Coping experiences in the work environment of men living with HIV/AIDS

ENFRENTAMENTOS EXPERIENCIADOS POR HOMENS QUE VIVEM COM HIV/AIDS NO AMBIENTE DE TRABALHO

ENFRENTAMIENTOS EXPERIMENTADOS POR HOMBRES QUE VIVEN CON HIV/SIDA EN EL AMBIENTE LABORAL

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ABSTRACT

The objective of this study was to understand the coping mechanisms of men living with HIV/AIDS in terms of their work environment. A qualitative study was carried out at a specialized outpatient clinic in Fortaleza-Ceará between March and June 2010, involving eleven men infected with the virus. Semi-structured and audiorecorded interviews were used. The statements were categorized through content analysis into the following categories: absence from work due to the infection; subterfuges used to hide the disease; disrespect for confidentiality in the work environment; suffering associated with the fear of rejection and prejudice; ways of coping after diagnosis of the disease; and the importance of work for personal accomplishment. In conclusion, men infected with HIV face counterproductive situations in the work environment, mainly evidenced by fear of discovery of the infection and prejudice. Associated with coping, absences for health monitoring purposes interfered with performance at work and increased the risk of losing their job.

DESCRIPTORS

Men
HIV
Acquired Immunodeficiency Syndrome
Working environment
Prejudice
Nursing

RESUMO

Objetivou-se apreender situações de enfrentamento experienciadas por homens que vivem com HIV/aids no ambiente de trabalho. Estudo qualitativo realizado em ambulatório especializado em Fortaleza--Ceará, de março a junho de 2010, com onze homens infectados pelo vírus. Utilizou-se entrevista semiestruturada, audiogravada, sendo os depoimentos categorizados mediante análise de conteúdo, cujas categorias foram: Afastamento do trabalho em virtude da infecção; Subterfúgios para omissão da doença; Desrespeito ao sigilo no ambiente de trabalho; Sofrimento associado ao medo da rejeição e do preconceito; Formas de enfrentamento após o diagnóstico da doença e a importância do trabalho para a realização pessoal. Concluiu-se que os homens infectados pelo HIV enfrentam situações contraproducentes no ambiente de trabalho, evidenciadas principalmente pelo temor da descoberta da infecção e pelo preconceito. Associadas ao enfrentamento, as ausências para o acompanhamento em saúde interferiram no desempenho do trabalho que implicariam no risco de perda do emprego.

DESCRITORES

Homens

HIV Síndrome de Imunodeficiência Adquirida Ambiente de trabalho Preconceito Enfermagem

RESUMEN

Se apuntó a entender situaciones de enfrentamiento experimentadas por portadores de HIV/SIDA en el ámbito laboral. Estudio cualitativo realizado en ambulatorio especializado en Fortaleza-Ceará, de marzo a junio 2010, con once hombres infectados por el virus. Se utilizó entrevista semiestructurada, grabada en video. categorizándose los testimonios mediante análisis de contenido, determinándose las categorías: Alejamiento del trabajo en virtud de la infección; Subterfugios para omisión de la enfermedad; Irrespeto al secreto en ambiente laboral; Sufrimiento asociado al miedo al rechazo y del preconcepto; Formas de enfrentamiento luego del diagnóstico de la enfermedad e Importancia del trabajo para la realización personal. Según se concluye, los hombres infectados por HIV enfrentan situaciones contraproducentes en el ámbito laboral, determinadas fundamentalmente por el temor al descubrimiento de la infección y por el preconcepto. Asociadas al enfrentamiento, las carencias para el seguimiento de salud interfirieron en el desempeño laboral e implicaron riesgo de pérdida de empleo.

DESCRIPTORES

Hombres
VIH
Síndrome de Inmunodeficiencia Adquirida
Ambiente de trabajo
Prejuicio
Enfermería

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INTRODUCTION

When a person discovers that she/he is infected with HIV. it marks the course of their and their family's lives because of the acceptance, adaptation and incorporation of new behaviors to keep healthy and, thus, prolong life to the longest.

