



## RESEARCH

## LIVING WITH THE HIV/AIDS CARRIER: OPINION OF CARNAVAL PARTICIPANTES

A CONVIVÊNCIA COM O PORTADOR DO HIV/AIDS: OPINIÃO DOS PARTICIPANTES DO CARNAVAL

CONVIVENDO CON EL PORTADOR DE VIH/SIDA: OPINIÓN DE LOS PARTICIPANTS DEL CARNAVAL

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## ABSTRACT

**Objective:** to identify people's opinion about the coexistence with HIV bearer. **Method:** this was a descriptive research with a quantitative approach, held in Rio de Janeiro in 2011. The sample was randomly composed by 630 participants of the samba school parades, by applying a structured interview script. The data were tabulated, organized and analyzed using descriptive statistics; being approved by the CEP of the University Veiga de Almeida number 270/11. **Results:** the majority of respondents would not have protected sex with a person with HIV/AIDS; they consider that this person should always work and would not worry that their child studies with a virus carrier. **Conclusion:** The results indicate that living with a person with HIV at work or school, have higher acceptance than the maintenance of sexual relationship, and is necessary to highlight the importance of demystifying the subject. **Descriptors:** HIV, AIDS, Prejudice, Quality of life.

## RESUMO

**Objetivo:** identificar a opinião das pessoas em relação a convivência com os portadores do HIV. **Método:** Tratou-se de uma pesquisa descritiva com abordagem quantitativa, realizada no Rio de Janeiro, em 2011. A amostra foi composta aleatoriamente por 630 integrantes dos desfiles das escolas de samba, pela aplicação de uma entrevista com roteiro estruturado. Os dados foram tabulados, organizados e analisados com auxílio da estatística descritiva. Sendo aprovado pelo CEP da Universidade Veiga de Almeida número 270/11. **Resultados:** A maioria dos entrevistados não teriam relações sexuais protegidas com um portador de HIV/AIDS, consideram que essa pessoa deve sempre trabalhar e não se preocupariam de seu filho estudar com um portador do vírus. **Conclusão:** Os resultados sinalizam que a convivência com uma pessoa acometida pelo HIV no trabalho ou escola, tem aceitação maior do que a manutenção do relacionamento sexual, sendo oportuno ressaltar a importância da desmitificação da temática. **Descritores:** HIV, AIDS, Preconceito, Qualidade de vida.

## RESUMEN

**Objetivo:** identificar la opinión referente a la convivencia con personas portadoras de VIH. **Método:** se trata de una investigación descriptiva con enfoque cuantitativo, que tuvo lugar en Río de Janeiro en 2011. La muestra fue compuesta aleatoriamente por 630 miembros de los desfiles de las escuelas de samba, mediante la aplicación de una entrevista con guión estructurado. Los datos fueron tabulados, organizados y analizados mediante estadística descriptiva. Siendo aprobado por el CEP de la Universidad Veiga de Almeida número 270/11. **Resultados:** la mayoría de los entrevistados no tenían relaciones sexuales protegidas con una persona con VIH/SIDA, consideran que esta persona siempre debe trabajar y no se preocuparían si su hijo estudiara con un portador del virus. **Conclusión:** los resultados indican que la convivencia con una persona con VIH en el trabajo o la escuela, tienen mayor aceptación que el mantenimiento de la relación sexual, destacando la importancia de desmitificar la temática. **Descriptor:** VIH, SIDA, Prejuicio, Calidad de vida.

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## INTRODUCTION

This paper studied the participants' opinions about Rio's Carnival in relation to living with people with HIV/AIDS.

The pandemic caused by the human immunodeficiency virus (HIV) currently affects around, 34 million people worldwide, in Brazil it is estimated that 370,000 are infected. Their routes of transmission are sexual, blood and vertical, and complications resulting from the immunosuppression caused by destruction of lymphocytes, but specifically the TCD4+ virus.<sup>1-2</sup>

The first cases were diagnosed at the beginning of the 1980s, in five gay men with an unusual type of pneumonia associated with severe immunosuppression. There was a lack of specific clinical concept of settled several new denominations moral disease as "gay cancer", "gay pneumonia" and "gay syndrome". New cases were being diagnosed injectable drug users and sex workers, the supposed selectivity population's infection did emerge the concept of risk group, in which deeply tarnished history of the epidemic. The current religious fundamentalists, major influencers of moral behavior, ethical and social, associated AIDS condemnation of what excessive and considered reprehensible.<sup>3</sup>

