

LIVING WITH HIV/AIDS: IMPACT OF DIAGNOSIS FOR USERS SERVED IN A REFERENCE SERVICE

Viver com HIV/aids: impactos do diagnóstico para usuários atendidos em um serviço de referência

Vivir con VIH/sida: impacto del diagnóstico para los usuarios servidos en un servicio de referencia

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ABSTRACT

Objective: to identify the impacts of people living with the diagnosis of HIV/aids in a reference service.

Method: it is a qualitative, exploratory research. Individual semi-structured interviews were conducted, digitally recorded, with users living with HIV/AIDS and participating in an adherence group. The collected data were evaluated based on Bardin's content analysis. **Results:** three categories emerged: reactions to the diagnosis, impacts resulting from the diagnosis and the experience of living with HIV/AIDS. The diagnosis generated repercussions on professional life, on social life and on affective and sexual relationships of people living with HIV / AIDS. **Conclusion:** the identified impacts were abandonment of sexual life, adoption of condom use, family separation, interruption of professional activities and psychological suffering associated with prejudice and stigma linked to infection.

DESCRIPTORS: Nursing; HIV/aids; Psychosocial impact.

RESUMO

Objetivo: identificar os impactos das pessoas que vivem com o diagnóstico do Vírus da Imunodeficiência Humana/Síndrome da Imunodeficiência Adquirida (HIV/aids) em um serviço de referência. **Método:** trata-se de uma pesquisa qualitativa, de caráter exploratório. Foram realizadas entrevistas individuais semiestruturadas, gravadas por meio digital, com usuários que vivem com HIV/aids e que participam de um grupo de adesão. Os dados coletados foram avaliados com base na análise de conteúdo de Bardin. **Resultados:** emergiram três categorias: reações diante do diagnóstico, impactos decorrentes do diagnóstico e a experiência de viver com HIV/aids.

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O diagnóstico gerou repercussões na vida profissional, no convívio social e nas relações afetivas e sexuais das pessoas que vivem com HIV/AIDS. **Conclusão:** os impactos identificados foram abandono da vida sexual, adoção do uso do preservativo, afastamento familiar, interrupção das atividades profissionais e sofrimento psicológico associados ao preconceito e estigma vinculados à infecção.

DESCRITORES: Enfermagem; HIV/aids; Impacto psicossocial.

RESUMEN

Objetivo: identificar los impactos de las personas que viven con el diagnóstico de VIH / SIDA em um servicio de referencia. **Método:** es una investigación cualitativa, exploratoria. Se realizaron entrevistas semiestructura das individuais, grabadas digitalmente, com usuarios que viven con VIH/SIDA y que participan em un grupo de adherencia. Los datos recopilados se evaluaron en base al análisis de contenido de Bardin. **Resultados:** surgieron três categorías: reacciones al diagnóstico, impactos resultantes del diagnóstico y La experiencia de vivir con VIH/SIDA. El diagnóstico género repercusiones em la vida profesional, la vida social y las relaciones emocionales y sexuales de las personas que viven con el VIH/SIDA. **Conclusión:** los impactos identificados fueron el abandono de la vida sexual, la adopción del uso del condón, la retirada familiar, la interrupción de las actividades profesionales y el sufrimiento psicológico asociado con los prejuicios y el estigma relacionado con la infección.

DESCRIPTORES: Enfermería; VIH/sida; Impacto psicossocial.

INTRODUCTION

Human Immunodeficiency Virus (HIV) infection and its clinical manifestation at an advanced stage, Acquired Immunodeficiency Syndrome (AIDS), still represent a public health problem of great relevance today, due to its wide dissemination and social relevance. AIDS is characterized as a severe dysfunction of the immune system in HIV-infected people without treatment, as CD4+ T lymphocytes, one of the main target cells of the virus, are destroyed.¹

Currently, it is estimated that 866,000 people live with HIV in Brazil. From 2007 to June 2019, 300,496 cases of HIV infection in Brazil were reported in the Acute Notification Information System (ANIS), of which 55,090 (18.3%) were in the Northeast region. Of these, 3,767 (6.83) were notified in Alagoas.² The notification of cases of HIV infection became mandatory from 2014, after the determination of Ordinance No. 1,271 of 06/06/2014 of the Ministry of Health.

