

Women living with aids and the family health program professionals: disclosing the diagnosis*

MULHERES VIVENDO COM AIDS E OS PROFISSIONAIS DO PROGRAMA SAÚDE DA FAMÍLIA: REVELANDO O DIAGNÓSTICO

MUJERES VIVIENDO CON SIDA Y LOS PROFESIONALES DEL PROGRAMA SALUD DE LA FAMÍLIA: REVELANDO EL DIAGNÓSTICO

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ABSTRACT

This qualitative study was carried out with women living with HIV/AIDS cared by a specialized STD/AIDS service and registered in a Family Health Program (FHP) unit. The purpose was to identify the motivations of women living with HIV/AIDS to provide private information to the FHP team. The study was performed using semi-structured interviews, analyzed with the bioethics theoretical framework. It was verified that women disclose the diagnosis to the FHP team when: the HIV/AIDS diagnosis was made in the unit; they feel there is better treatment for being HIV positive; they are bond as family members; there is trust; and women feel that they do not feel pity of them. Women so not disclose when: the professional's attitude produces fear and unreliability; they think that the FHP takes care of bedridden patients; they do not trust by fearing secret disclosure; and they already have all the care needed in the SCS.

KEY WORDS

Acquired immunodeficiency syndrome.
Women's health.
Confidentiality.
Family Health Program.

RESUMO

Trata-se de um estudo qualitativo realizado com mulheres infectadas pelo HIV/aids atendidas por um serviço especializado em DST/aids e matriculadas por uma equipe do Programa Saúde da Família. Teve como objetivo identificar quais as motivações para abrir a privacidade de suas informações para a equipe de PSF das mulheres soropositivas ao HIV/aids. Foi realizado por meio de entrevistas semi-estruturadas, analisadas com o referencial teórico da bioética. Verificou-se que as mulheres revelam o diagnóstico à equipe de PSF quando: o diagnóstico de soropositividade foi feito na unidade; sentem que são melhor atendidas por serem soropositivas ao HIV; têm vínculo como se fossem familiares; confiam; e sentem que não sentem pena. E não revelam quando: a atitude do profissional gerou medo e insegurança; acham que o PSF cuida de pessoas acamadas; não confiam por medo de quebra do sigilo; e já possuem toda assistência que precisam no SAE.

DESCRIPTORIOS

Síndrome de imunodeficiência adquirida.
Saúde da mulher.
Comunicação sigilosa.
Programa Saúde da Família.

RESUMEN

Este es un estudio cualitativo realizado con mujeres infectadas con el VIH/SIDA atendidas por un servicio especializado en DST/SIDA y matriculadas por un equipo del Programa Salud de la Familia. Tuvo como objetivo identificar cuáles son las motivaciones de las mujeres seropositivas al VIH/SIDA para abrir la confidencialidad de sus informaciones al equipo del PSF. Se llevó a cabo por medio de entrevistas semi-estructuradas, analizadas con el referencial teórico de la bioética. Se verificó que las mujeres revelan el diagnóstico al equipo del PSF cuando: el diagnóstico de seropositividad se realizó en la unidad; sienten que son mejor atendidas por ser seropositivas al VIH; tienen vínculo como si fuesen familiares; confían; y manifiestan que no sienten pena. Y no revelan cuando: la actitud del profesional generó miedo e inseguridad; consideran que el PSF cuida a personas enfermas; no confían por miedo a la quebra del sigilo; y ya poseen toda la asistencia que necesitan en el SAE.

DESCRIPTORIOS

Síndrome de inmunodeficiencia adquirida.
Salud de la mujer.
Confidencialidad.
Programa Salud de la Familia.

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INTRODUCTION

In Brazil, the AIDS epidemic gained visibility in 1980 and, since then, new cases have been progressively reported. Back in 1993, there were 71,259 cases and, in the five subsequent years, there was a substantial increase in the number of infected people, reaching 200,786 notified cases by 1998⁽¹⁾.

In São Paulo, the city with the highest number of notified cases in the country, 14,955 women over 13 years old had been notified with AIDS and 88.0% had heterosexual activity the hierarchy category of exposure until December, 2004⁽²⁾.

In women, biological and social determinants favor HIV transmission and the development of the disease. Regarding transmission, there are anatomical differences, namely higher HIV concentrations in the semen rather than in the vaginal mucosa, the occurrence of micro-lesions in the vaginal mucosa during intercourse (in a large area of the vaginal introitus), reduction of vaginal lubrication (variable, according to age and sexual stimulus) and the use of contraceptives that create a favorable environment for the penetration of the virus.

