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Ethics in research on adolescents living with HIV/AIDS

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Abstract

The article have sought to portray the experience of ensuring observance of the ethical aspects involved in data gathering with adolescents living with HIV/Aids. Data gathering in two studies is reported: one , using a quantitative approach with a cross-sectional design, with 23 adolescents, and another with a qualitative focus, with 8 adolescents. For both, the criteria for participation included current use of anti-retroviral therapy, awareness of their diagnosis, and being subject to outpatient monitoring at a specialized care service. Guaranteeing the ethical principles – autonomy, doing no harm, beneficence and justice involved: how to approach the adolescents to invite them to participate in the survey, the adolescents' fears regarding the research, the protection of family members and caregivers, the revelation of the diagnosis to the adolescent and to third parts, and confidentiality. The report of our experience aims to contribute to the discussion of issues involving the guarantee of ethical aspects in research.

Keywords: Acquired Immunodeficiency Syndrome. HIV. Adolescent health. Research ethics. Nursing.

Resumo

Ética na pesquisa com adolescentes que vivem com HIV/Aids

Com o presente trabalho, objetivou-se relatar a experiência de garantir os aspectos éticos envolvidos na etapa de coleta de dados com adolescentes que vivem com HIV/aids. Trata-se de relato de coleta de dados de duas pesquisas: uma, de abordagem quantitativa e delineamento transversal, com 23 adolescentes, e outra, de enfoque qualitativo, com 8 adolescentes. Para ambas, os critérios de participação dos adolescentes incluíram: estar em uso de terapia antirretroviral, ter conhecimento de seu diagnóstico e manter seguimento ambulatorial em serviço especializado. A garantia dos principios éticos – autonomia, não maleficência, beneficência e justiça – envolveram: a forma de abordagem para participar da pesquisa, os receios dos adolescentes quanto à pesquisa, a proteção dos familiares/cuidadores, a revelação do diagnóstico ao adolescente e a terceiros e o sigilo. O relato da experiência pretende contribuir para a discussão acerca das questões que envolvem a garantia dos aspectos éticos nas pesquisas.

Palavras-chave: Síndrome da imunodeficiência adquirida. HIV. Saúde do adolescente. Ética em pesquisa. Enfermagem.

Resumen

Ética en la investigación con adolescentes que viven con el VIH/SIDA

El presente trabajo tiene como objetivo informar la experiencia de garantizar los aspectos éticos involucrados en la etapa de recolección de datos de los adolescentes que viven con el VIH/SIDA. Esto es un relato de la recolección de datos de dos investigaciones; una de un enfoque cuantitativo y diseño cruzado con 23 adolescentes y otra de enfoque cualitativo con 8 adolescentes. Para ambas, los criterios de participación de los adolescentes incluyen: estar en uso de la terapia anti-retroviral, saber sobre su diagnóstico y estar bajo tratamiento de servicio especializado. La garantía de principios éticos – autonomía, no maleficencia, beneficencia y justicia involucró: la forma de abordaje para participar en la investigación, temores de los adolescentes con respecto a la investigación, protección de los miembros familiares y cuidadores, la revelación del diagnóstico al adolescente y a terceras partes, y sigilo. El estudio pretende contribuir a la discusión de cuestiones relacionadas con la garantía de aspectos éticos en la investigación.

Palabras-clave: Síndrome de Inmunodeficiencia Adquirida. VIH. Salud de los adolescentes. Ética de la investigación. Enfermería.

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Research article

Among adolescents, infection with human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS), are consequences of the vulnerability of these individuals to the conditions they are exposed to [1]. Vulnerability is defined as the chance of exposure of people to illness resulting from a number of aspects immediately associated with the individual and their relationship with the collective [2]. Therefore, this vulnerability can be classified in three planes: individual, social and program.

Individual vulnerability refers to limited knowledge of people, to beliefs and to risk perception by the individual. Social vulnerability depends on access to information, on the social context in which the person lives and coherence between knowledge and practice. Program vulnerability refers to access to services and programs of HIV/AIDS prevention and health promotion [2].

Regarding epidemiological aspects, HIV infection reveals the tendency towards juvenile epidemics, justified by the early start of sexual activity, by the need for acceptance within social groups, by the consumption of alcohol and other drugs, in addition to the issue of gender. Regarding social aspects, it is noted that the culpability of the individual because of the infection and the social stigma assigned to the disease are also remarkable. As to political aspects, programs oriented to the guarantee of infection and/or reinfection prevention and promotion of health of this population are highlighted [3].

