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Use of alcohol and drugs in the view of people living with HIV/AIDS: a qualitative study

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ABSTRACT

Objective: To investigate the meaning of the experiences of patients infected by HIV using antiretroviral therapy, regarding the use of alcohol and drugs.

Study design: A qualitative phenomenological study.

Method: A total of 25 patients receiving antiretroviral treatment participated in the investigation, of which 14 were male and 11 were females, who expressed their feelings and perceptions through participation in focus groups and the interpretation of costumes. The empirical material was transcribed in full and later organized and analyzed using the phenomenological method.

Results: Based on this amusing experience we realized that participants were unaware of the effects of the use of alcohol and drugs in the AIDS progression. Since they have kept with their smoking and alcoholism habits to be accepted in a social group and consequently prevent prejudice. We believe that our health education strategy was adequate to improve antiretroviral therapy, since it helped in subject comprehension and patients self-care body expression.

Conclusion: This phenomenological study made it possible to understand the experience of patients living with HIV regarding the use of alcohol and drugs, and contributes to the planning and implementation of intervention programs based on a participative model of care, with a view to prioritizing the holistic aspects involved in the treatment of people living with HIV/AIDS.

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Introduction

The advent of antiretroviral treatment (ART) has contributed to the increasing quality of life of people living with HIV/AIDS, as the drugs control the replication of the HIV virus and

increase the patients' immunity.¹ However, adherence to the treatment in the long-term is a major challenge for the health professionals who care for this clientele, requiring constant guidance regarding the importance of adherence to the treatment, and changes in lifestyle.²

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The regular use of ART has demonstrated an important reduction in morbidity and mortality resulting from AIDS;³ nevertheless, many patients who make use of alcohol and other illicit drugs do not manage to adhere to the treatment necessary for maintaining viral suppression and avoiding the development of resistant strains.⁴

The use of alcohol, among people living with HIV/AIDS, increases the risk of unsafe sexual behaviors and the chances of transmitting the virus,⁵ as well as contributing to the more rapid progression of the disease and the appearance of complications related to AIDS.⁶

Patients infected with HIV have higher chances of becoming involved in the use of alcohol and drugs than those who are not infected.^{7–10} Besides this, patients who are undergoing antiretroviral therapy concomitantly with the use of alcohol have a higher probability of developing other comorbidities.^{11–13}

Studies have shown that the use of alcohol leads to harm in the health of people living with HIV/AIDS, reducing their immunity through harming immune cells such as lymphocytes and macrophages, which are also targets of the HIV virus,¹⁴ and causes lesions in organs such as the liver¹⁵ and lungs,¹⁶ as well as neurological¹⁷ and cardiovascular dysfunctions.¹⁸

The significant morbidity resulting from the use of alcohol and drugs by patients infected with the HIV virus, and the various complications resulting from AIDS, have led health professionals to seek strategies for improving these patients' quality of life.¹⁹ Group attendance favors a joint experience, in which the experiences expressed by people living with HIV/AIDS empower the patient to cope better with the disease, adhere better to the treatment, and use healthy living behaviors.²⁰

Therefore, exploring the experiences of patients infected with the HIV virus regarding the use of alcohol and drugs during antiretroviral treatment will allow the elaboration of concrete and contextualized actions for this clientele, with strong implications in the undertaking of preventive measures and appropriate health actions in the control of this infection.

In the light of this, the present study aims to understand the meaning of the experiences of people living with HIV/AIDS using antiretroviral medications regarding the use of alcohol and drugs.

Method

Study design

This is an exploratory study with a qualitative character. The phenomenological method was adopted with the aim of describing, in depth, the experiences lived through and perceived by the people living with HIV/AIDS regarding the use of alcohol and drugs, so as to construct a meaning through the intensive dialog.²¹

The undertaking of the study complied with Brazilian and international norms for ethics in research involving human beings. The study was approved by the Research Ethics Committee, under Opinion number: 1,548,707. All the participants signed the terms of free and informed consent prior to joining the study.

Study location

The investigation was undertaken between October 2015 and February 2016 in a Municipal Referral Service attending to people living with HIV/AIDS in the Northeast of Brazil. The service is currently monitoring 1022 patients with HIV/AIDS and has a multidisciplinary team.

Participants

The subjects were recruited by convenience, while they were waiting for appointments with doctors or nurses, following invitations to participate in the focus groups and clarification relating to how these function. The following inclusion criteria were established: patients aged 18 years old or over, who had the HIV virus, and who were registered in the Municipal STD/HIV/AIDS Program and using antiretrovirals. The following were considered as exclusion criteria: patients with cognitive deficits, communication deficits, or who were seriously ill, who were unable to participate in the focus groups.

