ORIGINAL RESEARCH

Contribution of guarding to quality of life among chilean people living with HIV

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Abstract

Background: Guarding is a self-care process that individuals use to manage chronic illness; it refers to the process of maintaining vigilance over a person's self and network. This study evaluates the relationship between quality of life and guarding among people living with Human immunodeficiency virus/Acquired immunodeficiency syndrome (PLHA). Method: A cross-sectional study of 209 people living with Human immunodeficiency virus/Acquired immunodeficiency syndrome was conducted in Santiago, Chile. PLHA completed a questionnaire about characteristics of quality of life, human immunodeficiency virus symptoms status, social network, demographics, and guarding. Illness characteristics were obtained from medical records. Results: Hierarchical multiple regression revealed that having more close friends/relatives, fewer Human immunodeficiency virus symptom status, and less guarding behavior was significantly related to a higher quality of life. No relationship was found between quality of life and demographic and illness characteristics. Conclusion: Together, study variables explained 58.8% of the variation in the quality of life.

Keywords**:** Chronic illness, Guarding, HIV infections, Quality of Life, Regression Analysis, Self-Care.

Background

At the world of the 36,7 million people living in 2015 with human immunodeficiency virus/ acquired immunodeficiency syndrome (HIV/AIDS), 5.8 million were 50 or older.[1] In Chile, the first case of HIV/AIDS was diagnosed in 1984, and the number of new cases has increased steadily since. People between ages 20 to 39 years old are the most affected (2). Most infections are contracted through sexual transmission, especially among men who have sex with men and their female partners.[2,3] Since 2003, Ministry of Health has provided free highly active antiretroviral therapy (HAART) to people living with Human immunodeficiency virus/Acquired immunodeficiency syndrome (PLHA) as part of a national program.[4] Since the provision of antiretroviral therapy began, a decrease in mortality and a delay in the appearance of AIDS, as well as a decrease in major HIV-related complications and hospitalizations, have occurred.[5,6] Furthermore, PLHA with access to effective treatment is growing older, [7,8] while more people are acquiring HIV at an older age. [9,10] As is true for persons with other chronic diseases, studies have been carried out evaluating the impact of HIV/AIDS on the quality of life (QOL) of PLHA. [1]

In coping with a chronic illness, guarding refers to "the process of maintaining vigilance over self, the illness, the treatment regimen, the delivery of care, and important relationships" [11];

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and may play a critical role in understanding how PLHA deal with their chronic illness. Furthermore, HIV infection remains a globally stigmatized condition, and HIV stigma remains a complex concept [12-15] associated with blame, shame, disgrace, and social unacceptability. [16] A critical barrier to coping on PLHA is the HIV stigma that can devastating with life-inhibiting emotional, psychological, relational or material outcomes.[17] Also, it can be present ongoing concerns about disclosure [18] and uncertainty over how aging, HIV, and its treatment affect health.[19]

On the other hand, the concept of QOL refers to a subjective evaluation of various aspects of a person's life that are important to the individual; those aspects are the primary factors affecting that person's perception of overall QOL. [20] Previous studies report finding a negative relationship between QOL in higher age groups,[21-24] especially in the physical, independence and social relationships domains[22]

Concerns about memory difficulties, and depressive and anxious feelings, have been strongly associated with lower QOL.[22-24] Furthermore, self-isolating or decreased social participation, [25] discouragements to participate in treatment programs, and attend care facilities[26] can leads to social avoidance, real or perceived loss of friends. Also, the perceived discomfort of those they are in contact with, symptoms of depression and feelings of anxiety,[12] hopelessness, and unattractiveness are significant for PLHA. [27] All these aspects contribute to a decreased QOL as an outcome of HIV stigma for PLHA. [16]

While many studies provide important information on the correlates of self-care strategies on PLHA's perception of QOL, little research has been directed toward examining the concept of guarding and its impact on QOL. This study examines the relationship between guarding and QOL when controlling for individual, social network, illness factors, and HIV symptom characteristics. It also identifies factors distinguishing persons with low versus high levels of guarding and the implications of this behavior for QOL.

The health-related QOL conceptual model developed by Wilson and Cleary in 1995 [28] guides this research. PLHA's QOL is conceptualized as influenced by five levels of the individual's characteristics: socio-demographics, social networks, illness-related factors, HIV symptom status, and guarding. These five levels can be thought of as building blocks, each contributing to QOL. These five levels may also be interrelated with each other. The health-related QOL conceptual model treats the interaction between PLHA's characteristics (i.e., individual, social network, illness-related factors, HIV symptom status, and guarding characteristics) with equal importance, making each block of variables a unique contribution to PLHA's QOL.