In view of the increased life expectancy of infected individuals, AIDS is now referred to as a chronic disease, which implies new challenges to patients and healthcare professionals, which include: the social reinsertion in the labor market and in school, the promotion of healthy habits, including eating with quality and exercising, as well as maintaining sexuality, with the right to motherhood and fatherhood(1).

The social inclusion of HIV-positive individuals in the workplace is considered positive for their quality of life. However, the reality that is observed is one of discrimination by employers as well as co-workers. This fact culminated in the exclusion of the most elementary citizenship rights, with includes work(2).

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In addition to this problem, workers suffer several forms of discrimination, which are evidenced by: the obligation to take anti-HIV tests during recruitment and, consequently, not being hired in the case of a positive test result; dismissal because of a positive HIV-test result; being excluded from the training program and from promotion opportunities: ostracism by co-workers: exclusion from the company's health plan, among other forms of prejudice⁽³⁾.

In order to focus on the coping experiences of men with HIV in the labor market there is a need for a renewed view, which, in turn, requires a scientific and intellectual attitude that

integrates social inclusion and its relationships with the working world(2).

Workers have to foster the pathways to live in a structure and assign new meanings to life values and healthcare. Here, one's perception of the contradictions regarding their body emerges as a fully concrete fact. They gain a destructuring outline that is far from being organized or controlled, being fascinating and frightening at the same time. The body, initially criticized as a source of pleasure purged by the infection, is now seen as a working tool, which generates a duality between the anxiety towards the disease and the production regulation that apparently has no direct relationship with the training and qualification for the job, gender, age, competence and abilities, time and movement, rational and logical investments of the act of working, technology, workers' rights, and others.

Reflecting about these aspects, it is worth illustrating that the AIDS epidemics accounted for the death of 28

million workers worldwide until 2005. The problem and its solution still require further explorations and the discovery of meanings that would minimize the restlessness before the social neglect that still persists in society. We live a tendency without setbacks or hesitations. By 2015, the toll of the disease will have been 74 million lives. This situation places AIDS as a significant cause of death in the working world, definitely affecting the social, economic and cultural structure of countries, and, thus, consisting of a serious threat to the working world⁽⁴⁾.

The challenge for creating devices to support initiatives to cope with the disease, assumed by government leaders and institutions such as the World Health Organization (WHO) and International Labour Organization (ILO) originated the Consensus Statement on AIDS and the Workplace. As stated, work does not promote any risk of the virus being acquired or transmitted from one worker to another, or from a worker to a client, or from a client to a worker. It is also reinforced that HIV infection is no reason to end the work relationship⁽⁵⁾.

> In Brazil, since the early 1990's, it has been legally prohibited, in the federal public service, to demand HIV tests in pre-employment and periodical health examinations: it is stated that being HIV-positive does not harm the individual's working capacity, and maintaining a social and professional contact with HIV-positive individuals does not configure a risk of becoming infected⁽⁶⁾.

> The highlight on establishing risk-free relationships in the workplace encompassed new elements of the working condition: however, the everyday existence of this relationship does not set limits to sharing cultural values and ideas that permeate the whole process of being inserted in the work-

ing world, and, for this reason, the referred consensus statement does not address the thought that the worker is exposed to other life fragments that limit their interactions within the workplace.

From the perspective of labor relationships/employment, AIDS brings the following issues into discussion: the management of the working processes, the fundamental rights of the worker and changes in the working world that involve a network of complex relationships mechanisms and activities of HIV-positive workers. It is important to outline that many workers express wishes different from that of the other workers, which directly refer to clear acknowledgement that work is a factor that links health and disease. Factors such as unemployment, informal employment, and, most of all, being excluded from the labor market become associated and lead the individual towards a worsened health condition⁽⁷⁾. On one side, there is a contradiction that defends the individual's right, as a citizen, to work, not being discriminated, and



the confidentiality of their health condition, while on the other side, there is the community's right to health⁽⁸⁾ and also the authority and power of the organization, which is prepared to generate profits and defend the economical interests.

In the workplace, AIDS is not understood as a disease similar to others to which the company and institutions owe certain responsibilities, as segments of civil society. Contrarily, the disease causes problems in the workplace, as the companies are incapable of managing the situation⁽⁹⁾.