Also, the disease stage, presence of other sexually transmitted diseases, inflammations or rashes in the mucosa vaginal, nature and frequency of sexual intercourses (number of partners, unprotected intercourse during the menstrual period, etc), social inequality, issues related to gender, poverty and the lack of perception of the infection risks, especially in women who experience steady relationships should also be noted⁽³⁻⁴⁾.

Because of these characteristics, there has been an increase of HIV-infected women. Concerning care to women coping with HIV, in basic healthcare, the priority is the identification of vulnerable groups, provision of serologic testing to identify the virus and actions to promote health and prevent the disease. When treating HIV women, several public services are required in order to articulate the development of integrated activities, with a reference and counter-reference system, of the specialized services and basic health units.

In basic attention, as a special guideline, the Ministry of Health (MH) conceived in 1994 the Family Health Program (FHP). The FHP is a strategy in which the health promotion and HIV prevention actions can be intensified. Furthermore, people have their human and civil rights strengthened, guaranteeing better quality of life⁽²⁾.

The FHP, however, is supposed to perform integrated actions with the HIV reference services, in order to ac-

company the infected individuals. The collaboration among the healthcare services helps to ensure continuous care, and, therefore, the individuals will be accompanied in all the stages of infection, from prevention to treatment⁽⁵⁾.

On the other hand, the FHP may facilitate the spread of information, even the classified ones. The FHP is closer to the user, more specifically the community health agents, who live in the same neighborhood, and they often enter the households. The authors analyze that such a fact raises ethical implications regarding information privacy and user autonomy (which comprises intimacy, private life and people's honor), mainly regarding access to certain personal information that may imply some level of prejudice and/or negative stigmatization for the user, such as being a HIV-infected person⁽⁶⁾.

The authors⁽⁶⁾ argue that the users have the right to decide whether their personal HIV-positive information should be maintained under their control, and to whom, when, where and in which conditions the personal information should be revealed.

The FHP is a strategy in which the health promotion and HIV prevention actions can be intensified. Furthermore, people have their human and civil rights strengthened, guaranteeing better quality of life

With such aspects, the existing conflicts in maintaining the rights to privacy and the professional secrecy are the object of this study. The studies dealing with this theme have mainly focused the professional-user relationship in the hospital setting, and few of them deal with the HIV-FHP relationship⁽⁷⁾.

The ethical problems endured in basic health care should differ from those identified in other treatment settings. The solutions to resolve ethical problems may differ in several healthcare services, because, even if a similar ethical reasoning structure is found, the ethical subjects and contexts are distinct⁽⁷⁾.

There was the problematization of the conditions, in which women infected by the HIV disclose their privacy to the FHP teams and some hypotheses were drawn, among them: women are afraid of the stigma and prejudice that may come after revealing the seropositivity to the FHP; they do not think it is necessary to inform the FHP team, because they think that they have enough support at the reference center where they are accompanied; they are not aware of what the FHP can offer, regarding care; they fear that their privacy is invaded and that they may lack autonomy when it comes to revealing the diagnosis to the team.

This study aims at providing subsidies to improve the quality of care for HIV-positive women treated with the FHP. There is also the purpose of identifying the HIV-positive women's motivations to disclose private information to the FHP team.

METHOD

This is a qualitative, descriptive study. The issues that involve privacy and confidentiality were discussed according to the bioethical perspective.

In the present study, the privacy dimension will be discussed, related to health information provided by the professionals.

The study was carried out in conjunction with the Central-western Health Coordination of the São Paulo Health Municipal Secretariat, in Butantã, which oversees 14 Basic Health Units. Four of them act with the FHP strategy (Butantã Unit, São Jorge, Vila Dalva and Boa Vista Basic Health Unit) and a Specialized Care Service (SCS-Butantã), treating HIV.

Women included in the study were HIV-positive, over 18 years old, enrolled and being treated at the SCS-Butantã and were registered with a FHP team – São Jorge, Vila Dalva, Butantã or Boa Vista.

The research was performed in the Specialized Care Service (SCS), not in the basic healthcare units, because the SCS had both women who disclosed and women who did not disclose their seropositivity diagnosis secret. In the same place, women being accompanied at the Unit and those treated by the FHP of appointed basic health units together.

As a strategy to encourage workers to identify women with the required profile, there was an introductory meeting and they were handed pamphlets with the details of the research. These pamphlets would also be fixed on the bulletin boards.

In this study, the interviews with six women were used. They were performed from May 12 to July 4, 2006. Data were collected through interviews from a single meeting. A semi-structured script was used. The interviews were performed in a private room and took approximately 40 minutes each.