In Brazil, from 1980 to 2013, the reported AIDS cases among adolescents reached a figure of 15,480. Only in 2012, there were 923 cases, both in the vertical transmission category (mother to child infection during pregnancy, childbirth and/or breastfeeding) and horizontal transmission (sexual activity without condom, use of injectable drugs and/or blood transfusion) [4]. Over the past decade, there has been a downward trend in the proportion of vertical transmission cases in children under 5 years, as in 2003, this age group accounted for 63.8% of the identified cases and in 2012, to 41.8%. In contrast, in this same period, an upward trend is noted in the proportion of vertical transmission cases in youths aged fourteen (2.9%) or older (41.5%) [4].

HIV infection implies routine care involving daily medication, permanent care for clinical evaluation, as well as social repercussions [5]. Antiretroviral therapy (ART) aims to restore immunity in order to reduce morbidity and mortality, improving the quality of life of infected people [6]. Therefore, commitment to treatment is necessary, which depends on several factors, from the availability of access to medication and clinical exams to the type of daily routine of the individual, which makes it a dynamic and multifactorial process [7].

It is essential to understand the importance of commitment to treatment, but not even such understanding ensures compliance with this purpose. In addition to the difficulties identified before, the superficial understanding can also lead patients to failure and treatment abandonment [8]. In adolescence, commitment becomes even more complex, as it is necessary to invest in the understanding that adolescents have of their HIV status, as well as the importance of continuing clinical and therapeutic evaluations for the maintenance of their health status. In this sense, both the health team and the adolescent and their family should find care strategies that minimize the intake difficulties found in the use of daily medication [9].

Aiming to provide support in order to intensify strategies for this perspective, a study in two collection stages was developed – one of quantitative approach and a qualitative one - with adolescents aged 13 to 19 years treated at a specialized service center for people living with HIV/AIDS in the central-west region of Rio Grande do Sul state. The study directly conducted with adolescents, involved issues about: 1) daily medication use, such as facilities and difficulties and non-adherence to therapy factors; 2) the clinical aspects, such as monitoring and evaluation of infection; 3) the social aspects, such as diagnostic information at school and at work, the use of alcohol or drugs and sexual practices [10-12].

As it could not be in a study of people in this age group, the study encountered ethical aspects related to the participation of adolescents in research, involving information about their diagnosis, often hidden in the family, and issues related to sexuality and knowledge of a disease that remains, even today, stigmatized [11]. Ensuring the ethical aspects is of utmost importance in the study, because they will be the ones who will protect and ensure the confidentiality and secrecy of information provided by the participant. In this sense, it should be noted that the study literally followed the provisions of Resolution 466/2012 of the National Health Council [13], which excels in the defense of human dignity and the special protection due to the participants of scientific research involving human beings, expressed through the fundamental principles of autonomy, beneficence, non-maleficence and justice (or equity).

The application of the study allowed finding, therefore, how fundamental it is to reflect on the ethical aspects in studies with adolescents, main-

ly about methodological issues, because of the biopsychosocial vulnerability of these individuals. Thus, this article aims at reporting the experience of ensuring the ethical aspects involved in the data collection stage performed with adolescents living with HIV/AIDS, so as to contribute to the ethical regulation in research with human beings [14].

Method

This is a report of the experience of data collection stages from a matrix research project entitled "Adolescentes HIV/aids: demandas da sua necessidade especial de saúde" (Adolescents and HIV/AIDS: demands of their special health needs), included in the Healthcare to People, Families and Society Study Group. The project was approved by the Research Ethics Committee (*Comitê de Ética em Pesquisa* – CEP) of the Federal University of Santa Maria (*Universidade Federal de Santa Maria* - UFSM) in July 2009 and respected the ethical aspects of CNS Resolution 196/1996, in effect at the time.

The research setting was the Children's Infectious Diseases Clinic of the University Hospital of Santa Maria (*Hospital Universitário de Santa Maria* - Husm). The Husm is a specialized service center providing care to children, adolescents, adults and pregnant women with HIV/AIDS, located in the central-west region of the state of Rio Grande do Sul, Brazil. The study population consisted of adolescents living with HIV/AIDS registered in the clinic's appointment system.

The inclusion criteria were: 1) adolescents living with HIV/AIDS in the age group of 13-19 years, 11 months and 29 days, according to age criteria established by the National Department of STD/AIDS of Brazil [4]; 2) who were diagnosed with the virus; 3) who are on antiretroviral therapy (ART) for at least three months, due to the body's response to medication, which could influence the results with regard to adherence to ART; 4) who are outpatients. The exclusion criteria were: 1) adolescents with cognitive and/or mental limitations that made verbal expression difficult to respond to the interview; 2) who have not had access to diagnosis, given the difficult disclosure process in this context. It is worth highlighting that respect for the disclosure process is an ethical responsibility of the study. Thus, the responsible parties, when approached with the purpose of authorizing the participation of the adolescent in the studies, were questioned about the disclosure of the adolescent's diagnosis.