There is evidence of the need for companies to disseminate the recommendations reported by public organization such as the ILO so that the rights of HIV-positive individuals are respected, which include: not performing an anti-HIV test in the pre-employment examination; maintaining workplace confidentiality of any information regarding the disease as well as avoiding any situation that could cause constraint or prejudice towards the worker and strict rules regarding the confidentiality when accessing the personal data about a worker's HIV.

Within this context, recognizing the contradiction of the working world and the ways of coping used by the HIV-positive men in their everyday practice in view of the scarcity of studies on this issue, justify developing the present study.

OBJECTIVE

To understand the coping situations that HIV-positive men experience in the workplace.

METHOD

This is an exploratory, descriptive, qualitative study. Literature states that the qualitative approach permits to elaborate answers to intricate and particular questions, because it works with the universe of meanings, values, beliefs, motives, aspirations and attitudes. Thus, its focus transcends the mere operationalization of variables, and encompasses a deeper area of relationships, processes and phenomena⁽¹⁰⁾.

This study was developed during the months of March and June of 2010, at the HIV specialist ambulatory service, at *Hospital São José de Doenças Infecciosas* (São José Infectious Disease Hospital) in Fortaleza-Ceará. The participants were eleven HIV-positive men. The selection criteria were: 18 years of age or older; male; refer being employed or having been employed some time after becoming aware about their being positive for HIV. The number of subjects was not determined based on a numerical representation criterion, but on the representation regarding the sharing of experiences considered fundamental for the investigated issue. The sample size was not

determined, but the group of participants was considered appropriate to portray, by means of interviews, the experiences, meanings, values and behaviors associated to coping with various situations in the workplace in view of the HIV infection.

Data collection was performed using a semi-structured form aimed at gathering information regarding the participants' identification and the situations they have experienced in the workplace that are associated to their being HIV-positive. With the purpose to unveil the study objective, the following guiding question was used: Could you tell me if you have ever experienced any situation of constraint or happiness at the workplace related to your positive diagnosis for HIV?

With a view to guarantee the quality and trustworthiness of the data, the interviews, which lasted forty-five minutes, were audio-recorded upon the participants' consent and were performed in a private room.

As recommended, the interview contents were fully transcribed and subjected to content analysis. Literature defines this method as a group of communication analysis techniques that aims to achieve, by means of systematic and objective description procedures of the message contents, indicators that would allow for inferring knowledge related to the conditions in which these messages were produced and received. Therefore, it permits to analyze the participants' opinion, in between the lines, i.e., not being exclusively restricted to words that are stated directly, but also those that are implied in the discourse⁽¹¹⁾.

The analysis originated the following categories: absence from work due to the infection; subterfuges used to hide the disease; disrespect for confidentiality in the workplace; suffering associated with the fear of rejection and prejudice; ways of coping after diagnosis of the disease; and the importance of work for personal accomplishment.

As required, the study complied with the recommendations of resolution 196/96 regarding studies involving human beings and was approved by the Research Ethics Committee at *Hospital São José de Doenças Infecciosas*, under protocol number 60/2009. All the participants provided written consent. Aiming at preserving the subjects' identity, they were referred to by using the letter "I" (interviewee) follower by numerals according to the order in which the interviews were performed.

RESULTS

As mentioned above, the participants were eleven HIV-positive men, of age between 25 and 50 years. The mean education time of the participants was 8.7 years, while the interval time since they became aware about the infection was from one to nine years. In terms of their employment situation, four men were unemployed, three



had a formal job, three had informal jobs, and one was retired due to the serious effects of the disease. The income of most participants was between one and two minimum salaries (at the time the minimum salary was R\$ 465.00, or US\$ 233.00).

The participants' statements or discourses are presented in Chart 1. This chart shows the categories and main excerpts related to the participants' experiences and their ways of coping with situations at the workplace associated with being HIV-positive.