The interview script was divided into two parts. The first part refers to women characterization, regarding date of birth, educational background, employment, number of children living with them, children's age, people living in the house, family income, participation in associations, church, community centers or non-governmental organization (NGO), period living in the same neighborhood and HIV-positive diagnosis time. The second part explores the conditions in which the interviewed women was informed of their HIV infection diagnosis; with whom they shared the diagnosis for the first time and later, who received the information and how the situation was experienced. Furthermore, the relationship of the interviewed women with the community where they live was explored. They were asked whether the fact of being seropositive interfered in their lives with relatives and neighbors. And finally, how the FHP team learned about the diagnosis.

Data were organized by content analysis⁽⁸⁾. The content analysis method is composed of three phases: pre-analysis, the exploration of the material, treatment of the findings and interpretation. Hence, after the interviews, the women's testimony contents resulted in texts which were decomposed into sub-themes. They were grouped and constituted the empirical category *sharing the secret with healthcare professionals*.

The project was approved by the Ethics Committee of the São Paulo City Hall (No. 040/06-CEP/SMS). According to resolution no. 196/96 of the National Health Council, which established guidelines for researches involving human beings in Brazil, each woman was asked to agree to participate in the research. They were given a Responsibility Form, signed by the researcher and research adviser, which contains the study objectives, the guarantees to preserve anonymity, omission of names and details that make identification possible. In this form, they indicate how the researcher can contact with them, if necessary. They were free to participate, avoid or quit the research at anytime.

In the description of the results and discussion, the names of the interviewed women were replaced with fictitious names chosen by the researcher in order to preserve their anonymity.

RESULTS AND DISCUSSION

Six women were interviewed. All of them were HIV-infected, registered and being treated at SCS-Butantã, living in this neighborhood and enrolled in the FHP of the Butantã Area when the interview was performed.

Their ages ranged from 29 to 45 years; most of them attended school for over four years, except Aysha; only one was divorced and all of them lived with their 1-month to 23-year-old children. Four of them were unemployed; only Jade had a higher qualification and had the highest family income (5.7 times the minimum wage). The time living in the neighborhood varied, from a minimum of two years and maximum of 32 years. More than half of them were members of one of the evangelical churches of the region and three belonged to non-governmental organizations (NGO). Four of them (Safira, Mayara, Dalila and Aysha) had known the diagnosis for less than two years. Selena and Jade had known about their condition for six and nine years, respectively.

Half of them, Safira, Dalila and Aysha had the HIV-seropositivity diagnosis performed at the FHP unit in the Butantã Area. Dalila and Aysha's HIV infection diagnosis was performed during pre-natal treatment, through routine laboratorial exams.

Safira, Selena and Jade had their diagnosis performed after suspecting their sexual partners were infected. Safira had her seropositivity diagnosis revealed after suspecting that her inmate husband had tuberculosis. This disease is a pos-

sible indicator of HIV association. Jade was informed that her husband was hospitalized in the same occasion.

Among them, only with Mayara the diagnosis was performed from a previous history of alcoholism and tuberculosis.

After the HIV infection diagnosis, Safira, Dalila and Aysha, who were pregnant, were treated at the SCS-Butantã. They would control their pre-natal and take antiretrovirals during pregnancy and after labor, along with the children. The children born from these women had their virus-detecting laboratorial exams negative, that is, they were not infected.

Mayara and Selena were not diagnosed with HIV infection at the FHP units, but at another unidentified unit. Jade had her diagnosis performed at the SCS-Butantã. All of them were being accompanied at the SCS-Butantã. The FHP team is not likely to know Selena and Jade's seropositivity diagnosis. Only Mayara revealed her seropositivity condition to the FHP team.

Dalila, although registered at the FHP, does not control the health-disease process at the FHP. The team knows her diagnosis, though. Selena and Jade, also registered by the FHP team, are not treated regarding questions that involve HIV infection because the team does not know about these women's HIV seropositivity. They do not show interest in disclosing this information. Selena does not attend the FHP in order to treat a health-related process. She reports that she only uses the FHP services to treat her children.

Sharing the secret with the FHP professionals: the disclosure (or not) of the HIV diagnosis

This study was based on bioethics, a new way to deal with ethics in life and health sciences, combining *study and reflection, and building a bridge between biological and human sciences after an inclusive, plural and responsible dialogue in the search of wisdom. It is the understanding of knowledge for social welfare and for human dignity promotion and good quality of life*⁽⁷⁻⁹⁾

It comes from the autonomy principle, the right to privacy, which comprises intimacy, private life, honor and personal image⁽¹⁰⁾. Privacy refers to the principle in which people have autonomy to decide who and how their bodies are exposed to medical, diagnostic and health care procedures or which pieces of information regarding their health status should be shared⁽¹¹⁾.

