

## Quality of life of people living with HIV/AIDS: Effects of illness perception and coping strategies

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**ABSTRACT** - This study aims to investigate the quality of life (QOL) predictors of people living with HIV/AIDS (PLWHA), from the perspective of Leventhal's Self-Regulation Model, in which the influence of the illness perception on QOL is mediated by coping strategies. Ninety-five PLWHA answered to the instruments Brief IPQ, Brief Cope and WHOQOL-HIV BREF concerning, respectively, illness perception, coping strategies and QOL. The results indicate that illness perception has direct and indirect effects in QOL, mediated by coping strategies. The more HIV is perceived as threatening, the worse is the perception of QOL of PLWHA; however, the increased use of acceptance, distraction and instrumental support coping strategies and the less use of behavioral disengagement and positive reinterpretation could mitigate this negative effect.

**Keywords:** HIV/AIDS, self-regulation model, illness perception, coping strategies, quality of life

## Qualidade de vida de pessoas vivendo com HIV/aids: efeitos da percepção da doença e de estratégias de enfrentamento

**RESUMO** - A pesquisa objetivou investigar preditores da qualidade de vida (QV) de pessoas vivendo com HIV/aids (PVHA), baseada no modelo de autorregulação de Leventhal, no qual a influência da percepção da doença na QV é mediada por estratégias de enfrentamento. Foram 95 PVHA a responder aos instrumentos *Brief IPQ*, *Brief Cope* e *WHOQOL-HIV BREF* relativos, respectivamente, à percepção da doença, estratégias de enfrentamento e QV. Os resultados indicaram que a percepção da doença teve efeito direto e indireto na QV, mediado por estratégias de enfrentamento. Maior percepção de ameaça da doença associou-se à pior QV percebida; porém, o uso mais frequente das estratégias aceitação, distração e suporte instrumental e a menor utilização de desengajamento comportamental e de reinterpretação positiva amenizaram esse efeito negativo.

**Palavras-chave:** HIV/aids, modelo de autorregulação, percepção de doença, estratégias de enfrentamento, qualidade de vida

According to the Brazilian Ministry of Health's data, from 1980 to June 2014, 798,366 cases of AIDS were reported in Brazil (Brazil, 2015). These figures show not only the challenges in the field of prevention, but also the advances in medicine and antiretroviral therapy (ART). These resulted in the reduction of mortality from AIDS in many countries, including Brazil. As of June 2014, 290,929 deaths from AIDS have been identified in Brazil. However, the drop on mortality levels is attributable to the universal availability of ART (Brazil, 2015). Although the ART allowed expanding life expectancy, people living with HIV/AIDS (PLWHA) many times suffer undesirable effects of the therapy besides being victims of stigma and discrimination. The difficulties brought by this reality cannot be neglected, because these seem to have negative effects on the perception of seropositive people's quality of life (QOL).

Generally speaking, QOL is defined as a subjective and multidimensional concept. In this light, only the individual can evaluate his/her QOL, which can change depending on the moment and context and is dependent on many factors. One of the most broadly used definitions is that of the World Health Organization (WHO), according to which QOL is

“individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (The WHOQOL Group, 1995, p. 1405). Therefore, QOL is a far-reaching concept. It is constituted in a complex way by the perception of the physical and psychological state, degree of independence, social relations, personal beliefs and the environment surrounding the individual. Studies show that the scores of PLWHA's perceived QOL are lower if compared to that of people living without the disease or living with other chronic diseases (Hays et al., 2000; The WHOQOL-HIV Group, 2003). Defining the factors that favor the QOL of PLWHA has been one of the priority topics of research in the field of HIV/AIDS in psychology and other health sciences.

Studies point out that strategies to cope with seropositivity (Faustino & Seidl, 2010; Seidl, Zannon & Tróccoli, 2005) and the illness perception (Reynolds et al., 2009) are psychosocial aspects that potentially influence QOL in the context of HIV/AIDS, although the last variable is little studied in the Brazilian context of PLWHA. Leventhal's Self-Regulation Model (Meyer, Leventhal & Gutmann, 1985) is a model to predict QOL considering these variables. According to that model, individuals try to understand their illness based on

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three sources of information: existing cultural knowledge about the illness regardless of the disease itself; social environment and significant persons like family members (affective importance) or physicians (health authority); and, experience and living with the illness, the latter being the only internal source (Hagger & Orbell, 2003).

