult times and with whom he or she converses most and who helps him or her in the treatment, talking about boyfriends, sex and that he or she needs to take great care of him- or herself. They still cannot take the medications alone, as they are still adapting. He or she needs somebody to *remind and pay attention in the obtaining of medication so that it won't run out*.

[...] I say to Dad that he has to go get the medications, otherwise it'll run out. He goes and says how long it'll last (A3).

[...] my mother used to ask me from time to time [to take the medications] [...] and when she [mother] isn't home my niece also tells me [to take the medications] [...] so I can't, you know, directly take the medications on my own, without anybody telling me, because I'm still adapting (A5)

[...] my mother helps me too, daily (A7).

[...] an uncle of mine talked with me, got me out of that depression, so, you know,

It seems he relieved me more [the adolescent had experienced prejudice] (A8).

[...] my mother talks with me quite a bit, about this, about boyfriends, about these things, this business of dating, of sex, things like this, Mom tells me to take good care (A12).

[...] my friend is my Mom, who I talk with most, but apart from her I have a friend who I talk with, she's cool, [...] and helps me, but she's not that friend who you can talk to when things are really bad so I talk to my mother in difficult times (eyes filled with tears)(A15).

The discourses show that the adolescent receives help with his or her treatment. The families participate, in some way, in his or her therapeutic everyday, as well as in his or her world of life, in this daily coexistence, as a being-in-the-world.

The family presence is involved in the surrounding world of care with the adolescent. There are possibilities of promoting the well-being of the adolescent who has HIV/AIDS in

showing oneself as being-there-with. The being-there is "an entity in which in each case I am myself; and your being is in each case mine"^(14:27). The singularity of each presence with the other happens in a movement of reciprocal relationship. The being-with means along with some-thing or some-one, in the presence of the other, with characteristics of relating and living. It is the genuine participation in the relationships and in the world. If this mode of being-with were not, human life would have no meaning⁽¹⁴⁾.

Thus, the adolescent who has HIV/AIDS needs the other, which is Being-with, in which, through the open-ness of the co-presence of the others, a genuine relationship with the family may be established, especially with the mother, who helps him or her and who shares his or her therapeutic everyday. In this relationship, significant involvement can occur.

This mode of being-with reveals the mode of being of the solicitude of one to the others. Thus, this relating-oneself with another in an involving manner and with meanings is termed solicitude, which includes ways of coexisting with another, based on perspectives. "The solicitude is a state of being-there, which with its different possibilities is linked with its being to the world of its care, with its being authentic in relation to itself"^(14:41).

The family cares for the adolescent and participates in the care, with possibilities of being in an authentic or inauthentic way. It is understood that, in some way, the family member cares for the adolescent and is shown in worry.

The worry possesses two extreme possibilities: dominating worry and liberating worry. These modes of worry occur through the everyday coexistence and are based upon the modes of being-with the others. The dominating worry is substitutive, it withdraws from the other the care and determines the coexistence. Most of the time it concerns occupation, in which the other may be dependent, even if this dominion is silent. The liberating worry, which does not substitute the other, but which leaps anticipating it, not to withdraw care but to give it back as such. It helps the other to become him- or herself, promoting self-care. It allows the other to

take responsibility for his or her own paths, to grow, mature, to truly find him- or her-self⁽¹⁰⁾.

It is understood that the family, in particular the mother, in some way, participates in the everyday of the adolescent who has HIV/AIDS; whether in that which the illness triggers in his or her life, in the relationship with his or her peers, or in how the family/mother is occupied or worried in caring for and conversing with the adolescent.

The liberating worry can be a mode of being of the family/mother who cares for the adolescent, as it is concerned with providing clarifications such that this last may have the autonomy on the care with his or her health and life. Thus, the family/mother opens possibilities to the adolescent being-him- or her-self even in his or her everyday, discovering more appropriate ways of caring for him- or her-self.

FINAL CONSIDERATIONS

The adolescent lives in the facticity of having the virus or the illness. However, he or she also shows him- or her-self in his or her existing through his or her relationships in the world and his or her doubts to do with adolescence, which goes beyond his or her serological condition.