The quantitative stage aimed at knowing the profile and identifying the factors associated with non-adherence to ART. It is a cross-sectional design study. A total of 23 adolescents took part in the study. Data collection occurred between September 2011 and March 2012, by means of structured interviews, with the use of validated form [15] which included: questions about demographic, social, clinical, pharmacological and behavioral data of the participants and folder containing illustrations of antiretroviral (ARV) drugs for adolescents to identify what they are and how to use them [10, 11]. Collection was on Tuesdays and Thursdays, days of consultations of adolescents with HIV/AIDS, and the meeting took place individually, in a private room. For the analysis, the optimal adherence to antiretroviral therapy was defined as the intake of 100% of the prescribed dose for a 72-hour period, which includes the regular use of ARV for the purpose of suppressing viral load, reducing the possibility of appearance of new resistant viral strains, a factor that affects prognosis [16].

The qualitative stage, which did not depend on the quantitative stage, aimed at describing the daily routine of adolescents infected by HIV under treatment. Data collection was developed from January to June 2012, in two group meetings, each with four participants, totaling eight adolescents. The dynamics of creativity and sensitivity (DCS) was performed entitled Speaker Map (*Mapa Falante*), in which each participant drew their therapeutic itinerary [12]. The DCS proposes a collective discussion space where the experience lived is addressed through artistic production (AP) [17]. The implementation of the DCS was subdivided into five moments: 1) presentation of the group, in which pairs were formed, and after five minutes of talk, each partner of the pair introduced the other; 2) presentation of the DCS objectives and the guiding question of the AP: "How is it to take medication forever, everyday, the whole day?"; 3) preparation of the AP itself, in which every adolescent made their drawing to answer the question; 4) presentation of the AP by each adolescent and development of the discussion; 5) synthesis and collective validation of the results [12].

The research process that gave rise to this report complied with the provisions of CNS Resolution 466/2012.

Results and discussion

CNS Resolution 466/2012, which superseded CNS 196/96, ensures that any study involving human

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beings should always respect dignity, freedom and autonomy of the participants, in addition to ensuring the rights and duties of the scientific community and the public power. The resolution incorporates, by the individual's view and collectivities, the principles of the principialist theory: *autonomy, non-maleficence, beneficence and justice* [13].

The principle of autonomy is based on the notion of dignity of the human person. Autonomy is the ability of a person to decide doing or seeking that which they consider it is best for themselves [13,18]. Respecting the principle of autonomy means being aware of the points of view, opinions, values, convictions and choices of other people, and having the freedom to agree with them or not. In the two studies with adolescents living with HIV/AIDS, this principle was safeguarded because it is about people who have the ability to think and act in their personal and social life [19].

For compliance with this principle in the performance of data collection of the studies, first, there was a reflection as to the approach that would be performed with the adolescents to be included, and the choice was to do it at the service where they would go for clinical consultations. The process was developed in two moments. In the first, a conversation was held with the person responsible for the adolescent, explaining the study objectives. In case of adolescents that met the inclusion criteria, authorization by their legal representative was requested for participation in the study.

In the second moment, the study objective was explained to the adolescent and the confidentiality of information, and only then they were invited to participate. The signature of the informed consent form (ICF) was obtained from the legal representatives of participants under the age of 18 years, and the assent form was signed by the minor itself. Participants over the age of 18 years signed their ICF. These documents were submitted in two counterparts, of equal content, one being kept by the study participant and other filed by the researcher.

The assent form is a document especially prepared for minors or for legally incapacitated persons. Thereby, participants express their acceptance to take part in the study after being duly informed, without prejudice to the consent of their legal representatives. Therefore, although adolescents under the age of 18 years can only be included in the study upon consent of their legal representatives, they are entitled to information about the study, transmitted in a suitable manner and in accessible language for their age, as well as the right to refuse participating is ensured [13].

In this perspective, the researcher shall inform participants about the nature of the study, its length, its purpose, the methods through which it will be conducted, inconveniences, expected risks and effects that may occur [20]. Participants should have freedom of choice, without any intervention of forced, fraud, lie, coercion, slyness or restriction elements [20, 21].