With therapeutic advances and the introduction of new classes of antiretroviral drugs in recent decades, the panorama of this infection has evolved from a fatal to a chronic disease. In this sense, it is important to identify the impacts of the diagnosis on the various dimensions of life of people living with HIV/AIDS, since understanding this problem and the interfaces of living with HIV/AIDS requires more than just treating the disease.³

The relevance of this study in producing and disseminating knowledge that provides an opportunity to share the main experiences and impacts faced by people living with HIV/AIDS is highlighted, as the experiences reported and the reflections on the impacts of the diagnosis can help in building more appropriate ways to deal with these issues.

This study aims to identify the impacts of people living with a HIV/AIDS diagnosis on a referral service.

METHODS

It is an exploratory, descriptive, qualitative approach study, carried out in a university hospital located in the state of Alagoas. This institution is characterized as a field of practice of the Multiprofessional Residence in Adult and Elderly Health and has the Unit of Infectious Diseases (UID/HD), considered a reference in the care of people living with HIV / AIDS in the state of Alagoas. For this reason, the choice of the present study in this Unit, with users of the adherence group Coexistence of UID/HD.

The membership group Conviver began its activities in 2016, has a schedule of meetings every 15 days, and the meetings are conducted by a social worker from that institution, with support from the Multiprofessional Residence team. The number of users participating in the group is estimated at around 15, but this is not a fixed number, as it varies with each meeting, depending on the availability of each one.

Inclusion criteria were considered to be to participate in the membership group Living and being diagnosed with HIV/AIDS infection for a period of one year or more. The exclusion criterion considered was to have cognitive impairment that made verbal communication between the researcher and participant impossible.

Data collection was conducted from December 2019 to February 2020, after approval by the Research Ethics Committee of the Federal University of Alagoas. During the data collection period, it was possible to invite fifteen users of the service, but only six formalized their agreement to participate in the survey.

Users who refused to participate did not explain their reasons, but these refusals could be linked to a fear of exposing intimate aspects of their lives and a fear that the diagnosis might be revealed to others outside the health service, despite the explanation of the research's secrecy issues.

Data collection was carried out after informed consent, on an individual basis, from a semi-structured script based on the study "The experience of living with HIV/AIDS in old age",⁴ in a care room currently available. In order to preserve the identity of the participants, alphanumeric coding was established, where the letter P represented the participant and the number indicated the order of data collection.

The interviews were recorded digitally, transcribed, analyzed and interpreted, and the data collected was evaluated based on Bardin's content analysis, which consists of grouping the sense nuclei, that is, the themes that reveal values, conceptions and models undertaken in the speech contents. The operationalization of the analysis process followed the three stages of the method: pre-analysis, exploration of the material, and treatment of results, inference and interpretation. Three categories emerged from the analysis: reactions to the diagnosis, impacts resulting from the diagnosis and the experience of living with HIV/AIDS.

The research project for this study was approved on December 6, 2019, by the Research Ethics Committee of the Federal University of Alagoas under Opinion No. 3,748,940. The research was conducted in compliance with the required ethical standards and data collection was carried out by signing the Free and Informed Consent Term (FICT).

RESULTS

The interviews were conducted with six users, five men and one woman, aged between 41 and 62. Regarding schooling, one participant reported knowing only how to read and write, one had incomplete second grade, three complete second grade and one complete higher education. Currently, none of the participants has a profession/occupation and the personal income reported by four of them was a minimum wage, the others have no established income. All interviewees declared themselves to be single and the time of diagnosis of HIV/AIDS varied between 5 and 30 years.

After the characterization of the participants, the lines were analyzed so that the categories described below emerged.

- Reactions to the diagnosis

Through the reports from the interviews, one can see that the reactions of users to the confirmation of the diagnosis of HIV/AIDS infection were varied, highlighting the will to die, sadness, surprise and guilt.