The concept of risk group embodied the idea that the epidemic reached only to transgressors of social norms, immoral, promiscuous and addicted, and that the general population found itself "immune" infection. The use of this terminology marked the historical, cultural, and social imaginary of AIDS. Subsequently, a new concept was proposed to "risky behavior" in which gave fault only that individual for failing to preventive measures and protection.<sup>4</sup>

The establishment of poorly planned responses, both politically and socially, based on

the ideals of "risk group" and "risky behavior" caused changes in the course of the epidemic, being marked by feminization, heterosexual and impoverishment. The adoption of the term vulnerability during the 1990s was created to strengthen the response in the fight against the virus and its stigmas, considering that any individual has the chance to infect HIV, resulting in a number of individual, social and programmatic aspects.

After three decades, prejudice and discrimination against people living with HIV/AIDS become the biggest barriers in combating the epidemic, for fear of being diagnosed with a disease considered exclusionary reason hinders the board of health in early identification and treatment of infection. We also emphasize the fact that the bias is a violation of human dignity, human rights and fundamental freedoms.<sup>5-6</sup>

In seeking to provide better living conditions and respect the principles and guidelines of the National Health System, the Brazilian Government adopts an exemplary model by offering to all its users free antiretroviral treatment, which provided greater survival of the virus, modifying the course fatalistic disease to chronicity.<sup>7</sup> However, the quality of life should not be measured only by the increase in life expectancy, but in ensuring that issues of social life are respected.

This study is the result of the project "Only joy will infect", held since 1991, which develops educational sexual practices that promote safe sex and stigmatization of prejudice to HIV/AIDS at the Sambodromo in Rio de Janeiro, during the period of carnival time of year due to historical and anthropological profile of the party notices a greater tendency to occasional relationships.<sup>8</sup>

The aforementioned project is a partnership of the National Sexually Transmitted Diseases/AIDS and Viral Hepatitis of the Ministry of

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Health - Brazil, Program United Nations AIDS (UNAIDS), the State University of Rio de Janeiro (UERJ), Veiga de Almeida University (UVA), other government organizations and representatives of civil society.

This paper aims to identify people's opinions about living with HIV patients.

## THEORETICAL REFERENCE

The World Health Organization (WHO) defines health as a complete state of physical well-being, mental and social wellbeing and not merely the absence of disease.<sup>9</sup> In order to provide better quality of life for people with HIV/AIDS the Brazilian Government adopted several public health policies to their plan of action, as is the case of antiretrovirals free and methods of prevention and control.<sup>10</sup> It is noted, however, that the quality of life of HIV-positive is not only related to the possibility of a longer life, situations of discrimination, abandonment, segregation, stigmatization, lack of social and financial resources, breakdown in personal relationships and problems with sexuality are constant features in the lives of people with HIV.<sup>11</sup> In this regard it should be the importance of studies on quality of life in the theme of HIV/AIDS.

The stigma is seen as the depreciation of the attributes considered normal, this theory is built by us ("normal"), prepared by an ideology to justify the inferiority of the other based on the idea that pose danger to society.<sup>12</sup> The feeling of uncertainty dominates that individual stigmatized to the extent that he never knows whether it will be accepted by the so-called "normal" or will come to be perceived solely through its stigmatizing attributes.<sup>6</sup>

In order to change the social and cultural behavior in order to provide decent respect for the human person to the United Nations (UN) adopted in 1948 the Universal Declaration of Human Rights, although it is not a document that J. res.: fundam. care. online 2013. out./dez. 5(4):510-18

represents obligatorily cool, served as the basis for changes that aimed to freedom, equality and dignity. In Brazil the Federal Constitution of 1988 had doctrinal and ideological commitment to the Declaration of Human Rights; there is just the preamble to<sup>13:4</sup>:

*(...) To establish a democratic state, to ensure the exercise of social and individual rights, freedom, security, well-being, development, equality and justice as supreme values of a fraternal, pluralistic and without prejudice, founded on social harmony and committed, in the internal and international, with the peaceful settlement of disputes.*

Even with a backing Constitution Fundamental Rights of Man, stigma and discrimination against people living with HIV are expressed in society alarmingly. In 1989, during the National Meeting of NGOs working on HIV/AIDS in Brazil (ENONG), in Porto Alegre, was drafted and approved the "Declaration of Fundamental Rights of People with AIDS Virus" a milestone that affirms the right the worthy life and access to health care constitutionally guaranteed to all citizens.

