PSYCHOLOGY, HEALTH & MEDICINE, 2017
VOL. 22, NO. 2, 129–137
http://dx.doi.org/10.1080/13548506.2016.1146404

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Illness perception and quality of life of HIV-positive persons: mediation effects of tenacious and flexible goal pursuit

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ABSTRACT

Medical advances contribute to raise life expectancy of people living with HIV/AIDS (PLHIV). However, they still face challenges related to the disease, thus, quality of life (QOL) became a priority on the field. The self-regulatory model (SRM) guided this study. Illness perceptions (IP) are the beliefs, cognitions, representations of a disease, impacting PLHIV coping strategies and QOL. Tenacious goal pursuit (TGP) is the pursuit of goals with determination, flexible goal adjustment (FGA) is doing it with flexibility, disengaging if necessary, they can both be considered as coping strategies. This study aims to measure the impact of HIV Perception in the QOL of PLHIV mediated by the TGP and FGA. Data was collected from 196 PLHIV with the WHOQOL-HIV Bref, the Brief-IPQ and the FGA and TGP scales. Structural equation model provided a good fit consistent with the theoretical SRM. IP, TGP and FGA had direct effects on the QOL of PLHIV. IP had also an indirect effect (partially mediated by TGP/FGA), suggesting that TGP/FGA reduce the impact of a threatening IP in the QOL. Goal oriented interventions should focus in the HIV perception of PLHIV to ameliorate their QOL.

ARTICLE HISTORY
Received 16 June 2015
Accepted 19 January 2016

KEYWORDS
HIV/AIDS; self-regulatory model; goal pursuit; quality of life

Introduction

Medical advances have significantly reduced the number of HIV-related morbidity and mortality, contributing to the increase in life expectancy of people living with HIV or AIDS (PLHIV), which is now considered as a chronic disease. However, PLHIV still face the challenges related to the disease (Ion et al., 2011). Thus, improving quality of life (QOL) of PLHIV became a priority for practitioners, therefore the amount of researches on this field has been augmented.

QOL refers to the disease adjustment in the daily life of the persons. In the case of chronic diseases, it includes having to adapt to the demands of it. But it is worth noting that the QOL of PLHIV is worse than for patients with several other chronic diseases (Hays et al., 2000). QOL is defined as the '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,

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standards and concerns' (The WHOQOL Group, 1998). This definition emphasizes the subjective dimension of QOL and therefore should be assessed from the point of view of the person. It is also a multidimensional concept, consisting of physical, psychological, social, environmental, and spiritual aspects of the individual.

Studies show that the QOL of PLHIV is associated with several psychosocial aspects, such as social support (Beaulieu et al., 2012; Bekele et al., 2013; Slater et al., 2013; Vyavaharkar, Moneyham, Murdaugh, & Tavakoli, 2012), coping style (Slater et al., 2013; Vyavaharkar et al., 2012; Weaver et al., 2004), locus of control (Préau et al., 2005), attachment (Martin, Vosvick, & Riggs, 2012), anxiety and depression (Aranda-Naranjo, 2004; Préau et al., 2007; Psaros, O'Cleirigh, Bullis, Markowitz, & Safren, 2013; Vyavaharkar et al., 2012) and personality trait (Penedo et al., 2003).

Another aspect that can influence the QOL is the experience with the illness and its representation (Knowles, Wilson, Connell, & Kamm, 2011). A theoretical model used to understand this process is Leventhal's self-regulatory model (SRM) (Meyer, Leventhal, & Gutmann, 1985). This theory has proven useful with many chronic diseases, including the HIV/AIDS (Reynolds et al., 2009). The self-regulation process occurs in three phases: (1) illness perception (IP); (2) coping strategies; and (3) evaluation (Broadbent, Petrie, Main, & Weinman, 2006). Firstly the individual seeks to understand the illness. From the various internal and external information which the individual has access, he develops a representation of the illness. These perceptions occur in a sociocultural context and are determined by many factors, such as the perception of consequences, timeline, personal and treatment control, identity, concern, the emotional representation of illness and its understanding. Therefore it is not necessarily scientifically accurate (Reynolds et al., 2009).