The basic principle of confidentiality maintenance that health professionals have about a given user (professional secret) should be respected. Also, the diagnosis and all the information regarding HIV infection belong to the patients or their legal tutors, in case the patient is handicapped or under 18⁽¹²⁾.

The secrecy maintenance by all the team members is derived from the right to privacy. Not only the information revealed in confidentiality is classified, but also all the information that the healthcare members discover while performing their activities, even if the user is not aware of it⁽⁶⁾.

The analytical categories in bold were found, considering the discussion above and decomposing the interviewed women's speeches regarding privacy disclosure, that is, the sharing of information about the diagnosis with the FHP team. It is important to mention that these categories were divided into two large groups: *They tell the secret when* and *They do not tell the secret when*.

They tell the secret when:

The seropositivity diagnosis was performed in the unit.

Actually, since the seropositivity diagnosis was performed at the FHP unit, there was a disclosure of privacy regarding information.

When the diagnosis was performed by a FHP team, at least one team member is aware of the secret. Therefore, in these cases, there was no disclosure of secrets, but a sharing of secrets due to the diagnosis. The infected women may search for other team members and reveal the secret, or another team member may obtain this information for treatment reasons.

When women go for the exam, it is important that they receive support in the pre and post result counseling. Then, they will not be simply sent to a reference service. The professional performing the consultation

should promote a comfortable environment so as to establish attachment and discuss the meaning of life for these women. Also, there should be specific issues regarding prevention, sexuality and any questions related to the female reproductive health⁽¹³⁾.

She feels that she is better treated at the FHP for having HIV

Women tell the FHP team about their conditions when they feel that they will be understood. In a study⁽¹⁴⁾ on users' satisfaction in relation to FHP, most families were dissatisfied with the service provided by the FHP team and by the healthcare unit. However, it is interesting that one of the interviewed women evaluated that the treatment quality had improved because she was HIV-infected. She reported that her medical care, nursing and exam needs are done quickly.

Regarding the Community Healthcare Agent (CHA), it is worth mentioning that the researchers⁽⁶⁾ found that frequent contact with users often make them reveal their secrets to the CHAs, disclosing a part of their privacy so as to facilitate access to the healthcare service.

Privacy refers to the principle in which people have autonomy to decide (...) which pieces of information regarding their health status should be shared.

They feel attached to the FHP professionals as though they were relatives

Both the reception and support provided by the FHP professional team is a key condition so as to lead to privacy disclosure. The attachment with the professional is often compared with family bonds.

The FHP has a humanist feature that modifies the condition experienced for many years in the health system. It transforms the interpersonal relationship when it comes to treatment, which is often curative. The patients are looked after in their totality. Indeed, they are treated, not the disease⁽¹⁴⁾.

They trust the FHP professionals

One of the conditions that lead women to disclose their privacy is the trust established among users and professionals.

One of the elements that lead patients to trust the healthcare professionals is the understanding of the right to privacy. When they disclose it, the professionals are not allowed to reveal the secrets that they were told in the course of their activities, not even those that the user is unaware of⁽¹⁵⁾.

It is imperative that the right to secrecy is explained to the service users. Reinforcing trust, solving doubts and making the users' rights clear, both the professionals' attachment and credibility are strengthened.

A study⁽⁶⁾ found that the CHA is concerned about the ethical principle of privacy and the need of maintaining professional secrecy.

They feel that the professionals do not feel pity

HIV-positive women disclose their privacy on the condition that the professionals do not feel pity. This feeling of pity makes them feel somewhat inferior.

They do not tell the secret when:

The inappropriate professional attitude caused fear and insecurity when giving the diagnosis

The professional inappropriate attitude in the different health services may compromise the decision of privacy disclosing to the FHP team.

In one of the interviews, the professional caused fear and insecurity when communicating the seropositivity diagnosis to the user. It should be noted that the situation occurred during pre-natal treatment and the professional said *that the child would be born with problems, and an abortion would be better*.

In the beginning of the 1990s, HIV-infected women avoided pregnancy or were told to have an abortion, since

people thought there was a bad prognosis for the mother and for the baby. Today it is known that HIV infection does not affect fertility. Pregnancy does not accelerate the development of the disease and vertical transmission possibility is reduced to 2% with the use of preventive measures (breast-feeding suppression, cesarean incision, treatment with antiretrovirals, etc.)⁽³⁾.

They think that the FHP is related to critical and bedridden patients

One of the users claimed that she believed that the FHP treats critical and bedridden people. She did not need care because she felt fine. This situation characterizes their usual lack of knowledge regarding treatment and services provided by the FHP teams.

