

Occupational roles of HIV-positive people and perception of prejudice suffered

Papéis ocupacionais de pessoas soropositivas e percepção sobre os preconceitos sofridos

Roles profesionales de personas seropositivas y percepción de los prejuicios sufridos

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Objective: to describe the occupational roles of people living with HIV, and their perception of prejudice suffered and self-prejudice. **Methods:** a quantitative-qualitative, exploratory, descriptive and cross-sectional study, with people living with HIV for at least six months, hospitalized in a unit for the treatment of infectious-parasitic diseases between April and June/2018. The Occupational Roles Identification List was used and interpreted by descriptive statistics and thematic content analysis. **Results:** five men and two women participated, with a mean age of 40 years; the average time they lived with HIV was 13.14 years; Christian-based religion or belief in God; having a profession with paid work; infected at a young age. In occupational roles, all were *Students* in the past, and 43% still intended to return. The same performance of roles occurred in all *Domestic Service* in the past and, for *Family Member*, in the present and in general, there was a reduction of occupational roles in relation to the past. Three thematic categories were elaborated: *Prejudices*; *Negative Feelings*; and *Living with HIV and social support*. **Conclusion:** HIV generated prejudice and negative impacts on occupational roles.

Descriptors: HIV; Occupational Therapy; Prejudice.

Objetivo: descrever os papéis ocupacionais de pessoas que vivem com HIV, e sua percepção sobre preconceito sofrido e auto-preconceito. **Método:** estudo quanti-qualitativo, exploratório, descritivo e transversal, com pessoas que viviam com HIV há pelo menos seis meses, internados em uma unidade para tratamento de doenças infecto-parasitárias entre abril e junho/2018. Utilizou-se a *Lista de Identificação de Papéis Ocupacionais* e interpretou-se pela estatística descritiva e análise de conteúdo temática. **Resultados:** participaram cinco homens e duas mulheres, com média de idade de 40 anos; o tempo médio em que viviam com HIV de 13,14 anos; religião de base cristã ou acreditava em Deus; tendo profissão com trabalho remunerado; infectados ainda na juventude. Nos papéis ocupacionais, todos foram *Estudantes* no passado, e 43% ainda pretendiam retomar. O mesmo desempenho de papéis ocorreu em todos nos *Serviço Doméstico* no passado e, para *Membro de Família*, no presente e no geral, verificou-se redução dos papéis ocupacionais em relação ao passado. Elaborou-se três categorias temáticas: *Preconceitos*; *Sentimentos Negativos*; e *Convívio com o HIV e apoio social*. **Conclusão:** o HIV gerou preconceitos e impactos negativos nos papéis ocupacionais.

Descritores: HIV; Terapia Ocupacional; Preconceito.

Objetivo: describir los roles ocupacionales de personas que viven con el VIH; y su percepción sobre los prejuicios sufridos y los autoprejuicios. **Método:** estudio cuanti-cualitativo, exploratorio, descriptivo y transversal, con personas que viven con el VIH desde hace al menos seis meses, internadas en una unidad de tratamiento de enfermedades infecto-parasitarias entre abril y junio de 2018. Se utilizó la *Lista de Identificación de Roles Ocupacionales* y se interpretó mediante la estadística descriptiva y el análisis de contenido temático. **Resultados:** Participaron cinco hombres y dos mujeres, con una edad media de 40 años; el tiempo medio que llevaban viviendo con el VIH era de 13,14 años; religión de base cristiana o creían en Dios; tenían profesión con trabajo remunerado; infectados aún en la juventud. En cuanto a los roles profesionales, todos fueron *Estudiantes* en el pasado y el 43% de ellos seguía teniendo la intención de retomar los estudios. El mismo desempeño de roles se dio para todos en el *Servicio Doméstico* en el pasado y para el *Miembro de la Familia* en el presente y en general hubo una reducción de los roles ocupacionales en comparación con el pasado. Se elaboraron tres categorías temáticas: *Prejuicios*; *Sentimientos negativos*; y *Vivir con el VIH y apoyo social*. **Conclusión:** el VIH ha generado prejuicios e impactos negativos en los roles ocupacionales.

Descritores: VIH; Terapia Ocupacional; Prejuicio.

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INTRODUCTION

The human immunodeficiency virus, known as HIV, is a pathogen that, when in contact with the immune system, alters the DNA of cells, makes copies of itself, damages this system and stops the human organism's ability to respond to antigens. This set of problems caused to the body by HIV is called the Acquired Immunodeficiency Syndrome – AIDS¹.

