



HIV AND NURSING: DISCUSSION ABOUT THE PATIENT'S RIGHTS
O HIV E A ENFERMAGEM: DISCUSSÃO ACERCA DOS DIREITOS DO PACIENTE
EL VIH Y LA ENFERMERÍA: DISCUSIÓN ACERCA DE LOS DERECHOS DEL PACIENTE

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ABSTRACT

Objective: to analyze the knowledge of carriers of the Human Immunodeficiency Virus and their family members in relation to their rights. **Method:** it is a descriptive and exploratory study with a qualitative approach. The study subjects will be patients with the Acquired Immunodeficiency Virus and their family members enrolled in the STD/AIDS Control Program from a health center in the city of Rio das Ostras/RJ, Brazil. The data will be collected in 2013, through interviews with a semi-structured script and submitted to the categorization process. The research project was approved by the Research Ethics Committee, under CAAE n° 12760313.4.0000.5243. **Expected results:** it is believed that family members and bearers of HIV have unsatisfactory knowledge about their rights, thereby lacking guidance on the issue at stake. **Descriptors:** Acquired Immunodeficiency Syndrome; Patient's Rights; Knowledge.

RESUMO

Objetivo: analisar o conhecimento de portadores do Vírus da Imunodeficiência Adquirida e seus familiares em relação aos seus direitos. **Método:** estudo descritivo e exploratório com abordagem qualitativa. Os sujeitos serão pacientes portadores do Vírus da Imunodeficiência Adquirida e seus familiares, cadastrados no Programa de DST/AIDS de um centro de saúde em Rio das Ostras/RJ, Brasil. Os dados serão coletados em 2013, por meio de entrevistas com roteiro semiestruturado e submetidos ao processo de categorização. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE n° 12760313.4.0000.5243. **Resultados esperados:** acredita-se que, os familiares e portadores do HIV possuem conhecimento insatisfatório acerca dos seus direitos, carecendo de orientações sobre o assunto em questão. **Descritores:** Síndrome de Imunodeficiência Adquirida; Direitos do Paciente; Conhecimento.

RESUMEN

Objetivo: analizar el conocimiento de portadores del Virus de la Inmunodeficiencia Adquirida y sus familiares en relación a sus derechos. **Método:** estudio descriptivo y exploratorio con abordaje cualitativo. Los sujetos serán pacientes portadores del Virus de la Inmunodeficiencia Adquirida y sus familiares, inscriptos en el Programa de DST/SIDA de un centro de salud en Rio das Ostras/RJ, Brasil. Los datos serán recogidos en 2013, por medio de entrevistas con un guión semiestructurado y sometidos al proceso de categorización. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, CAAE n° 12760313.4.0000.5243. **Resultados esperados:** se acredita que, los familiares y portadores del VIH poseen conocimiento insatisfactorio acerca de sus derechos, careciendo de orientaciones sobre el asunto en cuestión. **Descriptores:** Síndrome de Inmunodeficiencia Adquirida; Derechos del Paciente; Conocimiento.

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INTRODUCTION

Since the beginning of the epidemic, in 1980, until June 2012, Brazil has registered 656.701 cases of the Acquired Immunodeficiency Syndrome (AIDS). In 2011, the incidence rate of the disease reached 20,2 for every 100 thousand inhabitants.¹ It appears that cases of AIDS have shown decreased sex ratio, whereas before, in 1989, men were the most affected (1:6). In 2011, the latest available data, reached 1,7 cases in men for every 1 in women.¹ This shows the growth rate of the epidemic of HIV/AIDS among women, featuring the reflection of social and sexual behaviors of the population, associated with aspects of the biological vulnerability of women.²

Regardless of sex, the age group most usual for AIDS notification is composed of people aged between 25-49 years, but it is important to remember that there are younger and older contaminated people. Currently, the index of very young Brazilians contaminated grows fast. It is estimated that about 10 million teenagers are living with the Human Immunodeficiency Virus (HIV) and run the risk of developing AIDS in the next 3 to 15 years.³

Regarding the international scenario, 4 million people are living with HIV, which still represents a severe epidemic, despite the significant reduction in mortality due to treatment with the antiretroviral cocktails.⁴ One of the reasons for the reduction is the effort of all countries in the fight against HIV, since AIDS is among one of the eight Millennium Development Goals (MDGs) to be achieved up to the year 2015.⁵

The current previous note, inserted into the Group of Studies and Research in Education, Management and Ethics in Nursing at the Fluminense Federal University (GEPEGENF/UFF), aims at investigating the knowledge of HIV patients and their family members about the socioeconomic and health-related rights with regard to the condition of being a carrier, in follow-up in a program for dealing with STD/AIDS from the Coastal Region II, city of Rio das Ostras, Rio de Janeiro State, Brazil.

