RESEARCH

EXPERIENCES OF ADOLESCENT WITH HIV/AIDS*

VIVÊNCIAS DO ADOLESCENTE COM HIV/AIDS

VIVÊNCIAS DEL ADOLESCENTE CON VIH/SIDA

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ABSTRACT

This study, featuring a qualitative study, aims to unveil the experience regarding antiretroviral treatment of adolescents with acquired immunodeficiency syndrome. The research was carried out within reference services in two municipalities from the southern region of Brazil. The data production was developed through creativity and sensitiveness dynamics of the talking map by a group of five participants. One applied the technique of content thematic analysis. The experiences regarding the disease, treatment, revelation and health care have emerged from the artistic productions and testimonies. Conclusion shows that the adolescent must acquire autonomy in order to take care of himself/herself. Therefore, it is indispensable to provide care focused on the adolescent and his or her family that mediates the knowledge and understanding of his or her diagnosis and his/her possibilities living with HIV/AIDS.

Keywords: Adolescent´s Health; HIV; Acquired Immunodeficiency Syndrome; Adhesion to Medication.

RESUMO

Neste estudo, caracterizado como uma pesquisa qualitativa, tenciona-se desvelar a vivência em relação ao tratamento antirretroviral do adolescente com síndrome da imunodeficiência adquirida. A pesquisa foi realizada em serviços de referência em dois municípios na região sul do Brasil. A produção dos dados foi desenvolvida com a dinâmica de criatividade e sensibilidade – mapa falante, por um grupo de cinco participantes. Foi aplicada a técnica de análise temática do conteúdo. Das produções artísticas e depoimentos emergiram as vivências acerca da doença, do tratamento, da revelação e do cuidado à saúde. Conclui-se que é necessário que o adolescente adquira autonomia para cuidar de si. Para tanto, é imprescindível um cuidado centrado no adolescente e sua família, que medeie o conhecimento e a compreensão do seu diagnóstico e de suas possibilidades no viver com HIV/AIDS.

Palavras-chave: *Saúde do Adolescente; HIV; Síndrome da Imunodeficiência Adquirida; Adesão à Medicação.*

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RESUMEN

Se desarrolló un estudio, caracterizado como investigación cualitativa, que intenta revelar la experiencia vivida con relación al tratamiento antirretroviral del adolescente con síndrome de inmunodeficiencia adquirida. El estudio se llevó a cabo en servicios de referencia en dos ciudades del sur de Brasil. La producción de datos fue desarrollada a través de la dinámica de creatividad y sensibilidad - mapa hablante, por un grupo de cinco participantes. Se aplicó la técnica de análisis temático de contenido. De las producciones artísticas y testimonios emergieron las experiencias vividas acerca de la enfermedad, del tratamiento, de la revelación y del cuidado de la salud. Se concluye que es necesario que el adolescente adquiera autonomía para cuidar de sí mismo. Por lo tanto, es imprescindible que la atención esté centrada en el adolescente y su familia, que medie el conocimiento y la comprensión de su diagnóstico y de sus posibilidades de vivir con el VIH/SIDA.

Palabras clave*: Salud del Adolescente; VIH; Síndrome de Inmunodeficiencia Adquirida; Adhesión a la Medicación.*

INTRODUCTION

From reports of cases of acquired immunodeficiency syndrome (AIDS) in Brazil and the history of human immunodeficiency virus (HIV) infection, it is possible to make a retrospective analysis of the epidemic growth in the country, which shows modifications in its epidemiological profile. It highlights the tendency of infecting a young population, marked by the distribution of AIDS cases among children and adolescents. In the period between 1980-2011, 12,891 cases have occurred in the 13 to 19 years old age group.[1]

The adolescent with HIV/AIDS assumes an important position in the epidemic context, both from the cases of horizontal and vertical transmission.[2] This chronic disease results in demands for permanent monitoring of health status in a specialized service and continuous use of antiretrovirals.[3] For that, the adherence is essential for health, promoted by professional and family care which would enable the development of autonomy to self care.[4] Adolescents with HIV/AIDS have routines to fulfill for the maintenance of health, therefore, is it urgent that they know their diagnosis and the demands of their particular health need.[5] Some adolescent experiences are inherent to their HIV status, their therapeutic routine – permanent use of medications –, to the frequency of medical appointments and performing routine exams.[6,7]

From this problematic background, a multicenter study was developed in the state of Rio Grande do Sul, in the cities of Porto Alegre and Santa Maria, entitled "Impact of adherence to antiretroviral treatment in children and adolescents, from the perspective of the family, children and adolescent". We opted for these two cities because they are reference centers for the care of sexually transmitted diseases (STDs) and HIV/AIDS of the regional vicinity. The research was developed in two phases – quantitative and qualitative –, aiming to unveil, in the second phase, the living experience of antiretroviral treatment for adolescents with AIDS.