The following dimensions were identified as constructs of illness perception: identity, consequences, cause, duration, control/cure, coherence and emotional representation (Leventhal, Diefenbach & Leventhal, 1992). Identity is related to the stereotype and nature of illness, and symptoms are associated with the condition. Consequences can be perceived either as positive or negative, of short or long term. The third dimension is the perception about what could have caused the illness or its development. Duration corresponds to the beliefs about how long the illness and/or its symptoms will last. The beliefs about the possibility of control/cure refer to personal control, as well as to treatment efficacy. The dimension of coherence refers to the patient's degree of understanding or knowledge about the disease (Moss-Morris *et al.*, 2002). Finally, emotional representation corresponds to feelings like fear, anger and anxiety that are elaborated simultaneously with the cognitive representations. Based on this information, individuals build their illness perception. This perception guides the selection of coping strategies to control, handle or eliminate the illness (Broadbent, Petrie, Main & Weinman, 2006).

The concept of coping comprises a set of cognitive and behavioral strategies that the individual uses to cope with a stressing situation (Lazarus & Folkman, 1984). There are two larger groups of coping strategies: those focused on the problem and those focused on emotion. The strategies focused on the problem are considered to be an attempt to change the situation and/or source of stress to control and cope with the threat, damage or challenge (Seidl, Tróccoli & Zannon, 2001). Those focused on emotion aim to regulate the emotional response because the situation seems to be uncontrollable. This can be of palliative nature (Câmara, 2009). Researchers observed that the use of problem-focused strategies was associated to better perception of the QOL (Armon & Lichtenstein, 2012; Vyavaharkar, Mooneyham, Murdaugh & Tavakoli, 2012) and better physical and psychological well-being (DeGrezia & Scrandis, 2015).

According to a literature review by Skinner, Edge, Altman and Sherwood (2003), more than 400 types of coping strategies have been identified. However, the different strategies - whether focused on the problem or the emotion - are not necessarily successful. Despite the tendency of considering problem-focused strategies as adaptive, and the emotion-centered ones as non-adaptive, the successful use depends on the characteristics of the stressful situation, the individual and the moment when the coping strategy is triggered.

According to the Leventhal's Self-Regulation Model, both the coping strategies and the illness perception are directly associated with the QOL (Meyer *et al.*, 1985). Moreover it is hypothesized that coping strategies mediate the relation between illness perception and QOL (Weinman, Petrie, Moss-Morris & Horne, 1996).

In this light, the objective of this study was to investigate the predictors of quality of life of people living with HIV/AIDS, based on the Leventhal's Self-Regulation Model, where the influence of illness perception on the QOL is mediated by coping strategies.

## Method

### Participants

This study addressed adult Brazilian individuals, male and female, living with HIV/AIDS. Altogether, 95 PLWHA completely responded to the instruments and assembled a convenience sample.

The mean age of the Brazilian participants was 39.38 years old ( $SD = 12.52$ ) and they had been living with HIV/AIDS for 8.77 years on average ( $SD = 7.94$ ). Most (75%) of the participants were men. The age difference ( $t(93) = 4.02$ ;  $p < 0.01$ ) and time living with HIV/AIDS ( $t(93) = 4.53$ ;  $p < 0.01$ ) between men and women was significant. This evidences that population was not homogeneous in both variables, men were younger ( $M = 36.96$ ;  $SD = 11.48$ ) and shorter time since diagnosis ( $M = 7.06$ ;  $SD = 7.22$ ) than women (age:  $M = 46.66$ ;  $SD = 12.5$ ; length of time living with HIV/AIDS:  $M = 13.91$ ;  $SD = 7.91$ ).