In Brazil, the epidemic shows concentrated, with a tendency to stabilize in the South, Southeast and Midwest and growth in the North and Northeast. In 2010 the incidence rate was 17.9 National AIDS cases per 100,000 inhabitants, the Rio de Janeiro the main affected in the Southeast with 28.2 cases. Regarding survival 74.3% exceeded six years carrying the disease.<sup>2</sup> The profile of HIV positive has changed, what was called the "Gay Plague", "African disease" and "Evil Rich" today can already be found disseminated in all genres, age groups, ethnicities and social classes, observing an increasing feminization, heterosexual and impoverishment.<sup>10</sup>

The data indicate that persistent involvement of people with the virus and that quality of life should be attributed with dignity, respecting the basic characteristics of social life, such as education, work, leisure and marital

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relationship. The fact that the epidemic be getting another profile reinforces the need demystification this theme, because patients may be unaware of their HIV status for the reason they do not fit the "supposed" risk groups and fear of being diagnosed with a disease where myths and fears shape the imaginary popular, which further aggravate this condition.<sup>14</sup>

Fighting discrimination and prejudice to people with HIV is a goal to be achieved by the proposed special session of the UN on STD/AIDS held in New York, June 21, 2001, which seeks to stimulate a massive response, worldwide to the crisis. Among its many goals we mention the need to create and develop strategies to combat stigma and social exclusion connected with epidemia.<sup>15</sup>

Scientific studies related to the theme prejudice, stigma and discrimination against people living with HIV/AIDS are needed for the assessment of quality of life and acceptance of people with HIV/AIDS in society.

## METHODOLOGY

This is a descriptive research with a quantitative approach, held in March 2011 at the Sambodromo in Rio de Janeiro during Carnival. The study included 630 people, randomly approached, having aged 18 years and linked to this great popular celebration - members of the samba schools, spectators and officials Sambodromo.

The study was assessed and approved by the Ethics Committee of the University Veiga de Almeida with the number 270/11, based on Resolution 196/96 of the National Health Council which regulates research involving human subjects.

Were selected as variables to compose the study those related to demographic, social, stigma and prejudice related to HIV/AIDS.

A structured interview with 20 questions was the instrument of data collection applied to

the study participants for undergraduate nursing students, trained by the coordinator of research, having approached the respondents in the area of concentration of the samba schools and in the stands of the sectors 1, 6 and 13.

Data were tabulated and organized being applied to descriptive statistics, and program feature Sphynx and discussed in the light of the theoretical.

## RESULTS AND DISCUSSION

The analysis shows that demographic characteristics (Table 1) in sample set are made by men (35.7%) and women (55.7%), aged 18 to 37 years old (54.6%). Has education level of High School Full (45.1%) and Upper Complete (19.5%); reside in Rio de Janeiro (85.9%) and living with partner (52.2%).

**Table 1: Sociodemographic profile of carnival people in "Sambodromo". Rio de Janeiro, 2011. (N=630)**

Sociodemographic	N	%
<b>Gender</b>		
Male	225	35,7
Female	351	55,7
No answer	54	8,6
<b>Age (years)</b>		
18 to 37	344	54,6
38 to 57	229	36,4
≥ 58	40	6,3
No answer	17	2,7
<b>Marital status</b>		
Lives with a partner	329	52,2
Does not live with a partner	268	42,5
No answer	33	5,3
<b>Literacy</b>		
Basic Incomplete	27	4,3
Basic Complete	94	14,9
Secondary Incomplete	61	9,7
Secondary Complete	284	45,1
Colledge Incomplete	41	6,5
Colledge Complete	123	19,5
<b>Lives in (State)</b>		
Rio de Janeiro	541	85,9
Other	85	13,5
No answer	4	0,6
<b>Total</b>	<b>630</b>	<b>100</b>



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Regarding the maintenance of relationships protected with a person with HIV/AIDS 32.1% 64.6% accept and reject, as maintenance work, 63.5% think that person should always work, 28.6% responded that will depend on each case and 6.8% mentioned that they should not work, as the ratio of their child with a child with HIV/AIDS in school 22.4% responded that care and 76.8% denied the fact (Table 2).