The participants consented to participate in the focus group. The first group began with a brief presentation from the team which would lead the actions; later, the participants were also invited to present themselves, so that familiarization could be created between the participants and researchers. Later, for detection of the study participants' knowledge and prior experiences in relation to the issue, a guiding question was elaborated 'Does the use of alcoholic drinks, and drugs, go with the HIV virus?' In addition, in order to obtain in-depth data, complementary questions were developed 'What do you know about the effect of alcohol and drugs on people's health?' and 'Does anybody have any experiences to report on this topic?'

Data collection took place through the patients' reports during the focus group, which were audio-recorded. Furthermore, a questionnaire was used for recording sociodemographic data, the use of antiretrovirals, and the patients' clinical condition, which were obtained through consulting the medical records.

During the undertaking of the focus groups, the participants of the same sex remained together, due to the fact that the experiences particular to each gender were considered important mechanisms for reflection on the topic. The identification of the participants deriving from the focus groups was codified using the letters 'MP' for 'male participant', and 'FP' for 'female participant', in order to ensure the confidentiality of the information provided.

Data analysis

The reports were transcribed in full and later organized and analyzed using the phenomenological method, as proposed by Colaizzi,²² which includes the following steps: (1) reading all the reports in order to visualize the whole; (2) reviewing each report and extracting the significant statements; (3) stating the meaning of each significant statement and elaborating meanings; (4) organizing the meanings formulated by grouping them into themes; (5) integrating the results in an exhaustive description of the phenomenon in question; (6)

formulating an exhaustive description of the phenomenon in question, with a statement of identification which is as unequivocal as possible; and (7) questioning the participants about the findings, as a final step of validation.

The themes of the present study were captured retrospectively based on all the reports generated in the groups. For the analysis of the reports, three judges participated; two nurses and one psychologist of the service, who received printed material for recording the recurrent accounts, containing data which were representative of the feelings, doubts, difficulties, and experiences with the topic addressed.

In consonance with the analyses of the content of the first focus group, the use of play was adopted as a strategy for guiding the second focus group, through the elaboration of costumes. Play is a form of language which allows an internal experience of the person who experiences it, allowing the human being to manifest ideas, beliefs, and feelings upon facing specified situations.²³

During the second focus group, the participants were requested to express their feelings which emerged from the experience of the phenomenon investigated, through the interpretation of costumes which were constructed for undertaking health education regarding the use of alcohol and drugs and what happens when these are combined with infection by HIV.

The data collected were validated by two nurses and psychologists who are specialized in research methods and in the care of persons with HIV/AIDS.

Results

A total of 25 patients undergoing antiretroviral treatment participated in the study. Of these, 14 were male and 11 were female, a minimum age of 28 years old, and the maximum age of 70 years old. In relation to educational level, 15 patients had studied for less than 10 years and 2 were illiterate.

The results are presented based on the focus groups held and the patients' reports regarding the costumes, in which the following two categories emerged: 'living through experiences regarding the relationship between alcohol and drugs and infection by HIV'; and 'learning experiences regarding the relationship between alcohol and drugs and infection by HIV'.

Living through experiences regarding the relationship between alcohol and drugs and infection by HIV

The experiences lived through show that the participants, in spite of being aware of the importance of the daily use of the drugs for viral control, are not aware of the effects of using alcohol and other drugs on the reduction of immunity, on the interaction with the antiretrovirals, and on the progression of AIDS.

Alcohol doesn't do any harm whatsoever, because I drink nearly every day and my viral load is zero, and my CD4 is way up there [...]. MP1

Yeah, I drink, I'm not going to lie about it, but I'm responsible – I never fail to take the medication, not even if I am drunk [...]. MP2

Alcohol doesn't influence the virus; all you have to do for the virus not to grow is remember to take the medication [...]. FP2

The participants experienced feelings of well-being after the use of antiretrovirals and, as a result of this, continued with the habits of drinking and smoking which they had had prior to the treatment, or which they had acquired after the diagnosis of the HIV virus, often in order to be accepted in a social group and not to suffer stigma, or to show society that they are citizens, just like those who are not infected with the virus.