According to the report published by UNAIDS in December 2017, in 2016 there were 1.8 million people living with HIV in Latin America, and it is estimated that, in the same year, there were 97,000 new infections. Despite this, between 2010 and 2016, the number of AIDS-related deaths in Latin America dropped by 12%².

The drop in the number of deaths may be associated with the quality of life of people with HIV/AIDS, which has improved in recent years with advances in treatment, and the meaning they attribute to life; as well as the level of involvement with medical treatment and the social changes generated³. However, despite progress in health care for this population, society has developed and maintains a stigma about this disease, which can lead to changes in the occupational roles of people living with HIV³.

Occupational roles consist of productive or leisure behaviors. Productive activities are those who contribute with some service or convenience that others need or want; and leisure activities are characterized by activities such as hobbies, sports, recreation and not linked to work, paid or not⁴.

HIV infection affects the individual in areas that go beyond their physical health, such as emotional, social and sexual life. Individual, cultural, social and emotional factors are related to the impact of diagnosis, treatment and daily living with a chronic disease⁵. The feeling of fragility is aggravated, as the people affected are mostly young people in the productive phase, who fail to perform their roles the way they would like⁶. In turn, Occupational Therapy seeks to understand disability and its implications for the performance of occupational roles, in order to assist in the establishment and recovery of these roles⁴.

Despite the long time that has elapsed since the beginning of the HIV/AIDS epidemic, in mid-1981, the presence of prejudice and stigmatization in the daily lives of HIV-positive people is still noted today. In addition, prejudice against this population is not restricted to common sense, sometimes it extends to health professionals. The stigmatizing idea comes from the inference that HIV-positive people have a single sexual orientation (homosexuals), have a promiscuous sex life

and maintain illegal behaviors, such as drug use⁷⁻⁹.

HIV and AIDS, as well as other diseases that have had a moral judgment on their carriers, diminish the social value¹⁰ of those who carry them. They lead the individual to suffer not only the biological difficulties of the disease, but also to lose part of their significant personal interactions and to face themselves through the social gaze, being a victim of the virus, stigma and self-prejudice, the one experienced by the individual against themselves¹¹. Thus, this study aims to describe the occupational roles of people living with HIV; and their perception of prejudice suffered and self-prejudice.

METHODS

This is an exploratory descriptive cross-sectional study of a quantitative-qualitative nature. The participants were people who had been living with HIV for at least six months and who were hospitalized in a unit for the treatment of infectious and parasitic diseases at a hospital linked to a federal public university in the state of Minas Gerais.

The sample was chosen for convenience and data collection took place between April and June 2018. The criteria established for inclusion were: being seropositive with a diagnosis recorded in the service's medical records for at least six months; and being hospitalized in the unit during the research data collection period. The unit had a capacity of 10 inpatient beds.

The time of living with the diagnosis was determined by the criteria of Vargas, who considered as "*chronic conditions*" any pathology or condition of chronicity, lasting more than six months¹², in order to reach the respondents' opinions about changes in their occupational roles after diagnosis and assess whether they had been a victim of prejudice.

An Occupational Role Identification List was used, which is a reliable assessment tool that aims to extract information about a person's occupational roles. It provides data on the individual's perception of their life, data regarding the degree of importance of each role and complementary information on a person's ability to maintain a balance between roles¹³.

Occupational roles consist of productive or leisure behaviors. Such roles organize behavior, contributing to the personal identity of individuals, leading social expectations to fulfillment, organizing the use of time and involving individuals in the social structure¹³. Numerical values were assigned to these data, which were subsequently subjected to a descriptive statistical analysis¹⁴.

The interview was also used in the search for useful data to explore the set of opinions about living with HIV and the perception of prejudice suffered due to the disease. The following questions were used: 1) *Have you ever been a victim of prejudice (or felt offended in any social situation) for having HIV?* 2) *Do you find yourself depriving/avoiding doing things because you have HIV?*

Data from the Occupational Roles Identification List was analyzed, raising the frequency of occupational roles performed over time (past and present) and what other roles the participant intended to play, as well as the degree of importance attributed, namely: student, worker, volunteer, caregiver, domestic service, friend, family member, religious, hobby, participation in organizations¹³.

From the open questions, a complete reading of all the material was carried out in an exhaustive way, seeking to have a global vision, to learn particularities, to elaborate initial assumptions that would serve as a parameter for the analysis and interpretation. Thus, the initial classification forms were chosen and the theoretical concepts were determined.