Chart 1 – Categories and statements of the eleven men with HIV

| Category | Statements |
|---|--|
| Absence from work due to the infection | () I had fevers, strong headaches, I fainted at times () I couldn't hide the disease any longer () E3 () I have already turned down jobs, because I can't balance it with the treatment, in case, here, right, and the schedule and everything else, so in that case I can't work ()E4 () it started out as a normal disease () then I began to have fevers, diarrhea () I was hospitalized () missed work and people would ask me why I wasn't coming to work () E10 () I was employed when I got sick () I was hospitalized for about 4 months because of some serious diseases () I couldn't work any longer () E11 |
| Subterfuges to hide the disease | I was very careful at work, I know there is a lot of prejudice () E1 () it's because I didn't even mention that I have this disease, because if I say that people will withdraw, especially at work E2 () I rather they do not know [the diagnosis of the disease], because once I travelled to sell natural medications then the employer terminated the trip, I wet back home without any money E3 |
| Disrespect for confidentiality in the workplace | At work they said: your position is open when you get better and come back. The word that I had HIV spread out and my boss didn't call me any more. E10 () I felt embarrassed because he was incapable of keeping the confidentiality [referring to a co-worker]. This is very painful for us, people have an incredible prejudice against us () feeling the prejudice is very painful, people see us and think we're a monster E11. |
| Suffering associated with the fear of rejection and prejudice | It is complicated because of people's prejudice and lack of information () when I think about these places [referring to work places], in these situations, without being prepared for the rejection () it's very delicate E1 I'm afraid in terms of my students, because when I'm teaching a class that addresses these issues [referring to HIV] I can see there is still a lot of prejudice () E8 I think that for people who are infected and will enter the labor market it is rather complicated, first because we know that jobs today barely make you slaves, and if they find out you are infected, you will have to face the prejudice E7 I'm searching [referring to his search for a job], like, for a position in construction, because if I look into any other field and take a blood test they will detect it () E11 |
| Ways of coping after diagnosis of the disease | I just decided not to look for a job any more, because it has already been difficult for people who are not infected, so for those who are it's farther more complicated () E1 () some people at work who I could tell, starting with the personnel department, took it nicely and they went home to visit me () E6 () as soon as I retired, like, solved the financial issue, I started studying, taking up a language course, today I study English and I'm fighting to attend a higher education course. I'm running after the time that was lost E7 I trusted them [referring to bosses] and asked that they would change their behavior, and continued treating me the same way as anybody else, and it was a joy. I have a greater affection for my coordinator. She hugs me and that brought us closer E8 |
| The importance of work for personal accomplishment | Work is a part of life, it's natural, () we feel like a part of it, right, working E4 I hope to work, move on with my life, look after the bar, it is how we make our living E9 |

DISCUSSION

The analysis of the data in the category *Absence from work due to the infection* revealed that men stated that in order to look after their health, it was required continuous and periodical medical follow up. These conditions are inherent to the HIV treatment, which require monthly or periodical appointments at the health service, causing work absences or delays because the health service is open only during business hours. Therefore, the workers' constant presentation of medical notes, despite not including any information stating *HIV/AIDS*, marks the beginning of a process of visibility of their condition and their stigmatization.

It was observed that the individual's health status affected their decision about staying or not in the job. In

order to avoid embarrassing situations, in addition to choosing to remain silent, the patient quits the job if any collateral effects of the antiretroviral medication or symptoms that indicate an advanced disease status emerge.

Within this context, it was evidenced that companies have weaknesses in terms of dealing with issues specific to the disease, such as the workers' having to leave work because of medical appointments and the fear of transmission within the workplace. In fact, the logic of the capitalism at the national level contributes with this deficit, most of all because of the legal determination regarding the responsibility that companies and institutions have towards their employees with HIV. This issue is present in between the lines of the recorded statements⁽⁹⁾.



As indicated in the category *Subterfuges to hide the disease*, studies show these situations when they reveal that HIV-positive workers are often dismissed, or not hired, because, in order to follow their health condition with medical care, the employee has to be away quite often, due to appointments, examinations, or, yet, to obtain medications ⁽¹²⁾.

Also regarding the statements of this category, as can be seen, workers with HIV/AIDS choose not to reveal their diagnosis, fearing embarrassment and losses at work, besides likely being dismissed.