### Instruments - Brief Illness Perception Questionnaire

**Brief Illness Perception Questionnaire.** The Brief Illness Perception Questionnaire - Brief IPQ (Broadbent, Petrie, Main & Weinman, 2006) was developed to serve as brief measure of the illness perception. It was adapted and validated in Portuguese by Nogueira, Seidl and Trocóllo (2016). In the version validated in the Brazilian context, the instrument measures the cognitive representations (individual control, treatment control and understanding) and emotional representations (consequences, identity, concerns and emotions) using a Likert scale of 0 to 10 points. The cause and duration dimensions are evaluated through open questions and will not be considered in this paper. The sum of different dimensions makes up the illness perception score. Very high values mean more threatening illness perception. Cronbach's alpha coefficient for this instrument was 0.64. High scores represent higher perception of the illness threat (0 to 70 breadth), and the closer the score to 70, the higher the perception of threat. Considering that a relevant threat perception happens when the score exceeds 33 (average value of participants in the validation study, thus used as cut-off point).

**Brief Cope.** The Brief Cope (Carver, 1997) is an instrument designed to measure coping strategies in stressful situations. Brasileiro, Costa and Cavalcante (2012) validated the Portuguese version. Altogether, 28 items evaluate 14 strategies: active coping (perform actions /behaviors to eliminate or restrict the stress generated by the situation); planning (planning active coping efforts); search for instrumental social support (ask for support through information about what to do); search for emotional social support (wing sympathy or emotional support of somebody); expression of feelings (be aware of the personal stress and of its expression); behavioral disengagement (give up an objective because of the stress agent); distraction (mental divestiture of an objective due to the stress agent); guilt (criticize and blame for what happened); positive reinterpretation (perceive the stressing situation in a less threatening way); humor (make jokes about the stressing situation); denial (deny the reality of the stressing event); acceptance (accept that the stressing situation is real); religion/spirituality (participate in religious/spiritual

activities); and, use of psychoactive substances (use alcohol or drugs to reduce reaction to stress). Items are responded in a 4-point Likert scale (1 = never did it; 4 = always do it). Final score is calculated using the average of two items corresponding to each strategy, ranging from 1 to 4. Higher scores correspond to more intensive use of a given coping strategy. Cronbach's alpha values ranged from 0.50 for expression of feelings to 0.90 for use of substances.

**WHOQOL-HIV Bref.** QOL was evaluated with the WHOQOL-HIV Bref instrument (The WHOQOL-HIV Group, 2003) translated and validated in Portuguese by Zimpel and Fleck (2007). The 31 items evaluated six QOL dimensions of PLWHA: physical; psychological; independence level; social; environmental; spiritual (O'Connell & Skevington, 2012). Participants selected their responses in a 5-point Likert scale. The score for each dimension is calculated by multiplying its average by four, with values ranging between four and 20. The higher the score, the better is the perceived QOL. Cronbach's alpha coefficients for the instrument range from 0.69 (spiritual dimension) to 0.82 (environmental dimension).

## Procedure

After being approved by the Committee of Ethics in Research of the Human Sciences Institute of the *Universidade de Brasilia*, according to Resolution 466/2012 by the *Conselho Nacional de Saúde*, the research was made available to participants.

Data were collected from an online research upon the construction of a specific internet website. The dissemination targeting the PLWHA was on websites of civil society

associations in the field of HIV/AIDS in Brazil that accepted publicizing the study link to be accessed on the internet. Data collection process ensured the criteria of confidentiality and voluntary participation.

## Data analysis

Firstly, it employed classic statistical techniques of data description such as frequency, indicators of centrality (average, mean), dispersion (quartile, standard deviation) and analysis of correlations between the study variables. These data were analyzed using the statistical software SPSS (Statistical Package for Social Sciences for Windows), version 17.

Then, methods of structural equations models were applied to investigate the effects of the "illness perception" and "coping strategies" variables on the QOL perception. The short number of participants justified the use of Partial Least Square (PLS) analysis, based on Tenenhaus, Vinzi, Chatelin and Lauro (2005). Modeling was made on the statistical software SmartPLS 3.0. The degree of significance considered was 5%.