METHODS

The research is a qualitative study, with a field phase developed in services specialized in STD/AIDS in the city of Porto Alegre (POA) and Santa Maria (SM), Rio Grande do Sul state. In POA, the Service of Specialized Care in STDs and AIDS, the Therapeutic Care Service of the Sanatorium Partenon and the Group of Care for Pediatric AIDS of the Pediatric Clinic at the Conceição Children's Hospital were included. In SM, the services included the Service of Pediatric Infectious Diseases of the University Hospital of Santa Maria.

The study participants, five adolescents aged between 11 and 14 years met the inclusion criteria: age ranged between 13 and 19 years, according to the criteria established by the Department of STD/AIDS and Viral Hepatitis of the Health Ministry; diagnosed with AIDS and under retroviral treatment for at least three months. The adolescents were selected from the first step of the same multicenter research developed with a quantitative approach.

For data production, the dynamics of creativity and sensitivity (DCS) were used, based in the Creative and Sensitive Method (MCS), subsidized by the critical and reflexive pedagogy of Freire. The use of DCS started in 1997 with the doctoral dissertation of the nurse and professor Ivone Evangelista Cabral. Since then, this dynamic has become an alternative to nursing research because it values the uniqueness of each member of a group, and the collectivization of experiences. DCS offers a space for collective discussion, in which the lived experience is addressed through an artistic production.[8]

The Creative and Sensitive Method was applied in five moments: in the first, there was presentation of each member of the group, with integration and interaction of the participants and the researcher. In the second moment, materials were made available to perform the dynamics, having as guiding questions the facilities and difficulties in relation to antiretroviral treatment (ART) and what has been used to overcome them. A free styled DCS was developed to create groups of adolescents, in order to reveal their experiences regarding antiretroviral use in their daily lives. In this study, the guiding question to create a debate with the adolescent group was: *how is it for you to take the medication forever, everyday?*

In the third moment, the participants presented their individual or collective artistic productions, socializing about what was produced. The coded guiding themes were negotiated with the participants that in the fourth moment decode them into subtopics for collective analysis and group discussion. Finally, in the fifth moment the thematic synthesis of theme and subthemes and validation of data were held.[8]

Regarding the logistics of the research, the meetings were previously planned, considering the choice of a suitable site and prediction of the materials to be available for the participants. The materials used were identification badges of participants, chairs arranged around a table, a k7 tape recorder, sheets of cardstock, pens and colored pencils and sheets of A4 paper.

Three workshops with duration of approximately 50 minutes to an hour and a half were held, and the DCS was coordinated by one of the researchers responsible for the project and relied upon undergraduate and graduate students in the role of research assistants.

For data analysis, the Content Analysis Technique was used, which consists of discovering clusters of meanings in which the presence of frequency are significant for the analytical objective, covering the phases: pre-analysis; exploration of material; treatment of the results obtained; and interpretation.[9] In the pre-analysis, information was organized into reading form. From the exploration of material, we sought the meanings and gathering of information, emerging themes or categories; and from the composition of an analytical framework, the following categories emerged: perceptions about the disease, treatment, revelation and health care. The last step consisted of the analysis and interpretation of the facets of perceptions of the adolescents, discussed among scientific studies about the theme.

The study was approved by the Ethics in Research Committee (CEP) of the institutions involved: approval protocols 2005446 (CEP/UFRGS), 23081.017341/2006-61 (CEP/UFSM), 001014268.07.8 (CEP/SMS/POA) and 113/08 (CEP/GHC). The ethical issues have complied with the protection of participants in the principles of: voluntariness, anonymity, confidentiality of study information, justice, equity, reduction of risks and increase of benefits, protecting their physical, mental and social integrity from temporary and permanent damages. As the participants are adolescents and considered a vulnerable group, their legal guardians signed an informed consent and the adolescents signed assent consent.