The following statements exemplify the main reports of the interviewees:

I wanted to kill myself. I had a big fall, thought about killing myself several times. I stood at the edge of the road waiting for the truck to come. I think 90% of people who catch AIDS have this thought.(P1)

It was very impacting, then I got a little depressed, tried to kill myself and other things, you see.(P5)

I cried so, so, so much. It's like the world opened up and I fell in. From then on it's depressing, it's medicine.(P4)

It was something like that, very strong for me at the time. Then you get stressed, the stress comes, I'm hospitalized in a psychiatric hospital.(P6)

I was very upset, I didn't expect it. And it wasn't for lack of using the condom, because I had used it with my partner. Unfortunately it broke.(P5)

I knew I took it because it was stupid of me. I knew the whole responsibility of it there. I knew no, I know the responsibility for all that in there is mine. I can't throw it behind anyone's back. I have an obligation to protect the person and to protect myself.(P3)

Confirmation of the diagnosis of HIV/AIDS infection has also produced apprehensions such as fear of death.

Because when we get the news, we panic, so, immediately, the biggest fear we have is of death, right? Then you think you're going to die and other things come.(P6)

- Impacts arising from the diagnosis

In this category, the impacts arising from the diagnosis of HIV/AIDS infection are mentioned, which involve several aspects, such as the impacts on sexual and affective relations, family withdrawal, interruption of professional activities, psychological suffering and other comorbidities.

I lost two safe, serious jobs that loved me, liked me, because I was honest. Because every time I came here, it took too long, until the day I called and spoke, I do treatment in HU. But why does it take so long? Because I am HIV positive, I was very sincere. Then I said, sit here for me to explain, but it doesn't stick, I explained that it doesn't stick, you see, but their ignorance, they just came to me and said, oh but there is no more vague because the movement is bad. And that's what makes me more outraged, because I lost jobs, I'm not old enough to get a job, I'm getting old.(P3)

Regarding the impacts on affective and sexual relationships, the six participants reported having experienced some change. One respondent only reported changes in this regard, but did not detail what they were. For three respondents, the diagnosis represented abandonment of sexual life, and two others reported the adoption of preventive practices.

Your thinking is complicated. You have no patience, you have no head for sex.(P1)

It had an impact on that. It hasn't. I don't want to. That's the hardest part. The hardest part is remembering that I have to talk. I'm crazy to fix someone. If all of a sudden I find the lid on my pot, then I'm gonna fall for the bullshit of telling the lid on my pot that and the lid goes off. And then, what's gonna happen to me?(P3)

Today I don't want to have access to man, because I was disgusted with man, you see. I don't care about man, because no one has ever brought me anything, only disgrace. Then I don't need it. Depending on me, I'll never have it. Condom or no condom, I'll never have it.(P4)

More prevention, more care. What I have, I don't want to pass on to the next one, you understand.(P5)

A lot. It changed a lot because I started taking more care of myself. And also making choices, trying to choose, I don't know, it's in the dark, but I tried to feel more.(P6)

The act of revealing the diagnosis to the family appears associated with family withdrawal. However, while for one participant it was the family that chose to withdraw after the diagnosis was revealed, for another participant the withdrawal happened by her choice, since she reported a change in her behavior.

My family got away from me. It's unfortunate. My family knows. Everyone knows about my family. One goes out telling the other. And that's where you drove everyone away.(P1)
My relationships with my children, to begin with my children, are no longer because I was aggressive to them, I was not, I was very patient with them, you see. My children were talking, I was already oi mainha, oi my son understood.

Today, the further away from me, the better. It is my self that is damaged. I feel the further away from me, the better. My children and my grandchildren don't spend the day with me anymore, but they spend weeks.(P4)

On the other hand, support from some family members was also mentioned and only one participant claimed to have had no impact on their social and family relations:

My family, the only one who has supported me and still supports me, is my mother. As soon as I found out, I had also passed to her, you understand. I just didn't tell my father because my father died first. But I was always open to tell everything that happened to me and until today I tell what happens to me I always pass on to my mother and to mine father.(P5)

Normal. My whole family knows, my friends know, my city knows, because I wanted to tell them and it didn't change my relationship with them, nor them with me.(P2)

According to five respondents out of six, it is possible to identify that prejudice and discrimination appear closely linked to HIV/AIDS diagnosis both from the participants' own reported experiences and from knowledge of the stigma linked to the infection. The fear of suffering prejudice also appeared as a determinant in the decision to keep the diagnosis confidential.