## Results

First, the average score of the variables evaluated in the study were calculated. Results are shown in Table 1. Participants scored higher in the QOL dimension independence level ( $M = 14.08$ ;  $SD = 3.32$ ). In turn, in the spiritual and personal beliefs QOL they scored lower ( $M = 12.92$ ;  $SD = 3.75$ ).

Table 1. Average scores of QOL, coping strategies and illness perception of PLWHA (N = 95)

Variables	M	SD	Minimum	Maximum
Illness perception	30.10	15.07	0	60
Distraction	2.68	0.63	1	4
Active coping	2.80	0.72	1	4
Denial	2.02	0.62	1	4
Use of substances	1.90	0.68	1	4
Social emotional support	2.41	0.67	1	4
Behavioral disengagement	1.88	0.56	1	4
Religion	2.61	0.72	1	4
Acceptance	1.83	0.62	1	4
Expression of feelings	2.05	0.77	1	4
Social emotional support	2.38	0.67	1	4
Positive reinterpretation	1.94	0.79	1	4
Guilt	2.81	0.76	1	4
Planning	2.66	0.62	1	4
Humor	1.46	0.58	1	4
Quality of life				
Physical	13.44	3.58	7	20
Psychological	13.10	3.12	6	20
Independence	14.08	3.32	5	20
Social	13.24	3.57	5	20
Environmental	13.11	2.79	6	19
Spiritual	12.92	3.75	4	20

Among coping strategies, guilt ( $M = 2.81$ ;  $SD = 0.6$ ) and humor ( $M = 1.46$ ;  $DP = 0.58$ ) were outstanding as the most and the least used, respectively. Regarding illness perception, the average score was 30.10 ( $SD = 15.07$ ), as an indication of non-relevant perception of the illness as a threat. However, the sample showed variability, with standard deviation equal to 15.07. The maximum score for this variable was 60.

Then, structural equation models were proposed based on the PLS method (*bootstrapping* = 1000) to understand the interaction among the study's variables. Because of the strong

correlation among the different QOL dimensions (Table 2), this can be considered to be a latent variable.

The first model considered the direct influence of illness perception on the QOL of PLWHA. Figure 1 shows negative, strong and significant impact ( $\beta = -0.78$ ;  $p < 0.001$ ) of illness perception on the QOL. The score of perceived QOL decreases as the harmful perception of seropositivity increases. However, coping strategies may also influence the QOL, reducing the effect of illness perception on this variable, as proposed by the theoretical Leventhal's Self-Regulation Model (Meyer et al., 1985). Therefore, a second model was tested, adding the different coping strategies analyzed (Figure 2).

Table 2. Pearson's correlation coefficients between the dimensions of QOL

	Physical	Psychological	Independence	Social	Environmental	Spiritual
Physical	1					
Psychological	0.70**	1				
Independence	0.76**	0.65**	1			
Social	0.53**	0.67**	0.56**	1		
Environmental	0.61**	0.69**	0.63**	0.66**	1	
Spiritual	0.40**	0.57**	0.30**	0.46**	0.34**	1

\* $p < 0.05$  \*\* $p < 0.01$

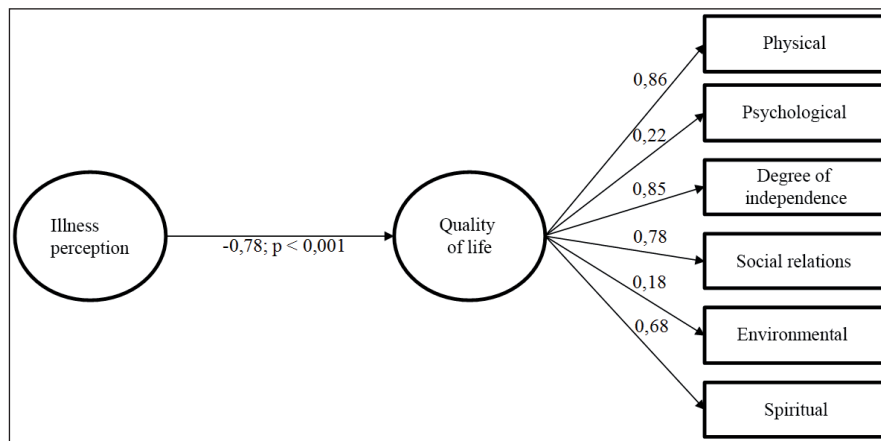


Figure 1. Direct influence of illness perception on QOL.