RESULTS

From the testimonies and artistic productions, the experiences about the disease, treatment, revealing and health care emerged. About the disease, the adolescent showed the perception of AIDS from information related to ways of transmission of HIV, viral load tests and CD4.

> *It's difficult to contaminate, but it may happen [...] They said in the TV that we can catch it doing tattoos if we don't have the right things, like the right needle (A1).*

> *We have to draw blood to know if our viral load is good. It has something to do with immunity; if the viral load is low it is okay because our body is protected against diseases, if it is high we get sick easier [...] we can become contaminated if I have a wound on my hand and there is a person bleeding profusely and I go there and try to help and the blood gets in my wound, I can get it (A2).*

> *We have to know if the viral load is high or low to not get sick [...] The viral load needs to be low and the CD4 have to be low [...] My mother said that I can do whatever I want [...] make time, make things balanced, not to do as the others (A3).*

It is observed that different people and circumstances present in the adolescent's life can drive the revealing.

> *I found out from my mother, my father and my brothers (A1).*

> *It was my [adoptive] mother that helped me, she said that I had HIV when I was around six or seven years old. Then I started to take the medication and she always helped me and explained that we had some little bugs in the blood [...] (A2).*

> *After I left the hospital I had an exam and on TV appeared that advertisement of HIV and I asked her what it was and then she said, explained me everything (A3).*

The adolescents know that having HIV/AIDS requires medical treatment and family help along with professional for adherence.

> *I started taking drugs after because my mother said that I didn't want to take it, and then she insisted, insisted and I took (A1).*

> *It was my mother who helped me [...] she always did [...] now only sometimes my mother helps, but it is rare [...] I talk with my mom (A2).*

> *Sometimes my mother remembers me [...] my mother gave it to me and I took it [...] I talk to my mom (A3).*

> *I take it at dawn (the medication); my mother wakes me up (A4).*

The way of taking care of yourself is learned gradually and this can be seen in the possibility, for example, of starting to go

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alone to health care services and demonstrating an understanding toward the disease, its effects in health and demands of care.

> *I go alone (to the exam) take the medication alone [...] I have alarm clock, I have cell phone, I put the alarm clock, and sometimes I leave it in my bedroom [...] I know the name (of medications) [...] I already learned [...] my mother said: DDI, Kaletra, DDI (A1).*

> *I take the medication by myself (A2 and A3).*

> *[...] I know the name, I record it [...] It is bad to have to take so many medications, but you need to (A3).*

However, adolescents who have HIV/AIDS show that their lives is not limited to serological conditions, since in addition to their duties with treatment, they have rights and needs arising from their own process of childhood and pubertal development.

> *You need to take care of yourself [...] we drink no alcohol, like things without alcohol [...] We have to take care of ourselves, because if someone who does not have this disease would take these drugs, they cause some effect [...] my friend felt sick and vomited. I went to sleep and he was awake and took it. And woke up and said he was feeling sick (A1).*

> *Everything has a solution, and every solution has a risk, then you have to try to keep the solution, to take care of yourself as much as possible (A2).*

> *Also, you know, we can't smoke, we can't drink, we can't do drugs (A3).*

The adolescents talk about the importance of play and being a child, respecting the time of each discovery and experience. Beginning to show the interests of sexuality and its possibilities, for example, teenage pregnancy. They realize that many adolescents, nowadays, are becoming parents at an early age and question the behavior of those who they live in relation to their attitudes and sexual experience.

> *Kids have to be kids, they have to have fun, play [...], but there are several children who had a son, I do not know if it is because they wanted to [...] but if someone abused them, I do not know why would they do that (A1).*

> *Within limits, you can do it all, like in my school it is a trend, but [...] well, because at my school the majority of girls between 13 and 14 years old are getting pregnant [...] they have sex without a condom and don't know if it is contaminated or not, if there is HIV or not, they don't think, and, besides that, they will not enjoy their life even though they don't have HIV, because they will lose much of their lives due to having a child (A2).*

Adolescents express an understanding of possibilities and experiences of sexuality that relies on cognitive and emotional development, and also on open dialogue in the family, school, among peers, with professionals in the health care service and the media.

