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The Contribution of Guarding on Quality of Life Among Chilean People with HIV

BY

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THESIS

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DEDICATION

This thesis is dedicated to God, who guided this experience and gave me the strength to carry out not only my studies but also to live in a foreign country and grow as a person.

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LIST OF ABBREVIATIONS

QOL	Quality of Life
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
HAART	Highly Active Antiretroviral Therapy
PLWH	People Living with HIV
ART	Anti-Retroviral Therapy
SES	Socio-Economic Status
CDC	United States Centers for Disease Control and Prevention
WHO	The World Health Organization
PI	Protease Inhibitor
NRTI	Nucleotide Reverse Transcriptase Inhibitors
NNRTIs	Non-Nucleoside Reverse Transcriptase Inhibitors
PUC	Pontificia Universidad Católica de Chile
RA	Research Assistant
HAT-QOL	The HIV/AIDS-Targeted Quality of Life Instrument
SCMP-G	The Self-Care Management Process–Guarding Instrument
SSC-HIVrev	The Revised Signs and Symptoms Checklist for Persons with HIV Disease
SPSS	Statistical Package for the Social Sciences
SD	Standard Deviation
MSM	Men who have Sex with Men
LCA	Latent Class Analysis

SUMMARY

This dissertation was devoted to providing information about two major interrelated topics of clinical research in the field of quality of life of people living with HIV: guarding and HIV-related symptoms. A cross-sectional study of 209 people living with HIV was conducted in Santiago, Chile. Participants completed a questionnaire about characteristics of their quality of life, HIV symptom status, social network, demographics, and guarding. Illness characteristics were obtained from medical records.

Guarding is a self-care process used by individuals in managing chronic illness; it refers to the process of maintaining vigilance over a person's self and network. This study evaluated the relationship between quality of life and guarding among people living with HIV. In a hierarchical multiple regression, more close friends/relatives, fewer HIV symptoms, and less guarding were significantly related to a higher quality of life. No relationship between quality of life and demographics or illness characteristics was found. All the above variables explained 58.8% of the variation in quality of life. In particular, guarding was negatively related to QOL. This may be due to the psychological effort that people living with HIV expended in guarding themselves and their network from their HIV condition.

Among the greatest concerns of people living with HIV are HIV-related symptoms, even for those receiving excellent HIV care and free antiretroviral therapy. There is less evidence regarding HIV-related symptoms among Latino groups either in the U.S. or in Central and South America, and there are no published studies of symptoms among Chilean people living with HIV. The purpose of this study was to determine the variables associated with the number of HIV-related symptoms and determine socio-demographic and/or clinical differences between patient clusters. In multivariate analysis, the number of HIV-related

SUMMARY (continued)

symptoms was related to number of years living with HIV and having completed college-level education. None of the other socio-demographics or clinical characteristics were correlated with the number of HIV-related symptoms. HIV-related symptoms with the highest prevalence were fear/worries (66%), anxiety (52%), gas/bloating (50%), and thirst (50%). For the clusters analysis, people living with HIV who had completed a college education were 2 times as likely to be classified in the subgroup with mild intensity of HIV-related symptoms than people living with HIV who did not have a college education. This is the first study that provides a profile and variables associated with a higher number of HIV-related symptoms among Chilean people living with HIV. Failure to assess for HIV symptom status can compromise long-term HIV treatment goals.

Keywords: Quality of life, Symptoms, guarding

I. INTRODUCTION

This dissertation has six chapters devoted to providing information about two major interrelated topics of clinical research in the field of quality of life (QOL) among persons living with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS): guarding and HIV-related symptoms. Chapter One introduces the (a) background, (b) statement of the problem, (c) purpose of the study, (d) significance of the problem, (e) significance of the study, (f) specific aims, and (g) research questions and hypotheses. Chapter Two provides a comprehensive overview of the relationship between guarding and QOL; it is divided into two sections: conceptual framework and review of related literature. In Chapter Three, the methodology is outlined; it is divided into (a) research design, (b) setting, (c) sample, (d) data collection methods, (e) measures, (f) procedure and protection of human subjects, (g) data analysis, and (h) limitations. Chapter Four and Chapter Five provide two manuscripts that show the main results of this dissertation. Chapter Six provides a summary and recommendations for future work.

Background

HIV represents a global epidemic with serious medical, economic, personal, and social implications. In fewer than three decades, since the first recognized case, this epidemic has affected millions of people on all five continents, stretching the response capacity of the different countries. In 2008, almost 34 million people around the world were living with HIV and AIDS, and there is evidence of continued fast growth. In fact, 2.7 million people were newly infected with HIV in 2008 (UNAIDS, 2009). South America has about 2 million people who are living with HIV (Estrada, 2006), with 170,000 people newly infected with HIV in 2008 (UNAIDS, 2009).

In Chile, the first case of HIV was diagnosed in 1984. Since then, an increasing number of cases have been observed. From January 1984 to December 2008, there were 20,099 HIV and AIDS cases, and 6,102 deaths were registered (MINSAL, 2009). The age group most affected is 20 to 49 years old (Martínez, Olea, & Chiu, 2006; Pérez et al., 1999). The proportion of men to women with HIV and AIDS was 3.6:1 for HIV infection and 5.6:1 for AIDS cases in 2007. The predominant transmission route is sexual, especially among men who have sex (MSM) with men and their female partners (Martínez et al., 2006; Pérez et al., 1999). Santiago, the capital of Chile, has the largest number of HIV cases. Since 2003, the Ministry of Health of Chile has provided highly active antiretroviral therapy (HAART) free of cost to persons living with HIV (PLWH) as part of the national HIV care guidelines (MINSAL, 2010). The incorporation and availability of HAART as a standard antiretroviral therapy (ART) has radically changed the prognosis of the HIV condition, decreasing mortality, the major HIV-related complications, and the frequency of hospitalizations among Chilean PLWH (Wolff, Cortes, Shepherd, & Beltran, 2010; Wolff et al., 2005; Wolff et al., 2001). As a consequence of improvement in HIV prognosis, the life expectancy for PLWH has increased, and, therefore, HIV now follows a pattern of chronic disease in Chile.

Chronic illnesses have become a major health problem. They are one of the principal causes of disability, and they contribute to increased morbidity, mortality, and to increased health care costs (Farrell, Wicks, & Martin, 2004; Pepper-Burke, 2003). The trajectory of a chronic disease may be characterized by phases of exacerbations and remissions. PLWH must learn to manage a treatment regimen that is typically complex. Delivery of care for chronic illness management has changed in the past years. Health care providers used to focus on patients as passive recipients of care, viewing chronic illness management in terms of compliance.

Currently, clinicians have become more aware of the importance of how patients manage their chronic illnesses (Chang, 1980). In fact, clinicians working with people with chronic illness are changing their focus from acute treatment to assisting chronically ill people to take responsibility for their self-care in order to achieve optimal QOL (Jones, 1990; Vosvick et al., 2003). QOL has been identified as a key factor affecting patient's health care outcomes. Maintaining an optimal QOL is one of the goals for health care providers (Hudson, Kirksey, & Holzemer, 2004) as well as for patients with chronic diseases in which complete cure is not possible (Bunch, 2004; Moons, Budts, & De Geest, 2006; Nokes & Nwakeze, 2005; Portillo, Holzemer, & Chou, 2007).

Nurses have identified QOL and self-care as important research priorities in the HIV arena (Sowell, 2000). There has been a growing interest in improving self-care for PLWH. This attention has focused on imparting skills, knowledge, and confidence to patients with HIV (Wantland et al., 2008). Guarding is a key component of self-care that has been little studied for PLWH, and it is a critical concept for understanding how patients deal with chronic diseases like HIV. Guarding, or vigilance, refers to “the process of maintaining vigilance over self, the illness, the treatment regimen, the delivery of care, and important relationships” (Jones, 1990, p. 63). In other words, guarding is the process a person with an illness uses to watch over or shield him- or herself and those they care about from danger or harm. Guarding has two main components: self- and social guarding. Self-guarding includes “attempts to protect one's self, check on the progress of the illness, and exert control over the treatment regimen and delivery of care.” Social guarding refers to “attempts by individuals to protect their social network members from the illness and negative aspects of the illness” (Jones, 2003a, p. 151). Four critical elements of guarding have been identified: perceived vulnerability, perceived controllability, self-absorption, and sense of obligation (Jones, 1990). Vulnerability is related to how persons who use guarding perceive that

they or their social networks are susceptible to psychological, physical, and social threats. Fear of dying and fear of difficulties created by the illness, such as making other persons feel uncomfortable, are examples of perception of vulnerability. Controllability refers to the perception of having the ability to prevent or reduce illness-related threats. Self-absorption refers to worry about one's health or condition when persons are acutely alert to and susceptible to internal and external cues. Their thoughts and lives can be dominated by this self-monitoring process. As an example, test and laboratory values are in individuals' minds all the time when they use guarding. Finally, sense of obligation refers to the ability to perceive a duty related to the illness. For example, persons feel some obligation to go to their medical appointments.

Statement of the Problem

Despite the effort to develop HIV prevention programs, there continue to be many new HIV infections (UNAIDS, 2009). In addition, for HIV-infected people, the HIV condition can be stabilized for years with ART (Anandan, Braveman, Kielhofner, & Forsyth, 2006; Corless, Nicholas, Davis, Dolan, & McGibbon, 2005; Holzemer et al., 1999; Hudson et al., 2004; Klaus & Grodesky, 1997; Phaladze et al., 2005; Reynolds et al., 2007a; Robinson et al., 2006; Tsai, Hsiung, & Holzemer, 2002). Therefore, there is a continuing rise in the population of PLWH as a chronic disease (Corless, Nicholas et al., 2005; Hopson, 2006).

Guarding has emerged as a new concept to help to explain how PLWH deal with their chronic condition and how guarding may interfere with their perception of QOL, and HIV-related symptoms play a critical role in PLWH's QOL. While many studies have provided important information on the correlates of QOL among PLWH, little research attention has been directed toward to examining the concept of guarding, a process that individuals use in managing

their chronic illnesses, and to evaluate differences between patient clusters based on HIV-related symptom intensity.

Purpose of the Study

The purpose of this study was twofold: (a) to determine the potential relationship between QOL and guarding for PLWH while controlling for socio-demographic, social network, clinical, and HIV symptom status characteristics; and (b) to examine the relationship of a higher number of HIV-related symptoms with socio-demographic, social network, clinical, and HIV symptom status characteristics among PLWH with good access to HIV care, and to determine patient differences between patient symptom cluster in terms of socio-demographic, social network, clinical, and HIV symptom status characteristics.

Significance of the Problem

Further research on QOL among PLWH is meaningful for both patients and health care providers. PLWH have reported greater improvement in their prognoses. Measures such as incidence of opportunistic infections, time of progression, or death from AIDS are no longer endpoints in research; therefore, QOL has arisen as an important health care outcome (Clayson et al., 2006; Webb & Norton, 2004). QOL is a sensitive outcome that has been used to measure health care interventions (Cowdery & Pesa, 2002; Hudson et al., 2004; Justice, Rabeneck, Hays, Wu, & Bozzette, 1999; Sousa, Holzemer, Henry, & Slaughter, 1999; Sousa & Williamson, 2003; Vosvick et al., 2003). In addition, QOL research will provide screening factors such as guarding in which clinicians can intervene. Health care providers can develop interventions targeting critical aspects of guarding by providing skills that help patients decrease their amount of guarding and improve their QOL.

Significance of the Study

Examination of the correlates of QOL and HIV-related symptoms, including socio-behavioral, demographic, and disease-related factors, has received considerable attention in the HIV research agenda. There have been an increasing number of published studies focusing on self-care behaviors and HIV-related symptoms; however, none of them address guarding or patient clusters among a population of PLWH who have had good access to HIV care. In addition, most of the previous studies were conducted in Europe, North America, African, and Asia, with few studies involving the Latino population. Specifically, PLWHs' QOL has been underexplored in Chile. Differences between the Latino population living in the U.S. and the Latino population living outside the U.S. have been found (Wantland et al., 2008), and, therefore, the generalization of studies of Latino or Hispanic populations living in the U.S. have to be made with caution for those living in South America.

Despite intensive research on QOL, guarding has also been underexplored among PLWH. This study fills this gap in the literature by extending earlier research on self-care among HIV-infected persons. This study examines correlates and predictors between guarding and QOL, contributing to the understanding of the role of guarding and its relationship with QOL in PLWH. In addition, patients' symptom clusters have been underexplored among PLWH. There is evidence supporting the relationship between QOL and frequency and intensity of HIV-related symptoms. There has been research into how a single symptom affects PLWH's QOL. However, symptoms may group together in patients with similar socio-demographics and clinical characteristics clustered by overall symptom intensity status, so that patients with high or low symptom intensity have different needs. Knowing those patients' characteristics may help health care providers to tailor health education to each specific cluster of patients in order to improve

assessment and management of HIV-related symptoms. Moreover, this study will support the efforts of the Chilean Ministry of Health to provide care for PLWH. Understanding the impact of guarding on PLWHs' perception of their QOL can help health care providers to determine if patients feel capable of preventing, reducing, or stopping illness-related threats that influence their perception of QOL. They can then take the first step toward targeting further health care education among this population in the current ART era.

Specific Aims

The specific aims for this study were to:

- Describe the characteristics of the socio-demographics, social networks, clinical characteristics, HIV symptom status, guarding, and quality of life of Chilean PLWH.
- Evaluate the relationship of guarding and quality of life among Chilean PLWH when controlling for characteristics of socio-demographics, social networks, clinical characteristics, and HIV-related symptoms.
- Determine differences between the effects of different levels of guarding on patient's quality of life when controlling for characteristics of socio-demographics, social networks, clinical characteristics, and HIV-related symptoms.
- Evaluate predictors of numbers of HIV-related symptoms such as characteristics of socio-demographics and clinical characteristics.
- Determine patient clusters based on HIV-related symptom intensity, differences in socio-demographics, and clinical characteristics.

Research Questions and Hypotheses

Question 1

What is the relationship between quality of life and guarding among people living with HIV at the selected university's private outpatient clinic when controlling for characteristics of socio-demographics, social networks, clinical characteristics, and HIV-related symptoms? And is there any difference between quality of life and levels of guarding when controlling for characteristics of socio-demographics, social networks, clinical characteristics, and HIV-related symptom?

Hypothesis 1

There is a relationship between QOL and guarding and between QOL and levels of guarding when controlling for characteristics of socio-demographics, social networks, clinical characteristics, and HIV-related symptoms.

Question 2

What characteristics of socio-demographics and clinical characteristics are related to high numbers of HIV-related symptoms reported among Chilean PLWH? And is there any difference in characteristics of socio-demographics and clinical characteristics between patient clusters at the selected university's private outpatient clinic?

Hypothesis 2

There are differences in socio-demographic and clinical characteristics between patient clusters.

II. CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Chapter Two provides a comprehensive overview of QOL research about PLWH and its correlations with characteristics of guarding, socio-demographics, social networks, clinical characteristics, and HIV-related symptoms. This chapter is divided into two sections: conceptual framework and review of related literature that supports the framework.

Conceptual Framework

The conceptual framework that guides this research integrates concepts from the health-related quality of life conceptual model developed by Wilson and Cleary (1995) into a new conceptualization of their components and relationships. The health-related quality of life model has been found to be a useful model for conducting research on QOL among PLWH (Corless et al., 2000; Henry, Holzemer, Weaver, & Stotts, 1999; Phaladze et al., 2005; Portillo et al., 2005) because of its broad perspective and incorporation of a biomedical and social science paradigm. The health-related quality of life conceptual model links physiological and psychological variables with individual and environmental characteristics; it focuses on the relationship among biological and psychological variables (Wilson & Cleary, 1995).

The health-related quality of life conceptual model links five main components: biological and physiological factors, symptom status, functional status, general health perceptions, and overall QOL. In addition, the health-related quality of life conceptual model proposes other components, such as characteristics of the individual, characteristics of the environment, and nonmedical factors that can influence a patient's QOL. All of the components of the health-related quality of life conceptual model can be thought of as existing on a continuum of increasing biological, social, and psychological complexity with individual and environment characteristics at the beginning of the continuum.