In general, the coping phenomena understood through the subjects' statements reveal a diversity of anguishing feelings, such as fear, shame, stigma, and the social isolation in view of their discovering the diagnosis, issues mentioned in the category and found in literature⁽¹³⁾.

Regarding the category *Disrespect for confidentiality in the workplace*, confidentiality regarding the disease is justified by the subjects as a form of protecting themselves from prejudice, discrimination and shame, set by the social representations of HIV/AIDS.

After becoming aware about the diagnosis of the disease, the HIV-positive patient faces, within their environment of social interaction, the experience of being exposed, discriminated against and isolated. Therefore, the individuals are required to learn how to cope with the situation, which requires obtaining social and personal resources. In view of this situation, these patients prefer not to comment about their health condition with others, and, therefore, try to hide any information that would disclose their condition, by establishing certain criteria to avoid any socialization⁽¹⁴⁾.

In an attempt to hide the disease, many patients omit their true health conditions when asked about the treatment that force them to attend the health service so frequently. However, according to the statements of the present study subjects, not always is it possible to maintain confidentiality, and, when their health condition regarding HIV is disclosed, employers and co-workers demonstrate prejudice, exposing the patient to a situation of constraint or even their voluntary or arbitrary dismissal⁽¹⁴⁾.

The infection by HIV does not justify dismissing the individual from work. People with HIV and any associated disease are capable of working in a location considered appropriate and clinically adequate for performing the professional activities.

What has been defended for long is guaranteeing the job of individuals with HIV: their job contract cannot be terminated by theme simple fact that they carry the virus in their body. Thus, the guarantee of employment would be the workers' right to remain in their job, protected under the Constitution of 1988⁽¹⁵⁾.

In the category Suffering associated with the fear of rejection and prejudice, the individuals with HIV feared that

if their co-workers found out about their health condition, there would be prejudice. In some cases, the fear of transmission also generates a certain discomfort at work, while in others, discrimination becomes a strong factor for their not returning to work⁽¹⁶⁾.

When referring to AIDS, fear was often emphasized and the existence of the disease appears as a threat. The possibility of being infected raises concern, because AIDS is represented with great dread. Furthermore, the fact that there is no cure for the disease and the risk of infection suggest a catastrophe that, often, should not even be mentioned (17).

When diagnosed, AIDS overwhelms the patient with doubts and uncertainties; such as whether the disease will develop or not and how painful and inevitable its progress will be, forcing the patient to live permanently with the certainty of an early death⁽¹⁸⁾. In addition, the patients' concern about their infection being revealed is often self-imposed by the fear of being subjected to prejudice and stigmatization⁽¹²⁾.

As observed, some patients who were employed, quit their jobs because of the fear of being known to have HIV; others were fired because of prejudice; and others gave up on looking for a job due to their fear of pre-employment examinations.

However, it is illegal to force candidates to taking an anti-HIV test, in addition to being highly discriminatory, as determined in several legal ordinances, such as Law number 9029/95. Similarly, the ministerial decree 869, of 11 August 1992 prohibits: in the federal public service, to demand a test to detect the human immunodeficiency virus in either pre-employment or periodical health examinations⁽⁶⁾.

According to the statements, today, many of the subjects are either unemployed or keep an informal job. They fight to get their retirement or right to sickness allowance to minimize their financial burdens. Jobless, they become anxious and depressed. They were once contributors and now they see themselves as a burden to society.

In the study, some reports referred to episodes of discrimination at the workplace due to the lack of confidentiality by others who became aware of the worker's HIV infection.

Hence, it is understood that the issue regarding the disclosure, at the workplace, of the worker's condition of being HIV-positive is complex and represents a threat to their continuing in the job. When their HIV-positive *status* is revealed to their superiors or co-workers, they face difficult situations at the workplace. It is, therefore, necessary to deal with the prejudice of withdraw from peers. Within this context, the results confirm that their silence represents a search for self-protection and a way of coping with HIV/AIDS.



Thus, one of the problems revealed in the workplace is the fear of their co-workers finding out about their infection, and the resulting prejudice. In some cases, the fear of transmission also causes a certain discomfort at work $^{(16)}$.