I drink because I have to show people that I have not changed ... I am not some weirdo; I have a normal life [...]. FP7

If I go to a party and don't drink, people ask me why... And then I have to remember that I have this disease... If I reveal [that I have HIV/AIDS] I will suffer prejudice, so for that reason, I prefer to drink [...]. MP8

I take the medication in the morning, so as not to run the risk of forgetting it... And in the afternoon, at a barbecue with my friends, it is always good to have a beer in order to forget my problems [...]. MP5

When I am drinking, I don't even remember that I have this virus... Sometimes, having a drink is good in order to feel that you are normal [...]. FP7

Based on the experiences in relation to the phenomenon observed, it was shown that the participants did not relate the appearance of other morbidities which affect organs such as the lungs or liver to infection by HIV; in the view of these patients, the progression of AIDS is not influenced by the use of alcohol or drugs.

The problem with alcohol and other drugs is that they destroy your liver and lungs, but the virus itself doesn't increase, all you have to do is not stop taking the medications [...]. MP3

I myself drink every day - my problem isn't the virus... Now, my liver is ruined... I'm actually about to go for an ultrasound... [...]. MP5

In relation to the virus, everything is under control – my problem is this diabetes, which appeared recently [...]. MP3

There is not any relation between alcohol and the virus, they are two different subjects... the most important is to not stop taking drugs to control it... Alcohol is only going to be bad for the liver, besides the hangover the next day [...]. MP23

Smoke goes to the lung there isn't any relation with the virus that's in the blood [...]. FP13

Learning experiences regarding the relationship of alcohol and drugs with infection by the HIV virus

The benefits arising from the use of antiretrovirals, revealed from the favorable results of the tests which detect the

quantity of the viral load and the T-CD4 lymphocytes, expressed through the experience of the treatment, were illustrated by the costume termed 'balancing adherence', which was later interpreted by the participants (Fig. 1.)

The balancing of adherence shows that we must not stop taking the medication, if our CD4 is to remain way up there, and the virus really low [...] MP2

Balancing adherence shows that alcohol and other drugs decrease our defenses, since it decreases CD4 levels and lead us to get severe diseases [...] FP20.

In my case when I drink alcohol the balance stays incorrectly calibrated with more virus than CD4 [...] FP19.

In spite of not understanding how the use of alcohol and drugs acts on the appearance of comorbidities which affect various organs, and contributes towards the progression of AIDS, the participants expressed their wish to find out how this relationship occurs. With the aim of offering meaning for the understanding of this relationship, two costumes were presented, entitled: 'Mr. Healthy', and 'Mr. Sick' (Figs. 2 and 3), later interpreted by the participants.

I don't know what happens if I drink and use the medications... I would like to know... But I don't think it is very serious, because I know lots of people here who receive the treatment and drink and smoke and even use other, heavier, drugs and who have had HIV for a long time [...] FP4

They always tell me not to mix drugs with alcoholic drinks. I've never wondered why, but I think that there isn't a relation with the virus [...] PF 22.

Fig. 1 – The 'balancing adherence' costume, a representation of the benefits of adhering to the antiretroviral treatment, expressed by the favorable results of the routine laboratory tests.

Fig. 2 – The 'Mr. Sick' and 'Mr. Healthy' costumes, representations of the organs which are harmed by the use of alcohol and drugs, and of the organs which are healthy due to the acquisition of healthy living habits.

The mixture of drugs and alcohol must be bad for the liver, but no for the virus [...] MP14.

We believe that our health education strategy was adequate to improve antiretroviral therapy, since it helped in subject comprehension and patients self-care body expression.

I don't drink anymore, but my poor old liver is in a very bad way... it has to put up with so many things... There is the medication and alcohol; I want to be Mr. Healthy [...] MP3

Now, I understand: the medication combats the virus, but in combination with alcohol or drugs, can destroy my liver... I am impressed... My God... [...] FP4

Looking at "Mr. Sick", I was sure that alcohol, virus and drugs don't combine [...] FP16

Tobacco destroys the protection of my lungs... I think it is because of this that I always have a cold ... It lowers my protection... I can't stop... I get anxious, and I have to smoke... But I will think about this nasty lung ... [...] MP5

I am going to try to avoid mixing it all... alcohol with drugs because I want to stay with lungs like "Mr. Healthy" [...] MP8.

It's going to be hard to stop smoking, since the tobacco calms me down... my lung must be similar to "Mr. Sick"... that is why I always have a cough and flu... the smoke destroys protection [immune system]... I'm going to decrease the smoke since I want to be like "Mr. Healthy" [...] FP12

Discussion

The people who live with HIV/AIDS, undergoing antiretroviral treatment, expressed—through the focus group—their experiences and feelings in relation to the use of alcohol and drugs, through verbal language and the interpretation of costumes.