Materials and methods

Design, Participants, and Setting

This study used a cross-sectional, correlational design. A convenience sample of 209 PLHA was recruited from an outpatient clinic in Santiago, Chile, between December 2009 and March 2010. The outpatient clinic serves approximately 580 HIV-infected clients at an average of 100 patients per month. PLHA receive clinical assessments at regular intervals (three or four times per year), including monitoring standard antiretroviral therapy and related medications, performing laboratory testing such as CD4+ T cell count and viral load, and monitoring health as part of the Chilean national standard guidelines of HIV care. [5]

To be eligible for the study, individuals had to: (a) have tested HIV positive; (b) be 18 years of age or older; (c) received antiretroviral therapy for more than three months in order to stabilize its early side effects; (d) no past medical history of dementia; and (e) no hospitalizations during the last month. The study's sample size was calculated at 209 PLHA to allow a power of 0.95 with α level set at 0.05 and a medium effect size (0.15) for a hierarchical multiple linear regression.

Ethical considerations

The research team obtained ethical approval to conduct the study from both the Institutional Review Boards at the University of Illinois at Chicago and Pontificia Universidad Católica de Chile. Potential participants received general information about the study from their health care providers at the time of their routine medical appointment. They were told that participation was entirely voluntary and that their decision to agree or decline to enroll in the study would not affect their treatment in any way. If the patient decided to be contacted, the first author approached potential participants to check eligibility criteria in a private room at the clinic. The research team explained to all eligible participants the nature of the study, including procedures for maintaining confidentiality. The research team obtained consent from those who agreed to participate. Then, a face-to-face interview was conducted at the outpatient clinic with a standardized questionnaire after a medical appointment, followed by a medical record review to obtain illness characteristics.

Measures: data collection

Quality of life, the dependent variable, was measured using the 34-item version of HIV/AIDS—Targeted Quality of Life scale (HAT-QOL).[29] Each item is rated on a five-point Likert scale ranging from 1 (*all of the time*) to 5 (*none of the time*). The HAT-QOL has nine subscales: overall functioning, sexual functioning, disclosure worries, health worries, financial worries, medication worries, HIV mastery, life satisfaction, and provider trust. Medication worries and sexual function subscales were excluded from the total score because not all of the participants answered those questions. Not taking HIV medication (22%) and not being sexually active (20%) at the time of the interview were the main reasons given by the participants who did not answer medication worries and sexual function questions. Therefore, for this study, the HAT-QOL consisted of 27 items with a total scale score range from 27 to 135. The reliability coefficient (α) was 0.86 with a higher score indicating higher QOL.

Independent variables were guarding, HIV-related symptoms, socio-demographics, and illness characteristics. The *Self-care Management Process—Guarding scale (SCMP-G)*[30] is designed to measure guarding as a self-care management process that individuals use in managing illness self-care. Guarding measures the perception of vulnerability, controllability, self-absorption, and a sense of obligation that persons with chronic illness have in performing self-care behaviors. The SCMP-G measures all four of these aspects of guarding. The original SCMP-G scale has 35 items divided into two subscales: self-guarding (20 items) and social guarding (15 items). Each item is rated on a five-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Exploratory factor analysis for this study showed that the two subscales were highly interrelated and only one factor was identified. Therefore, the research team used the total score of the SCMP-G scale to measure guarding. After the instrument was pretested in a Chilean population, four items related to self-guarding and one item related to social guarding were dropped because these items did not apply to Chilean culture. The revised total possible scale score with 30 items ranges from 30 to 150. A higher score indicates more use of self-care guarding. [30] Cronbach's α coefficient for this study was 0.85.

The Revised Signs and Symptoms Checklist for Persons with HIV Disease (SSC-HIVrev)[31] is a 45-item instrument, used to assess HIV symptom status (frequency and intensity of HIV-related symptoms); it consists of 11 factors: fatigue, numbness, fear, gastrointestinal upset, bruising/bleeding, headache, sore throat, rectal itch, fever, body changes, and shortness of breath. Each item is rated on a four-point Likert scale from 0 (*not present*) to 3 (*severe*). The final score is calculated by the sum of the 11 factors. Each factor is calculated by adding the item scores (0–3) and dividing them by the number of items in each factor. The total score was used to measure HIV symptom status because it synthesized frequency and intensity of HIV-related symptom in one score. The total scale score ranges from 0 to 33. A higher score indicates more troubling HIV symptom status. The internal consistency of the SSCHIVrev scale for this study was 0.88.