IP will lead to the second stage, the selection of coping strategies to eliminate or control the threat of disease (Broadbent et al., 2006). This will influence the outcomes of the disease, such as anxiety and depression, and the individual's QOL (Knowles et al., 2011) including PLHIV (Johnson & Folkman, 2004).

Two coping mechanisms that have not been studied in this context are the assimilative and the accommodative coping strategies, also known as flexible goal adjustment (FGA) and the tenacious goal pursuit (TGP). According to the authors (Brandtstädter & Renner, 1990), individuals are confronted with unattainable goals during their life and when facing this situation they can either be tenacious or flexible. This dual-process model has originally been created to account for successful aging and although it has not been study in the context of PLHIV, FGA and TGP seems to be relevant in this context as changes related to the disease are not negligible and need constant adaptation.

The TGP involves striving for the goal with determination, using the assimilative coping to modify the environment according to personal preferences to achieve the goal (Brandtstädter & Renner, 1990). The individual will tend to avoid stimuli that could divert his goal attainment or activate other. Our culture and society tend to overvalue stubborn behaviors and coping strategies of assimilation and consider inadequate to abandon a project or goal.

FGA means pursuing the goals with flexibility, even abandoning it, if necessary (Brandtstädter & Renner, 1990). Individual uses accommodative coping and change their personal preferences to adapt to stress and change objectives to face obstacles. The accommodative adaptation is considered as a neutralizing agent and is not an active solution. In

this case, the individual changes his cognitions so the new situation seems less negative or more acceptable. Adjusting to personal goals or ambitions is then less demanding and depends on available resources.

The way a person respond to frustrated goal attainment evolve during life and depends on the context (Brandtstädter, 2009). When the individuals are faced with unattainable goals, they may continue to seek to achieve other important projects to alleviate the suffering associated with what can't be achieved (Wrosch, Scheier, Miller, Schulz, & Carver, 2003). Thus, individual differences related to goals adaptation can be a predictor of QOL (Rasmussen, Wrosch, Scheier, & Carver, 2006).

Finally, the third phase of the SRM is the evaluation of the effectiveness of the adaptation strategy and the resolution to continue or not with this strategy (Broadbent et al., 2006). Note that this process is dynamic and the original perceptions are modified by the observations, judgments and reactions of the individual that led him to undertake the same or other strategies to achieve a goal (Reynolds et al., 2009).

The objective of this article is to measure the effects of the IP mediated by TGP, FGA in the QOL of PLHIV.

Method

Design and participants

196 PLHIV (21.4% of women and 78.6% of men) participated on this cross-sectional study. The mean age was 49.07 years old (SD = 10.26). They were living with HIV for a mean of 15.97 years (SD = 8.66). An independent-samples *t*-test was conducted to compare the age and time living with HIV from men and women. The age difference between men ($M = 49.45$, SD = 10.19) and women ($M = 47.71$, SD = 10.53) was not significant, $t(194) = -.97$, $p = .33$. There was also a not significant difference, $t(194) = 1.08$, $p = .28$, concerning time living with HIV between men ($M = 15.62$, SD = 8.81) and women ($M = 17.26$, SD = 8.09).

Sampling procedures

Before screening, this study was approved by the French Ethics Committee CCTIRS (*Comité Consultatif sur le Traitement de l'Information en Matière de Recherche dans le Domaine de la Santé*), Ministry of Higher Education and Research, Paris.

Participants that received questionnaires met inclusion (both sexes, age from 18 years old, ability to read and write French, having signed an informed consent for their participation in the study) and non-inclusion (presence of a severe cognitive or medical condition, recent HIV diagnoses – less than one year) criteria.

To preserve the confidentiality of data, questionnaires were given to the patients by their doctors, during their follow-up visit with a pre-stamped pre-labeled envelope to be mailed to our research team. Thus, participants could complete the questionnaire at their pace at a convenient place to them.