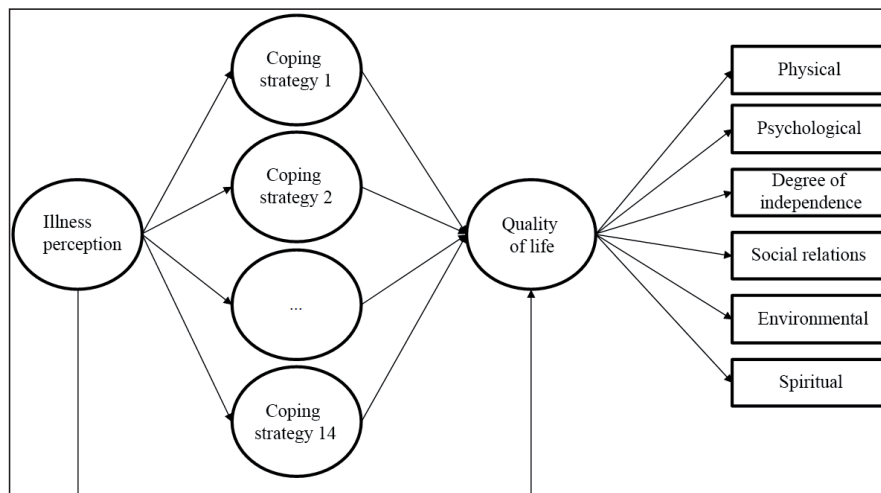


Figure 2. Theoretical model do be tested.

The final model (Figure 3) excludes variables with extremely reduced predictive load and significance below 0.05. As can be observed, several coping strategies were excluded from the final model, including expression of feelings

( $\beta = 0.02$ ;  $p = ns$ ) and use of substances ( $\beta = -0.10$ ;  $p = ns$ ) (lowest and highest non-significant factorial loads among coping strategies, respectively).

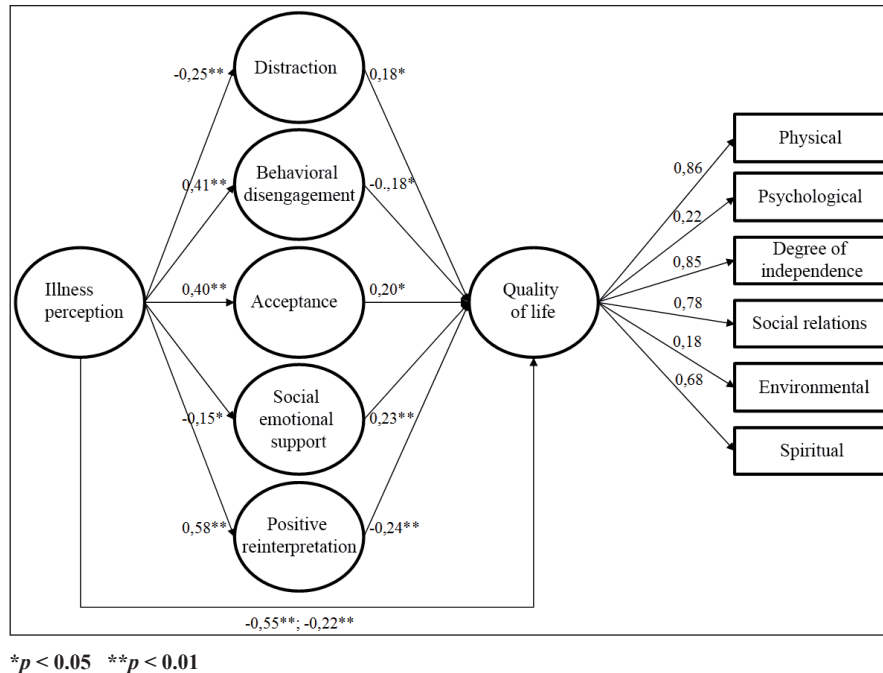


Figure 3. Influence of illness perception on QOL mediated by coping strategies.