> *If the girlfriend had the disease as well, the disease could get more complicated, and never get better, and we would have to do a surgery to deliver a child and not get the disease. If the girl has it, she passed to a boy and if the boy has, he will pass to the girl (A1).*

> *HIV is not a disease that heals if you touch it, it is a disease that you have to take care, when you have a girlfriend you have to use protection, protect you life and her life [...] using condoms to prevent the disease to be transmitted [...] but besides that you can have friends, like normal people (A2).*

DISCUSSION

In the reports of adolescents with HIV/AIDS, the ways of transmission of the infection are well noted. And without announcing their serological condition, they reproduce the media discourse about the ways of transmission, in which prevention is seen as responsibility of the other and does not show the prevention of a person already infected.[2]

In this sense, it appears that the interpretation of the disease comes from the terminology used by health professionals. It seems clear that the reproduction of the expressions viral load and CD4 comes from the professional discourse, considering that they are not everyday teenage words.

It is necessary that health professionals broaden their approach beyond clinical aspects and pay attention to the specific demands of adolescence in relation to treatment adherence. However, it is essential that everyone is involved for greatest extent of compliance.[10] The service needs to be constructed from a therapeutic alliance between health professional and adolescent, through individualized listening, respecting the responsibility of each one in this process and of everyone who may be involved in the treatment. Counseling during the service includes explanations about the exams CD4 and viral load, but also must stimulate questions and concerns regarding treatment.[11]

It also has the understanding of possibilities, limitations and consequences of living with the virus. The adolescents reveal the ambivalence generated by the medication daily routine and the difference compared to other adolescents who do not experience this situation. They can do everything that other adolescents do, but they need a regimented routine with limitations caused by the treatment.

Schemes and drug dosages required by everyday medication may hinder the adolescent routine, because, besides the quantity of medications and their side effects, there is also a need for time availability.[6] It is observed that the situations of controlling schedules and attitudes demonstrate that treatment appears as a limit to the experience of adolescence. The aspects related to autonomy are fundamental and treatment adherence is not limited to the imposition of clinical aspects of the disease and treatment. Suitable adherence processes provide the adolescent the possibility of coping, from the perspective of comprehension of reality, encouraging choices and decision-making before their HIV seropositivity.[5,12]

For that, the importance of the adolescents know their diagnosis aiming take care of their health status is highlighted. Thus, the process of revealing involves the family or caregivers and the health professionals, considering the adolescent and his/her particularities.

Disclosure of the diagnosis, as can be noticed in the statements, occurred by the adoptive family, by the biological mother and also was driven by the media. In relation to the adoptive parents, it can be noticed that these caregivers were more likely to face difficulties related to living with HIV and AIDS and were more capable in the revealing process, because, in this case, the revelation of adoption itself had occurred before the disclosure of the diagnosis. Accordingly, it can be more easy to deal with question related to stigma and prejudice, because this caregivers did not directly experienced this situation due to having an adopted child.[11]

The situation of the mother also living with HIV/AIDS can make the process of revealing more complicated, time consuming and painful, due to the possibility of a feeling of responsibility and guilt related to vertical transmission of HIV. This process can be experienced by the mother as a double revelation: of her own diagnosis and of the child or adolescent; and expose issues related to family history.[13]

One of the difficulties that can be faced by caregivers and families before and after revelation is the possibility that the revealing process of the infection to a child or adolescent may involve other delicate or stigmatized aspects in the family or in its own history. It can be cited as examples the loss of a family member motivated by AIDS, the severity of the child's illness and fear of the impact of disclosure in the child development.[5,13,14]

Also, it is noteworthy that revelation may be often pushed by the media, in which campaigns to prevent HIV/AIDS are present in both the health services where the adolescent do the treatments, as in the communication channels.

Therefore, it may be illusory to judge that a school-age child or an adolescent will not associate such advertisement to the situation experienced in their treatment, despite the pact of silence between caregivers, health professionals, children and adolescents in relation to HIV and AIDS.

The discovery by comparing demands even more intense care, listening and observation, by family members and health professionals, so that the truth can be shared in trust interactions and well-reasoned explanations, contributing to keep the treatment satisfying.

Especially due to dependence of drug technology[15], AIDS involves the adolescent in a network of professional and family care.

During childhood, the subject demands integral family care; in preadolescence or adolescence, the subject starts to take care of himself/herself from having responsibilities and having help from health professionals and family members. Thus, they live the process of learning and achieving autonomy of care.