It is not the disease that kills, it is the discrimination, it is the prejudice. That's why I say don't count no. I told a brother and everyone knew. Family, everybody and everything moving away from me. There's a party and they don't call. Nobody's gonna want HIV. People walk away, because of discrimination, it's hard for you to live with AIDS. It is very complicated (P1)

Very few people know. Because most are full of prejudice. I was already prejudiced because I was gay.(P5)

But that way, I had no discrimination, that helped me a lot. I mean, I had more discrimination outside, with some professionals than with the family.(P6)

I sometimes stare at people's ignorance. And did you know that among ourselves, there are people who are HIV-positive, but they are prejudiced. I think so, we tell a best friend, then suddenly the best friend has another best friend, who will tell, and when you see, the street is full of best friends knowing.(P3)

Now my fear is what? It's of telling a [person] and stinking. Because I know you have prejudice, I know you do. We're not gonna take any chances.(P4)

Three research participants reported having other comorbidities that they think are associated with the diagnosis of HIV/AIDS, such as high blood pressure, diabetes and depression.

High blood pressure and depression. I didn't have any of that. Then when HIV came, it all came, the depression, the high blood pressure.(P4)

So, after the time I learned about this problem, I've discovered that I have high blood pressure and an insomnia problem. I'm taking medication to relieve it.(P5)

After I contracted HIV, I became diabetic, hypertensive, I don't know. I was emotionally unbalanced, but I met a person who did meditation and that helped me a lot. Meditation is something that, to me, is like a medicine.(P6)

- HIV and AIDS vivercom experience

When asked about the experience of living with HIV/AIDS infection today, after the time of diagnosis and initiation of treatment, three participants said that with the change of some habits, increased prevention, adequate treatment and accumulated experience it is possible to live well.

You do your treatment right, you can live normally. Now you're preventing yourself so that you don't see the other opportunistic diseases that you have out there and you take care of yourself as much as possible and prevent the next one. If you go out with other people, always use a condom and always prevent yourself.(P5)

It's easy for me because of the experience. It's very easy for me. Because it's something that we didn't know, because it came suddenly and then everything that we don't know, we're ignorant about it. But not now, now I'm fine. I can live together. I drank, smoked, went out a lot at night. You just change some habits.(P6)

It's a rewarding experience for me to have found out right away. Because today I can live.(P2)

In contrast, two participants reported the loss of happiness and esteem for life.

Life gets small. You don't have that love, you know. You take care, but you don't have that appreciation as a normal person. It's complicated. One day you're in a good mood, the next day you want to kill yourself.(P1)

Horrible. It's horrible. I don't know where these people at meetings say everything's happy. There's no happiness. Unless the guy's very miserable. There's no happiness.(P4)

The participation in the adhesion group Living together as a support and strengthening point for the confrontation of the diagnosis is highlighted, being this space propitious for the sharing of difficulties, exchange of experiences, mutual support, yearnings and doubts, favoring the listening and the reception of these users.

The group is very important. It saves people's lives because you talk to each other, it lets out something you could talk about at home and you can't. Even the family that knows, you will talk and the person walks away. And one day we're great, the other day we're terrible, we want to talk to someone. Only the group that can do this.(P1)

The group is very important. Especially for the people who are coming now and those who have already passed, who have a little more experience, which you can share with those people.(P6)

DISCUSSION

The diagnosis of HIV/AIDS is crossed by reactions that encompass psychological, physical and social aspects. The first feelings experienced after the diagnosis and associated with the perspective of death and guilt represent the stigma of the infection, bringing even more suffering to the patient.