Socio-demographic and social network information were gathered from the socio-demographic data form. Age, gender, sexual orientation, educational level, employment status, having children, having co-morbidities besides HIV, number of close friends or relatives, and living with spouse or partner variables were asked. Illness-related information was extracted from the medical records review, for example, length of time since HIV diagnosis, in treatment with antiretroviral therapy, HIV disease staging at the time of diagnosis according to the 1993 CDC criteria, markers of immune suppression (CD4+ T cell count), and HIV viral burden (viral load).

The SCMP-G, HAT-QOL, and SSC-HIVrev original instruments were translated from English to Spanish using the translation/back-translation method described by Guthery & Lowe. [32] First, the SCMP-G, HAT-QOL, and SSC-HIV original instruments were translated from English to Spanish by a bilingual person who is a native speaker of Spanish. Second, the instruments in Spanish were translated back into English by a native speaker of English. Then the original and the back-translated English versions were compared by the authors of this research to provide the final version in Spanish.

A team of six Chilean HIV care experts determined the adequate content validity of measures for a Chilean population and evaluated possible normative problems.[33] Then, the Spanish versions of the SCMP-G, HAT-QOL, and SSC-HIVrev were tested with 10 Chilean cognitive interviewers to assess semantic clarity and coherence of items.[34]

Data Analysis

Statistical Package for the Social Sciences (SPSS) for Windows Version 19.0 was used to analyze the data. Descriptive statistics (frequencies, percentage, means, and standard deviations) were computed to summarize demographic characteristics and study variables. Bivariate correlation analyses were conducted to assess correlations between variables.

Hierarchical multiple linear regression was conducted to evaluate the relationship between guarding and QOL in PLHA when controlling for individual, social network, illness, and HIV symptom status characteristics based on the proposed conceptual framework of this study. Results of evaluation satisfied the assumptions of linearity, normally distributed errors, and uncorrelated errors. [35] Nominal variables were recorded as dummy variables for inclusion in this analysis as specified under each block.

Five blocks were used to conduct a hierarchical multiple regression predicting the dependent variable, QOL. The order of entry of the variables in blocks was based on the conceptual framework of this study. Demographic characteristics, including age, gender (female or male), sexual orientation (men who have sex with men/bisexual or heterosexual), level of education (completed college-level or less than college level), having employment (yes or no), and having children (yes or no) were entered in Block 1. Social network characteristics, number of close friends and relatives, and living with spouse or partner (yes or no) were entered as a characteristic of the social network in Block 2. Illness characteristics, e.g., length of time living with HIV, CDC classification at the time of diagnosis (AIDS or HIV), taking HAART (yes or no), latest CD4+ T cell count, latest viral load (detectable or undetectable level), and having a comorbidity (yes or no), were entered into the regression model in Block 3. HIV symptom status was added in Block 4. Guarding was entered into the regression in Block 5. This procedure allows examination of the additional variation explained by each new block.

Also, differences between groups with high and low guarding were compared. Chi-square test for categorical variables and *t*-tests for continuous variables were carried out to determine differences between two groups. A significance level of 0.05 was used to determine if differences between the two groups were statistically significant.

Results

Sample Characteristics

Table 1 reports sample characteristics. The mean age of the participants was 41 years (range = 18 to 76). Ninety percent of the sample was male. Forty-six percent of the participants had at least completed a college education. Seventy-eight percent were employed at the time of the interview. The mean number of close friends or relatives was 5.5.

The mean age of the participants at HIV diagnosis was 37 years old; 52% of them had AIDS at the time of diagnosis based on the CDC classification. Seventy-nine percent of the participants were currently taking HAART and 68% of the sample had an undetectable viral load (<80 copies/mL). Twenty-seven percent of the participants had at least one co-morbidity in addition to HIV. Diseases of the circulatory system and endocrine, nutritional, and metabolic diseases were the most frequent co-morbidities reported by PLHA. The mean participants' guarding score was 102.6 (SD=16.1; range 56-135); the mean for QOL score was 102.6 (SD =16.0; range 48-135); and the mean HIV-symptom status score was 3.8 (SD = 2.8; range 0–17).