The conceptual framework proposed for this study involves six main components of the health-related quality of life conceptual model: biological and physiological variables, symptom status, characteristics of the individual, characteristics of the environment, nonmedical factors defined as guarding, and overall QOL. PLWH's QOL is conceptualized as influenced by individuals' socio-demographics characteristics, their social networks, illness characteristics, HIV symptom status, and guarding. Characteristics of individuals refer to basic conditions that reflect features of individuals (i.e., age, sex, sexual orientation, educational level, employment status, and having children). Social network involves variables related to social support, such as number of friends and relatives and living with a partner. Clinical characteristics refer to HIV disease progression (i.e., length of time being HIV infected, illness stage, use of antiretroviral therapy, virologic control, and comorbidity). HIV symptoms status involves the frequency and intensity of HIV-related symptoms. Guarding refers to the level of vigilance that PLWH use in dealing with their chronic illness. This conceptual framework recognizes that the six dimensions described above do not exist in isolation; all five dimensions are interrelated, and QOL is result of the reciprocal effects of a combination of PLWH's individual, social network, clinical characteristics, HIV symptom status, and guarding characteristics.

Literature Review

This chapter examines the scientific literature relevant to QOL and guarding, socio-demographics, social networks, and clinical and HIV symptom characteristics, along with their conceptual definitions. The sources of information for this literature review were The Cumulative Index to Nursing and Allied Health Literature, The American Psychological Association's database, PubMed, and Scientific Electronic Library Online. Those databases were

selected because they are the most comprehensive resources for nursing, psychological, biomedical, allied health, and South American literature.

The inclusion criteria for selecting articles were (a) written in English or Spanish; (b) published from 1990 to October 2009; this period allows a comprehensive period of time to obtain a greater understanding of QOL in the HAART era; and (c) focusing on HIV and AIDS, self-care, and QOL. The exclusion criteria were (a) about palliative care, (b) about pediatric care, (c) access to abstracts only, and (d) literature reviews because this review is limited to primary sources of information. The search in the databases listed above used the following key words: “HIV/AIDS,” “Self-care,” and “Quality of Life”; combined they retrieved 53 articles. After reading all of the abstracts from the above search, a sample of 46 research articles was selected from the University of Illinois at Chicago Library and from the Scielo database.

The concepts involved in this literature review are organized by the conceptual framework proposed for this study as follows: (a) quality of life, (b) guarding, (c) socio-demographics, (d) clinical characteristics, and (e) HIV-related symptoms.

Quality of Life

There are a number of QOL definitions available in the literature; however, there is no consensus on the definition (Moons et al., 2006). For the purpose of this literature review and conceptual framework, the following working definition of QOL is proposed: QOL is defined as “a subjective concept and it consists of a subjective evaluation of various aspects of one’s life” (Demmer, 2001, p. 482) in which there is satisfaction with the aspects of life that are important to the individual (Ferrans, 1990, 1996). For this study, the dependent variable, QOL, is the degree to which a person positively evaluates the overall quality of his or her life.

Previous studies have demonstrated that a PLWH's QOL can be affected by several factors. In the proposed study, PLWHs' QOL can be affected by guarding as well as socio-demographics, social networks, clinical and HIV-related symptom characteristics. QOL among HIV-infected persons has been widely studied in the last 20 years. A negative relationship between frequency of HIV-related symptoms and QOL has been established by previous studies. PLWH with a higher number of HIV-related symptoms reported worse QOL than those with a lower number of symptoms (Abboud, Nouredine, Huijter, DeJong, & Mokhbat, 2010; Burgoyne & Saunders, 2001; Phaladze et al., 2005; Tangkawanich, Yunibhand, Thanasilp, & Magilvy, 2008). HIV-related symptoms play a critical role in explaining PLWH's QOL, and it is the single variable that affects QOL the most.

Researchers also reported a positive relationship between QOL and social support (McInerney et al., 2008; Tangkawanich et al., 2008; Yang, Chen, Kuo, & Wang, 2003). PLWH who have better social support also have better QOL than PLWH with less social support among Colombian (Vinaccia, Fernández, Quiceno, López, & Otalvaro, 2008) and Brazilian (Seidl, Zannon, & Tróccoli, 2005) HIV-infected populations.

Previous research also has found a relationship between QOL and HIV clinical biomarkers. A negative relationship between QOL and viral load (Burgoyne, Rourke, Behrens, & Salit, 2004; Mrus, Leonard, et al., 2006; Weinfurt et al., 2000) and stage of the disease (Phaladze et al., 2005; Protopopescu et al., 2007; te Vaarwerk & Gaal, 2001) have been found. Researchers reported a positive relationship between QOL and CD4+ T cell counts (Mrus, Leonard, et al., 2006; Mrus, Schackman, et al., 2006; Protopopescu et al., 2007; Vidrine, Amick, Gritz, & Arduino, 2005; Weinfurt, Willke, Glick, Freimuth, & Schulman, 2000), PLWH taking

antiretroviral therapy (Tangkawanich et al., 2008), duration of the disease (Mrus, Leonard, et al., 2006; Santos, Franca, & Lopes, 2007), and self-care (Reynolds et al., 2007).

Guarding

Guarding reflects those factors or activities that PLWH can do beyond their medical treatment in order to enhance their QOL, therefore guarding is a self-care management process. Self-care provides the framework to develop guarding; self-care is a learned behavior, a deliberate action with a purpose; therefore, it is a rational action of individuals who have the ability and motivation to perform the action (McElmurry & Huddleston, 1991). In fact, guarding is viewed as a process that is conceptualized as an “ongoing adaptive mechanism in performing self-care” (Jones & Preuett, 1986, p. 75).

Guarding is defined as “adaptive behavioral, psychological, and cognitive mechanisms individuals use in performing a variety of illness self-care actions” (Jones, 2003b, p. 150). Specifically, guarding refers to “the process of maintaining vigilance over self, the illness, the treatment regimen, the delivery of care, and important relationships” (Jones, 2003b, p. 151). There is inadequate research within the context of HIV and guarding to make propositions about its relationship to QOL among PLWH. In the proposed study, guarding is conceptualized as a critical component that can affect PLWH’s QOL. Currently, what is known is that self-care behaviors, defined by the type of activities that PLWH performed, affected PLWH’s QOL positively (Henry et al., 1999; Tangkawanich et al., 2008).

Socio-Demographic Characteristics

Demographics characteristics of the individual are conceptualized as PLWH’s personal characteristics that can influence QOL as well as guarding. In defining demographic characteristics, Dodd et al. (2001, p. 670) states: “Demographic, psychological, sociological, and

physiological [characteristics] are intrinsic to the way an individual views and responds to symptom experience.” In addition, the researchers also suggest that “personal variables may be expanded or contracted depending on the symptom(s) and the population of interest” (Dodd, et al., 2001, p. 670). Age, gender, sexual orientation, socioeconomic status (SES), and having children are the core elements of demographic characteristics.

Current age is defined as the length of time that one has existed. Age as a variable reflects one of the stages of life. There are contradictory findings in the literature on the relationship between QOL and age. Age has been identified as having positive effects on QOL (Nogueira, Comini, & Crosland, 2009; Tangkawanich et al., 2008) as well as being a negative predictor of QOL (Protopopescu et al., 2007); however, the majority of researchers have found no relationship between QOL and age (Burgoyne & Saunders, 2001; McInerney et al., 2008; Nogueira et al., 2009; Phaladze et al., 2005; Subramanian, Gupte, Dorairaj, Periannan, & Mathai, 2009).

Gender is the most important factor of a personal contextual condition; it is one of the most frequent and accurate variables used to measure the effect of personal variables and their correlation with dependent variables (Moore & Pichler, 2000). Gender has been identified as a significant predictor of QOL (Subramanian et al., 2009); men reported better physical domains of QOL (Vosvick et al., 2003) and general well-being than women (Rao, Hahn, Cella, & Hernandez, 2007). In addition, men reported better improvement in the physical domain of QOL over time than women did (Mannheimer et al., 2005). Following this trend, women with HIV scored lower in the environmental and psychological health domains of their QOL than men (Santos, Franca, & Lopes, 2007). However, there is evidence that suggests no gender difference in the total QOL score (Abboud et al., 2010; Burgoyne & Saunders, 2001), and, in longitudinal

studies, women with HIV reported significant improvement in the physical and psycho-social summary scale in QOL over four months of follow-up (Sarna, van Servellen, Padilla, & Brecht, 1999). In addition, researchers have reported that women tended to score higher than men on the physical, current health perceptions, and social functioning domains of QOL (Huba et al., 2000).

Gender condition, such as gender roles, can have different influences on PLWH's QOL. Women's gender roles are related to being a mother, spouse/partner, homemaker, friend, and paid worker. As an example, researchers have found that QOL is related to social role quality among women living with HIV (Planch, Stevens, Heidrich, 2006). On the other hand, men in general are associated with gender roles related to paid worker in the Chilean society, and, therefore, this may also influence their QOL.

Social economic status is a "descriptive term for a person's position in society, which may be expressed on an ordinal scale using such criteria as income, educational level attained, occupation, value of dwelling place, etc." (Last, 1988, p. 123). Employment and educational level are the main variables of social economic status. Employment will be defined as paid work, full-time (45 hours/weekly) or part-time (less than 45 hours/weekly), and education level refers to the patient's highest degree. The contribution of employment on QOL is illustrated in a study by Sowell et al. (1997) in which having employment may help PLWH to perceived a better QOL by providing resources to handle the effects of the HIV condition. PLWH who are employed have been found to report higher QOL than those who are unemployed (Burgoyne & Saunders, 2001; Sowell et al., 1997; Worthington & Krentz, 2005) even after controlling for disease severity by CD4 count and viral load (Blalock, McDaniel, & Farber, 2002). In particular, employment status had a relationship with scores on the role functioning and physical domains of QOL, increasing when PLWH reported having employment (Cowdery & Pesa, 2002).

Level of education was significantly and positively correlated with QOL (Corless, Nicholas, et al., 2005). This was a direct correlation; the higher the education level attained, the better the individual's perception of his or her QOL (Buseh, Kelber, Stevens, & Park, 2008). For example, PLWH who had university degrees reported better QOL in all of its domains than PLWH who had not completed high school (Worthington & Krentz, 2005). Following this trend, PLWH who did not attend school or complete middle school reported lower scores on the physical health (Santos et al., 2007; Wig et al., 2006), work-role functioning (Vidrine, Amick, Gritz, & Arduino, 2003), and environmental domains of QOL than those with higher education (Santos et al., 2007).

With regard to having children, researchers have found no relationship between QOL and having children (Phaladze et al., 2005); however, a correlation has been found between number of children and PLWH's QOL. PLWH who have more children also reported lower scores of QOL than PLWH with fewer children (Li et al., 2009). Overall, characteristics of the individual, such as years of age, gender, level of education, employment status, and having children can influence a PLWH's perceptions of QOL by adding variables that represent his or her point of view. These are independent of the environment and health condition.

Social Network

In this conceptual framework, characteristics of the social network are conceptualized as characteristics of social support that can influence QOL and guarding. Social support refers to the aggregate conditions or the context within which symptoms occur; that is, it includes physical, social, and cultural variables (Dodd et al., 2001).

Social network is the main element of characteristics of social support. Social network is defined as the physical and emotional comfort given to the patient by family, friends, and other

people he or she comes into contact with (Last, 1988). Principally, a number of close friends and family has been significantly associated with a better perception of social support (Ncama et al., 2008), which strongly affects PLWH's QOL (Tangkawanich et al., 2008). Researchers have suggested that social support improves PLWHs' QOL in cross-sectional studies (Nokes, Chew, & Altman, 2003; Yang et al., 2003). For example, PLWH who reported greater family support had better QOL in the environment domain than others (Wig et al., 2006). This improvement in QOL is also observed in longitudinal studies in which baseline social support was a significant predictor of better physical function QOL over time (Jia, Uphold, Wu, Chen, & Duncan, 2005).

Researchers have reported a significant relationship between social support and physical functioning among PLWH taking ART therapy; greater social support was associated with better physical functioning (McInerney et al., 2008) when controlling for co-morbidities and symptom frequency (Ncama et al., 2008; Viswanathan, Anderson, & Thomas, 2005). Moreover, social support had a relationship with scores in the mental health and health perceptions domains of QOL; when PLWH's social support increased, their mental and health perceptions scores increased (Cowdery & Pesa, 2002). The social support domain of QOL is correlated inversely with viral load, indicating that increased social support was associated with decreasing viral load (Nicholas et al., 2003).

Variables such as marital status had significant influence on QOL (Subramanian et al., 2009). Researchers have suggested that married PLWH reported better QOL than single PLWH (Abboud et al., 2010). Living with a partner has also been identified as a positive contributor to the QOL among PLWH (Seidl et al., 2005). However, some researchers have also found no association between relationship status and QOL (Burgoyne & Saunders, 2001). Overall, though,

characteristics of social support such as social networks and living with a spouse or partner can affect PLWH's QOL by adding to the aggregate condition when the illness occurs.

Clinical Characteristics

In the proposed conceptual framework, the main components of the clinical characteristics are related to biological and physical factors. In defining biological and physical factors, Wilson and Cleary (1995, p. 60) state that “the most fundamental determinants of health status are molecular and genetic factors,” and the assessment of them “focuses on function cells, organs, and organ systems.” In this conceptual framework, biological and physical factors involve length of time being infected with HIV, the medical classification system used by the 1993 United States Centers for Disease Control and Prevention (CDC) to classify HIV disease and infection, ART status, HIV virologic status, and comorbidity.

In the ART era, indicators of HIV severity, such as length of time being infected with HIV, have been associated more with QOL than CD4 count and viral load; therefore, it may be more appropriate to measure the status of the HIV condition in PLWH taking ART (Mrus, Leonard, et al., 2006). Length since a positive HIV diagnosis refers to how long people have been living with a diagnosis of being HIV infected; it is a factor that influences people's perceptions of QOL. As an illustration, PLWH who knew their HIV status for two to five years perceived better QOL than those who knew it less than two years (Santos et al., 2007). In addition, length of time since the diagnosis has been reported as a significant predictor over time in the social functioning domain of QOL (Jia et al., 2005).

Severity of illness has been negatively associated with QOL (te Vaarwerk & Gaal, 2001). In particular, having an AIDS diagnosis has been identified as a negative predictor of QOL (Burgoyne & Saunders, 2001; Phaladze et al., 2005; Protopopescu et al., 2007) although there

are researchers who have not found a relationship between QOL and having an AIDS diagnosis (Phaladze et al., 2005).

The World Health Organization ([WHO], 2009) provides the following as the definition of a standard ART: “Standard antiretroviral therapy consists of the use of at least three antiretroviral drugs to maximally suppress the HIV virus and stop the progression of HIV disease.” One of these drugs is usually a protease inhibitor (PI). The ART will be classified into three classes of agents: nucleotide reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTIs), and PI (WHO, 2006). In addition, researchers defined ART as PLWH taking medications such as PI, NRTI, and NNRTI (Bolge, Mody, Ambegaonkar, McDonnell, & Zilberberg, 2007). Standard ART influences PLWH’s perceptions of their QOL by improving their immunologic systems as well as triggering different side effects.

ART has been reported to have a positive effect on PLWH’s QOL (Echeverria, Jonnalagadda, Hopkins, & Rosenbloom, 1999; Mannheimer et al., 2005; Tangkawanich et al., 2008). PLWH taking ART had significantly fewer HIV-related symptoms than those not taking it, indicating that ART therapy’s positive effect in reducing HIV-related symptoms outweighs its side effects among PLWH (Rivero-Mendez, Portillo, Solis-Baez, Wantland, & Holzemer, 2009). In addition, improvement in physical functioning, pain, mental health, health distress, and overall health were also found (Corless, Nicholas, McGibbon, & Wilson, 2004; McInerney et al., 2008). On the other hand, weight gain as a result of taking PI has been reported by PLWH (Echeverria et al., 1999), and this has been related to worse mental health and vitality domains of QOL (Corless et al., 2004). Following this trend, body image has been related to QOL; as an illustration, appearance satisfaction correlated negatively with QOL on the following domains:

mental health, physical functioning, social support, partner intimacy, and sexual functioning (Nicholas et al., 2003).