This research is justified, because it addresses the shortage of publications before the HIV patients' rights, as found in searches conducted in the Virtual Health Library, using the following descriptors: HIV, AIDS, patient's rights. From the use of these descriptors in languages: Portuguese, English and Spanish, 44 publications were found. Of these, only seven dealt with HIV patients' rights, and the right treated in these publications was under

the perspective of the sexual and reproductive health. Another justification refers to the high rate of HIV that still lingers in the national and international scenario and, therefore, aims to contribute to the dissemination of rights originated from the diagnosis of seropositivity for the virus at stake. Accordingly, we have elaborated the following guiding question: what is the knowledge that people with HIV and their family members have in relation to the rights arising from its carrier's condition?

That said, from such considerations, the present study aims to analyze the knowledge of carriers of the Human Immunodeficiency Virus/HIV and their family members in relation to their rights.

METHOD

It is a qualitative research, with descriptive and exploratory nature. The choice of qualitative research refers to the fact that it answers to particular issues and due to it works with the universe of meanings, motives, aspirations, beliefs, values and attitudes, which constitute the core of the discussion on the above mentioned references.⁶

The scenario chosen for this research will be a health institution of the Coastal Region II, city of Rio das Ostras, Rio de Janeiro State, Brazil, which offers the STD/AIDS Control Program.

The research subjects will be patients with HIV and their family members who are accompanying them during the nursing consultation and/or medical appointment in the STD/AIDS Control Program. In reference to the limit of the sample, we will use the theoretical saturation point from which the researcher suspends the inclusion of new participants in the research when the collected data show repetition and add no new data to the collection.⁷

With regard to the selection criteria of the subjects in this study, the following will be taken into account in relation to patients with HIV: acceptance to participate in the study; being aged over 18 years; having been diagnosed with HIV; being registered in the STD/AIDS Control Program. In relation to the selection criteria of the subjects in relation to the family member, they will be the following: acceptance to participate in the study; being aged over 18 years; being present during the medical/nursing consultation accompanying the carrier of HIV. It should be clarified that the family member, in this study, will be regarded as any person close to the patient with HIV, regardless of blood ties, provided that accompanies it in the medical

and/or nursing consultation in the STD/AIDS Control Program.

The data will be collected through interviews recorded in digital system, with the completion forecast for 2013, as soon as being achieved the pending approval by the Research Ethics Committee.

It is noteworthy to highlight that, after collection, the interviews will be immediately transcribed. After transcription, the text will be submitted to the proofreading process, which will correct Portuguese grammar mistakes, punctuation and repetitions, without changing the meaning of the text.

After transcribing the interviews, they will be subjected to successive readings aimed at analyzing them through the categorization process. Categorization refers to ideas and objects that are recognized, differentiated and classified, i.e., organizing objects into categories. These are common elements that relate to each other.

It should be emphasized that, in view of the ethical and legal issues advocated by the Brazilian National Health Council, this project was submitted to the Research Ethics Committee from the Antônio Pedro University Hospital, as CAAE nº 12760313.4.0000.5243.

All subjects will receive information about the investigated object and sign the Free and Informed Consent Form (FICF), thereby formalizing their agreement in participating in this survey, as required by the Resolution nº 196/96⁹, before starting the interviews. The participants' anonymity will be preserved through the adoption of codes for identification of their statements, using the word "patient" (in the case of the person bearer of HIV, in medical follow-up) or "family member" (in the case of the person who are accompanying the sick person in treatment) followed by Arabic numerals, according to the order of the conduction of the interview.

EXPECTED RESULTS

This research will provide reflections on the knowledge of carriers and their family members inherent in the rights of seropositive individuals for HIV. It is believed that family members and bearers of HIV have poor knowledge about their rights, thereby lacking guidance on the issue at stake.

Finally, we aim that this work might give greater visibility to issues related to the rights of seropositive patients, increasing discussions and dissemination of information about the topic at hand. It is hoped that this paper might serve as an inspiration to other researchers concerned with the discussion and

promotion of issues concerning the rights and duties of patients and professionals in the context of health services.

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