Subsequently, we sought to dialogue with the parts of the analysis text, identifying, through inferences, the nuclei of meaning pointed out by the text fragments in each class of the classification scheme, creating and dialoguing with the nuclei of meaning with the assumptions initials. The interpretative synthesis was constructed through an essay that would dialogue with the data found in the research¹⁵.

Respondents signed the Free and Informed Commitment Term and chose a fictitious name to guarantee confidentiality and preserve privacy, favoring more open communication. This research had the consent of the Hospital de Clínicas for its accomplishment and approval of the Research Ethics Committee of the Universidade Federal do Triângulo Mineiro, according to the CAAE opinion No 83027518.7.0000.5154.

RESULTS

Seven people participated; five were male and two were female; the mean age was 40 years; the average time they lived with HIV was 13.14 years; Christian-based religion or belief in God; all declared to have a paid job; four men were married and the women were single; most were infected by the virus in their youth, ranging from 16 to 27 years of age, with the exception of one of them, who was diagnosed at age 43 (Table 1).

Table 1. Characterization of people living with HIV/AIDS. Uberaba/MG, 2018.

Fictitious Name	Age	Sex	Marital Status	Occupation	Religion	Time of Diagnosis
Adenísio	43	M	Married	General Services	Believes in God	16 years
Andreia	38	F	Single	Cleaning Assistant	Spiritists	11 years
Bauer	55	M	Single	Chemical Dependency Technical Coordinator	Evangelical	12 years
Francisca	34	F	Single	Housekeeper	Catholic	08 years
Garotinho	35	M	Married	Motorcycle Taxi-Driver	Believes in God	13 years
José	50	M	Married	Machine Operator	Believes in God	23 years
Otávio	25	M	Married	Waiter	Agnostic	09 years

In occupational roles, all were *Students* in the past, and 43% still intended to resume this role. The same role performance (100%) occurred in the *Domestic Service* categories in the past and for *Family Member* in the present. There was a 14% increase in the performance of *Family Member* roles and 15% in *Hobby/Amateur* roles. Also, 71% of those surveyed reduced the occupational roles performed in relation to what they had in the past (Table 2).

Table 2. People living with HIV/AIDS according to occupational roles over time. Uberaba/MG, 2018.

Occupational Roles	Past	Present	Future
Student	100%	0%	43%
Worker	86%	29%	71%
Volunteer	71%	14%	57%
Caretaker	71%	57%	57%
Domestic Services	100%	86%	71%
Friend	86%	86%	71%
Family Member	86%	100%	86%
Religious Person	29%	29%	29%
Hobby/Amateur	71%	86%	57%
Member in Organizations	71%	14%	29%

Regarding the degree of importance of occupational roles, 57% attributed no importance to *Member in Organizations*; 86% gave some importance to being a *Friend* and 57% gave a lot of importance to: *Student*, *Worker*, *Caregiver*, *Family Member*, and *Religious Person* (Table 3).

Table 3. People living with HIV/AIDS according to the degree of importance of occupational roles. Uberaba/MG, 2018.

Occupational Roles	No importance at all	Some importance	A lot of importance
Student	14%	29%	57%
Worker	0%	43%	57%
Volunteer	0%	71%	29%
Caretaker	0%	43%	57%
Domestic Services	0%	57%	43%
Friend	0%	86%	14%
Family Member	14%	29%	57%
Religious Person	14%	29%	57%
Hobby/Amateur	14%	57%	29%
Member in Organizations	57%	29%	14%

From the content of the speeches, it was possible to elaborate three thematic categories, namely: *Prejudices*; *Negative Feelings*; and *Living with HIV and social support*.

Prejudices

In this category, suffering was shown when perceiving prejudiced and/or embarrassing situations due to HIV, both in the family environment, in their circle of friends or in social life. It was noticed in the reports that the stigmatization of close people, who could have been support networks, left negative emotional marks:

"Oh, a lot of humiliation on the street, discriminated by everyone, they talk, point fingers, curse... I couldn't sit at the door of my house because they would already start laughing, then my father would hear them laughing, he would come and sit there with me." (FRANCISCA)

"Wow, I was with some colleagues, then a colleague mentioned it and the person said: God, it's bad for us to be close to this person, because we can get this disease'." (OTÁVIO)

"A cousin of mine, who was a very good friend, and when he found out I was HIV positive, he became like an enemy of mine and exposed me on the bus, shouted that I was HIV positive for everyone to hear, for my wife; I felt really down, I felt really depressed." (JOSÉ)