Many of the perverse consequences of the stigmatization of people and/or specific groups involve discrimination in public spaces and private institutions, which generate hostility, segregation, exclusion and/or self-exclusion of individuals whose HIV-positive *status* is revealed. The AIDS stigma overlaps the preexisting stigma associated with different social groups, such as homosexuals, sex workers and drug users, thus evoking multiple meanings. These pre-conceived concepts and images are part of a cultural and social matrix that establishes differences, creates hierarchies, and sanctions structures of social inequalities⁽¹⁹⁾.

The few subjects that revealed their HIV-positive condition to some people reported experiencing prejudice from their friends or at the workplace.

By observing the statements in the category *Ways of coping after diagnosis of the disease*, it is evidenced that the subjects seek different forms of minimizing the suffering in face of their unemployment.

Facing or coping with these situations triggers deep stress in these individuals. According to literature, this type of coping has been defined as the cognitive and behavioral efforts towards managing the intrinsic and extrinsic demands of the individuals, which are evaluated as an overburden to their personal resources (20).

Therefore, living with a disease that implies discrimination, such as AIDS, requires the individuals to deal with different situations. In this setting, the search for religious support has been one way of achieving adaptive results in the process of coping with AIDS.

In the present study, taking initiative and having the courage to face the disease start with believing in a *God*; next, the patient's decision to seek alternative therapies is used as an attempt to dodge the different coping situations.

As observed in the category *The importance of work for personal accomplishment*, having a job surpasses the individuals' economical needs, it is, most of all, a source of well-being, self-respect, dignity, self-esteem, and citizenship. These feelings can improve their quality of life, and promote *social reinsertion*, considering that working means they are contributing with the society, hence they feel useful⁽²¹⁾. This is further evidence when gender issues are considered, because for men work is a source of social identity⁽¹⁶⁾.

The process of disseminating the news about the HIV infection proliferates an *epidemics of meaning*, implying that the individual must constantly cope, either in silence

or explicitly, with stigma and discrimination⁽¹⁶⁾. To men, living intensively and with quality of life requires relating with the world, and, most of all, counting on the support from family, friends and from those from the workplace⁽²²⁾.

CONCLUSION

In general, it appears that living with HIV in the work environment is not a harmonious situation. The diagnosis of the disease triggered a series of experiences with different effects on the HIV-positive individual, most of which are counterproductive. Furthermore, the need to feel useful and productive contrasts with the obligation of being absent from work due to the manifestations of the disease and attending clinical follow up.

In view of the fear of having their diagnosis revealed and, thus, produce feelings of prejudices and rejection from employers and co-workers, the HIV-positive men choose to be silent about their disease and consciously decide to quit their jobs as a coping strategy. There were also reports of the embodiment of prejudice, evidenced by the disrespect of the confidentiality, dismissal after knowing about their diagnosis and several other situations that caused constraint at the workplace.

This study reinforces the thesis that understanding the issues related to HIV infection among productive men is a complex task, as they carry the stereotype of a disease associated with connotations of devaluation, which have an impacting effect on their right to work. From this perspective, the present study findings may help companies and employers reflect about how to support and include HIV-positive workers in the work environment. On the other hand, workers should also seek asserting their legal rights, through and active by notifying situations involving prejudice and exclusion at the workplace.

This study does not aim to exhaust the investigation about experiences and the ways that HIV-positive men cope with the disease in the labor market. Rather, the purpose is to raise awareness about the theme, as a first step to implement specific methodological approaches, as well as the utilization of a larger study sample. Further studies should investigate the social representations of employers towards HIV. Moreover, interventional studies should be performed, in addition to investigations of public policy studies that encourage including HIV-positive individuals in the context of labor should be prioritized.

In view of this reality, it is highlighted that nurses, particularly those who specialize in occupational nursing, are promoters of the support and inclusion of HIV-positive individuals in the workplace. Therefore, we hope to encourage equal and humanized treatment, free from prejudice, that would promote, above all, the quality of life of this clientele in terms of work, which is considered one of the main forms of affirmation of men.



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