HIV virologic status focuses on cell function, and it is conceptualized as having two main components: CD4 count and viral load. The CD4 cell is the primary cell target of the HIV virus, and the CD4 count is the standard test for assessing HIV stage and prognosis (Sousa & Kwok, 2006). Moreover, viral load testing quantifies the HIV viral burden in the plasma. The viral load test is a standard tool used to monitor treatment response in PLWH taking ART and, in combination with the CD4 cell count, to assess HIV disease progression. Mixed findings exist for the relationship between HIV clinical markers of the disease progression and QOL. Researchers have reported that CD4 counts had independent effects on QOL (Nojomi, Anbary, & Ranjbar, 2008). For example, immunologic changes in CD4 were related to improvement in physical functioning (Burgoyne et al., 2004) and the social and role functioning domains of QOL (Vosvick et al., 2003). For example, PLWH with higher CD4 counts reported better emotional and social well-being than PLWH with lower CD4 counts (Rao et al., 2007). In addition, CD4 counts have been identified as a significant predictor over time of social functioning and physical functioning domains of QOL (Jia et al., 2005). PLWH with higher levels of CD4 had better scores on work-role functioning and psychological and physical domains of QOL (Vidrine et al., 2003). On the other hand, researchers did not find significant differences between CD4 counts and the psychological social relationship or environmental domains of QOL (Santos et al., 2007). Nor were CD4 counts associated with any domain of the QOL as measured by the following instruments: Medical Outcomes Study SF-12 (Viswanathan et al., 2005), World Health Organization Quality of Life (Yen et al., 2004), Multidimensional Quality of Life Questionnaire

for HIV/AIDS (Nicholas et al., 2003), Medical Outcomes Study Short-Form-36 (Burgoyne & Saunders, 2001), and HIV/AIDS-targeted quality of life (Mrus, Leonard, et al., 2006).

Because of the mixed results related to the association between CD4 count and QOL, researchers have suggested that viral load may be more appropriate for predicting QOL among PLWH than CD4 count (Weinfurt et al., 2000). Mellors et al. (1996) found that CD4 count changes are meaningful in longitudinal studies, and viral load can be a better predictor in cross-sectional studies. In addition, even though CD4 counts have been used in the literature as markers of disease progression (Jia et al., 2005), researchers have suggested that some clinical markers, such as CD4 count or clinical stage of HIV condition, may be of limited relevance in the ART era (Vidrine et al., 2003). Detectable viral load has been significantly and negatively correlated with QOL (Corless, Kirksey, et al., 2005). As an illustration, better physical and mental domains of QOL have been detected among PLWH with virologic suppression over a four-year follow-up (Burgoyne et al., 2004).

PLWH experience comorbidities in addition to their HIV disease. Depression, hepatitis, hypertension, diabetes, and asthma were the most frequent comorbidities reported by PLWH (Atkinson et al., 2008). There are no differences in HIV-related symptoms between patients who have comorbidities and those who do not (Corless et al., 2008; Phaladze et al., 2005). Overall, the elements of biological and physical factors, such as time since HIV diagnosis, HIV virologic status, standard ART status, and comorbidities, may influence the current perception of QOL among PLWH by adding determinants to their health status.

HIV-Related Symptoms

Symptom refers to a “patient’s perception of an abnormal physical, emotional, or cognitive state” (Wilson & Cleary, 1995, p. 61). Following this definition, symptoms are

subjective experiences that represent a change from a normal to a sickness health status (Rhodes & Watson, 1987; Sousa, Tann, & Kwok, 2006). For that reason, researchers emphasize that symptoms are the most specific patient-reported measure of health status (Cleary et al., 1993). Specifically, HIV-related symptoms involve those that arise from the illness, those secondary to ART, and those from opportunistic infections (Mendias & Paar, 2007). In the proposed conceptual framework, the main components of HIV symptom status are frequency and intensity of HIV-related symptoms.

Researchers have suggested that HIV symptom status measured by prevalence and intensity of HIV-related symptoms is a key predictor of QOL (Holzemer et al., 2009; Sousa et al., 1999; Sousa & Williamson, 2003) and has a strong relationship with different QOL domains (Burgoyne & Saunders, 2001; Lee, Portillo, & Miramontes, 2001; Lorenz, Cunningham, Spritzer, & Hays, 2006). As an illustration, symptom status has been negatively correlated with general health perceptions; when symptom status increases, general health perceptions decrease (Sousa et al., 1999). In addition, HIV-related symptom status has been found to explain the largest amount of variance in perceived cognitive functioning (Corless et al., 2000). Therefore, HIV-related symptoms status can be used as a clinically relevant dimension of QOL (Sousa & Williamson, 2003).

Frequency of HIV-related symptoms refers to the number of occurrences of a specific HIV-related symptom during a particular time period. Researchers have suggested that prevalence of HIV-related symptoms affects PLWH's QOL; when symptoms increase, QOL decreases (Wilson & Cleary, 1996). For instance, PLWH who defined themselves as "asymptomatic" reported higher QOL scores than those who defined themselves as symptomatic (Bastardo & Kimberlin, 2000; Lenderking, Testa, Katzenstein, & Hammer, 1997; Murri et al.,

2003; Smith, Avis, Mayer, & Swislow, 1997). Specifically, PLWH who did not report any HIV-related symptoms during the previous three months reported higher scores in the physical health domain of their QOL (Santos et al., 2007). Following this trend, increasing numbers of HIV-related symptoms have been negatively correlated with QOL (Inouye, Flannelly, & Flannelly, 2000; Tangkawanich et al., 2008; Webb & Norton, 2004). In fact, HIV symptom status frequency was significantly related to four dimensions of QOL: overall function, life satisfaction, health worries, and medication worries (Holzemer, et al., 2009). In addition, the number of HIV-related symptoms has been identified as an independent predictor of the general overall perceptions, health distress, and energy levels domains of QOL (Worthington & Krentz, 2005) and with the role functioning domain of women who are HIV infected (Hudson et al., 2004).

Intensity refers to the strength of a specific HIV-related symptom during a particular time period. Researchers have suggested that the intensity of HIV-related symptoms affects PLWH's QOL (Burgoyne & Saunders, 2001). For instance, the rate of symptom intensity contributes 5.6% of the variance of QOL among African American PLWH (Buseh et al., 2008). Having a high intensity of HIV-related symptoms has been associated with poor QOL (Corless et al., 2002; Hudson et al., 2004) and poor adherence to medication regimes (Chou, 2004; Corless, Nicholas, et al., 2005). In addition, symptom intensity had a significantly negative correlation with the general health perception domain of QOL; PLWH with less intense symptoms reported better general health perceptions, health transition, and social and cognitive functioning than PLWH with more intense symptoms (Corless, Kirksey, et al., 2005). Following this trend, intensity of HIV-related symptoms was negatively correlated with general health perceptions; when symptom status increased, general health perceptions decreased (Sousa et al., 1999).

Overall, HIV symptom status, such as frequency and intensity of HIV-related symptoms, can influence PLWH's QOL by adding a patient-reported measure of their HIV health status.

Summary

In summary, there is little understanding of guarding and its association with PLWH's perception of QOL. Fifty-three articles were found using a combination of these terms: "HIV/AIDS," "Self-Care," and "Quality of Life." Most research has been conducted in two main areas: To understand how self-care strategies can influence QOL and how an intervention program focused on developing self-care skills can enhance PLWH's QOL. Furthermore, for this literature review, the investigator was not able to find any studies that employed the concept of guarding in the HIV arena to provide insight about its correlation with the perception of QOL among PLWH. Therefore, guarding is underdeveloped in the HIV literature. Understanding the concept of guarding among PLWH can help health care providers to determine if patients feel themselves capable of preventing, reducing, or stopping illness-related threats that could influence their perception of QOL, and it can help health care providers target health care education programs. Health care education focused on imparting skills, knowledge, and confidence to patients with chronic diseases has the potential to improve a patient's QOL (Lorig & Laurin, 1985; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

One of the major limitations in analyzing QOL among PLWH investigations is the fact that researchers classify QOL inconsistently. There is no one standard definition for QOL, making comparison within the existing literature very difficult. In addition, clinical markers such as CD4 count and viral load have mixed findings; in fact, CD4 count and viral load are the most controversial measures. Some researchers did not include data related to clinical markers such as CD4 count (Buseh et al., 2008; Chang, Boehmer, Zhao, & Sommers, 2007; McInerney et al.,

2008). However, the majority of them include CD4 count and viral load from self-report sources (Nicholas et al., 2003). Vidrine et al. (2003) point out that self-report measures can cause biases from inaccuracy in recalling and reporting the data.

III. METHODOLOGY

Chapter Three provides an outline of the study methodology and is divided into (a) research design, (b) setting, (c) sample, (d) data collection methods, (e) measures, (f) procedure and protection of human subjects, (g) data analysis, and (h) limitations.

Research Design

A cross-sectional, correlational, descriptive design was used: (a) to determine the potential relationship of QOL and guarding for PLWH while controlling for demographic, social network, clinical and HIV symptom status characteristics; and (b) to examine the relationship between a higher number of HIV-related symptoms and both socio-demographic and clinical characteristics among PLWH with good access to HIV care, and to determine differences in socio-demographic and clinical characteristics patient clusters based on HIV-related symptom intensity. It is expected that hypotheses will be generated for future studies based on the results obtained from this dissertation.

A face-to-face questionnaire method was used to gather self-report data via self-administration of questions (Polit & Beck, 2007). The rationale for choosing a interview to collect the data is that the response rate is high. Researchers have reported response rates from 95.4% (Cowdery & Pesa, 2002) to 100% (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004). In contrast, researchers who use telephone interviews to gather self-report data reported low responses, between 31% and 74% (Echeverria et al., 1999; Watson, Samore, & Wanke, 1996).

Setting

A university private outpatient clinic in Santiago, Chile, was selected to collect a purposive sample. The rationality for selecting Santiago is that it has a greater number of HIV

patients than other regions of the country; more than 70% of the HIV-infected people in Chile live in Santiago (Pérez et al., 1999). The university private outpatient clinic belongs to Pontificia Universidad Católica de Chile (PUC). PUC was founded on June 21, 1888, to offer training in the traditional and emerging professions. Seven university private outpatient clinics belong to the PUC; Centro Médico San Joaquín is one of them. Centro Médico San Joaquín offers the program of infectious diseases to the community, a program in which physicians and nurses provide care to PLWH.

The university private outpatient clinic is a comprehensive clinic that provides care to HIV-infected persons with clinical assessments at regular intervals (three or four times per year). Standard ART, side effects–related medications, and laboratory testing, such as CD4 count or viral load, are covered as part of the national standard guideline of care (Wolff et al., 2010). The outpatient clinic serves approximately 580 HIV clients, and it sees an average of 100 HIV-infected persons per month. The rationale for selecting this specific outpatient clinic is that it reaches a greater heterogeneity of PLWH in terms of demographic characteristics compared with public clinics.

Sample

Selection criteria

There were five recruitment eligibility requirements. (1) Participants had to be age 18 years or older. This project targeted the adult group because the principal group affected is those between 20 and 49 years of age (Martínez et al., 2006). (2) HIV infection diagnosis must have been based on positive HIV antibody testing. (3) If prospective participants were taking standard ART, they must have been taking the treatment for more than three weeks in order to stabilize its primary side effects. (4) PLWH had to attend periodical consultations with an infectious disease

specialist, such as a nurse or physician. (5) They had to participate voluntarily. The exclusion criteria were (1) having a medical diagnosis of dementia because PLWH who are receiving psychiatric treatment have reported the lowest QOL in all of their domains (Santos et al., 2007); (2) current hospitalization; (3) pregnant women.

Selection strategy

All of the patients coming in for their periodic visits with the infectious disease specialist at all visiting hours available and all days of the week during the study period were invited to participate in the present study. Health care providers such as physicians and nurses from the outpatient clinic approached the potential participants at the time of their medical appointments. Then, if the participants were interested in this study and they gave oral permission, the principal investigator contacted them in order to evaluate inclusion criteria, explain the study's objectives, and to obtain their informed consent.

Sample size

A convenience sample was used to select participants for this research because this non-probability sampling method allows the researcher to find participants who provide adequate information about the phenomena under study (Polit & Beck, 2007). The rationale for calculating the sample size is explained below. The smallest sample needed to accomplish the study aims was used to avoid having effects secondary to a large sample size but not scientifically important (Knapp, 1996). Power analysis was used for estimating the sample size.

Power analysis has effect size, power, and statistical significance as its main components. Effect size is the statistical expression of the magnitude of the relationship between two variables; a medium effect size is suggested for behavioral studies; therefore $R^2=.15$ was used (Polit & Beck, 2007). A power analysis was determined a priori to estimate sample size; a power

of .95 was set for this study; this power is recommended for studies that are not clinical trials. A statistical significance (α) of .05 was set for this study (Connelly, 2008). In the proposed study, there were 16 variables considered for the multivariate analysis. Based on these parameters, a statistical power analysis program, G*Power 3, was applied to calculate the sample size needed. A total sample size of 204 HIV-infected persons was needed to accomplish the research proposal aims.

Data Collection

Procedures

The study procedures and methods are divided into pre-data collection and data collection phases. The pre-data collection phase involved meetings with the health care providers working in the program of infectious diseases at the Centro Médico UC San Joaquín Clinic in Santiago, Chile. These meetings introduced the overall study, including its protocol and procedures. In addition, the research assistant (RA) was trained in how to conduct the interviews and enter the data; she also took the online version of the Investigator 101 course provided by the Collaborative Institutional Training Initiative as ethics preparation for conducting research with humans.

During the data collection phase, all PLWH coming in for their regular visits with the infectious disease specialist, nurses, and physicians, during all working hours and all days of the week, were invited to participate by their health care providers. The health care providers were trained to use the health care provider's referral script (see Appendix A) to invite all possible participants in the same way. In addition, a letter of invitation (see Appendix B) with the name of the study and the name and phone number of the principal investigator were provided to all HIV-infected persons. The principal investigator was at the clinic after the patients' medical

appointments to answer possible questions and to recruit them, checking the eligibility criteria of the potential participants with the screening forms (see Appendix C). If the participants met the inclusion criteria, informed consent process took place in a private room at Centro Médico San Joaquín in Santiago, Chile (see Appendix D). After giving informed consent, the participants completed an interview using a survey (see Appendix E). The interview required 22 minutes to complete and was filled out at the same time the principal investigator met the participants in a private office/room at the outpatient clinic. If the participants could not complete the interview at that time but were interested in participating, the principal investigator offered them the opportunity to do the interview at another time that was more convenient for them. Patients who chose to do the interview later provided telephone numbers and days and times at which they could be contacted in order to set an appointment to return to the clinic. The principal investigator made all of the calls.

Only HIV clinical characteristics were taken from the medical records. The principal investigator of this study, who is a registered nurse licensed to practice in Chile, had access to the medical records. A medical record abstraction instrument was used to collect the data (see Appendix F). The information collected from the medical record included only information that had already been collected; prospective data were not needed for this study.

Data management

Every interview was identified with a code. Only the medical record abstraction instrument was identified with the code and the name of each participant; no personal information was entered on the interview. After the medical record data were collected and transferred to each interview, the medical record abstraction instrument was destroyed. At that point, the completed interviews had no personal identification.

The principal investigator and RA entered all paper-based interviews into a database. Individual passwords were required to access the database. Once data entry had been completed, the data were converted into a statistical program for statistical analysis. Following the data entry, all paper interview forms were stored in a secure, locked location.

Protection of Human Subjects

Ethical approvals from the Institutional Review Boards at the University of Illinois at Chicago (see appendix G) and at the Pontificia Universidad Católica de Chile (see Appendix H) were obtained to ensure that risks were minimized and potential benefits were maximized. In addition, Appendix I has written documentation of cooperation in the form of letters of support from Carlos Pérez, M.D., Head of the Program of Infectious Diseases, Centro Médico San Joaquín, Pontificia Universidad Católica de Chile and from Enrique Donoso, M.D., Director of the Centro Médico San Joaquín Clinic, Faculty of Medicine, Pontificia Universidad Católica de Chile.

This private outpatient clinic was already in existence before the epidemic of HIV began in Chile in 1984. This clinic has long-term patients; the majority of them are HIV-infected persons, and the rest have other infectious diseases. Because in Chile PLWH must have between two to four medical appointments per year, most of the patients know each other. Besides, patients are familiar with research settings; currently, there are two clinical trials running at the outpatient clinic targeting HIV-infected people.

Informed consent was obtained by reading through the study information document with each PLWH; verifying comprehension of the purpose of the study; going over what would be asked of the participants; explaining the potential benefits and risks to the participants; clarifying any questions; and verifying that they still wished to participate. A copy of the informed consent

form was given to each participant (see Appendix D). Then, potential participants received a detailed explanation of the procedures, the potential benefits and risks, and their rights as participants. There were no direct benefits for study participants; however, they would have the opportunity to talk about their QOL. In the future, the information obtained from this study as a whole will serve as an important foundation for the development of effective interventions to improve patients' QOL. The principal investigator referred participants in need of psychological counseling, social support, or basic health care to the appropriate institutions. Participants chose voluntarily to participate in the present study; if they chose not to participate, it would not affect any services that they were receiving and would not affect their relationship with their health care providers, the health care center, or Pontificia Universidad Católica de Chile.