Depression is the most frequent psychiatric diagnosis in people living with HIV/AIDS. The most common feelings are sadness, lack of motivation, apathy, feeling of guilt, diminished ability to feel pleasure from previously pleasurable events, sleep changes, decreased libido, among others.⁵

The risk of suicide, which may be associated with some reports from research participants, is three times higher in people living with HIV/AIDS than in the general population. Uncertainty regarding prognosis and high morbidity and mortality rates before the antiretroviral therapy era are factors linked to suicide ideation and attempted suicide in this population.⁵

Studies point to changes in various dimensions of life after HIV/AIDS diagnosis, such as sexual practices, social interaction, psychological impacts and changes in lifestyle. Financial concerns probably related to low income and time away from work are also mentioned as one of the impacts on the lives of people living with HIV/AIDS.⁶ It is important to note that people living with HIV/AIDS have the right to maintain confidentiality regarding their HIV status in the workplace, as well as in admissions, periodicals or dismissals.⁷

Studies that corroborate the results of this research assert that the fear of contaminating another person or of being rejected by a new partner in the face of a diagnosis is very present.⁸ Sexuality is an aspect of life compromised by the impact of the diagnosis and the emotional and social consequences of HIV/AIDS infection, since the prejudice and stigma associated with this condition are difficulties often encountered in trying to maintain normal life.⁶

These aspects addressed both in the scientific literature and in the reports of people living with HIV/AIDS help to think about the complexity of health promotion, the specificities of health work and the current challenges faced by those who work with these users, since the repercussions of HIV/AIDS diagnosis go beyond the physical and biological aspects.

People living with HIV/AIDS often suffer prejudice and rejection in their families and social groups, as well as constraints in health services. For this reason, many isolate themselves due to difficulties in sharing their HIV status with others and fear of being rejected in affective, social and sexual relationships. These situations can lead people living with HIV/AIDS to a state of psychological distress, which is not necessarily a mental disorder, but which in many cases generate important emotional demands that need to be embraced by all health professionals, including specialized care, from a humanized and integral perspective.⁷

It is worth noting that universal access to treatment and prevention of HIV infection has made it possible to transform the scenario of the epidemic in Brazil and has increased the expectation and quality of life of people living with HIV/AIDS. Although it does not represent a cure, therapeutic

adherence and the adoption of new habits of life, which allow a considerable decrease in clinical manifestations associated with HIV and improve the immunological capacity of the infected person represent an important component for improving the quality of life of these individuals.⁹

Welcoming people living with HIV/AIDS by including them in the health service, considering their expectations and needs, helps the user to clear up their doubts and allows them to talk about their fears and concerns about HIV infection. In this sense, activities such as the adherence group can provide individuals with HIV/AIDS with emotional and social support to strengthen links between users and the service, so that the disease can be better addressed, enabling a better quality of life and also greater adherence to treatment.¹⁰

CONCLUDING REMARKS

The study revealed that after the diagnosis of HIV/AIDS infection, participants in the research presented fear of death, sadness, surprise, guilt, and a desire to die closely associated with reports of depression. Based on the interviews conducted, it is possible to conclude that the diagnosis of HIV in these users generated great impacts on affective and sexual relations, leading to abandonment of sexual life due to fear of being rejected after revealing the diagnosis and, in cases where sexual activity was maintained, the adoption of condom use in the prevention of other sexually transmitted infections was mentioned.

In social coexistence, the impact generated was the family withdrawal due to prejudice linked to the infection. Participants also reported impacts on professional activities, since living with HIV/AIDS led to dismissal when the diagnosis was disclosed. The psychological impact was mentioned and related to the risk of committing suicide, depression and the use of psychiatric drugs.

The results should be considered within the specific reality as they do not seek to establish generalizations regarding the impacts of HIV/AIDS diagnosis. This study presented as a limitation the number of users who attended the meeting of the adherence group in which the invitation was made, who accepted to participate in the research, and who were within the inclusion criteria.

The questions raised can serve as a basis to guide professional practices, considering the complexity of the impacts of HIV/AIDS diagnosis in the various areas of this individual's life, and the stigma and prejudice surrounding this issue. It is suggested that new studies be carried out that may contribute to the construction of strategies for dealing with the impacts of HIV/AIDS diagnosis.

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