**Table 2:** Opinion of the people about possible relationships with people with HIV/Aids. Sambodromo, Rio de Janeiro, 2011. (N=630)

Opinion	N	%
<b>Protected sexual relationships</b>		
Yes	202	32,1
No	407	64,6
No answer	21	3,3
<b>Work maintenance</b>		
Always	400	63,5
Depends of the case	180	28,6
No	43	6,8
No answer	7	1,1
<b>Worry about children studing with HIV/AIDS carer</b>		
Yes	141	22,4
No	484	76,8
No answer	5	0,8
<b>Total</b>	<b>630</b>	<b>100</b>

Although the education level is high among participants, one can observe the presence of prejudice in matters of basic social interaction in human relations. According to a study conducted in São Paulo, the number of people who believe that social contact with people infected by the virus poses risk of transmission remains high.<sup>5</sup>

Another study reports that the representations related to the individual bearer of HIV/AIDS exceeded the biological aspect and reached the psychosocial aspects in which prejudice, segregation, stigma and social integration are still quite present. AIDS was represented as a disease that affects the human being in its entirety reflecting on various aspects of life such as productivity, social empowerment and quality of life.<sup>11</sup>

The denial in sexual relations with the person with HIV/AIDS is an important problem in the physical, psychic and social Carrier immunodeficiency virus, despite being very clear choice in sexual intercourse prevented. A survey in Florianopolis with 60 people living with the AIDS virus reports that sexual intercourse with a person who has HIV involves the belief most contagious even with a condom, than with people whose HIV status is unknown. Individuals mention the difficulty of having sexual relations after the revelation about seropositivity and define AIDS as a disease that hinders affective relationships.<sup>16-7</sup>

A second study portrays the very difficulties faced by people with HIV/Aids in maintaining sexual desire after diagnosis, with a diminished and disrupted other relations. Anxiety and fear of transmitting HIV/AIDS to the partner creates psychological barriers causing the gap sexual harming the wearer and making it unable to seek support. And even during this hurricane of feelings and emotional conflicts anguishes the person requires interpersonal contacts.<sup>18</sup>

The human-being can not be treated as asexual beings, from birth to death have sexual energy and why sexuality should always be studied and addressed.

*Sex is not mere physiology, but affection, amorous conquests, core venerable institutions like marriage and family, inspiring art, source of incantations and spells. Sex dominates almost every aspect of culture. It is much more than a carnal relationship between people: sexuality has a huge cultural and sociological force.*<sup>19:15</sup>

The fear of being abandoned and rejected by the partner is a common feature in the lives of people with HIV. The maintenance of affective and sexual relationships is vital in these people's lives and contributes to improve the quality of life. Even the fear of transmitting the virus to his partner and constant maintenance of safe sex partnerships are sources of emotional support, including the difficulties associated with

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seropositivity, as adherence to medication and health care.<sup>17</sup> Social support, friends, family, or even institutional (churches and support groups), has been important contributors to the increase in quality of life associated with the lower psychological distress, less frequent psychiatric symptoms and lower levels of anxiety and depression.<sup>20</sup>

The concealment of seropositivity by shame or not to suffer the prejudice is still a common reality in the lives of people living with the AIDS virus. This concealment, generated by fear of being judged by society, creates the feeling of being accepted; as it is still seen as linking aids the deviant behavior. This duplicity in the lives of HIV patients, the lack of social support and/or prejudice inflicted by society cause serious disorders such as social isolation, loss of will to live, loss of self-esteem and difficulty in developing romantic relationships.<sup>4</sup>

Working with the theme of sexuality in relation to people living with HIV, counseling and demystifying are important actions to improve the quality of life. The HIV-positive patients present sharp deterioration in their immune system when compared to non-depressed. The most appropriate treatments are those that emphasize the increased self-esteem, guide and inform on ways to find support in the community and assistance agencies.<sup>18</sup>