In his or her therapeutic everyday, the adolescent knows that he or she has to care for him- or her-self, and undergo the treatment to maintain his or her health. With this, he or she minimizes the possibility of the manifestation of the visible symptoms of the illness. It seems

that if he or she does not become ill, there is the possibility that the others will not learn about his or her diagnosis. Occupying oneself seems to be a way of not announcing that one has HIV/AIDS.

The family participates in the adolescent's life, either in the mode of solicitude, which is in the relating in an involving and significant way, or in the occupation, which takes place through the obligation to have to assist the adolescent in his or her treatment. A question of care emerges from the modes of being of the family/mother with the adolescent. However, only a family that cares in some way and participates in the adolescent's everyday can say that this is what care is.

It can be made out that the production of this knowledge can contribute in the intervention practices mediated through actions of care, health promotion, and health education, valorizing the existential questions of the adolescent-being in his or her therapeutic everyday with his or her family. Based on a comprehensive view, the need emerges for nursing care, founded in dialogicity with the adolescent and his or her family. Through this interaction between the adolescent, the family and the health professional, it is possible to make the adolescent the protagonist of his or her ongoing care.

COTIDIANO TERAPÊUTICO DO ADOLESCENTE QUE TEM HIV/AIDS: OCUPAÇÃO EM SE CUIDAR E SOLICITUDE DA FAMÍLIA

RESUMO

Investigação fenomenológica com objetivo de compreender o cotidiano terapêutico do adolescente que tem HIV/aids. Após a aprovação pelo Comitê de Ética, desenvolveu-se a entrevista, no período de dezembro de 2009 a maio de 2010, com 16 adolescentes que têm HIV/aids, faixa etária de 13 a 19 anos, assistidos pelo serviço de saúde e que conheciam os seus diagnósticos. O cenário é um hospital universitário no sul do Brasil, em três unidades: ambulatório pediátrico, adulto e obstétrico. Os depoimentos, analisados pelo método heideggeriano, revelaram que, em seu cotidiano terapêutico, o ser-adolescente: está determinado pela facticidade de ter HIV/aids; se mantém na ocupação uma vez que tem de se cuidar, tomando remédios, indo às consultas, se alimentando bem e fazendo exercícios. A solicitude da família está em conversar sobre a adolescência e ajudar no tratamento. A partir do olhar compreensivo, emerge a possibilidade do cuidado de enfermagem, pautado na dialogicidade com o adolescente e sua família, a fim de torná-lo protagonista de seu cuidado permanente.

Palavras-chave: Síndrome de Imunodeficiência Adquirida. Saúde do Adolescente. Família. Enfermagem Pediátrica. Cuidados de Enfermagem.

COTIDIANO TERAPÉUTICO DEL ADOLESCENTE QUE TIENE VIH/SIDA: OCUPACIÓN EN CUIDARSE Y SOLICITUD DE LA FAMILIA

RESUMEN

Investigación fenomenológica con el objetivo de comprender el cotidiano terapéutico del adolescente que tiene VIH/sida. Tras la aprobación por el Comité de Ética se desarrolló la entrevista, en el período de diciembre de 2009 a mayo de 2010, con 16 adolescentes que tienen VIH/sida, faja etaria de 13 a 19 años, asistidos por el servicio de salud y que conocían sus diagnósticos. El escenario es un hospital universitario en el sur de Brasil, en tres unidades: ambulatorio pediátrico, adulto y obstétrico. Las declaraciones, analizadas por el método heideggeriano, revelaron que, en su cotidiano terapéutico, el ser-adolescente: está determinado por la facticidad de tener VIH/sida; se mantiene en la ocupación una vez que tiene de cuidarse, tomando remedios, yendo a las consultas, alimentándose bien y haciendo ejercicios. La solicitud de la familia está en hablar sobre la adolescencia y ayudar en el tratamiento. A partir de una mirada comprensiva, emerge la posibilidad del cuidado de enfermería pautado en la dialogicidad con el adolescente y su familia, a fin de tornarlo protagonista de su cuidado permanente.

Palabras clave: Síndrome de Inmunodeficiencia Adquirida. Salud del Adolescente. Familia. Enfermería Pediátrica. Cuidados de Enfermería.

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