Table 1
Socio-demographic, Social Network, Illness, HIV Symptom Status, Guarding, and QOL Characteristics of the Study Sample (N=209)

Variables	Mean (SD)	%
Individual characteristics		
Age (years)	41.0 (11.4)	
Male		90.0
Heterosexual		23.4
Educational level		
Less than high school		3.9
High school		23.4
Technical school		26.3
College		46.4
Employed		78.0
Having children		27.8
Social network characteristics		
Numbers of close relatives/friends	5.5 (7.8)	
Living with spouse or partner		61.7
Illness characteristics		
Length being HIV infected (years)	4.1 (4.5)	
HIV at the moment of diagnosis		46.9
In-treatment with antiretroviral therapy		78.5
Current CD4$^+$ T cell Counts	433.2 (224.4)	
Undetectable Current Viral load		68.9
Having comorbidity besides HIV		27.3
HIV symptom status		
HIV symptom status scores	3.8 (2.8)	
Guarding		
Guarding scores	102.6 (16.1)	
Quality of life (QOL)		
QOL scores	102.6 (16.0)	

Source: self- elaboration.

Correlations Between Study Variables

Having completed college and a number of close friends were found to be positively associated with QOL. In contrast, scores on both HIV-symptom status and guarding correlated negatively with QOL. None of the illness characteristics measured in the study were found to be statistically significant in association with QOL.

Relationship between Guarding and QOL

The hierarchical multiple regression results are presented in table 2. Although socio-demographic (except high education) and illness characteristics were not associated with QOL in the bivariate analysis, these characteristics were included in the regression because they are theoretically relevant variables.

The regression model explained 58.8% of the variance of QOL, F (1, 166) = 83.8, p<.0001. Only three variables, number of close friends, HIV symptom status, and guarding, were statistically significant in explaining the variation of QOL. Guarding accounted for 20.8% of the QOL's variance after all the other variables were added in the model, and HIV symptom status accounted for 26.6% of the QOL's variance. In contrast, socio-demographics (i.e., age, gender, sexual orientation, educational level, employment level, and having children) and illness characteristics (length of time being HIV-infected, current CD4+ T cell count, current viral load, CDC classification at the time of diagnosis, being in treatment with ART, and having comorbidity besides HIV) were not significant contributors to the QOL variance.

Discussion

This study showed that less guarding behavior, having more close friends/relatives, and fewer HIV symptom status, was significantly related to higher QOL. No relationship was found between QOL and demographic / illness characteristics. Together, study variables explained 58.8% of the variation in QOL.

Confronting a new condition, coupled with the unique difficulties that the serological status presents to the individual's life, has been one of the challenges faced by PLHA, especially those aged 50 or over. [1,36-38] One possible interpretation of this relationship may be that the vigilant monitoring and controlling nature of

Table 2
Summary of Hierarchical Multiple Linear Regression Analysis for the Contribution of Guarding on the QOL Controlling for Individual, Social Network, Illness, and HIV Symptom Status (N=209)

Step and Variable	*B*	R^2	ΔR^2
Step 1: Individual characteristics		.028	.028
Years	.009		
Male	.008		
Heterosexual	.025		
Completed college level of education	-.002		
Unemployed	.022		
Having children	.012		
Step 2: Social network characteristics		.108	.081*
Living with spouse or partner	.020		
Number of close relatives/friends	.211*		
Step 3: Illness characteristics		.114	.006
Length of time being HIV infected	-.009		
CDC classification at diagnosis: AIDS	-.093		
In treatment with antiretroviral therapy	-.025		
Currently $CD4^+$ T cell count	-.068		
Currently detectable viral load	-.002		
Having comorbidity	-.016		
Step 4: HIV Symptoms status characteristics		.381	.266*
HIV-symptom status score	-.351*		
Step 5: Guarding characteristics		.588	.208*
Guarding score	-.513*		
Constant	164.604		

Note. * $p<0.01$
Source: self- elaboration.

guarding may require a great deal of self-abortion and mobilization of energy. In PLHA, higher levels of guarding on the part of PLHA may result in excessive self-monitoring of their disease and their network, increasing worry and the burden of the illness. As with other incurable chronic diseases, the progression of HIV disease is uncertain and unpredictable,[39] contributing to the burden of the disease. Furthermore, PLHA with greater resilience had better physical, emotional and functional well-being, indicating that resilience may diminish the adverse effects of stress.[40] So, decreasing levels of stress may help PLHA feel less threatened by their HIV condition.