The FHP proposal is the development of actions to promote health, prevent, cure and rehabilitate, both individually and collectively through a multidisciplinary work-group devoted to the health of individuals, families and communities⁽⁵⁾. Yet, there is the idea that the health services are designed to assist sick people, with little emphasis on disease prevention and health promotion.

They do not trust these professionals because they are afraid that their secret will be spread (telling other professionals, people in the community, relatives).

The users do not disclose their private information regarding seropositivity when they do not trust the healthcare professionals. This happens because they are afraid that their secret will be shared.

Even though secrecy is recommended by the professional code of ethics, its maintenance is quite complex and it is often broken, especially when it comes to diseases with compulsory notification⁽¹⁵⁾. The authors point out that the healthcare professional-patient relationship is often based on trust and mutual respect.

The fear of having their secret spread is expressed mainly in relation to CHAs who live in the same neighborhood, sometimes next-door or who is a family member.

They already have the health care support at the SCS, have no need of the FHP

The professional discourses related to HIV treatment reveal emphasis on sending patients to specialized services. The users are disconnected from the basic units and the responsibility for the treatment is transferred⁽⁵⁾.

Likewise, the interviewed women chose the specialized service as the place to provide all the health care support that they need. There is no need of disclosing their privacy to the FHP team. The users evaluated the specialized service positively.

When the HIV seropositive women face the challenge

of coping with AIDS, they also continue facing the power relationships in society, especially those regarding gender inequality, which affects the woman's role in society.

The fear of prejudice is present in these women's routine. Struggling for life becomes more complex when it comes to such a stigmatizing disease. The fear of revealing the diagnosis is believed to stem from social judgment, that is, the fear of humiliation, embarrassment and guilt, since AIDS is still regarded as a synonym of social exclusion⁽¹⁶⁾.

CONCLUSIONS AND FINAL CONSIDERATIONS

HIV, specifically in women, brings great challenges to society and the healthcare services. These challenges refer mainly to the prejudice entrenched in society and the HIV meanings.

Healthcare services, especially basic healthcare, may contribute with measures to face the HIV epidemic in women⁽¹⁷⁾.

The FHP is seen to stand out as a service with potential to assist these women, mainly, regarding questions of the health-disease processes. As the FHP acts in communities, especially with families, it ought to understand the processes belonging to the family and community relationships of women with HIV.

Some people have an AIDS representation related to prejudice and fear caused by discrimination coming from healthcare professionals. The secrecy defense is justified by the high level of social disinformation, and also by some healthcare professionals. The consequence is that patients do not want professionals to know their seropositivity diagnosis and spread it⁽¹⁸⁾.

This study found that women disclose their private information to the FHP team when the diagnosis was performed in the same unit. In this case, privacy has already been disclosed to one team member. The healthcare professionals are urged to maintain secrecy.

The FHP is characterized by the attachment and team responsibility regarding local families. However, it is necessary to establish contracts that maintain secrecy. Also,

the establishment of professional-user limits is required⁽⁹⁾. These HIV-positive women are likely to feel that they are better treated by the FHP team for having HIV.

It should be considered that the healthcare service setting is characterized by trust given by the users to the institution through its constituent members. In case of trust negligence, the revelation of private information may repel the service users. Then, they lose opportunities of negotiating and learning to share⁽¹⁸⁾.

There are clear expectations, both from a hospitalized group and from non-hospitalized people, to keep private information from health professionals. There should be some restriction to information access, essential to carry out high-quality care to the service users⁽¹⁸⁾.

The interviewed women do not unveil their seropositivity condition to the FHP. There was a professional who inappropriately informed the diagnosis to the user, causing fear and insecurity. Some women lived through embarrassing situations, biased attitudes when revealing the diagnosis. These negative experiences may lead to isolation⁽¹⁹⁾.

Some women reported that they already have all the health care support needed at the SCS and they do not think it is necessary to attend other health institutions.

Previous studies⁽⁵⁾ have concluded that there is no information regarding who has HIV and is treated at the FHP. There is no demand for care, given that there are no users in this condition. Such findings differ from the results of the present study.

Regarding HIV seropositive patients and FHP professionals, the latter are not aware of the form of users' access and SCS routine and actions performed in this service. The basic information that the professionals should have access is related to treatment criteria in this service⁽⁵⁾.

Issues that do not belong to clinical procedures should be looked after by the specialized healthcare services, and also the basic units. It is important to understand and counsel these women, mainly regarding the aspects that are affected by the seropositivity condition such as social life, work, family, children care and future⁽²⁰⁾.

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