Measures

WHOQOL-HIV bref

The WHOQOL-HIV Bref (O'Connell & Skevington, 2012) is a 31 items QOL questionnaire. It assesses six domains: Physical, psychological, independence level, social relationships, environmental and spiritual of the QOL of PLHIV. The WHOQOL-HIV Bref is a well-established measurement, with a good internal consistency reliability, discriminant validity and an overall good fit for a six domains model, with confirmatory factor analyses (CFA) supporting scoring. Each item is in a question form for which participants answer on a five points Likert scale. The domain scores are scaled in a positive direction, a higher scores denote higher QOL perception.

Brief IP questionnaire

The Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent et al., 2006) was developed for the rapid measurement of the perception of the disease. It is a nine items questionnaire that explore the illness cognitive representation (consequences, timeline, personal and treatment control, identity, concern), the emotional representation of illness, its understanding and the causal representation (this last item has a open qualitative response and will not be used in this study). The interpretation is simple, a score increase means a linear increase of the measured dimension. The overall score is calculated by the sum of each dimension and a higher score represents a more threatening view of the illness. This score validity depends on the illness studied and for that reason this questionnaire was evaluated in this study with a CFA and IP was found to have a good model fit ($\chi^2 > .01$, $\chi^2/N = 1 - 2$, CFI > .90, RMSEA < .08) using all eight items. The item 'understanding of the illness' was maintained despite its load contribution of $\beta = .07$, because its elimination could have influenced further analyses.

Flexible goal adjustment (FGA)/Tenacious Goal Pursuit (TGP)

To measure the use of assimilative and accommodative coping, a questionnaire comprising two scales was developed (Brandtstädter & Renner, 1990). The TGP to assess the assimilative coping strategie and the FGA to evaluate the accommodative style. The French version was validated with ten items for each scale (Bailly, Hervé, Joulain, & Alaphilippe, 2012). Presented in a statement form, the participant responds if it corresponds to him on a six points Likert scale, a higher score indicating a greater use of the coping strategy.

FGA/TGP have mixed reviews on the literature. For that reason a CFA was undertaken to test the scale. A first model with the 20 items was unsatisfactory ($\chi^2 > .01$, $\chi^2/N = 1 - 2$, CFI > .90, RMSEA < .08). To improve model fit, two items were excluded because of their lower saturations and 18 items were retained (nine for TGP and nine for FGA). A good model fit ($\chi^2 > .01$, $\chi^2/N = 1 - 2$, CFI > .90, RMSEA < .05) was observed, supporting Brandtstädter's theory.

Statistical analysis

Descriptive and correlational analyses were conducted to study the different variables and the possible relation between them using SPSS Statistics 17.0. Then, a structural equation model (SEM) was tested using the Amos Statistical Package (v.17). To attain the final model,

Table 1. Pearson's correlations (and significance values) of IP, TGP, FGA, and QOL.

	M	*σ*	1	2	3	4	5	6	7	8
1. Illness perception	37.80	11.33	1							
2. TGP	3.15	.74	−.18*	1						
3. FGA	3.55	.63	−.37**	.16*	1					
4. Physical QOL	14.57	3.25	−.52**	.28**	.19**	1				
5. Psychological QOL	13.74	3.06	−.59**	.39**	.34**	.69**	1			
6. Independence level QOL	13.73	3.15	−.39**	.17*	.09	.67**	.45**	1		
7. Social QOL	13.87	3.28	−.49**	.31**	.26**	.55**	.66**	.38**	1	
8. Environmental QOL	14.22	2.68	−.37**	.31**	.28**	.49**	.59**	.45**	.61**	1
9. Spiritual QOL	13.57	3.78	−.56**	.30**	.29**	.43**	.62**	.26**	.55**	.36**

*$p < .05$; **$p < .01$.

improvements were made using modification indexes without compromising the theoretical framework.