The theories of moral and cognitive development strengthen bioethical discussions and constitute the theoretical support for the construction of guidelines related to the autonomy of adolescents. While focusing on adolescents with HIV as study subjects, it is necessary to consider that they are living in a period of growth and development in which situations of vulnerability permeate their daily lives. In this sense, it is pertinent to advocate the participation in ethically conducted research, because it brings fewer risks than their daily living [22].

The principle of non-maleficence refers to the researcher's duty to intentionally do no harm and/or damage to research participants [13,18]. For its guarantee, it was avoided, in the development of this study, that foreseeable damages were committed, and it was intended to ensure the confidentiality and privacy, image protection and non-stigmatization of the disease. Thus, a data confidentiality, privacy and security agreement was executed, which both studies were committed to.

The quantitative stage used a validated instrument [23], which ensured credibility and security in the collection of information. Whereas in the qualitative stage, in which the dynamics of creativity and sensitivity was used, it allowed researchers to learn how to coordinate dynamics and encourage the making of artistic production by the participants. Both studies allowed the creation of a quantitative and qualitative database, which are kept in the study group's room, for five years, under the custody of the teacher in charge. Both may serve as basis for further studies.

However, in the development of the quantitative stage, adolescents demonstrated shyness when questioned about the behavioral, sexual aspects and knowledge of the disease, because they were afraid of having their answers disclosed to their legal representatives. Hence, participants were informed about the secrecy and confidentiality that the study would keep as to collected information. In the qualitative study, it was noted the difficult expression of adolescents about their experiences with the infection, because it is often hidden in their family and social relations, due to stigmatization they may be

victim of. The fear of speaking about the disease manifests itself in the non-disclosure of the infection with the purpose of hiding it from people who do not belong to their social circle. This aspect further reinforces the need for confidentiality, which every study participant is entitled to. However, this difficult expression was overcome upon support of the health service team and of the pairs in the group dynamics. There being confidentiality and respect between adolescent and researcher, crucial subjects may arise, for many studies. Confidentiality is one of the basic pillars for the construction of a therapeutic or research relationship with anyone, especially with adolescents [22].

It is worth mentioning that some legal representatives, when approached to authorize the participation of adolescents in the studies, reported that the diagnosis had not been disclosed to the adolescent yet, a fact that prevented the inclusion of seven adolescents in the study. Hence, it is necessary to remember that ethics in research has the strict commitment to protect the adolescent who did not have their diagnosis disclosed. Therefore, the study will not disclose the diagnosis. Confidentiality and privacy between researcher and participant are ensured by the *Code of Ethics for Nurses* [24] and by the *Child and Adolescent Statute* [25]. It is also worth mentioning that non-disclosure of the diagnosis is associated with fear of social stigma, resulting in postponed dialogue between legal representatives and adolescents [26].

In this sense, disclosure carried out in a suitable and planned manner, as a gradual and continuous process, may favor adaptation and development of autonomy to face the health condition. Therefore, all adolescents infected by HIV have the right to know their diagnosis, regardless of means of transmission. Investments are necessary for the improvement of and expanded access to sexual and reproduction health services for adolescents, aimed at HIV diagnosis and treatment, as well as the provision of contraceptive information and prevention inputs [27].

However, vertical transmission infection may sometimes deprive them of the diagnosis disclosure, because of overprotection, reluctance of and/or unprepared family and/or health team. In addition to the difficulty in disclosing the diagnosis, there is also the fear of sharing this information with other people [28]. Non-disclosure of HIV diagnosis may give rise to delayed physical and emotional development of the adolescent, generating, for example, a childish behavior [29].

Thus, the concern of the legal representative to protect the adolescent with HIV from possible damages may result in omission and exclusion from studies that have the potential to bring benefits to them. The principle of beneficence obliges the researcher to go beyond non-maleficence, demanding that it contributes for the wellbeing of participants by means of preventive actions and removal of evil or damage, as well as by the practice of goodness, understood as physical, emotional and mental health [18].

To guarantee this principle, during data collections performed at the clinic, it was sought to approach these people in a careful and attentive manner, avoiding the disclosure of diagnosis to third parties and aiming to not cause discomfort to adolescents, in order to allow their voluntary participation in the study. Despite the difficulties of moral, ethical and legal nature to conduct scientific studies with adolescents, they are necessary for the construction of knowledge aimed at promoting the reduction of vulnerabilities, as well as health prevention and education for this population [22].

The weighing of risks and benefits is essential, because the researcher should commit itself with maximum benefits and minimum damage and/or risks to participants [13]. It is worth noting that some legal representatives demonstrated concern as to the diagnosis disclosure to people other than the health team and family members. Such attitude is based on the ethics of care and their rights, because their desire is that there is no labeling arising from the disease and that the treatment is not carried out differently because of HIV infection [29].