This daily care consists of actions directed to health of adolescents and actions of the own teen for care of self and of the other arising from the family. The concern and attention of the family are expressed in attitudes of care from childhood, regardless of HIV status. Children are biologically and socially vulnerable, and therefore, dependent upon family care, which is enhanced in the presence of a disease. With regard to children being infected by vertical transmission of HIV, the care add to those specific to clinical fragility.[16]

Among family members, especially the mothers assume that care.[17] The social role of women is culturally defined since childhood as looking after the home and family; this care appears as support and it is centered on a female figure, whether mother, grandmother, aunt or another woman who may assume this role.

Facing AIDS, the family care alerts, especially, to the demands of treatment and occurs by the daily incentive to treatment and help in managing the schedules of medications, replacing the charges that afflict them by productive stimulus that strengthens.[4]

In this sense, the importance of dialogue in the care relation between family and adolescent is emphasized. In adolescence, family and health professionals realize the need to reveal the diagnosis, both by the start of sexuality, as the adherence to treatment is necessary. They need to talk openly, so that the adolescent can undertake their care consciously, with the knowledge and tools necessary to protect their health and that of others.[17] The adolescent must learn how to take care of himself/herself, and assume responsibility of their health needs and discover strategies to maintain treatment given the difficulties they experience in everyday life.

The development of autonomy for care should be consistent with the psycho cognitive social development of each adolescent. Each person has their own way and time to develop abilities to reflect, understand and assume their own possibilities and limitations. Thus, the adolescent needs to know the diagnosis from a process of revelation shared among family members and health professionals, who provide monitoring, support and help in the process of reflection, understanding the serological status, expressing their feelings and assuming a position before others and yourself[5,13], committing to hospital monitoring, exams, taking medications, eating and exercising to control their immunity.[4]

The reports of adolescents living with HIV/AIDS expressing the understanding of care that they need to have, due to their serological condition and, specifically, to the antiretroviral therapy (ART). They learn this information with family/caregivers and health professionals, and reproduce them in their speech. Regarding the care to others, the adolescents say that, besides taking care of their own health, they must be concerned with the health of people to whom they relate daily. They express that in relation to friends who visit their homes and do not have the habit of taking medications and get curious about the treatment.

It is essential that adolescents perceive the importance of taking care of their health so they do not perform it just because family and health professionals prompt it, but understand why they need to take care and be able to choose how to develop the care that best suits their routine[11,12], because the care is not restricted to the demands of HIV status, but extends to more health care and care for others.

In the development of care actions it is necessary to understand that adolescents need to be careful in their uniqueness and professionals should not limit it to children or dismiss it as "adolescence". It is needed to respect the singular time with strategies such as games during the introduction. Considering the moment of adolescence, it can be organized with meeting spaces with peers who share experiences of what they have in common and different, and build ways of coping with difficulties of adolescence and getting sick.[18]

In this phase of adolescence, they have access to understanding sexual and reproductive rights and duties, that despite being universal, they have specificities because of their positive HIV status. This is evident in the care needs of themselves to prevent reinfection and care to others to prevent transmission of the virus.[11] Adolescents express understanding of different ways of HIV transmission, comprehend that they can transmit it through unprotected sexual intercourse and by vertical transmission. This knowledge comes from dialogue with different actors and it is recommended that an open discussion of the care with itself and others be done. Thus, prevention is addressed in how the sexual life happens, and is not considered a problem.

Attention should be paid to reproductive rights, which adolescents that have HIV/AIDS need to be aware and should have guaranteed access by public policies, by health services and education, and by their own family, community in which they are inserted and the society in general. [11]

FINAL CONSIDERATIONS

It is observed that the adolescent, somehow, knows the disease and its treatment, but there is a reproduction of professional speech, which can keep him or her stuck in a superficial understanding of his/her situation. The adolescent knows that he/she needs to take care of himself/herself, and demonstrates responsibility in maintain his/her health. And, among the difficulties of accomplishing treatment are the prescribed times and adverse effects. The family member/caregiver is essential in this context, helping in the treatment and chatting with the adolescent. However, the adolescent indicates his or her autonomy in the care of his or her health.

It is considered that adherence to treatment is fundamental for the health of adolescents, but it is necessary that the adolescent acquires autonomy and for this process to happen it is essential to share knowledge and comprehension of their diagnosis. These issues are intrinsic to the process of revealing the diagnosis and psychosocial aspects involved in living with HIV /AIDS.

The importance of interdisciplinary monitoring in this population is noted, developing a care focused in the adolescent and his or her family, in order to encourage the occupation of a social space to fight for their rights as citizens and provide tools that support the development of a sense of individual empowerment, aiming toward autonomous self care.

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