In relation to work, despite the transmissibility of HIV is hardly likely, this factor has long been used by employers as a reason to fire or not hire workers with HIV/AIDS. The question of socialization carrier about their HIV positive diagnosis in the work is complex and represents a threat to the continuity and stability of employment in the same, and the silence and the search for self-protection found the best way to combat the disease.<sup>21</sup> The bias effect has serious consequences for people living with HIV/AIDS. Job loss diminishes the prospect of

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reintegration into the labor market, besides causing damage to health and maintenance of self-esteem.

Results of a study conducted in São Paulo leads the difficulties employers and unprepared to accept an HIV carrier, considering them unable to perform his duties as other professionals. This same work also reports the testimony of a respondent who received full support from the company, this practice should be followed by all the others, because it improves self esteem and strengthen actions to combat HIV/AIDS. There are numerous difficulties faced by people living with the AIDS virus to exercise their labor activities due to the presence of prejudice, many times “daz veiled”, regarding the admission of virus carriers.

It is emphasized that the work constitutes one of the main rights of citizenship, freedom and autonomy. With the advent of anti-retroviral drugs to people with HIV/AIDS can take years for symptoms of opportunistic infections, and can perform their professional activities normally and continue with their daily tasks.

Considering the impact of HIV/AIDS in the world to the International Labor Organization (ILO) in its 99th session on June 2, 2010 in Geneva prepares the "Text of the Recommendation on HIV/AIDS and the World of Work." Among the general principles set out in the meeting were that: there should be no discrimination or stigmatization of workers, particularly those who seek and those who apply for employment because of their HIV serostatus, no worker shall be required to perform HIV test or disclose their HIV status to HIV, prevention of all means of HIV transmission should be a key priority, among other principles.<sup>23</sup>

In relation to school life a study of college at the University of Brasilia found that 15% of participants manifested exclusionary position in relation to children with the AIDS virus, opining by restricting your acesso.<sup>6</sup> Another study reports

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that 63.2% of participants not let your children be in the company of a person who has the AIDS virus but this research has been observed that people with lower education had higher intention of discrimination.<sup>5</sup>

It is important to commend the actions promoted by the Ministry of Health in the development of campaigns in which combat discrimination and stigma inflicted on HIV/AIDS, as follows: "Where is AIDS?", "Living with HIV is possible. With no prejudice.", "Equality is the best treatment.", "All against prejudice."

The high levels of discrimination to people with HIV/AIDS, in addition to socio-cultural patterns, can be justified by the fact that many people still have questions about the ways and means of infection and HIV infection, and as a consequence of this deficit of knowledge people tend to isolate patients as a preventive.<sup>6</sup> A study of adolescents from public schools in São Paulo state reveals that, although related to HIV transmission ways and means widely refuted by the media and specific literature, such as handshake, hug, kiss on the cheek, common use of pools, insect bites and use of toilets, glasses and cutlery after use by a carrier of the virus.<sup>24</sup>

### CONCLUSION

The prejudice to people with HIV/AIDS becomes the main barrier to combat the epidemic due to fear of being diagnosed and consequently hindering early intervention with measures of health education and clinical monitoring. In Brazil with the increase in life expectancy press for the quality of life, and the discriminatory processes supported by legal issues.

The results highlight that despite the high educational level of respondents living with a person with HIV/AIDS, whether at work or school, have greater acceptance than the maintenance of living with that fellow, highlighting the importance of demystifying this theme.

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One limitation of the study was the absence of open questions to understand the subjectivities of living with an HIV/AIDS. However, because it is a dynamic and festive, the instrument used for data collection aimed to facilitate the capture of information from participants.

The importance of continuity of educational and awareness to the problem of discrimination to HIV/AIDS is sustained, considering that the disease represents a major public health problem for the country and that freedom and fundamental rights of the human person must be respected. While a cure is not discovered society must learn to live with AIDS and educational processes are the main tool for breaking the cycle of new infections and disruption of stigmas.

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**Received on: 19/11/2012**

**Required for review: no**

**Approved on: 21/05/2013**

**Published on: 01/10/2013**