

# Perceptions that People Newly Diagnosed with HIV Have on Health

ORIGINAL

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## Abstract

**Introduction:** The perception of health is an important tool in promoting the quality of life of newly diagnosed people living with HIV/AIDS, since the understanding of this reality is a decisive factor in the decision making process.

**Goal:** To evaluate the perception that newly diagnosed people with HIV have on health.

**Methodology:** Exploratory and descriptive research with quantitative and qualitative approach carried out between June and October 2015 in a reference center for treatment of sexually transmitted infections in Fortaleza-CE, Brazil. People living with HIV/AIDS diagnosed in the last 6 months participated in the study. Data were collected through semi-structured interviews with guiding questions, whose data were analyzed based on the technique of the discourse of the collective subject and absolute and relative frequencies were used for analysis of quantitative data.

**Results:** There was a predominance of males (83.3%) aged  $\geq 39$  years (53.3%), homosexual or bisexual (70%), with level of schooling  $\geq 8$  years (76.7%), users of illicit drugs (16.7%), and consumers of alcohol at a frequency of once a month (50%). Testimonials revealed the following core ideas: 1. Health means to have balance; 2. Health means not being sick; 3. Be healthy despite living with HIV; 4. Changes in lifestyle after diagnosis and 5. Factors that prevent a healthy life.

**Conclusion:** According to the perception of newly diagnosed people with HIV, health is intrinsically linked to the absence of diseases, regular attendance at follow-up visits, the adherence to antiretroviral therapy and healthy eating.

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## Keywords

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## Introduction

With the advent of Antiretroviral Therapy (ART), there was a decrease in morbidity and mortality associated with HIV (AGWU *et. al*, 2012). Allied to the control of opportunistic infections, the treatment allowed a better quality of life for people living with HIV/AIDS (PLWHA) (CUNHA *et. al*, 2015).

Thus, AIDS has become a chronic disease linked to challenges such as complex treatments, chronic fatigue and social stigma. Other aspects related to living with HIV/AIDS are depression, stress and uncertainty of life plans. These aspects are directly related to physical, spiritual, social, economic and mental problems that influence the quality of life and health promotion of PLWHA (SADAJJI *et. al*, 2015).

Health promotion can be understood as the training of individuals for the purpose of make them assume the control of their health, and so improve it (EDELMAN; KUDZMA; MANDLE, 2014). The most common strategies for health promotion aimed at PLWHA are carried out in the context of health education, where information about ways to change the lifestyle, and the prevention of comorbidities and co-infections are shared (TOLLI, 2012).

Thus, the perception of health is an important tool in promoting the quality of life of PLWHA, as the understanding of this reality is a decisive factor in decision making. Individuals generally act when they have the purpose of controlling situations of health and illness to which they are exposed. This occurs only when they realize that they are susceptible to health disorders or that these diseases could have serious implications for their life (RENESTO *et. al*, 2014).

Still, how individuals perceive health and HIV influences the motivation to practice risky behavior, so that little understanding about their vulnerability is associated with more risk behaviors, such as non-adherence to drug therapy, use of alcohol and other drugs, as well as practice of unprotected sex (XIANHONG *et. al*, 2015).

Thus, studying aspects of health perception from the perspective of people living with HIV/

AIDS is critical because enables the realization of interventions focused on their real needs, ensuring a comprehensive and holistic care to this population. In this context, this study aimed to evaluate the perception of health that newly diagnosed people with HIV have.

## Methods

This is an exploratory and descriptive research with quantitative and qualitative approach carried out between June and October 2015 in a reference center for treatment of sexually transmitted infections in Fortaleza, the capital of Ceará state, northeastern Brazil. Quantitative and qualitative research can identify the presence, frequency and amplitude characteristics related to the object of study. In addition, features that cannot be measured, such as feelings, perceptions, and afflictions other aspects are evaluated in this type of methodological approach (KIRSCHBAUM, 2013).

The participants consisted in 30 newly diagnosed ( $\leq 6$  months) people living with HIV/AIDS, adults of both sexes under clinical follow-up, selected by convenient sampling. Patient recruitment occurred through verbal invitation prior to routine outpatient visit. In the period of the study, there were 40 clients with time of diagnosis  $\leq 6$  months.

An interview was conducted in a private room using a form divided into two parts. The first part investigated sociodemographic and clinical characteristics: gender, age, sexual orientation, marital status, occupation, education, religion, use of alcohol and other drugs, CD4 + T lymphocytes and viral load. The second part sought qualitative information obtained from the following guiding questions: In your opinion, what is health? Do you see yourself as a healthy person? What do you do to have/to maintain health? A pilot test with PLWHA using another health service was conducted to check the adequacy of the form. The testimonials were recorded and lasted an average of 30 minutes.