Psychological discomfort, coercion, and loss of privacy and confidentiality were some of the anticipated risks of this study. Psychological discomfort refers to the feelings of worry, shame, or embarrassment caused by some questions asked during the interview. Coercion refers to the act or process of persuading someone forcefully to do something that they do not want to do. For example, patients could have felt forced to participate in this study because their health care providers informed them of it. Loss of privacy refers to patients' possibly forgoing the opportunity to seclude themselves or keep information to themselves; rather they chose to reveal themselves selectively and confidentiality. Loss of confidentiality refers to the revelation of information that is intended to be confidential. For instance, a breach in the security medical records abstraction instrument would have been a loss of privacy and confidentiality. All of these risks were addressed with specific procedures.

Confidentiality of participant data was protected in this study through numerous precautions. First, subjects' identities were not revealed to health care providers who work in the

selected clinic. After the interview was completed, only the principal investigator had access to the medical records to obtain disease-related information. After the information from the medical records was collected, she destroyed the names associated with each interview. Second, all the interviews were kept in locked file cabinets at Pontificia Universidad Católica de Chile, School of Nursing. Third, all paper-based interview and consent forms collected for this project will be destroyed five years after completion of the study or after publication is completed. Fourth, individual passwords are required to access the database. The database did not identify any of the subjects. Finally, findings from the study will not include any personal identifiers.

In addition, several procedures to minimize the possibility of undue influence on the subjects were used. First, in order to maximize autonomous decision making, only the principal investigator recruited and gathered informed consent from each participant. Health care providers were only informing possible participants about the purpose of this study at the moment of their routine medical appointment; they used a referral script to invite each participant in the same way. Health care providers did not know if their patients were participants in this study. In addition, the principal investigator made an extra effort to ensure that no participants felt coerced into participation by reminding them their participation was voluntary. Participants were free to agree or refuse to participate in the present study. They were reminded that if they chose not to participate it would not have any effect on any of the services that they were receiving and would not affect their relationships with their health care providers, the health care center, or Pontificia Universidad Católica de Chile. In the informed consent, participants were informed that they could refuse to answer any question and were free to withdraw from the study. This information was clearly stated in the informed consent.

Everyone who consented to participate received a gift card with the equivalent value of US\$10 to compensate them for their time. Such compensation is considered small and is consistent with the level of compensation used in other research-based interviews in Chile. Although the compensation given to the study participants was minimal, it could attract potential participants who might have misrepresented themselves in order to be eligible for the study. To prevent this misrepresentation, the principal investigator screened all study participants prior to each interview.

In addition, several precautions were taken to minimize the possibility of the loss of privacy during initial identification of the subjects, subject recruitment, and data collection. There is an overlap between precautions of loss of confidentiality and loss of privacy. First, after the initial identification, the eligibility criteria screening and informed consent were conducted in a private room at the outpatient clinic by the principal investigator of this study or the RA. The eligibility criteria form was destroyed if the person was not eligible or upon enrollment for those who were eligible. No flyers were displayed at the outpatient clinic, potential participants were invited by their health care providers, and they were informed by a letter of invitation that their health care providers gave them at the time of their medical appointments. Third, each participant completed a survey in a private room using face-to face interview methodology administered by the principal investigator or RA. Fourth, after the interview was completed, only the principal investigator had access to the medical records, using a screening of the participant's eligibility criteria form. Only the principal investigator had access to the participant identification. After all the data were collected from the medical records, the principal investigator transferred the information to the interview and destroyed the medical record abstraction form. At that point, none of the questionnaires had any personal information. Fifth,

individual passwords for the principal investigator and RA were required to access the database or enter data. Following the data entry, all paper-based interviews were stored in a secure, locked location at Pontificia Universidad Católica de Chile, School of Nursing. The principal investigator had access to the database and paper-based interviews. Finally, any publications or scientific presentations of the findings from this project will be presented as statistical summaries in which the identities of individual subjects cannot be determined or deduced.

Measures

Study variables

The variables of interest are QOL (i.e., overall score), guarding (i.e., total score), socio-demographics (i.e., age, gender, sexual orientation, level of education, employment status, and having children), social networks (i.e., living with spouse or partner and number of close relatives or friends), clinical characteristics (i.e., length of time being HIV infected, CDC classification at the time of diagnosis, taking ART, CD4 count, viral load, and having comorbidities), and HIV symptom status (i.e., frequency and intensity).

Instruments

The HIV/AIDS-Targeted Quality of Life ([HAT-QOL] Holmes & Shea, 1998), the Self-care Management Process–Guarding ([SCMP-G] Jones, 2003), and the Revised Signs and Symptoms Checklist for Persons with HIV Disease ([SSC-HIVrev] Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001) were used in this study to measure QOL, guarding, and HIV symptom status (see Appendices J, K, L, respectively). First, HAT-QOL, SCMP-G, and SSC-HIVrev were translated into Spanish with the back-translation method. Original instruments were translated from English to Spanish by a bilingual person who is a native speaker of Spanish; then the instruments in Spanish were translated back into English by a person who is a native speaker

of English. Then both English versions, the original and the back-translated version, were compared by the principal investigator and committee members to provide the final version in Spanish. A team of six Chilean HIV-care experts was used to determine adequate content validity for a Chilean population and to evaluate possible normative problems (Behling & Law, 2000). Then, the Spanish versions of the SCMP-G, HAT-QOL, and SSC-HIVrev were tested to assess semantic clarity and coherence of items using 10 native-Chilean-cognitive interviews with unknown HIV status (Higgins & Straub, 2006). A brief description of each instrument and the socio-demographic form follow.

(a) The HIV/AIDS-Targeted Quality of Life (HAT-QOL) instrument: The 34-item HAT-QOL developed by Holmes and Shea (1998) was used to measure self-perception of QOL. The HAT-QOL was developed using grounded theory and includes content provided solely by PLWH (Holmes & Shea, 1997, 1998, 1999). The latest version of this instrument, developed by Holmes and Ruocco (2008), was used in this study (Appendix J). This instrument comprises nine dimensions: life satisfaction, overall functioning, sexual functioning, disclosure worries, health worries, financial worries, medication worries, HIV mastery, and provider trust. Each item is rated on a five-point Likert scale ranging from 1 (all of the time) to 5 (none of the time). The total score of this instrument ranges from 34 to 170, with 34 being the worst and 170 being the best. A higher score indicates higher life satisfaction. The reliability coefficient (α) for this study was .86.

The HAT-QOL instrument was selected to measure QOL in this study because it is a condition-specific measure that is responsive to the HIV population (Clayson et al., 2006) and it is practical. The HAT-QOL is self-administrated with minimal respondent burden because it has fewer than 50 items and takes about 15 minutes to complete (Holmes & Shea, 1997, 1998).

Furthermore, this instrument includes those dimensions that are universal for defining QOL as well as having dimensions of QOL that are specific for HIV (Shumaker, Ellis, & Naughton, 1997). For this reason, this instrument is capable of capturing the complexity of the HIV condition and the effects of HAART (Shumaker, et al., 1997). The advantage of using a condition-specific instrument is it can detect and quantify small changes that can be meaningful for health care providers and their patients (Patrick & Deyo, 1989). In addition, the current HAT-QOL includes sexual function as a separate domain of QOL, which makes this instrument distinctive in comparison with other QOL instruments that include sexual functioning as part of the social domain. The HAT-QOL is psychometrically sound; researchers have consistently reported adequate internal consistency, reporting Cronbach's α coefficients are above .80 (Buseh et al., 2008; Nicholas et al., 2007; Portillo et al., 2005).

(b) The Self-care Management Process–Guarding (SCMP-G). The SCMP-G (Appendix K) is designed to be useful in assessing guarding in chronic illness. The SCMP-G is an instrument that measures guarding as a self-care management process that individuals use in managing illness self-care (Jones, 2003). The purpose of SCMP-G is to determine which individuals use guarding in managing their chronic illnesses (Jones, 1990).

The instrument uses an ordinal five-point Likert scale (1= strongly disagree to 5= strongly agree). Participants were asked to place a mark to indicate how they are dealing with their illness. The SCMP-G has 35 items divided into two subscales: self (20 items) and social guarding (15 items). The possible range of scores is 20 to 80 for the self-guarding subscale and 15 to 60 for the social guarding subscale. A high score indicates high use of guarding (Jones, 1990, 2003). As far as the SCMP-G's psychometric properties are concerned, the instrument has adequate internal consistency; the Cronbach's α coefficients range from .75 to .78 for the entire

instrument, e.g., $\alpha=.75$ for the SCMP-G total score, $\alpha=.78$ for the self-guarding subscale, and $\alpha=.78$ for the social guarding subscale (Jones, 2003). In the SCMP-G, which is a new instrument, both subscales were above the minimum reliability criterion level of .70 (Nunnally & Bernstein, 1994).

Because exploratory factor analysis showed that the two subscales were so highly interrelated that only one factor was identified, the total score of the SCMP-G scale was used to measure guarding. In addition, four items related to self-guarding and one item related to social guarding were deleted from the total score. Although this instrument was pretested in a Chilean population, these five questions appear to have posed comprehension problems. An example of a question that posed a problem is “There is a little I can do to control my illness.” The revised total possible scale score with 30 items ranges from 30 to 150. A higher score indicates more use of guarding (Jones, 2003). Cronbach’s α coefficient for this study was .85.

(c) The Revised Signs and Symptoms Checklist for Persons with HIV Disease (SSC-HIVrev). The SSC-HIVrev (Appendix L) was used to measure symptom status. HIV symptom status (frequency and intensity) was assessed with a self-report instrument for the following reasons. First, symptoms are subjective phenomena for which PLWH are in a better position to rate than are health care providers (Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997; Rhodes & Watson, 1987). Second, there is limited agreement on rating HIV-related symptoms between health care providers and PLWH; health care providers have underreported prevalence and intensity of symptoms (Fontaine, Larue, & Lassauniere, 1999; Justice et al., 1999; Ottervanger, Valkenburg, Grobbee, & Stricker, 1998). Third, PLWH’s self-report symptoms are clinically meaningful; they are related to survival rates and risk of recent hospitalization regardless of laboratory markers such as levels of CD4 count and viral load (Justice, Chang, Rabeneck, &

Zackin, 2001). Therefore, the patients' self-reports were used to measure the symptom status in this proposed study. In addition, SSC-HIVrev is the only instrument that currently includes gynecological aspects and secondary effects of the ART therapy, which makes this instrument unique among other self-report instruments.

The SSC-HIVrev is a tripartite self-report form used to assess HIV patients' symptom status and the frequency and intensity of the symptoms (Holzemer et al., 2001). Part 1 consists of 45 items that cluster into 11 factors. Part 2 consists of 19 HIV-related symptoms that do not cluster into factor scores. Part 3 consists of 8 items related to gynecological symptoms for women. Patient intensity rates are assessed by an ordinal four-point Likert scale (0= not present, 1=mild, 2=moderate, and 3=severe). The SSC-HIV has adequate internal consistency; the Cronbach's α coefficients range from .86 to .91 for the entire instrument. In addition, other researchers have been reporting good reliability of the SSC-HIVrev as indicated by the values between $\alpha=.86$ and $\alpha=.97$ for African-American, Asian/Pacific Islander, and Anglo populations (Hudson et al., 2004; Nokes et al., 2007; Reynolds et al., 2007a). It is therefore psychometrically sound. For the current study, the internal consistency (Cronbach's alpha) was computed. Test-retest reliability was not measured in this study because HIV-related symptoms are conceptualized as transitory (Reilly et al., 1997). For the original instrument, content validity was assessed for the SSC-HIVrev through a literature review, nursing care plans, and experts' opinions. The SSC-HIVrev also used a factor analysis method to ensure construct validity (Holzemer et al., 2001). Content validity has been reported by other researchers, a country-level team of HIV care experts was used to show an adequate content validity of the African (Makoe et al., 2005; Phaladze, et al., 2005), Taiwanese (Tsai, Hsiung, & Holzemer, 2003), Mexican, Puerto Rican, and Colombian populations (Nicholas et al., 2007).

For this dissertation, the SSC-HIVrev was used in two ways. First, participants rated 64 items with HIV-related symptoms. The total HIV-related symptom frequency score is the sum of the number of symptoms (possible range 0–64). If the symptom was present, they were asked to report the intensity using a scale from 1 (mild) to 3 (severe). In addition, a distress total score was calculated for each symptom as the sum of the total intensity score divided by the number of PLWH who reported each symptom (Webel & Holzemer, 2009). The SSCHIVrev internal consistency for this study was .92. Second, SSC-HIVrev was used to assess HIV symptom status (frequency and intensity of HIV-related symptoms). It assesses 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 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 symptoms in one score. The total scale score ranges from 0 to 33. A higher score indicates more frequency and/or or more troubling severe HIV symptom status. The internal consistency of the SSCHIVrev scale for this study was .88.

(d) Socio-demographic data form: A survey was used to measure characteristics of the individual (i.e., age, gender, marital status, education level, employment status, type of insurance, having children, and number of children) and social network (i.e., living with spouse or partner and number of close friends or relatives).

(e) Medical records data form. HIV clinical information extracted from the medical records included length of time being HIV infected, in treatment with antiretroviral therapy, sexual orientation, and HIV disease staging at the moment of the diagnosis established according

to the 1993 CDC criteria. Laboratory assessment included markers of immune suppression (i.e., CD4⁺ T cell count) and HIV viral burden (i.e., viral load).

Data Analysis

Before data analysis, descriptive statistics (frequencies, means, and standard deviations) were computed to verify accuracy of data entry (checking for outliers), determine the extent of missing data, assess assumptions for multivariate procedures, and describe each patient's perception of overall QOL, demographic, social network, HIV symptom status, and guarding characteristics. In addition, internal consistency, Cronbach's alpha, was computed for each instrument. Statistical Package for the Social Sciences (SPSS) for Windows Version 19.0 and Latent Gold program 4.5 were used to analyze the data.

Descriptive analysis was used to describe the characteristics of QOL, guarding, demographics, social network, HIV clinical information, and HIV-related symptoms of Chilean PLWH. The HAT-QOL, the SCMP-G, and SSC-HIVrev instruments were summarized with descriptive statistics (frequency, means, and standard deviations). The summary description of the perceived QOL was reported as overall QOL, the summary descriptions of the perceived guarding was reported as guarding total score, and the summary descriptions of the current HIV symptom status were reported as frequency of HIV-related symptoms and intensity of HIV-related symptoms.

Bivariate correlation, Spearman for categorical variables, and Pearson correlation for continuous variables were used (1) to determine the relationship between PLWH's QOL and characteristics of guarding, demographics, social networks, clinical characteristics, and HIV-related symptom status, and (2) to determine the relationship between number of HIV-related symptoms and characteristics of socio-demographics and clinical information.

Hierarchical multiple regression was conducted to evaluate the relationship between guarding and QOL in PLWH when controlling for socio-demographic, social network, clinical characteristics, and HIV symptom characteristics based on the proposed conceptual framework of this study. Results of the evaluation of assumptions of linearity, normally distributed errors, and uncorrelated errors were satisfactory (Cohen & Cohen, 1983). The order of entry of the variables in blocks was based on the proposed conceptual framework of this study. Nominal variables were codified 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. Demographic characteristics, including age, gender (female or male), sexual orientation (homosexual/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 factors, including number of close friends and relatives and living with spouse or partner (yes or no), were entered as characteristics of the social network in Block 2. Clinical characteristics, including length of time living with HIV, CDC classification at the time of diagnosis (AIDS or HIV), taking ART (yes or no), latest CD4⁺ T cell count, latest viral load (detectable or undetectable level), and having comorbidity (yes or no) were entered into the regression model in Block 3. HIV symptom status characteristics, as SSC-HIV total score were added in Block 4. Guarding characteristics were entered into the regression in Block 5 as the guarding total score.

Finally, analyses of guarding group differences were carried out in PLWH who had ≤ 90 points (low-guarding level) or ≥ 91 points in the guarding scores (high-guarding level). The rationale for choosing 90 points on the score of guarding as a cutting point for dividing the group was based on the scatterplot graph analysis. Chi-square for categorical variables and *t* test for

continuous variables analysis were carried out to determine differences between groups. A significance level of .05 was used to determine if differences between the two groups were statistically significant.