Secrecy as to diagnosis consists of an essential ethical issue in healthcare, mainly in research. Secrecy is related to the pursuit of non-exposure of the adolescent, *i.e.*, preservation of their image and their opinions, because it is a crucial factor for their wellbeing and better quality of life. Thus, meetings with the adolescent's legal representative and, further, with the adolescent occurred individually, in a private room at the health service center.

Therefore, the understanding that the individual has related to the right to decide on the diagnosis disclosure is essential. Hence, the different ethical, social, moral and legal aspects that involve the disclosure should be considered. However, the information provided to the researcher can only be shared with the staff and family when the participant consents or is at risk [30]. Therefore, it is worth mentioning the organization of the research group, which has infrastructure and technical support with

previous experience in the collection of quantitative data and production of qualitative data, which provides the qualification of the developed actions. It is also worth mentioning that, before the start of each data collection, researchers were trained with the purpose of minimizing possible biases.

The principle of justice contemplates equity, based on the affirmation that all people are entitled to a fair, appropriate and equitable treatment, because of something that is deserved by or due to them. That includes guarantees of equal rights, equity in the distribution of assets, risks and benefits, respect for individual differences and the search for alternatives to meet them, freedom of expression and fair consideration of the interests involved [13,18]. According to this principle, a study must have social relevance, with significant advantages for participants and minimized burden on the most vulnerable, ensuring equitable consideration of the interests involved and their socio-humanitarian purpose [31]. Thus, for the intrinsic vulnerability to the disease as well as the understanding ability of the adolescent not become obstacles to the research, the ethical aspects must be respected [7].

The principle of justice was ensured in the study, because both stages, quantitative and qualitative, provided indirect benefit to participants, as the final study report returned to the assistance service and, thus, contributed for improved attention to their health. In addition, the study concern was to not cause any kind of restriction nor prejudice in anyway, the participants.

In the quantitative stage, the study was conducted with the total population of adolescents under assistance; *i.e.*, everyone who met the inclusion criteria took part in the study. In the qualitative study, the population that was present on the day available for the study was approached, however, it was noted the difficulty to contact and gather the adolescents that met the inclusion criteria on the same day of assistance at the health service center, given the absenteeism of adolescents, the appointment schedule and the interruption of the study because of the service center's activities. Thus, the difficulties were overcome with the support of the health service team and availability of adolescents to participate in the study.

The concept of justice establishes the need to equitably disclose to the involved parties and society, the benefits arising from the studies. In addition, the ethical principles provide for the non-deprivation of the participation of adolescents in studies and, hence, their possible direct and indirect benefits . Act 8.069/1990 (*Child and Adolescent Statute*) should be complied with, especially the fundamental rights, namely: right to life, right to health, as well as rights to freedom, respect and dignity [25].

Both in healthcare and in the development of academic research, the application of the four bioethical principles *per se*, is not sufficient to ensure respect for individual rights [32]. It is necessary that health professionals reflect on the healthcare they develop, in order to avoid inequalities, promote humanized attention, stimulate institutional and public health ethics, in addition to providing effective protection of the rights of adolescents with HIV/AIDS.

Final considerations

The experience report of the ethical issues involved in the data collection performed with adolescents living with HIV/AIDS aims to highlight the importance of the guarantee of ethical principles (autonomy, non-maleficence, beneficence and justice) in studies with human beings. Therefore, it is crucial to identify and understand the specific demands to the health condition of participants, in order to improve the study guidelines with adolescents and provide guidance for the resolution of ethical issues with which researchers are faced during data collection with this particular population.

The study focused on adolescents that live with a disease that is often hidden in their family and social relations, because of possible stigma, that tends to lead to their suffering, which, on its turn, results in silence. The feeling of shame, associated with social discrimination is often internalized as part of the identity. Due to such situation, the need to effectively promote policies to fight the AIDS epidemics in Brazil is urgent, both in prevention of the infection transmission and in the improvement of the life quality of these populations. While incorporating the social issues of adolescents with HIV to the academic bioethical discussion, it is aimed to also contribute to an attitude of ethical responsibility and competence in healthcare, in order to respect human rights. This further reinforces the need for confidentiality, which every study participant is entitled to.

Under this perspective, it is aimed to stimulate the debate on ethical issues in studies involving adolescents, in addition to contributing to the dissemination of studies that include them in research, with the purpose of giving visibility to

this population. Thus, more data collection reports with adolescents are indicated, in order to identify aspects of this process to be improved. Therefore, the purpose is to ensure quality control, respect for the people involved and knowledge of ethical issues that should be considered for a study design.

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Participation of the authors

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