The qualitative data analysis was based on the technique of the Discourse of the Collective Subject (DCS). This technique is a proposal for the organization and tabulation of qualitative data of verbal nature from the most representative excerpts of the speech, that is, excerpts that reveal key expressions of the essence of the content of representations (LEFÉVRE; LEFÉVRE, 2005). The DCS is composed of four operators: key expression, central ideas, anchoring and discourse of the collective subject. Key expressions are speech excerpts highlighted by the researcher, excerpts that represent the essence of the testimonial's content. The central ideas are words or phrases that reveal, in a clear and objective manner, the meaning of the statements. Anchoring is a general statement used to "frame" particular situations. Finally, the DCS is a written speech-synthesis in the first person singular that brings together key expressions with central idea or equivalent anchoring (LEFÉVRE; LEFÉVRE, 2016).

The analysis of the testimonials based on the DCS technique, followed these steps: I. full transcription of responses of each subject; II. Identification of key expressions, central ideas and anchorages of each response; III. Description of the central idea and of the anchoring taken from key-expressions, placing them in the corresponding column; IV. Grouping of key ideas that had the same meanings, assigning a letter to each group; V. Creating a central synthetic idea for each group; VI. Construction of the DCS from the central synthetic idea (LEFÉVRE; LEFÉVRE, 2005; LEFÉVRE; LEFÉVRE, 2016).

Quantitative data were entered into the program Statistical Package for Social Sciences (SPSS) version 22.0. Absolute and relative frequency of variables were calculated.

The research project was approved by the Ethics Committee of the Federal University of Ceará, under Opinion number 1.252.440.

## Results

Among the 30 interviewed people, there was a predominance of males (83.3%) aged  $\geq 39$  years (53.3%), homosexual or bisexual (70%), with schooling  $\geq 8$  years (76.7%), users of illicit drugs (16.7%) and consuming alcohol at a frequency of once a month (50%) (Table 1).

**Table 1.** Distribution of the domains and facets of QoL. João Pessoa, PB, 2015.

Variables	(N)	%
Gender		
Male	25	83.3
Female	5	16.7
Group Age (years)		
<29	14	46.7
$\geq 39$	16	53.3
Sexual orientation		
Heterosexual	9	30.0
Homosexual/Bisexual	21	70.0
Years of Schooling		
$\geq 8$	23	76.7
< 8	7	23.3
Use of illicit drugs		
Yes	5	16.7
No	25	83.3
Frequency of alcohol consumption (n = 21)		
Once a month or less	15	50.0
2 to 4 times a month	5	16.7
2 to 3 times a week	1	33.3

Regarding the results of the analysis of the speech in the light of the discourse of the collective subject, four central ideas emerged: 1. Health means to have balance; 2. Health means not being sick; 3. I can enjoy health despite living with HIV; 4. I did changes in lifestyle after diagnosis and 5. There are factors that prevent me from having a healthier life (Table 2).

**Table 2.** Central ideas and DCS generated from testimonials.

Central Idea	Discourse Of The Collective Subject
Health means to have balance	Health is to have physical, mental and behavioral balance; it is the basis of everything for a human being. It is to feel good with yourself, live well, take care of yourself, have quality of life, eat well, have the possibility of practice exercises, work, have comfort, have the desire to have fun, have a good relationship with friends and go out for a leisurely. DCS 1
Health means not being sick	Health is not living with any disease, is to prevent yourself so that you do not get diseases. As I am infected with HIV, I do not feel that I am healthy. I have faced many problems in my life after I found out the diagnosis. Sometimes I think I'm going to die soon, or that I'll have greater chance of getting cancer. DCS 2
Be healthy despite living with HIV	Despite the diagnosis of HIV, I have no health problem. I live well, I feel good, I have self-esteem, work, go out with friends, so consider myself healthy. After I got the virus I started to see my life with other eyes, I see that my health comes first and if I do not take care of myself, no one will. DCS 3
Changes in lifestyle after diagnosis	Today I try to take care of myself, eat better, do physical exercise, I avoid drinking alcohol and smoking - I try to have a different routine that I used to have before. Also, I regularly go to the doctor to make my follow up and I take my medicine daily. DCS 4
Factors that prevent a healthy life	As my work routine is intense, I do not have time to eat as healthily as I wanted, or to work out and control smoking. In addition, the medication that I take causes me unease, causes headache and nausea. Psychological issues also hinder my health. DCS 5

## Discussion

Discovering that you are facing a chronic and still incurable illness may raise insecurity in newly diagnosed PLWHA on how to achieve or maintain health. The start of ART is one of the most difficult steps, as it implies a new routine of life and the use of drugs constantly reminds patients of their ill condition (SANTOS *et. al.*, 2011). In addition to the daily dose of antiretroviral drugs at this early stage, it is necessary to make behavioral changes in lifestyle for prevention of comorbidities, changes such as a balanced diet, regular physical exercise and avoiding using alcohol and illicit drugs (BRASIL, 2015).