Multivariate regression was used to determine if socio-demographic, social network, and clinical characteristics are predictors of numbers of HIV-related symptoms. Only the significant correlated variables at the bivariate level were selected for inclusion in a multiple regression model. Categorical variables that were incorporated in the correlation and multivariate analysis were dummy coded. In addition, HIV-related symptom intensity was used as indicators to build the cluster model analysis to determine subgroups of PLWH that experienced similar types of symptoms. Three clusters, or subgroups, of patients were identified. However, PLWH with severe HIV-related symptom intensity (cluster 3) were excluded from the multivariate analysis because of the small sample size ($n=10$). Chi-square for categorical variables and Student's *t* test distribution for continuous variables analysis were carried out to determine differences between subgroups. A significance level of .05 was used to determine differences between subgroups. Finally, binary logistic regression analysis was conducted to determine variables related to each subgroup membership

Limitations

A number of limitations must be acknowledged. This was a cross-sectional descriptive study; longitudinal studies are needed to further explore guarding in this population over time. A significant proportion of study participants were men, reflecting the Chilean trend of the disease (MINSAL, 2009). Although women were kept in the analysis, the results of this research may have limited generalizability to females. These results are limited to outpatients from only one outpatient clinic that provides exemplary care and 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 ART. Hospitalized PLWH and patients from other public outpatient clinics need to be included in further studies. This study measured severity of the disease that refers to “the severity and importance of a specific diagnosis (often the principal diagnosis), irrespective of a patient’s other health conditions” (Smith, Nitz, & Stuart, 2006, p. 220); therefore, severity of the HIV condition refers to the severity and importance of the HIV diagnosis regardless of a patient’s other diseases. Finally, this study has to acknowledge that because the instruments are self-reported by PLWH, they can have a social desirability bias.

IV. THE CONTRIBUTION OF GUARDING TO QUALITY OF LIFE AMONG CHILEANS LIVING WITH HIV

Introduction

The availability of HAART since 1997 has radically changed the medical prognosis of people infected with the human immunodeficiency virus (Echeverria et al., 1999). PLWH can expect a delay in the onset of AIDS and extended survival (Viswanathan et al., 2005). As a result, HIV has become a chronic illness (Holzemer, 2002; Mrus, Leonard, et al., 2006; Vinaccia et al., 2008).

Through their years of living with a chronic illness, PLWH must learn to manage a complex treatment regimen and deal with the trajectory of a chronic disease characterized by phases of exacerbation and remission. Guarding refers to “the process of maintaining vigilance over self, the illness, the treatment regimen, the delivery of care, and important relationships” (Jones, 1990 p. 63); and may play a critical role in understanding how PLWH deal with their chronic illness. While many studies have provided important information on the correlates of self-care strategies on PLWH’s perception of QOL, little research has been directed toward examining the concept of guarding and its impact on QOL. The purpose of this study was to examine the relationship between guarding and QOL when controlling for individual, social network, illness factors, and HIV symptom characteristics and to identify factors distinguishing persons who had low and high levels of guarding among Chilean PLWH.

In Chile, the first case of HIV was diagnosed in 1984. Since then, an increasing number of cases has been observed. From January 1984 to December 2008, there were 20,099 HIV and AIDS cases and 6,102 deaths were registered (MINSAL, 2009). The proportion of men to women with HIV and AIDS was 3.6:1 for HIV infection and 5.6:1 for AIDS cases in 2007.

The age group most affected is 20 to 49 years old. The predominant transmission route in Chile is through sexual transmission, especially among men who have sex with men and their female partners (Martínez et al., 2006; Pérez et al., 1999). Since 2003, the Ministry of Health of Chile has provided free HAART to PLWH as part of a national program (CONASIDA, 2003; Wolff et al., 2005). Since the provision of HAART began, there has been a decrease in mortality and a delay in the appearance of AIDS as well as a decrease in major HIV-related complications and hospitalizations (MINSAL, 2010; Wolff et al., 2001). Therefore, HIV now follows a pattern of chronic disease in Chile. As is true for persons with other chronic diseases, QOL is among the greatest concerns of PLWH (Portillo et al., 2007).

QOL is a subjective evaluation of various aspects of a person's life (Demmer, 2001) that are important to the individual; those aspects are the primary factors affecting that person's perception of overall QOL (Ferrans, 1990, 1996). QOL among HIV-infected person has been widely studied in the last 20 years. A negative relationship between QOL and HIV symptoms status has been established by previous studies (Abboud, et al., 2010; Burgoyne & Saunders, 2001; Phaladze et al., 2005; Tangkawanich et al., 2008). Previous studies also reported a positive relationship between social support and QOL (McInerney et al., 2008; Seidl et al., 2005; Tangkawanich et al., 2008; Vinaccia et al., 2008; Yang et al., 2003). Other factors that have been related to PLWH's QOL include a positive relationship with CD4+ T cell count (Mrus, Leonard, et al., 2006; Mrus, Schackman, et al., 2006; Protopopescu et al., 2007; Vidrine et al., 2005; Weinfurt et al., 2000) and a negative relationship with viral load (Burgoyne et al., 2004; Mrus, Leonard, et al., 2006; Weinfurt et al., 2000), stage of the disease (Phaladze et al., 2005; Protopopescu et al., 2007; te Vaarwerk & Gaal, 2001), duration of the disease (Mrus, Leonard, et al., 2006; Santos et al., 2007), and taking antiretroviral therapy (Tangkawanich et al., 2008). In

addition, researchers have reported that self-care behaviors have a positive relationship with QOL (Reynolds et al., 2009).

Guarding as a self-care process that individuals use in managing their chronic illnesses, is a key component of self-care that has been little studied for PLWH; it is a critical concept for understanding how patients deal with their chronic diseases like HIV. Guarding is the process that persons use to watch over, or shield from danger or harm from a chronic illness, themselves and those they care about. Four critical elements of guarding have been identified: perceived vulnerability, perceived controllability, self-absorption, and sense of obligation (Jones & Preuett, 1986). Vulnerability is related to how persons who use guarding perceive that they or their social network are susceptible to psychological, physical, and social threats. Fear of dying and fear of difficulties created by the illness, such as making other persons feel uncomfortable, are examples of perception of vulnerability. Controllability refers to the perception of having the ability to prevent or reduce illness-related threats. Self-absorption refers to worry about one's health or condition in that persons become acutely alert to and susceptible to internal and external cues. A person's thoughts and life can be dominated by this self-monitoring process. As an example, test and laboratory values are in the mind of a person all the time when he or she uses guarding. Finally, sense of obligation refers to the ability to perceive a duty to others related to one's illness. For example, persons feel under some obligation to go to their medical appointments.

The health-related quality of life conceptual model developed by Wilson and Cleary (1995) guides this research. PLWH'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 can be thought of as building blocks each contributing to QOL. These five factors may also be interrelated with each other. The health-related quality of

life conceptual model treats the interaction between PLWH'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 PLWH's QOL. The theoretical relationships among study variables are shown in Figure 1.

Methods

This study used a cross-sectional, correlational, descriptive design. Data collection occurred in an outpatient clinic in Santiago, Chile. The data for this study were collected using a face-to-face interview. Ethical approval to conduct the study was obtained from the Institutional Review Boards at the University of Illinois at Chicago and Pontificia Universidad Católica de Chile.

Participants and Settings

A convenience sample of 209 PLWH was recruited from an outpatient clinic in Santiago, Chile between December 2009 and March 2010. This outpatient clinic serves approximately 580 HIV-infected clients and serves an average of 100 patients per month. Clinical assessments for Chilean PLWH are done at regular intervals (three or four times per year), including monitoring standard ART 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 (MINSAL. 2010).

The sample size was sufficient to allow a power of .95 with α level set at .05 and a medium effect size (.15) for a hierarchical multiple linear regression. Selection criteria for the study were (1) infected with HIV based on a positive HIV antibody testing; (2) 18 years of age or older; (3) receiving ART for more than three months in order to stabilize its early side effects; (4) no past medical history of dementia; and (5) no hospitalization during the last month.

Procedure

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 agreed to be contacted, potential participants were approached by the principal investigator of this study to check eligibility criteria in a private room at the clinic. The nature of the study, including procedures for maintaining confidentiality, was explained to all eligible participants. Written consent was obtained from those who agreed to participate. Then, a face-to-face interview was conducted at the outpatient clinic after a medical appointment, followed by a medical record review to obtain illness characteristics.

Measures

QOL, the dependent variable, was measured using the 34-item version of HAT-QOL (Holmes & Ruocco, 2008). 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 is divided into 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 (21.5%) and not being sexually active (20.1%) 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 had 27 items, with a total scale score range from 27 to 135. A higher score indicates higher QOL. The reliability coefficient (α) for this study was .86.

The SCMP-G (Jones, 2003) 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 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 total score of the SCMP-G scale was used 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 (Jones, 2003). Cronbach's α coefficient for this study was .85.

The SSC-HIVrev (Holzemer et al., 2001) 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 or more troubling HIV symptom status. The internal consistency of the SSCHIVrev scale for this study was .88.

Socio-demographics and social network information was gathered from the socio-demographic data form. Age, gender, 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 about. Illness-related information was extracted from the medical records review, for example, length of time since HIV diagnosis, in treatment with antiretroviral therapy, sexual orientation, HIV disease staging at the moment of the 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 and Lowe (1992). 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 person who is a native speaker of English. Then both English versions, the original and the back-translated version, were compared by the authors of this research to provide the final version in Spanish.

A team of six Chilean HIV care experts was used to determine adequate content validity for a Chilean population and to evaluate possible normative problems (Behling & Law, 2000). 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 (Higgins & Straub, 2006). The main study variables with the operational measure, number and example of items, possible range, and internal consistency coefficient are summarized in Table I.

Statistical Analysis

SPSS for Windows Version 19.0 was used to analysis 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 PLWH when controlling for individual, social network, illness, and HIV symptom status characteristics based on the proposed conceptual framework of this study. Results of evaluation of assumptions of linearity, normally distributed errors, and uncorrelated errors were satisfactory (Cohen & Cohen, 1983). Nominal variables were codified 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 (MSM/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 as covariates 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 ART (yes or no), latest CD4⁺ T cell count, latest viral load (detectable or undetectable level), and having 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 after variation between previously entered block.

In addition, differences between groups with high and low guarding were compared. Chi-square for categorical variables and *t* test for continuous variables were carried out to determine differences between two groups. A significance level of .05 was used to determine if differences between the two groups were statistically significant.

Results

Sample Characteristics

Table II 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 numbers 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 ART, and 68% of the sample had undetectable viral load. Twenty-seven percent of the participants had a comorbidity besides their illness characteristics. Diseases of the circulatory system and endocrine, nutritional, and metabolic diseases were the most frequent comorbidities reported by PLWH.

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).

Correlations Between Study Variables

Having completed college was the only demographic characteristic found to have a significant positive correlation with QOL. The number of close friends correlated positively with QOL. HIV-symptom status score and guarding scores correlated negatively with QOL. None of the illness characteristics were correlated with QOL. The correlations between study variables are presented in Table III.

Relationship of Guarding and Quality of Life

The hierarchical multiple regression results are presented in Table IV. Socio-demographic (except high education) and illness characteristics did not correlate with QOL in the bivariate analysis. However, 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.

Quality of Life and Guarding Levels

QOL and guarding scores were plotted to visualize the nonparametric relationship among the variables. This method was used to assess the structural change among variables. The

resulting cluster of points was nearly linear with a decreasing slope constantly showing a negative relationship between guarding and QOL. Thus, PLWH with higher guarding scores tended to have lower levels of QOL. Although the line was essentially linear, a break was observed at 90 points of the guarding scale in the scatterplot graph analysis (Figure 2); this fact was used as a rationale for choosing 90 points on the score of guarding as a cutting point for dividing the group. Therefore, analyses of guarding group differences were carried out in PLWH who had ≤ 90 points (low level of guarding) or ≥ 91 points in the guarding scores (high level of guarding).

In the bivariate analysis, the group with a high-guarding level was significantly more likely to have a comorbidity besides HIV ($\chi^2=3.867, p<.05$); worse QOL, ($t(207)=9.61, p<.001$); and worse HIV symptom status, $t(207)=-4.84, p<.001$, than the group with low guarding. A correlation analysis was then conducted separately for the high- and low-guarding groups. For the group with high guarding, number of close friends/relatives correlated positively with QOL ($r=.366, p<.01$), and HIV-symptom status score ($r=-.548, p<.01$) and guarding scores ($r=-.503, p<.01$) correlated negatively with QOL. In contrast, the group with the low guarding did not show any correlation between QOL and socio-demographics, social network, illness-related information, or HIV symptom status characteristics. In the hierarchical multiple regression analysis for the group with the high levels of guarding, the entire group of variables was significant, accounting for 54.6% of the QOL variance, $F(1, 125) = 29.89, p<.0001$. Numbers of close friends/relatives, HIV symptom status, and guarding characteristics were each significant contributors to the variation in the QOL. In contrast, for the group with low guarding, none of the socio-demographic, social network, illness-related information, or HIV symptom status characteristics were significantly related to QOL (Table V).

Discussion

This study explored the factors that contributed to QOL for PLWH in Chile, including guarding and socio-demographics, social network, and illness-related and HIV symptom status characteristics. In the multivariate analysis, number of close friends or relatives, HIV symptom status, and guarding characteristics were significant contributors to the variation in the QOL score. The same pattern of results was found among the group with a high level of guarding. These results suggest that only higher levels of guarding, above 90, affect PLWH's QOL, indicating a potential need to intervene to improve patient's QOL in this target population. In contrast, lower levels of guarding, below 90, do not affect PLWH's QOL.

A moderately strong negative relationship between guarding and QOL was found. PLWH with high levels of guarding reported worse QOL. One possible interpretation of this relationship may be that the vigilant monitoring and the controlling nature of guarding may require a great deal of self-absorption and mobilization of energy. Higher levels of guarding on the part of PLWH 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 (Tangkawanich et al., 2008), contributing to the burden of the disease. Reducing stress has been found to moderate the need for self-monitoring HIV-related symptoms (Heckman et al., 2002), so decreasing levels of stress may help PLWH feel less threatened by their HIV condition. Another explanation for this phenomenon is that stigmatization may increase the level of guarding among PLWH. They may feel threatened because of discrimination that they experience related to their HIV condition. HIV-related stigma has been identified as a major barrier affecting secondary HIV prevention (Holzemer & Uys, 2004) and QOL (Greeff et al., 2010).

Among Chilean PLWH, HIV symptom status had a moderately negative relationship with QOL. PLWH 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 (Abboud et al., 2010; Burgoyne & Saunders, 2001; Justice et al., 2001; Phaladze et al., 2005; Tangkawanich et al., 2008).

The relationship between having a higher number of close friends or relatives and QOL implies that participants who have more persons in their networks have better QOL. These findings are consistent with previous studies that found that PLWH with a larger social network felt more supported than PLWH with few close friends or relatives whom they could count on as support (Subramanian et al., 2009) or talk to about their illness (Abboud et al., 2010). Also, PLWH who have few close relationships may have experienced rejection since their diagnosis.

No relationship between QOL and illness-related characteristics was found in this study. One potential explanation for this is the excellent care provided in the clinic where the study was conducted. PLWH are seen three or four times a year, they have an adequate virologic control, and they have low HIV symptom status compared with other populations (Makoae et al., 2005; Portillo et al., 2005; Valencia, Canaval, Rizo, Correa, & Marín, 2007). In this sample of PLWH 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 PLWH's QOL. Others researchers also have found no relationship between QOL and duration of the HIV infection, CD4⁺ T cell count, and viral load (Brechtel, Breitbart, Galietta, Krivo, & Rosenfeld, 2001; Santos et al., 2007).

A number of limitations must be acknowledged. The relationship between QOL and guarding may be dynamic and, therefore, longitudinal studies are needed to further explore

guarding in this population over time. A significant proportion of study participants were men; reflecting the high prevalence of Chilean males 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; thus, the men: women proportion was 15:1 in 1991; 7:1 in 1998; and 3.6:1 in 2008 (MINSAL, 2009). For women, social gender roles such as motherhood and caring for others may play a role in Chilean 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 one outpatient clinic that provides exemplary care. Participants may represent a subpopulation of HIV-infected persons in Chile who all have adequate virology control, low rates of complications, and acceptable adherence to ART.