Moreover, significant and positive influence of the following coping strategies were observed: acceptance ( $\beta = 0.20$ ;  $p < 0.05$ ), distraction ( $\beta = 0.18$ ;  $p < 0.05$ ) and instrumental support ( $\beta = 0.23$ ;  $p < 0.01$ ). Likewise, the following significant and negative effects were observed: behavioral disengagement ( $\beta = -0.18$ ;  $p < 0.05$ ) and positive reinterpretation ( $\beta = -0.24$ ;  $p < 0.01$ ). The illness perception's effect was reduced ( $\beta = -0.55$ ;  $p < 0.01$ ) pointing out partial mediation of the aforementioned coping strategies. To confirm this result, the indirect effect of illness perception on the QOL was estimated ( $\beta = -0.22$ ;  $p < 0.01$ ), confirming mediation.

### Discussion

This study aimed to verify predictors of quality of life of persons with HIV/AIDS, where the influence of illness perception on the QOL is mediated by coping strategies. A structural equation model was proposed based on the PLS method. This approach particularly fits into predictive applications and supports samples of relatively low size (Tenenhaus et al., 2005). This was the situation observed in this study. Therefore, the analyses of the structural equation model were more robust, overcoming the restriction posed by a sample shorter than the expected.

First, the proposed model highlighted the direct influence of HIV perception on the QOL. The more the illness was perceived

as threatening, the worst the QOL perception of the PLWHA in the sample under study. These results corroborate international studies (Reynolds et al., 2009), showing that illness perception can affect the QOL of Brazilians living with HIV/AIDS.

However, some variables seem to buffer this negative effect. In the second model test, most of the coping strategies were not significant and, therefore, were excluded from further analyses. The final model showed that higher use of coping strategies, acceptance, distraction and instrumental support, added with lower use of behavioral disengagement and positive reinterpretation, were QOL predictors, thus reducing the illness perception effect.

Therefore, higher use of distraction - i.e., mental diversion of the stressful situation -, acceptance of the stressing event as real and of the instrumental social support - comprising help, information and advices about the best thing to be done - could reduce the negative effect of illness perception on the QOL. On the other hand, behavioral disengagement - like ceasing the search for an objective because of the stressful situation - and positive reinterpretation, i.e., take the most of the situation or perceive it in a more favorable way, would amplify this negative influence. These results corroborate most of the Brazilian literature about coping strategies (Faustino & Seidl, 2010; Seidl et al., 2005), except for the negative influence of positive reinterpretation. This strategy is part of those focused on the problem and its use should

reduce rather than expand the impact of illness perception. This aspect deserves deeper analysis in further studies.

According to the results, how PLWHA perceive their illness is an important predicting factor for QOL. Also worth of notice is the fact that some variables related to coping proved to predict the QOL of Brazilian PLWHA in a broader model, like the one tested in this paper. Mediation is confirmed by the significant indirect effect found.

The study also has practical implications: a potential way of improving the QOL perception of seropositive individuals is that of reinforcing psychological resources like the coping strategies highlighted herein. This demands investments in interdisciplinary teams including psychologists, in order to change dysfunctional cognitions about the disease and/or promote the adoption of strategies that could reduce its negative effect, notably based on cognitive-behavioral interventions, that have been proved effective (Brito & Seidl, 2015).

Finally, as limitation of the study, one should consider the data collection process adopted. Participants completed an on-line questionnaire available on a website specific to the survey. This strategy was selected to favor the nationwide access of seropositive individuals to the study, ensuring their anonymity. However, it has also posed barriers to participation because it was publicized on websites of entities that fight against the HIV/AIDS. Therefore, to learn about the study, potential participants should use a computer and have access to those websites. So, we can problematize who participated in this study and their representativeness in the context of PLWHA in Brazil.

Lastly, the study is worthy because it expanded knowledge about QOL predictors in the context of HIV/AIDS, mainly highlighting the important role of the illness perception. The study ratified the self-regulation model proposed by Meyer et al. (1985), because both illness perception and coping strategies proved to have effect on the QOL.

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