Also, self-prejudice with one's own health condition and/or deprivation of maintaining romantic relationships was reported, mainly for fear of rejection by partners, with social distancing for fear of judgment, to avoid invasion of privacy that can remember unpleasant situations or that were forgotten:

"Since I know, I've moved away from some people, yes, not to ask me questions, although I don't think about what others think, but it's good to avoid... I prefer to walk away. I prefer animals, they recognize what you do for them, people don't. My dream is to live on a farm so I can have more animals and be alone there, away from people." (ANDREIA)

"Today, for example, I'm afraid of being alone, so it becomes a difficult thing... I'm not going to say that I created a cocoon, but then I created a world of my own, you know. It's very difficult, you know, it's really difficult to see people turn their backs on you, to let an illness speak louder than love... But the annoying thing about all this is that when you start to like a person, then you have to say 'hey, wake up, wake up because you can't no, you can't', and also, no one accepts it, no matter how much the person says they love you, that they found the right guy, that everything will be all right, that they did I have been after a person for a long time, it is very difficult for them to accept it, you take it and open your mouth and say: 'look, I have something to tell you, I am HIV positive'; then blocks you on the phone, may even call the police. It's hard, but it's the truth, and that's where I have to take it and deprive myself and walk away and be in this pain." (BAUER)

"My daughter doesn't know, people don't know either, they think I'm a drug user, they think I use crack, when in fact "anhanh", actually my immunity is low, if get an opportunistic disease... My kid will only know when God speaks (that is, when he dies)." (GAROTINHO)

Negative Feelings

The main ones were: anger, sadness, denial of the disease, regret of the situations that led them to contract the virus, anguish in relation to HIV and the personal impacts resulting from it:

"I didn't want to take medicine, I wanted to kill myself." (FRANCISCA)

"I still can't live with the disease, there are days when I get angry, but unfortunately it's this annoyance. [Do you know when you contracted the disease?] I know, it was my ex-husband, when I met him, I had no idea... But he didn't lie to me, he said he had his suspicions, but I didn't believe it, when I got pregnant I found out... It's because I didn't believe it, I looked for it, understand? That he told me and I didn't believe it, I had no idea what it was and after the person attests that the person will stop to think. [Did you get angry with him?] No, not until then, it gave me my life." (ANDREIA)

"I fell into depression, I stopped taking the medication one year ago, one year and a half, difficult time, continuous use of a lot of marijuana, use of beer, cachaça – stopped all the medication." (GAROTINHO)

Living with HIV and social support

In this category, living with HIV and daily complications were reported. It was also identified that, during and after the HIV discovery process and initiation of treatment, support was received to deal with this health condition. This support came from people from the family nucleus and also from the team of health professionals:

"Very worried about the disease, yes, I take care of myself a lot." (BAUER)

"I try to live normally." (JOSÉ)

"Just move on, lift your head and that's good." (OTÁVIO)

"The doctor saw how shaken I was – [doctor] I'll help you, bring her here - [doctor asked him to take his wife for an HIV test, and he would help him keep her secret] – she = nothing; the baby = nothing. [Did you keep it a secret until when?] I kept it a secret until the day of delivery – the doctor was present, he gave assistance." (GAROTINHO)

"My family used to say that so I didn't care what others said on the street, it was not something out of this world, many people had it, it was normal, it was just being treated, that those on treatment live much longer than other people. I went to the psychologist, I went to the psychiatrist, I talked more with my father, at home with my brothers." (FRANCISCA)

"But he accompanied me both for the exam and for the result (the father)." (JOSÉ)

DISCUSSION

The marital relationship is a protective factor against the worsening of chronic diseases, possibly because there is a partner, people have more social support¹⁶.

Men are more infected by the disease, which was confirmed in a 2015 study¹⁷, which analyzed 142 medical records of patients admitted to the university hospital, who died, describing a socio-demographic profile consisting mainly of a population of men, young and single¹⁷.

Another gender HIV prevalence survey found that men are more susceptible to infection than women. Some likely hypotheses for this finding are that men have more unprotected sex than women, do not adhere to treatment efficiently, maintain more risk behaviors than women, and seek treatment later¹⁸.