Another explanation for this phenomenon is that PLHA may feel threatened because of discrimination that they experience related to their HIV condition. The relationship of low QOL and concern with identified secrecy may be related to fears of non-acceptance, feelings of guilt and shame attached to the negative image of HIV, which can significantly impact on increased anxiety, depression, and death wish of PLHA.[1,36-38] The practical and psychological burdens of stigma create formidable obstacles to effective HIV prevention. Individuals at risk, particularly those who are members of marginalized and at-risk groups, may internalize stigma; with an associated impact being self-stigmatizing beliefs and actions. Furthermore, this stigma has been identified as a barrier negatively impacting QOL[26] and contributing to a detrimental impact on a variety of health-related outcomes in PLHA.[41]

Interventions to improve QOL in PLHA should consider establishing and enhancing resilience through promoting active coping strategies and coping self-efficacy, building social supports, and encouraging hope for the future. More specifically, three components of active coping (social support seeking, spirituality, and solution-focused coping) should be incorporated into interventions that focus on strengthening active coping strategies among PLHA.[40]

The relationship between having a higher number of close friends or relatives, and QOL suggests that participants who have more persons in their networks have better QOL. These findings are consistent with previous studies that found that PLHA with a more extensive social network feel more supported than PLHA with few close friends or relatives whom they could count on as support

[23] or talk to about their illness. [42] Also, PLHA, who have few close relationships, may have experienced rejection since their diagnosis. Furthermore, being a partnership is a strong predictor of QOL, and loneliness is an essential factor in terms of depressive feelings in older PLHA, and not being a partnership may similarly contribute to lower QOL associated with isolation. [22]

Regarding to practicing religion, the increase in QOL may be related to the role of religion as a source of support and hope in coping with problems.[43] However, the risk of disclosure of the diagnostic condition may reinforce HIV as a sin, increasing responsibility for the acts and guilt for infection, [1,44] even becoming considered as a divine punishment. [45]

Among Chilean PLHA, HIV symptom status had a moderately negative relationship with QOL. PLHA with higher levels of HIV-related symptoms reported worse QOL. These results are consistent with the previous findings that HIV-related symptoms play a critical role in and are strongly associated with QOL.[39,42] Furthermore, no relationship between QOL and HIV disease marker characteristics was found in this study. One potential explanation for this is the excellent care provided in the clinic where the study was conducted. PLHA are seen three or four times a year; they have adequate virologic control. In this sample of PLHA with effective clinical management resulting in long-term immunological improvement, illness-related characteristics did not affect their QOL, while guarding played a crucial role in PLHA's QOL. Other researchers also have found no relationship between QOL and $CD4^+$ T cell count and viral load. [46]

A number of limitations must be acknowledged. The relationship between QOL and guarding may be dynamic and, therefore, longitudinal studies are needed to explore further guarding in this population over time. A significant proportion of study participants were men; reflecting the Chilean high prevalence of men infected with HIV/AIDS. Thus, the results of this research may have limited generalizability to females; even though the development of the epidemic indicates an increase in the number of women. [2] For women, social gender roles such as motherhood and caring for others may play a role in women´s QOL. The sense of responsibility to fulfill the expected gender role may influence not only guarding status but also QOL among women.

Further studies are needed to measure the impact of gender roles among women's QOL. These results also are limited to outpatients from only one clinic. Participants may represent a subpopulation of the HIV-infected persons in Chile who all have adequate virology control, low rates of complications, and acceptable adherence to HAART.

Conclusions

This study supports and extends previous research on self-care among PLHA. First, these results helped to clarify the relationship between guarding and QOL. This study is novel in suggesting that guarding has a negative relationship with QOL. This negative relationship with QOL suggests that PLHA with high guarding may expend energy in protecting themselves and their social networks from the consequences of their HIV chronic illness.

Health care providers have an opportunity to develop education for PLHA with higher levels of guarding. Diminishing the level of guarding that PLHA have over their HIV condition may have the potential to enhance PLHA's QOL. Nurses are in a unique position to influence a patient's QOL because they have direct contact with the patient and his or her close social network. Stressful life circumstances existed before contracting HIV, with HIV-related stressors adding further coping challenges. To address the multiple stressors experienced, efficacious interventions to address these psychosocial challenges are needed. [47] Know the current needs of HIV-infected persons could help in decreasing levels of distress.

Moreover, nurses can provide information and teach strategies for HIV symptom management. Also, exploring the feasibility and effectiveness of individual or group interventions to help reduce levels of stress and increase social support should be explored. Those strategies may help PLHA to feel less threatened by their HIV condition and, therefore, have the potential to reduce their levels of guarding.

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