Fig. 3 – Use of the costumes in a health education activity for people living with HIV/AIDS regarding the use of alcohol and drugs.

The participants demonstrated, through the discourses, that the adherence to the drug treatment has meaning which is relevant to improving quality of life and social insertion, and that they are unaware of the impact which drug and alcohol use can have on reducing immunity and on the appearance of comorbidities and the progression of AIDS.

The life expectancy of people infected by HIV has been prolonged, as a result of ART. Liver, lung, neurological and cardiovascular comorbidities, and other clinical manifestations, have taken on greater importance as causes of morbidity and mortality in people living with HIV/AIDS, being associated with the infection itself through the virus, and with the prolonged use of ART.²⁴

Hepatic diseases and neurological disturbances, in particular, can be worsened through the consumption of alcoholic drinks. ART frequently has hepatotoxic effects, in addition to this, many patients who live with HIV/AIDS are also infected with hepatitis B and C, which also cause hepatic lesions. As a result, it is necessary to understand the progression of the hepatic disease in the context of infection by HIV, and alcohol use becomes an important issue in the care of these patients.¹⁵ Understanding these clients' experience with alcohol use has important implications for avoiding serious hepatic diseases.

Likewise, pulmonary health can also be impaired in patients infected by HIV who use alcohol.¹¹ Among other effects, alcohol impairs the functioning of the cells which are targets of the HIV virus, the T-CD4 lymphocytes and macrophages, increasing the reduction of these patients' immunity.²⁵

The description of the patients' experiences sheds light on repercussions relating to the continuation of drinking and smoking habits as a means of being accepted in social groups, concealing one's positive HIV serological status, and avoiding prejudice. In the light of this perspective, the strategies for preventing harm to the health of, and for treatment of, people

living with HIV/AIDS must investigate the use of alcohol and drugs in this clientele, and promote concrete actions which motivate the patients to acquire healthy living habits in order to avoid complications of the disease, in addition to emotional support for coping with the stigma.¹⁹

The presentation of the costumes in a playful way raised new meanings in relation to the disease and treatment, facilitating the patients' understanding in relation to the topic addressed, demonstrating this to be a relevant instrument in education and the health of those participants with a low educational level, with the patients expressing the wish to acquire healthy living habits, caring better for their bodies. The use of creative and innovative health actions in the guidance of these patients, in the concretization of effective care, inserts the being who is cared for within the health-illness process, as a subject who is responsible and active in self-care.²³

In the light of the repercussions noted in the present study, it is important for health professionals to be open to strengthening dialog with patients in the follow-up consultations, being alert to contradictory feelings awoken by the wish to be accepted in the social groups, which also mixed with the life histories and the results of previous experiences of dealing with antiretroviral treatment and the use of alcohol and drugs. The group activities allow experiences to be shared with other people who experience similar conditions, allowing better understanding of the treatment and of the difficulties which they need to face, and through meeting the other people, finding motivation for adhering to healthy living practices.

The phenomenological method adopted in the present study made it possible to understand the experience of people who live with HIV/AIDS involving the use of alcohol and drugs, contributing to supporting the work of the health professionals in the detecting of possible behaviors of risk and in

planning strategies for prevention and control of the complications arising from AIDS, based in a participative model of health which prioritizes listening to the patients and their understanding of the treatment, with a view to valuing the holistic aspects involved in the relationship between the use of alcohol and drugs and the progression of AIDS.

The present investigation presents some limitations for the generalization of the findings: the sample was restricted to a single locale and cultural scenario, and there was no differentiation of the accounts according to time since infection and quantity of alcohol and drugs were consumed.

It is recommended that this study design should be reproduced in such a way as to overcome the above-mentioned limitations, so as to explore other problematizations and relativizations. In this way, it will be possible to construct a more consistent panorama of the experience of patients infected with the HIV virus, involving alcohol and drug use.

Conclusions

Understanding the meaning of the use of alcohol and drugs in the routine of people living with HIV/AIDS receiving ART treatment made it possible to explore, discover, and understand their ideas and feelings. Investigating these patients' experiences is important for the organization of the health actions geared towards the care for this clientele. The knowledge produced in the present investigation favors the understanding of the routine context of the person who is cared for, contributing to the humanization of the health spaces.

Author statements

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Ethical approval

The study was approved by the Committee for Ethics in Research with Human Beings of the Federal University of Maranhão, under opinion 1,548,707. All the participants signed the terms of free and informed consent prior to joining the study.

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Competing interests

None declared.

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