Studies show that spirituality has a positive influence on living with chronic diseases, communicable or not¹⁹⁻²⁰. This can happen, as it presents itself as a perspective for the future and relief from the suffering of individuals, playing an important role in health¹⁹. Also, faith, regardless of religion, helps to better accept the condition of life and to persevere in the treatment²⁰. In a study carried out on the spirituality of people with HIV/AIDS²⁰, it was found that the relationship with a superior being contributed to a better quality of life and increased self-esteem.

The highest percentage of respondents intends to remain active as a family member, worker, friend, and to carry out their routine tasks in domestic service. The treatment adherence manual for people living with HIV and AIDS²¹ confirms that, due to situations of prejudice and discrimination experienced, people living with HIV can isolate themselves or restrict themselves from social relationships, which has a negative impact on the maintenance and structuring of the support network.

The network is strengthened when there are actions that support social support. The affective-emotional modality of social support refers to the human support given by close people

such as family, friends, neighbors, religious groups, volunteers, health service professionals, through affection, company and active listening. The support network also provides daily concrete-operational actions, such as assistance with household chores or practical aspects of the treatment itself, such as accompanying to a consultation, seeking medication at the dispensing unit, managing the house and/or taking care of the children when main guardian is undergoing treatment²¹.

Many participants attached some or a lot of importance to the role of volunteer and the desire to play that role. This answer may have a cultural relationship with society's view of the role as good and worthy, influencing the respondents' response and does not necessarily represent a real desire of all. However, when going through a difficult moment in life and receiving help from people who were not part of their social circle, as happens with volunteers in hospitals, those surveyed were possibly sensitized, and this can mobilize feelings of the need for retribution and altruism, the which is in line with the results obtained in another study²².

The prejudices suffered and self-inflicted accompany the life trajectory of the seropositive person from the moment the diagnosis is confirmed. In addition to being a disease with an impact on physical and psychological health, studies⁷⁻¹¹ show that this disease has been marked by prejudice and stigma since the beginning in the 1980s and, even today, even with advances in antiretroviral therapies and information, prejudice remains, related to social beliefs about the disease²³. The perception of these prejudices permeates the patient's heart, as well as their family and close friends, influencing the care that the person will have with the disease, and may neglect them, for fear of having the diagnosis discovered by attending a specialized service²⁴.

There are many feelings that the HIV positive person manifests as a result of their diagnosis, which has a direct influence on the organization of daily life, whether due to the treatment or the way of having a sexual relationship, with greater care to avoid transmission, or even omitting the disease from close people. A study carried out in 2014²⁵ pointed out that the discovery of HIV as a critical moment, full of anguish, fear of the disease, abandonment and rejection.

Another feeling reported is anxiety due to experiencing discriminatory situations and fear of social rejection. Living with HIV, in addition to the suffering caused by the disease, is surrounded by stigma, contributing to the person's social death²³. Stigma is experienced in different circles of society, depriving the HIV-positive person of full coexistence, leading them, many times, to omit

this information from friends, family and in the workplace, making it even more difficult to live with the disease²⁰.

Participants who perceived support from family members after diagnosis reported that they maintain the necessary health care and their daily relationship with HIV. A survey of people living with HIV²⁶ showed that social support is an important factor for the development of resilience and for facing the daily challenges of an HIV positive person²⁶. Another study pointed out that social support is a factor for better adherence to antiretroviral therapy in adults²⁷.

Family support helps with emotional stability and treatment, with an improvement in quality of life and a positive perception of social support helps individuals to adhere to treatment, prolonging the years of life. The positive perception about the services provided contributes to the reduction of social isolation and helps in coping with HIV/AIDS²³. In turn, the negative perception can discourage people from maintaining treatment.

CONCLUSION

The study showed that people who have been HIV positive for more than six months undergo changes in some of their occupational roles. These changes occurred both in the abandonment of some roles (or the importance attributed to them) and in the beginning of the performance of others, suggesting the management of the new situation faced. The desire to resume some abandoned roles was mentioned, as well as the maintenance of those they currently play, being able to re-signify some of the occupational roles they play, despite the diagnosis.

The prejudiced situations experienced throughout life (with HIV) by the interviewees are still remembered and caused unfavorable impacts, which brings the need for actions that ensure respect for this population and public policies to minimize the suffering of seropositive people in relation to self-prejudice and prejudice arising from themselves and society.

As a limitation, the small number of researched and being carried out in a single institution, does not allow generalizations, but at the same time, shows the need for deepening, especially in the subjective experience. However, the work points out the need to review public policies and social support for people living with HIV/AIDS.

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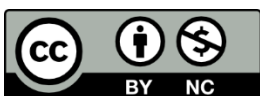
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