It was noted that the participants of the survey described health as a balance between body, mind and lifestyle contrary to the biomedical model in which the concept of health is restricted to biological and individual dimensions, which is insufficient to meet the needs of the population. This demonstrates the need to host PLWHA with recent diagnosis with the perspective of health promotion, based on approaches that promote emotional well-being and social support (SUN *et. al.*, 2013).

The discovery of positive serostatus for HIV generates many different feelings and behaviors in individuals that may compromise their quality of life (SILVA, 2015). In this study, newly diagnosed people with HIV mentioned the fear of death, in line with another study carried out with women (GALVÃO *et. al.*, 2013). Facilitating the restoration of emotional and social well-being of individuals affected with the virus is an important aid for effective results in the process of acceptance of disease (LEMONS *et. al.*, 2013).

After the initial period of diagnosis comes the desire to overcome the feelings related to the initial impact of seeing oneself affected by HIV/AIDS, where the individual needs to continue life. Changes in lifestyle occur not only for individuals but also for those who are part of the support network. Changes are related to health habits, routines, conceptions of health and life itself (PINTO, 2014).

In this study, change in the daily routine, with constant monitoring of health and permanent care to attempt the maintain the well-being, was repor-

ted by individuals. Large portion of the participants reported changes in health habits, expressing concern with the use of alcohol and smoking. They also showed significant changes, such as the search for a healthier diet and physical activity. A similar result was reported by Costa (2015) that shows change such as increased water intake and the number of meals that correspond to the recommended for the benefits of a more disciplined life.

The daily dose of medication was mentioned as a challenge due to adverse effects, the main reason for irregular taking of antiretroviral drugs (ALMEIDA *et. al*, 2011). Narratives of women living with HIV/AIDS pointed daily struggles to take medication due to fear of being discriminated by colleagues and society in general, and fear of not being included in many activities if the positive diagnosis for HIV would be revealed (MATOVU *et. al*, 2012).

Health professionals working in the various areas of care, among them HIV/AIDS, should intervene for an expanded concept of health, making an exchange between the psychosocial and cultural aspects so that we can see the user as a whole being, one that has rights and main author of his health (LOPES *et. al.*, 2014).

The incentive for regular meetings with all staff involved in patient care, discussing the main problems faced both by patients and by the staff, in order to improve adherence to treatment, creating opportunities and fostering the meeting of the patients among themselves to exchange experiences are simple steps that may be planned and carried out and may favor changing the current reality, improving health indicators (SILVA *et. al.*, 2015).

## Conclusion

For newly diagnosed people living with HIV, health is intrinsically linked to the absence of diseases, regular attendance at follow-up visits, the adherence to antiretroviral therapy and healthy eating. In addition, the positive diagnosis of HIV is related to the

lack of health only due to the fact of having to live with this virus.

The results indicate the need to implement activities aimed at promoting health and improving quality of life, which should include: adherence to drug therapy, physical activity, healthy eating, health-related rights, social support, healthy lifestyle and health care.

There is a need to put a specific plan of care in practice for newly diagnosed people with HIV/AIDS, aiming not only at good clinical results, but also at promoting the psychological and social health in order to improve the quality of life. It is recommended to carry out studies to propose and evaluate interventions aimed at promoting the health of PLWHA, especially the newly diagnosed ones.

As study limitation, it is not possible to generalize the findings because of the chosen method.