Results

Descriptive and correlational analyses

Participants mean scores to each QOL domain, accommodative and assimilative coping and IP, as well as their correlations are presented in Table 1. Participants QOL mean score varied from $M = 13.73$ (SD = 3.15) in the level of independence QOL domain to $M = 14.57$ (SD = 3.25) in the physical domain. They tended to use more accommodative ($M = 3.55$, SD = .63) then assimilative coping ($M = 3.15$, SD = .74) and the IP mean was 37.80 (SD = 11.33).

The different QOL domains had a moderate to strong positive significant correlation to each other (Table 1), the smaller being $r = .26$, $p < .01$ between independence level QOL and spiritual QOL, and the strongest $r = .69$, $p < .01$ between psychological QOL and physical QOL. These results indicated that the different QOL domains were clustered. Individuals with a higher QOL in a certain domain, in general had a better QOL in all others.

Overall, the correlation between the different QOL domains and TGP/FGA were also positive and significant. They ranged from weak (the most modest $r = .17$, $p < .05$ between level of independence QOL and FGA) to moderate ($r = .39$, $p < .01$ for psychological QOL and TGP). This data suggested that individuals who used more accommodative and assimilative coping had a better QOL.

On the opposite, a higher IP score had a moderate to strong negative correlation with all domains of QOL, the smaller being $r = -.37$, $p < .01$ between IP and environment QOL and the strongest $r = -.59$, $p < .01$ between IP and psychological QOL. This indicated that PLHIV with a threatening IP had a lower QOL in all domains.

Finally, it was found a negative weak correlation between TGP and IP ($r = -.18$, $p < .05$) and a negative moderate one between FGA and IP ($r = -.37$, $p < .01$). These results showed that the more IP was threatening, less individuals used accommodative or assimilative coping strategy.

These first results suggested the importance of the accommodative and assimilative coping strategies. The following analysis focused on their role in the associations observed between IP and QOL.

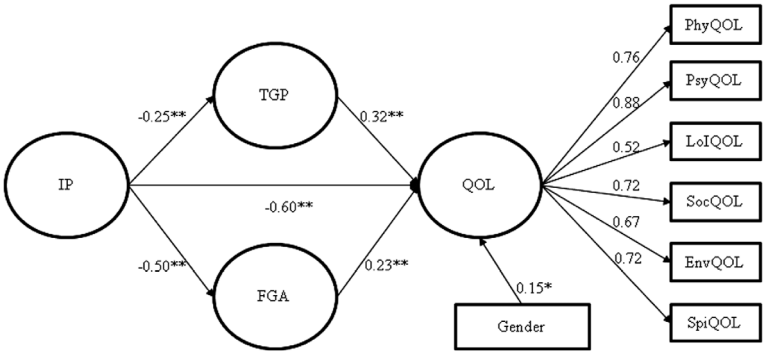

Figure 1. Final model: IP, TGP and FGA effects on the QOL.
*$p < .05$; **$p < .01$.

Structural equation model

A second level of analysis was then carried out. The different variables (IP, TGP/FGA and QOL) were represented as latent variables in a SEM, according to the SRM. Age, gender and time living with HIV were added as observed control variables.

First the direct effect of IP on QOL was tested. As a result, a significant negative effect was observed ($\beta = -.75$, $p < .01$). Then the mediation paths (TGP/FGA) were added and the direct effect of IP on QOL dropped ($\beta = -.60$, $p < .01$), which suggested a partial mediation. As the Baron and Kenny (1986) technique is considered to have some limitations, the indirect effect were estimated with bootstrap, a more rigorous approach (Zhao, Lynch, & Chen, 2010) and a significant indirect effect was found ($\beta = -.19$, $p < .01$) which confirmed the partial mediation.

The final model was improved with modification indexes. Two control variables (age and time living with HIV) had a low non significant addition to the model and were removed. All the others paths were significant.

As hypothesized and consistent with the SRM, IP had both direct ($\beta = -.58$, $p < .01$) and indirect effects on QOL. Also, TGP and FGA had a significant direct influence on QOL ($\beta = .31$, $p < .01$, $\beta = .20$, $p < .01$ respectively) (Figure 1). This model presented good fit to data (χ^2/df = 1.33, CFI = .93, RMSEA = .04, SRMR = .07), which suggested that it correctly represented the relationship between the different variables.