Conclusion

This study supports and extends previous research on self-care among PLWH. 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. High levels of guarding as a negative relationship with QOL suggests that PLWH may expend energy in protecting themselves and their social networks from the consequences of their HIV chronic illness. Future research may address the specific way in which guarding is related to QOL.

Health care providers have an opportunity to develop education for PLWH with higher levels of guarding. Diminishing the level of guarding that PLWH have over their HIV condition may have the potential to enhance PLWH'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. Knowing the current needs of HIV-infected persons can help in decreasing levels of distress (Heckman et al., 2002). Moreover nurses can provide information and teach strategies for HIV symptom management. In addition, 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 PLWH to feel less threatened by their HIV condition and, therefore, have the potential to reduce their levels of guarding.

Clinical Considerations

The present research has a number of important clinical implications.

- Now that HIV is a chronic condition, health care providers need to not only evaluate HIV disease biomarkers but also assess psychological factors, including guarding, to help patients deal with their chronic illness.
- Careful assessment and intervention to decrease levels of guarding by clinicians may contribute to ensuring the long-term effectiveness of HIV care.
- Providing knowledge to improve patients' symptom management may help in decreasing the perception of guarding among PLWH.
- Strategies such as support groups should be explored to provide symptom management knowledge, increase social networking, and decrease the level of guarding among PLWH.

Table I

Instrument Descriptions With Variables, Number and Example of Items, Possible Range, and Internal Consistency Coefficient

Instrument	Variable	Number and sample items	Range	α^*
Self-care Management Process-Guarding Scale (SCMP-G)	Guarding	30 items - I have to be careful with the way I live my life - I manage my illness by learning all I can about it. - I must have a positive attitude about my illness for the sake of others	30–150	.85
HIV/AIDS-Targeted Quality of Life (HAT-QOL) Scale	Quality of life	27 items - I've felt that having HIV has limited the amount of work I can do at my job/routine daily activities. - I've enjoyed living. - I've been afraid to tell other people that I have HIV.	27–135	.86
Revised Signs and Symptoms Checklist for Persons with HIV Disease Scale (SSC-HIVrev)	HIV symptom status	45 items - Fatigue - Depression - Day sweats - Diarrhea - Numbness/Tingling of arms	0–33	.88

Note. * Internal consistency coefficient, Cronbach's alpha

Table II

Socio-Demographic, Social Network, Illness, HIV Symptom Status, Guarding, and Quality of Life Characteristics of the Study Sample (n=209)

Variables	Mean (SD)	%
<i>Individual characteristics</i>		
Age (years)	41.0 (11.4)	
Male		90
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
<i>Social network characteristics</i>		
Numbers of close relatives/friends	5.5 (7.8)	
Living with spouse or partner		61.7
<i>Illness characteristics</i>		
Length of time 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 (<80 copies/mL)		68.9
Having comorbidity besides HIV		27.3
<i>HIV symptom status</i>		
HIV symptom status scores	3.8 (2.8)	
<i>Guarding</i>		
Guarding scores	102.6 (16.1)	
<i>Quality of life</i>		
Quality of life scores	102.6 (16.0)	

Table III
Bivariate Correlations of Potential Covariates With Quality of Life Total Scale

Variable	HAT-QOL total score r/ρ	N	p value
Years	.002	209	NS
Male	.064	209	NS
Heterosexual	-.043	195	NS
Having children	-.008	209	NS
Completed college level	.144	209	.04*
Unemployment	.022	208	NS
Living with spouse/partner	-.002	207	NS
Numbers of close relatives/friends	.278	208	.000**
Length of time being HIV infected	-.010	206	NS
CDC classification at diagnosis: AIDS	.011	205	NS
In treatment with antiretroviral therapy	-.015	209	NS
Current CD4+ T cell count	.068	204	NS
Current viral load: Detectable	-.043	198	NS
Having comorbidities besides HIV	-.050	209	NS
HIV symptom status score	-.545	209	.000**
Guarding score	-.630	209	.000**

Note. * Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

NS= Not significant

Table IV

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

Step and Variable	B	R²	ΔR²
<i>Step 1: Individual characteristics</i>		.028	.028
Years	.009		
Male	.008		
Heterosexual	.025		
Completed college level of education	-.002		
Unemployed	.022		
Having children	.012		
<i>Step 2: Social network characteristics</i>		.108	.081*
Living with spouse or partner	.020		
Number of close relatives/friends	.211*		
<i>Step 3: Illness characteristics</i>		.114	.006
Length of time being HIV infected	-.009		
CDC classification at diagnosis: AIDS	-.093		
In treatment with antiretroviral therapy	-.025		
Current CD4 ⁺ T cell count	-.068		
Current detectable viral load	-.002		
Having comorbidity	-.016		
<i>Step 4: HIV symptom status characteristics</i>		.381	.266*
HIV-symptom status score	-.351*		
<i>Step 5: Guarding characteristics</i>		.588	.208*
Guarding score	-.513*		
Constant	164.604		

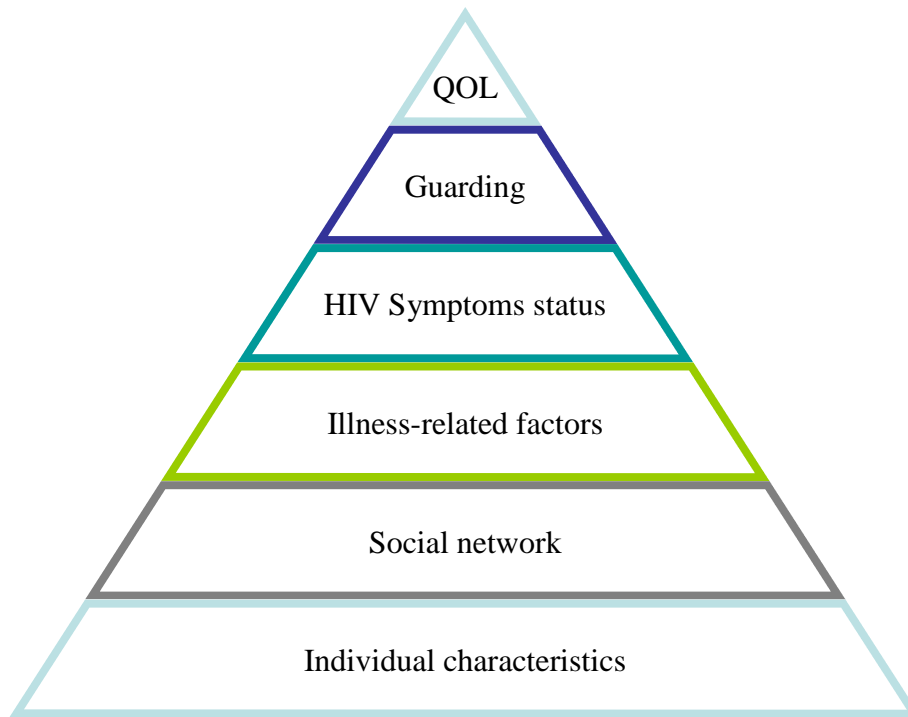
Note. * p<0.01

Table V

Summary of Hierarchical Multiple Linear Regression Analysis for Groups With Low And High Levels Of Guarding

Step and Variable	Low Intensity of Guarding			High Intensity of Guarding		
	<i>B</i>	<i>R</i> ²	ΔR^2	<i>B</i>	<i>R</i> ²	ΔR^2
<i>Step 1: Individual</i>		.132	.132		.039	.039
Years	-.384			.025		
Male	.091			-.004		
Heterosexual	-.083			.051		
Completed college education	-.386			.063		
Unemployed	-.247			.013		
Having children	-.093			-.029		
<i>Step 2: Social network</i>		.140	.008		.174	.135*
Living with spouse or partner	.053			.022		
Number of close relatives/friends	-.172			.282*		
<i>Step 3: Illness-related</i>		.369	.229		.213	.040
Length of time being HIV infected	-.220			.008		
AIDS classification at diagnosis	.374			-.122		
In treatment with antiretroviral therapy	.560			-.082		
Current CD4 ⁺ T cell count	.224			-.066		
Current detectable viral load	.402			-.029		
Having comorbidity	.488			-.047		
<i>Step 4: HIV symptom status</i>		.443	.074		.437	.223*
HIV-symptom status score	-.399			-.384*		
<i>Step 5: Guarding</i>		.444	.001		.546	.109*
Guarding score	-.036			-.369*		
Constant	117.709					

Note. * $p < .001$



*Figure 1.*Representation of the variables related to the quality of life model for people living with HIV.

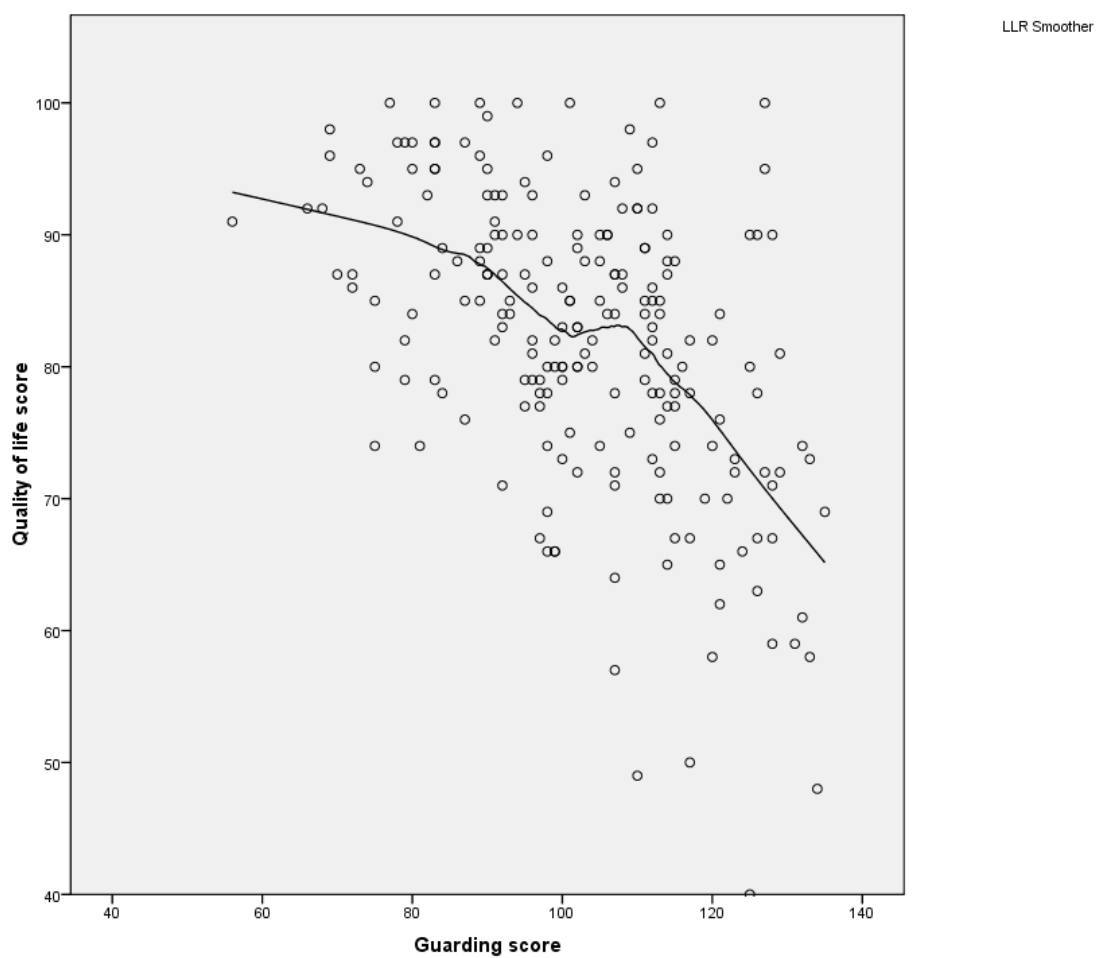


Figure 2. Nonparametric relationship between quality of life and guarding.

V. HIV-RELATED SYMPTOMS AND PATIENT CLUSTERS: THEIR RELATIONSHIP TO SOCIO-DEMOGRAPHICS AND CLINICAL CHARACTERISTICS

Introduction

HIV is now considered a chronic disease because the availability of HAART has led to long-term survival (Corless, Nicholas, 2005; Hudson et al., 2004; Reynolds et al., 2009; Tsai et al., 2002). As with other chronic diseases, HIV-related symptoms are one of the major concerns for those who have the disease. Patients' interpretations of their symptoms have been identified as indicators of incentives to initiate self-care behaviors (Robinson & Rempel, 2006) and key motivators to seek health care assistance (Chou, 2004; Wu et al., 2004),

Predictors of frequency of HIV-related symptoms for PLWH receiving HIV care remain underexplored. In addition, the majority of the research on HIV symptoms has been conducted outside South America where Latinos have very different social and cultural backgrounds. There are important differences between the health care system in the U.S and Chile; the Latino population in the U.S. has been identified as a low-income community with poor access to health care (Markides & Coreil, 1986). In contrast, in Chile, HIV treatment is free and therefore access to care is not affected by PLWH's financial status. In addition, Latinos born in the U.S. have been linked with poor clinical outcomes. As an example, Latinos born in the U.S. have higher rates of opportunistic infections than Latinos born in Central America (Wohl et al., 2003). There is a lack of HIV symptom research reported from Latino natives living in their country of origin, and there are no published studies of symptoms among Chilean PLWH. The purpose of this study was to describe and determine differences for patients clustered based on overall symptom intensity in socio-demographic, social network, and clinical characteristics.

PLWH experience a constellation of concurrent symptoms across different levels of HIV-diseases markers (e.g., CD4) and regardless of their ART status (Willard et al., 2009). The etiology of an HIV-related symptom is difficult to determine because symptoms can arise from the HIV illness itself, from HAART's side effects, and from opportunistic infections. PLWH also experience symptoms related to other comorbidities, making more difficult the task of differentiating the etiology of their symptoms. For example, specific comorbidities, such as depression, hypertension, and hepatitis B or C, increase fatigue severity significantly (Corless et al., 2008). Comorbidity influences HIV-related symptoms by adding symptoms from other diseases that have a direct influence on their current HIV-related symptoms. Besides, symptoms do not occur in isolation; instead, they occur in a cluster or pattern (Pennebaker, Gonder-Frederick, Stewart, Elfman, & Skelton, 1982). Groups of symptoms can be found together among patients with certain socio-demographic and clinical characteristics. Being able to recognize subgroups of patient that experience a similar group of symptoms brings with it the possibility of improving accuracy of symptom assessment and management.

Frequency and intensity are key components in HIV-related symptoms (Justice et al., 2001). Having a high number of HIV-related symptoms has been associated with poor QOL (Corless et al., 2000; Silverberg, Jacobson, French, Witt, & Gange, 2009; Sousa et al., 2006; Tangkawanich et al., 2008; Yang et al., 2003), poorer adherence to medication (Corless et al., 2002; Sousa, et al., 2006; Tsai, et al., 2002), poor role functioning (Hudson, et al., 2004), poorer emotional well-being (Burgoyne & Saunders, 2001), having an AIDS diagnosis (Silverberg, et al., 2009), lower CD4 counts (Lee et al., 2009; Wu, et al., 2004), low initial viral set point level (Kelley, Barbour, & Hecht, 2007), and patients taking ART (Lee, et al., 2009; Rivero-Mendez ey al., 2009). However, there are mixed findings related to HIV bio markers. Other researchers have

found no association between the number of HIV-related symptoms and CD4 counts (Leserman, Barroso, Pence, Salahuddin, & Harmon, 2008; Sullivan & Dworkin, 2003; Willard, et al., 2009), viral load (Leserman, et al., 2008; Sullivan & Dworkin, 2003), or PLWH taking ART (Valencia et al., 2007; Willard, et al., 2009). In addition, the number of HIV-related symptoms have been shown to vary by race/ethnicity (Corless, et al., 2008; Israelski et al., 2007; Johnson et al., 2005; Silverberg, et al., 2009; Voss, 2005). In relation to HIV-symptom intensity, having a high intensity of HIV-related symptoms has been associated with poor QOL (Corless, et al., 2002; Hudson, et al., 2004) and poor adherence to medication regimes (Chou, 2004; Corless, et al., 2005).