## References

- Agwu AL.; Siberry GK; Ellen J; Fleishman JA, Rutstein R, Gaur AH, *et. al*. Predictors of Highly Active Antiretroviral Therapy Utilization for Behaviorally HIV-1–Infected Youth: Impact of Adult Versus Pediatric Clinical Care Site. *Journal of Adolescent Health*. 2012; 50(5):471-7.
- Cunha J, Maselli LMF, Stern ACB, Spada C, Bydlowski SP. Impact of antiretroviral therapy on lipid metabolism of human immunodeficiency virus-infected patients: Old and new drugs. *World Journal of Virology*. 2015; 4(2):56-77.
- Sajjadi M, Rassouli M, Bahri N, Mohammadipoor F. The Correlation Between Perceived Social Support and Illness Uncertainty in People with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome in Iran. *Indian Journal of Palliative Care*. 2015; 21(2):231-5.
- Edelman CL, Mandle CL, Kudzma EC. *Health Promotion Throughout the Life Span*. 4th ed. Missouri: Elsevier Mosby; 2014. 632p.
- Tolli M. V. Effectiveness of peer education interventions for HIV prevention, adolescent pregnancy prevention and sexual health promotion for young people: a systematic review of European studies. *Health Education Research*. 2012; 27(5): 904-13.
- Renesto HMF, Falbo AR, Souza E, Vasconcelos MG. Enfrentamento e percepção da mulher em relação à infecção pelo HIV. *Rev Saude Publica*. 2014; 48(1):36-2.

- Xianhong L, Yunxiao L, Honghong W, Guoping H, Ann BW. The Health Belief Model: A Qualitative Study to Understand High-risk Sexual Behavior in Chinese Men Who Have Sex With Men. *Journal of the association of nurses in aids care*. 2016; 27(1):66-6.
- Kirschbaum C. Decisões entre pesquisas quali e quanti sob a perspectiva de mecanismos causais. *Revista Brasileira de Ciências Sociais*. 2013; 28(82):181-3.
- Lefèvre F, Lefèvre AC. Discurso do sujeito coletivo: Principais conceitos. Available from: [http://hygeia.fsp.usp.br/quali-saude/Discurso\\_principais\\_conceitos.htm](http://hygeia.fsp.usp.br/quali-saude/Discurso_principais_conceitos.htm) (Accessed 23 March 2016).
- Lefèvre F, Lefèvre AMC. Discurso do Sujeito Coletivo. Um novo enfoque em pesquisa qualitativa (Desdobramentos). Caxias do Sul: Educ; 2005.
- Santos WJ, Drumond EF, Gomes AS, Corrêa CM, Freitas MIF. Barreiras e aspectos facilitadores da adesão à terapia antirretroviral em Belo Horizonte-MG. *Rev. bras. enferm.* 2011; 64(6):1028-37.
- Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de DST, Aids e Hepatites virais. Protocolo clínico e diretrizes terapêuticas para manejo da infecção pelo HIV em adultos. Brasília: Ministério da Saúde; 2015.
- Sun W, Wu M, Qu P, Lu C, Wang L. Quality of life of people living with HIV/AIDS under the new epidemic characteristics in China and the associated factors. *PLoS One*. 2012; 8(5):e64562.
- Silva JAG, Dourado I, Brito AM, Silva CAL. Factors associated with non-adherence to antiretroviral therapy in adults with AIDS in the first six months of treatment in Salvador, Bahia State, Brazil. *Cadernos de Saúde Pública*. 2015; 31(6):1188-1198.
- Galvão MTGG, Lima ICVL, Cunha GHC, Santos VF, Mindêllo MIA. Estratégias de mães com filhos portadores de HIV para conviverem com a doença. *Cogitare Enferm.* 2013; 18(2):230-7.
- Lemos LA, Fiuza MLT, Pinto ACS, Galvão MTG. Grupo de promoção da saúde para portadores do vírus da imunodeficiência humana. *Rev. enferm. UERJ*. 2013; 21(4):521-6.
- Pinto ACS, Fiuza MLT, Pinheiro PNC, Vieira NFC, Galvão MTG. Estágios de mudança dos portadores do HIV no grupo de autoajuda. *Revista de Enfermagem da UFPE*. 2014; 8(9):3076-81.
- Costa TL, Oliveira DC, Formozo GA. Qualidade de vida e AIDS sob a ótica de pessoas vivendo com o agravo: contribuição preliminar da abordagem estrutural das representações sociais. *Cadernos de Saúde Pública*. 2015; 31(2):365-76.
- Almeida EL, Araújo GBS, Santos VA, Bustorff LACV, Pereira AVL, Dias MD. Adesão dos portadores do HIV/AIDS ao tratamento: fatores intervenientes. *Revista Mineira de Enfermagem*. 2011; 15(2):208-16.
- Matovu SN, La cour K, Hemmingsson H. Narratives of Ugandan women adhering to HIV/AIDS medication. *Occupational Therapy International*. 2012; 19(4):176-4.
- Lopes LM, Magnabosco GT, Andrade RLP, Ponce MAZ, Wysocki AD, Ravanholi GM, et. al. Coordenação da assistência prestada às pessoas que vivem com HIV/AIDS em um município do Estado de São Paulo, Brasil. *Cadernos de Saúde Pública*. 2014; 30(11):2283-97.

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