Discussion

This study aimed to explore the impact of IP on the QOL of PLHIV and the mediation role of TGP and FGA.

Correlational analyses revealed that, as hypothesized, IP was negative related with QOL. The more the HIV was perceived as a threatening illness, the lower was the QOL (constituted by different domains of QOL) of the PLHIV. This confirmed the findings of others studies with PLHIV (Johnson & Folkman, 2004; Reynolds et al., 2009). The assimilative and accommodative coping strategies (respectively TGP and FGA) were both positively related to QOL and an increase on the use of each strategy implicated in a better QOL. This was the first study that used these coping strategies with PLHIV and it came to add to the findings with an adult/aging population (Brandtstädter, 2009). IP had also a negative relationship

with TGP and FGA. A worse IP leaded to a decrease in the use of both coping strategies, as hypothesized. This data suggested that when PLHIV faced an unattainable goal, with a threatening perception of their illness, they would neither adjust their goal (which could had appraised the frustration of not achieving it), nor fight with determination for it.

Finally, a SEM was undertaken to measure both direct and indirect effects from the different variables simultaneously. Control variables (age, time living with HIV and gender) were included in the model, but only gender had a significant impact on the QOL. The impact of gender in the QOL is well established in studies with PLHIV and also with a general population, showing that women's QOL are worse than men. The debate of it being an actual difference into the QOL or if scales should be adapted to take into consideration this difference will not be discussed here. But this difference has to be taken into consideration into a model that intends to contribute to the explanation of PLHIV's QOL.

There was a good fit observed in the final SRM. IP, TGP and FGA had direct effects on the QOL of PLHIV. IP had also an indirect effect on their QOL (mediated by TGP and FGA). The assimilative and accommodative coping strategies reduced the impact of a threatening IP in the QOL.

These findings supported the importance of IP, which needs to be taken into consideration when working to improve PLHIV QOL. HIV is still associated with moral disapproval (as its transmission involves practices or behaviors that can be considered deviant), with the idea of death (as it is an incurable disease) and the fear of contagion. This stigmatization contributes to a degrading view of this illness that impacts the way PLHIV see their disease and as a consequence their QOL. Implementation of interventions to ameliorate the way HIV is perceived is needed.

Finally, our data also underlined the importance of these two underexplored coping strategies. Both processes (assimilative and accommodative coping modes) were important at eliminating discrepancies between a possibly unachievable goal and life perspective, which occurs in an aversive life situation (Brandtstädter & Renner, 1990). PLHIV are constantly facing a reality that needs adaptation. In this context, the way they deal with unattainable goals was very important, as more threatening IP implicated in a lower use of both coping strategies, meaning that PLHIV in this situation would neither adjust their personal goals, nor increase their efforts to achieve it. Psychological interventions could probably optimize the attitudes and behaviors of PLHIV when facing unachievable goals. Identifying resources to deal with a specific goal can create satisfaction during an active goal pursuit. On the other hand, when assimilative strategies are not successful, the adaptation of personal preferences to situational constraints, by restructuring individual's cognitions so an adjustment on the goal would be acceptable, could reduce frustration and as a consequence optimize QOL.

This study had some limits. First, the size of the sample could be increased. To reduce error, the instruments (QOL excluded) were statistically validated with a CFA. Other than that, this study didn't measure classical coping strategies to compare with the assimilative and accommodative coping modes. Future studies could take emotion-focused and problem-focused coping strategies into consideration to build a more comprehensive model, as well as other illness outcomes, such as emotional distress variables. Psychological support could be an interesting manner to improve the use of those coping mechanisms when facing unattainable goals and consequently improving QOL, further research could confirm this hypothesis. Finally, to our knowledge, this was the first study that investigated assimilative

and accommodative coping strategies with SRM and a chronic disease population, therefore further studies should confirm our findings.

Disclosure statement

No potential conflict of interest was reported by the authors.

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