Methods

Study Design and Participants

This descriptive, cross-sectional study was conducted using a convenience sample of 209 PLWH recruited from an outpatient clinic in Santiago, Chile, between December 2009 and March 2010. Eligible participants were HIV-infected adults over 18 years of age. If potential participants received ART, they must have taken it for at least three months to avoid the initial side effects that are likely. Exclusion criteria were a diagnosis of dementia or having been hospitalized during the last month. These patients were excluded as this study focuses on symptoms in stable and cognitively non impaired patients able to give self-report information.

Settings

Since 2003, the Ministry of Health of Chile has provided free expanded access to ART (CONASIDA, 2003; Wolff et al., 2005) and therapeutic care using international standards (Wolff et al., 2010). Patients' HIV care includes routine visits planned every three months for patients receiving ART and every four or six months for patients without ART. Laboratory tests (i.e.,

CD4, viral load, and HIV genotypic resistance test); medication to treat side effects of ART; and health expenses for opportunistic complications are also covered (Wolff et al., 2010). In Chile, HAART shows decreased mortality, major HIV-related complications, and hospitalizations (CONASIDA, 2003; Wolff et al., 2001). Resistance to the HAART therapy has low rates (Afani et al., 2007). In 2008, the probability of survival by Chilean patients on ART at 1 and 5 years were 0.95 and 0.89, respectively, with a global mortality of 9% (Wolff et al. 2010).

Procedure

All study procedures were approved by the Institutional Review Boards at the University of Illinois at Chicago, IL, USA, and at the Pontificia Universidad Católica de Chile at Santiago, Chile. Patients were informed about this study by physicians or nurses at the clinic during their routine medical appointments. PLWH who were interested in participating were referred to the principal investigator to check eligibility criteria and to obtain informed consent. During their office visits, participants completed a interview that elicited socio-demographics and HIV-related symptom information. Following their visits, medical records were reviewed to obtain information about clinical characteristics.

Measures

(a) HIV-related symptoms. The SSC-HIVrev checklist was used to assess HIV-related symptoms (Holzemer at al., 2001).The SSC-HIVrev was originally created in English; therefore, a Spanish version of this scale was developed for this study following the translation/back translation method (Guthery & Lowe, 1992). The SSC-HIVrev Spanish version content validity was assessed by clarity and coherence of the items based on a panel of three Chilean HIV care providers, and it was pretested with 10 native Chileans with unknown HIV status (Higgins & Straub, 2006). The SSC-HIVrev has three parts. Part 1 and 2 were used in the analysis of this

study. Part 3 was excluded from the analysis because it focuses on gynecological symptoms. Most PLWH in Chile are male and the measure would not be comparable if included. Part 1 consists of 45 items that cluster into 11 factors. Part 2 consists of 19 HIV-related symptoms that do not cluster into factor scores. Participants rated 64 items on HIV-related symptoms to assess symptom intensity; they were asked to report the intensity using a scale from 0 (not present) to 3 (severe). Possible ranges are 0–64 for number of symptoms and 0–192 for symptom intensity. The SSC-HIVrev internal consistency for this study was .92. A distress total score was calculated for each symptom as the sum of the total intensity score divided by the number of PLWH who reported each symptom (Webel & Holzemer, 2009).

(b) Socio-demographic: Data collected were age, gender (female/male), sexual orientation (MSM/bisexual and heterosexual), marital status (single, married, separate, widow/widower), having children (yes/no), having employment (yes/no), level of education (completed college level or less than college level), living with spouse/partner (yes/no), and number of friends/relatives.

(c) Clinical characteristics: Clinical data included age at HIV diagnosis, length of time being HIV infected, age when started ART, taking ART (yes/no), type of ART used, latest CD4 counts, latest viral load, stage of illness based on the 1993 CDC classification (HIV/AIDS), and comorbidities (yes/no).

Statistical Analysis

Descriptive statistics were used to assess HIV symptom status, socio-demographics, and clinical characteristics. Data were described as mean and standard deviation for continuous variables and as percentages for categorical variables. Pearson or Spearman correlations were calculated between the number of HIV-related symptoms and socio-demographics and the

clinical characteristics. Then, significant correlated variables were selected for inclusion in a multiple regression model. Categorical variables that were incorporated in the correlation and multivariate analysis were dummy coded. For the multivariate analysis, total number of HIV-related symptoms was selected as a dependent variable. SPSS for Windows Version 19.0 and Latent Gold program 4.5 were used to data analysis.

Latent Class Analysis (LCA) was used to find groups in multivariate categorical data predicting class membership. HIV-related symptoms were used as the indicator to build the cluster model analysis to determine subgroups of PLWH that experienced similar type of symptoms. Chi-square for categorical variables and *t* test for continuous variables analysis were carried out to determine differences between subgroups. A significance level of .05 was used. Binary logistic regression analysis was conducted to determine variables related to each subgroup membership.

Results

Socio-Demographic and Clinical Sample Characteristics

The socio-demographics and clinical characteristics of this sample of PLWH are presented in Table VI. The mean age of the sample was 41.0 (SD=11), with a range of 18–76 years. Of the total sample, 90% were males. The majority identified themselves as MSM/bisexual (75%). More than three quarters of the PLWH were single (79%), and more than a quarter were living with their spouses/partners (38%). Of the total sample, 28% reported having children; the mean number of children was 2.2 (SD=1), with a range of 1–5.

The mean time living with HIV was 4.1 years (range <1–26); the majority of PLWH had CD4 counts higher than 350 cell/mm³ (62%) and undetectable viral loads (74%). The majority of the participants were taking ART (79%). Lamivudine/Zidovudine and Efavirenz were the most

frequent types of HAART reported. More than a quarter (27%) of PLWH reported having comorbidity besides HIV; the mean of comorbidities was 1.7 (SD=.7), with a range of 1–4. Diabetes mellitus, hypertensive diseases, hypertriglyceridemia, and hypothyroidism were the most frequent comorbidities reported. Clinical characteristics of PLWH are presented in Table VII.

HIV-Related Symptom Characteristics

Frequencies and mean distress for the most frequent HIV-related symptoms are presented in Table VIII. PLWH reported a mean frequency of 15 different HIV-related symptoms (range 0–53). HIV-related symptoms with the highest prevalence were fear/worries (66%), anxiety (52%), gas/bloating (50%), thirst (50%), and fat deposit in the abdomen (48%). HIV-related symptoms with low prevalence were breast pain (2%), blood in spit and/or sputum (3%), sores or lumps on genitals (5%), rectal discharges (7%), and vomiting (7%) were the HIV-related symptoms with the lowest prevalence. For those PLWH who reported having symptoms, prominent leg veins (1.8), concern over weight gain (1.8), and concern about weight loss (1.8) were the HIV-related symptoms with the highest distress scores. In contrast, blood in spit and/or sputum (1.1), painful swallowing (1.1), white spots in mouth and/or thrush (1.1), mouth ulcers (1.1), and sore throat (1.1) were the HIV-related symptoms with the lowest distress scores.

In the bivariate analysis, only two factors, years living with HIV and having completed a college-level education, were correlated with number of HIV-related symptoms (Table IX). None of the other socio-demographic characteristics such as age, being male, being MSM/bisexual, employment status, having comorbidities, living with spouse/partner, having children, or number of close friends/relatives were correlated with a high number of HIV-related symptoms. In addition, other clinical characteristics, such as stage of illness at the moment of the

diagnosis, taking ART, CD4 counts, and viral load were not correlated with the number of HIV-related symptoms. In the multiple regression analysis, years living with HIV and having completed college remained significantly related to number of HIV-related symptoms, accounting for 5.7% of the numbers of HIV-related symptom variance, $F(2, 203) = 6.1, p = .003$ (Table X).

Patients' Cluster Analysis

Three clusters, or subgroups, of patients were identified. Cluster 1 included PLWH with moderate symptom intensity ($n=110$), cluster 2 included PLWH with mild symptom intensity ($n=89$); and cluster 3 included PLWH with severe symptom intensity ($n=10$). Cluster 3 was excluded for the inferential statistics analysis because of the small sample size. Socio-demographic and clinical characteristics for each group are presented in Table XI. For PLWH with mild symptom intensity, HIV-related symptoms with the highest prevalence rate were: fear/worries (42%), fat deposit in the abdomen (37%), skinny arms/legs (28%), thirst (27%), and depression (26%). The highest prevalence rate among PLWH experiencing moderate symptom intensity were: fear/worries (81%), anxiety (69%), gas/bloating (67%), thirst (63%), and weakness (62%).

Differences in level of education were found between clusters of patients. Fifty-five percent of PLWH with mild symptom intensity had completed a college education, but only 40% of PLWH with moderate symptom intensity did so ($\chi^2=4.48, p=.034$). There were no differences among subgroups on other demographics and clinical characteristics. Although college-level education was the only significantly different variable among groups, socio-demographics and clinical characteristics were also included as theoretically related variables in the binary logistic regression analysis to find variables related to group membership.

In the first logistic regression analysis, all the socio-demographic and clinical variables were included. The model explains the 13.8% of membership variance. Sex and education level were significantly related to group membership. Therefore, a simplified model with those two variables was conducted. The second model significantly explained 2.8% of membership variance, $\chi^2=5.66$, $df=2$, $N=199$, $p=.05$. PLWH with a completed college education were 2 times as likely to be classified in the subgroup with mild intensity of symptoms than PLWH with less than college-level education (OR=1.83, $p=.037$).

Discussion

There are two main findings this research. First, this research demonstrates that PLWH who receive the best standard of HIV care, including free ART, showed an adequate control of HIV disease markers, and those markers were not associated with a high number of HIV-related symptoms. Providing excellent HIV care can be a strategy for improving health care outcomes among PLWH. Second, this is the first study that describes HIV-related symptoms and their relationship with socio-demographics and clinical characteristics among Chilean PLWH.

In the regression analysis, years living with HIV and having completed a college-level education remained significantly related to the number of HIV-related symptoms. This study also shows that symptoms vary according to the demographic characteristics of PLWH. In the latent cluster analysis, only education remains significantly related to symptom intensity for the group of PLWH with a moderate intensity of symptoms. Completing college had a negative relationship with the number of HIV-related symptoms, that is, participants who had completed college reported fewer symptoms. This result is concordant with other studies (Atkins et al., 2010; Kemppainen et al., 2003). This could be because educated PLWH may have more access to informational resources to deal with their chronic illness, which may cause them to have fewer

symptoms than persons with lower levels of education. Higher levels of education were also linked with higher socioeconomic status, which then leads to better access to medical care and other benefits and therefore less social vulnerability (Atkins et al., 2010).

Years living with HIV had a positive relationship with number of HIV-related symptoms. One explanation for this result is that PLWH with a higher number of years living with HIV can accumulate symptoms from the illness itself and also from ART's secondary effects, which may cause them to have more symptoms than PLWH with fewer numbers of years living with HIV. Surprisingly, this study found no correlation between HIV-related symptoms and HIV disease markers, such as stage of illness, CD4 counts, and viral load. This may be because traditional HIV disease markers may be less representative of those symptoms related to the psychological aspects of HIV illness or those related to patients' comorbidities. Another potential reason is that the study site was a model clinic that provides the best HIV care for their clients. Most of the participants had their disease under good control, and, when PLWH are receiving good HIV care, HIV biomarkers do not play a major role in their symptomatology.

Chilean PLWH receiving excellent HIV care showed lower numbers of HIV-related symptoms than other populations (Makoe et al., 2005; Portillo et al., 2005; Valencia, et al., 2007). However, they were not symptom free, and researchers have found that even a low number of HIV-related symptoms still caused significant problems among patients under ART (Lampe et al., 2010). Fear, worries, and anxiety were the most frequent symptoms reported by more than 50% of Chilean PLWH, which is concordant with other studies (Kagee & Martin, 2010; Lampe, et al., 2010; Rivero-Mendez, et al., 2009; Valencia, et al., 2007). Those psychological symptoms may represent an emotional response to a perceived threat. HIV disease progression is uncertain, and this fact can contribute to higher levels of anxiety (Gifford &

Sengupta, 1999; Valencia, et al., 2007). Fear of death and fear of the future are the most frequent cause for anxiety reported by PLWH (Kemppainen, et al., 2003). Regarding HIV-symptom distress, prominent leg veins and concern over weight gain were the most distressing HIV-related symptoms. One explanation for these results is that symptoms related to lipodystrophy can render HIV visible to other people. PLWH may feel distressed because people can guess that they are HIV infected. Stigma and fear about disclosure increase the distress experienced by this population.

One limitation of this study is that HIV-related symptoms are a dynamic concept and, therefore, longitudinal studies are needed to find predictors over time. Also, the sample included a disproportionate number of men, and, thus, generalizability of the findings for women remains tentative. Indeed, women's gender roles, such as being spouse/partner, having children, and taking care of others, may play a role in HIV-related symptom status. Further research is needed in this field in order to measure the effects of gender role differences between women and men. Patients were recruited from one outpatient clinic that provides exemplary HIV care and may not be representative of the total population of HIV-infected persons in Chile. Furthermore, patients were receiving HIV care three to four times a year and, therefore, constitute a highly selective group.

Conclusion and Implications for Practice

The results of this study highlight the fact that PLWH receiving excellent HIV care are not symptom free. This emphasizes the need to be more comprehensive in assessing symptoms among PLWH.

The results show that Chilean PLWH had a large number HIV-related symptoms secondary to the HIV infection, side effects of ART, and comorbidities such as depression;

therefore, the observation of symptoms cannot be attributed solely to HIV condition or ART. The etiology of HIV-related symptoms is complex (Silverberg et al., 2004; Silverberg, et al., 2009) because symptoms arise from the HIV condition, HAART's side effects, opportunistic infection, and comorbidities and, further, they vary according to a patient's demographic characteristics. HIV care providers have focused on recognized symptoms related to the HIV infection, side-effects from ART, and opportunistic infections (Willard, et al., 2009); however this approach needs to change. The fact that PLWH experience different types of symptoms, including those related to their comorbidities, requires that health care providers recognize the spectrum of symptoms among the HIV-infected population. Symptom assessment can protect patients from ART nonadherence and virologic rebound (Lampe, et al., 2010).

As part of the routine HIV clinical care, symptom assessment is a challenge in which self-report symptom instruments can play an important role. Patients' self-reports are clinically meaningful because they are related to survival rates and risk of hospitalization regardless of levels of CD4 counts and viral load (Justice, et al., 2001). There is limited agreement on rating HIV-related symptoms between health care providers and PLWH; health care providers have underreported prevalence and intensity of symptoms (Justice, et al., 2001). Using self-report instruments for symptom assessment may help clinicians to recognize current HIV-related symptoms among PLWH. After the recognition of the symptoms, complete alleviation or decreasing the number of HIV-related symptoms has to be one of the goals of HIV care.

TABLE VI

Socio-Demographic Characteristics of Participants (N=209)

Characteristics	M(SD)	(%)
Age at time of interview	41 (11)	
Male		90%
Men who have sex with men/bisexual		74.9%
Marital status		
Single		78.5%
Married		6.2%
Separate		12.9%
Widow/Widower		2.4%
Having children		28%
Mean number of children	2.2 (1.2)	
Highest level of education completed		
Elementary school		3.8%
High school		23.4%
Technical school		26.3%
College		46.4%
Employment status		
Full-time		70.2%
Part-time		8.2%
Unemployed		21.6%
Health insurance		
Public		60.8
Private		39.2%

TABLE VII
Clinical Characteristics of Participants (N=209)

Characteristics	M(SD)	%
Number of HIV-related symptoms		
0–7		23.4%
8–13		22.5%
14–19		23.0%
20 or more		31.1%
Intensity of HIV-related symptoms	21.7 (16.5)	
Years living with HIV	4.12 (4.5)	
HIV CDC classification at the time of diagnosis		47.8%
Taking ART		78.5%
Years living under ART	4.6 (6.0)	
CD 4 count: ≥ 350 cell/mm ³		60.8%
Undetectable viral load level (≤ 80 copies/mL)		68.9%
Frequency of HIV-related symptoms	15.2 (9.6)	
Having comorbidities		27.3%
Mean of comorbidities	1.4 (.7)	

TABLE VIII

Rank Order, Number of PLWH, and Mean Distress Score of the Most Frequent HIV-Related Symptoms of The Study Sample From the SSC-HIV Scale (N=209)

HIV-related Symptoms	Rank Order	Percentage of PLWH (%)	Mean Distress Score (0-3)*
Fear and/or worries	1	65.1	1.6
Anxiety	2	51.7	1.6
Gas and/or bloating	3	49.3	1.5
Thirst	4	49.3	1.5
Fat deposit in the abdomen	5	48.3	1.5
Depression	6	46.4	1.6
Weakness	7	45.9	1.4
Difficulty concentrating	8	45.0	1.5
Muscle aches	9	44.0	1.3
Memory loss	10	42.1	1.4
Insomnia	11	40.7	1.6
Headaches	12	38.3	1.3
Fatigue	13	37.3	1.4
Shortness of breath with activity	14	35.9	1.3
Dry mouth	15	35.9	1.4
Itchy skin	16	33.0	1.3
Skinny arms and legs	17	32.5	1.5
Painful joints	18	32.1	1.3
Prominent leg veins	19	31.6	1.8
Concern over weight gain	20	31.1	1.8

Note. * Mean distress score is the total intensity score of each symptom divided by the number of PLWH who have had each symptom, PLWH: People living with HIV/AIDS.

TABLE IX.

Correlation Coefficients Between Socio-Demographics and Clinical Characteristics of Participants With Number Of HIV-Related Symptoms (N=209)

Characteristics	Number of HIV-Related symptoms	N
<i>Socio-demographic characteristics</i>		
Age at time of interview (years)	-.016	209
Being male	-.102	209
Being homosexual/bisexual	.007	195
Having completed college-level education	-.178**	209
Having employment	-.056	208
Number of close friends and relatives	-.058	208
Living with spouse or partner	-.045	207
Having children	-.051	209
<i>Clinical characteristics</i>		
Having comorbidities	.018	209
Years living with HIV	.152*	206
HIV CDC classification at the time of diagnosis	-.035	205
Currently taking ART	.012	209
Current CD 4 count < 350 cell/mm ³	.052	204
Current detectable viral load (>80 copies/mL)	.065	198

Note. *p<.05, **p<.001

TABLE X

Regression Analysis for Socio-Demographics and Clinical Characteristics With Number of HIV-Related Symptoms

Variable	B	T	P
Having completed college-level education	-.184	-2.691	.008
Years living with HIV	.144	2.111	.036
Constant		14.159	.000

Note. $R^2 = .057$ (N=209, $p=.003$)

TABLE XI.

Socio-Demographic and Clinical Characteristics of Participants and Group Differences by Chi-Square And t Test

Variable (categorical)	HIV Symptom Intensity		
	Mild (n=89) (%)	Moderate (n=110) (%)	Severe (n=10) N (%)
Male	92.1	87.3	100.0
Heterosexual	24.7	22.7	20.0
Completed college	55.1*	40.0*	40.0
Unemployed	25.8	17.3	30.0
Having children	30.3	27.3	10.0
Living with spouse or partner	40.4	36.4	20.0
Having AIDS at diagnosis	52.8	50.9	40.0
In treatment with ART	80.9	76.4	80.0
Currently detectable viral load	22.5	29.1	20.0
Having comorbidity	28.1	24.5	50.0
Variable (continuous)	Mean	Mean	Mean
Years	42.1 (11.5)	40.1 (11.5)	41.7 (10.1)
Number of close relatives/friends	5.4 (8.1)	5.9 (7.7)	3.1 (4.0)
Length of time being HIV infected	3.8 (4.1)	4.5 (4.5)	5.8 (7.0)
Current CD4 ⁺ T cell count	436.2 (216.2)	430.78 (234.1)	432.4 (211.4)
Numbers of HIV-related symptom	6.8 (3.7)**	18.7 (5.0)**	36.8 (7.6)

Note. *p<.05, **p<.001

VI. CONCLUSIONS

Conclusions and Implications for Practice

This dissertation provides information about two major interrelated topics of clinical research in the field of PLWH's QOL: guarding and HIV-related symptoms. First, the unique contribution of guarding on PLWH's QOL was highlighted (Chapters IV). This is the first study that incorporates guarding as a factor that can affect PLWH's QOL. Guarding is viewed as a psychological variable that represents people's need to protect themselves and their social networks from their HIV condition. Guarding affects QOL; PLWH with highest level of guarding reported worst QOL. The results presented in Chapter IV provide evidence that can serve as a rationale for larger and multicenter studies. Further research in this area should focus on examining the relationship between guarding and self-care behaviors.

Second, patient clusters based on HIV-related symptom intensity were examined among a population that received excellent HIV care (Chapter V). Having completed college was the only variable related to the group membership. The subgroup of PLWH with low symptom intensity was likely to be more educated than PLWH with a moderate intensity of HIV-related symptoms. Identifying unique characteristics across clusters of patients that experienced similar group of symptoms can increase accuracy in symptom assessment and facilitate development tailored education addressing the particular needs of each subgroup of patients. Further research is also needed in the area of symptom-cluster identifying symptoms that are more likely to group together as well as the sentinel symptom. A symptom cluster is a group of symptoms that are interdependent on each other and they have a clinical significance. A sentinel symptom refers to a concept that anticipates the presence of other symptoms that have not yet been experienced b

the patient. The identification of a sentinel symptom may lead to specific treatment for a defined symptom cluster.

This dissertation also has advanced measurement related to PLWH's chronic illness and QOL with the incorporation of the Self-Care Management Process–Guarding instrument into the HIV research arena. The SCMP-G instrument was originally created to address concern about guarding among people with chronic kidney problems. This dissertation extended the utilization of this instrument among PLWH as well as in providing a Spanish version. Although, the HIV/AIDS-Targeted Quality of Life (HAT-QOL) instrument and the Revised Signs and Symptoms Checklist for Persons with HIV Disease (SSC-HIVrev) have been applied in Spanish-speaking populations previously, this dissertation extended the utilization of this instrument using both instruments in a population that have not been used before as well as by providing a Spanish version of HAT-QOL and SSC-HIVrev instruments for Chilean PLWH.

Finally, this dissertation helps fill a gap in the literature about QOL among Chilean PLWH. No prior research has been conducted on this topic among a Chilean population. Knowing factors that affect PLWH's QOL is expected to help in disease management as well as in tailoring future HIV education in order to decrease the burden of the HIV condition among Chilean PLWH.

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APPENDICES

Appendix A
Health Care Providers' Referral Scripts

“The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive”

A Research Project of the Pontificia Universidad Católica de Chile &
 University of Illinois at Chicago
 Principal Investigator: Alejandra Araya, R.N.

HEALTH CARE PROVIDERS REFFERRAL SCRIPT

HEALTH CARE PROVIDERS: Thank you for your participation in this study. Please read this information to each one of your patients who are HIV positive that you provide care in this clinic. If you have any question feels free to ask me at any time. This script will take about 5 minutes to read.

1. Mr. Or Ms (name of the potential participants), I would like to give you information about a study that is going on in the clinic. The purpose of the study is to examine the potential contribution of self-care guarding to quality of life for people who are HIV positive. This information will be used to design effective programs that will increase the successful delivery of care in Chile.

2. You are free to choose whether or not participate. If you like to receive more information, the principal investigator of this study, Alejandra Araya. RN can contact you, she is right now in the office number (TBA), you can stop in and talk with her about the study, or you can contact her by phone 654-5831. if you give oral permission, the principal investigator will contact you at the telephone, time, and day that is more convenient for you.

Appendix A (continued)

3. I will give you this *letter of invitation* that has the same information that I just explained to you. If you have any question feel free to contact and ask the principal investigator Alejandra Araya, RN.

APPROVED
NOV 23 2009 TO NOV 23 2010
UNIVERSITY OF ILLINOIS CHICAGO
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Appendix A (continued)**La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos Chilenos con Infección por Virus de Inmunodeficiencia Humana”**

EM Alejandra Araya, Profesor asistente

Un Proyecto de Investigación de la Pontificia Universidad Católica de Chile
y Universidad de Illinois en Chicago

GUIA DE REFERENCIA: TRABAJADORES DE LA SALUD

PROFESIONAL DE LA SALUD: Muchas gracias por su participación en este estudio. Por favor lea esta información a cada uno de sus pacientes que son VIH positivo a los cuales usted atiende en esta clínica. Si usted tiene alguna consulta no dude en preguntarme, en cualquier momento. Esta guía toma 3 minutos en ser leída.

1. Me gustaría darle información sobre un estudio que se esta haciendo en este centro médico. El propósito de este estudio es examinar la contribución del auto-cuidado en la calidad de vida de pacientes adultos chilenos con infección por virus de inmunodeficiencia humana (VIH). A futuro, esta información será usada para diseñar programas educativos destinados a mejorar la atención de salud.

2. Usted es libre de participar o no en este estudio. Si usted nos autoriza y desea recibir más información, el investigador responsable de este estudio, EM Alejandra Araya lo puede contactar inmediatamente después del término de su hora con su médico tratante o pueden acordar un día y hora que le sean más convenientes para usted. Si usted lo prefiere puede contactar directamente a investigadora responsable de este estudio, ella se encuentra en el centro médico y puede conversar con ella acerca de este estudio.

Appendix A (continued)

3. Yo le entregaré esta carta de invitación que tiene la misma información que yo le acabo de leer. Si usted tiene cualquier pregunta sobre este estudio, siéntase libre de contactar al investigador responsable, EM Alejandra Araya, al teléfono 354-5834. Si usted desea ser contactado, déjenos su nombre y numero telefónico.

 RESEARCH
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Appendix B
Participant's Letter of Invitation

“The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive”

A Research Project of the Pontificia Universidad Católica de Chile &
University of Illinois at Chicago
Principal Investigator: Alejandra Araya, R.N.

LETTER OF INVITATION

We would like to invite you to be part of a new research study called “ *The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive*”. The study purpose is to examine the potential contribution of perceived self-care to quality of life for people who are HIV positive”. This information will be used to design effective programs that will increase the successful delivery of care in Chile.

You might qualify for this new research study. We need HIV positive who are 18 years or older. Taking part in this study involves: (1) Getting more information on the research study, (2) signing a consent form, (3) answering some confidential questions about your medical history and behaviors at a single study visit, and (4) Having the principal investigator review your medical records to see CD4 and viral load. We will compensate you with a gift for a total amount of \$10 at the end of your visit for your time.

To help protect your privacy, your name or other personal identifiers will never appear on any form used to record information that you tell us during your interview or that is obtained from your medical record.

Appendix B (continued)

If interested in participating, please contact, EM. Alejandra Araya, the Study Principal Investigator at the clinic in room TBA or by phone at 354-5834. Or if you preferred, the principal investigator will contact you at the telephone, time and day that is more convenient for you to inform you about this study.

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 NOV 2 3 2009 TO NOV 2 3 2010
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Appendix B (continued)

“La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos Chilenos con Infección por Virus de Inmunodeficiencia Humana”

EM Alejandra Araya, Profesor Asistente

Proyecto de Investigación de la Pontificia Universidad Católica de Chile
y Universidad de Illinois en Chicago

CARTA DE INVITACIÓN

Nos gustaría invitarlo(a) a ser parte de un nuevo estudio llamado “*La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos Chilenos con Infección por Virus de Inmunodeficiencia Humana*”. El propósito de este estudio es investigar la importancia del autocuidado en la calidad de vida de personas que han contraído el VIH (Virus de Inmunodeficiencia Humana). Los resultados de esta investigación serán usados para diseñar programas educativos destinados a mejorar la atención de salud en Chile de esta enfermedad.

Usted quizás puede ser parte de este nuevo estudio. Nosotros necesitamos personas con VIH que sean mayores de 18 años. Participar de este estudio implicaría que usted:

- (1) Obtenga mayor información sobre este estudio médico,
- (2) Firme un consentimiento informado,
- (3) Conteste algunas preguntas confidenciales, una sola vez, sobre su historia médica, autocuidado y calidad de vida; y
- (4) Dar autorización al investigador principal de este estudio para que obtenga algunos indicadores de salud desde su ficha clínica tales como: CD4, carga viral, clasificación del su enfermedad y tipo de tratamiento antirretroviral que esta recibiendo.

En retribución al tiempo empleado en este estudio, usted recibirá una tarjeta de regalo por la suma de \$4,000 (cuatro mil pesos).

Su nombre y/o información personal, nunca aparecerán en ningún instrumento de recolección de datos; un código de identificación se usará para proteger su privacidad.

Appendix B (continued)

Si usted esta interesado(a) en participar, la investigadora responsable de este estudio lo puede contactar inmediatamente después del termino de su hora con su médico tratante o pueden acordar un día y hora que le sean más convenientes para usted.

Si usted lo prefiere puede contactar directamente a investigadora responsable de este estudio, personalmente en el centro médico o al teléfono 354-5834.

ENCLOSURE
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INSTITUTIONAL REVIEW BOARD

Appendix C
Participants' Screening Eligibility Criteria

“The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive”

A Research Project of the Pontificia Universidad Católica de Chile &
 University of Illinois at Chicago
 Principal Investigator: Alejandra Araya, R.N.

SCREENING OF PARTICIPANT'S ELIGIBILITY CRITERIA FORM

A. INFORMATION

A1. Participant Code: _ _ _

A2. Date of Abstraction: _ _ / _ _ / _ _ _ _
 Month/Day/Year

A3. Name of Abstractor: _____

INTERVIEWER: CHECK, circle all those apply:

INTERVIEWER INCLUSION CRITERIA CHECKLIST		YES	NO
1	Are you older than 18 years of age?	<input type="checkbox"/>	<input type="checkbox"/>
2	Do you know your HIV positive status based on a positive HIV antibody test?	<input type="checkbox"/>	<input type="checkbox"/>
3	Are you taking standard ARV therapy for more than three weeks?	<input type="checkbox"/>	<input type="checkbox"/>
INTERVIEWER EXCLUSION CRITERIA CHECKLIST		YES	NO
4	Have you ever been diagnosed with dementia?	<input type="checkbox"/>	<input type="checkbox"/>
5	Currently, are you acutely ill?	<input type="checkbox"/>	<input type="checkbox"/>
6	Are you pregnant?	<input type="checkbox"/>	<input type="checkbox"/>

Appendix C (continued)

**“La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos
Chilenos con Infección por Virus de Inmunodeficiencia Humana”**

EM Alejandra Araya, Profesor asistente

Un Proyecto de Investigación de la Pontificia Universidad Católica de Chile
y Universidad de Illinois en Chicago

**FORMULARIO DE EVALUACIÓN: CRITERIOS DE ELECCIÓN DE
PARTICIPANTES**

A. INFORMACIÓN

A1. Código del Participante: _ _ _

A2. Fecha: _ _ / _ _ / _ _ _ _

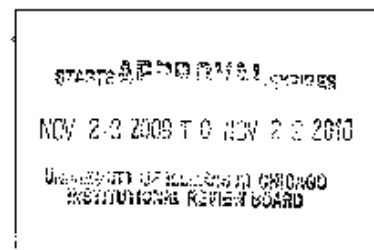
Día/Mes/Año

A3. Nombre del investigador: _____

ENTREVISTADOR: MARQUE, con una cruz todas las alternativas posibles:

LISTA DE CHEQUEO: CRITERIOS DE INCLUSIÓN		SI	NO
1	¿Es usted mayor de 18 años?	<input type="checkbox"/>	<input type="checkbox"/>
2	¿Conoce usted su condición de VIH positivo basado en un examen de sangre (anticuerpos VIH positivo)?	<input type="checkbox"/>	<input type="checkbox"/>
3	¿Esta usted tomando terapia antirretroviral?	<input type="checkbox"/>	<input type="checkbox"/>
4	¿Esta tomando la terapia antirretroviral por más de tres semanas?	<input type="checkbox"/>	<input type="checkbox"/>
LISTA DE CHEQUEO: CRITERIOS DE EXCLUSIÓN		SI	NO
5	¿Usted ha sido diagnosticado alguna vez con demencia?	<input type="checkbox"/>	<input type="checkbox"/>
6	¿Actualmente, está usted agudamente enfermo?	<input type="checkbox"/>	<input type="checkbox"/>

Appendix D Informed Consent



“The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive”

A Research Project of the University of Illinois at Chicago & Pontificia Universidad Católica de Chile

Principal Investigator: Alejandra Araya, RN

Participant’s Consent to be Interviewed in this study English Version

My name is [identifying your self to the participant by name.]

1. You are being invited to participate in a research study that will help us to learn more about the social, medical, and self-care factors that contribute to how people perceive their quality of life. This study focuses on people who are HIV positive. The purpose of this study is to examine the potential contribution of self-care guarding to the perceived quality of life. This information will be used to design effective programs that improve HIV care in Chile. As someone who is living with HIV, you know a lot about which factors influenced your perception of quality of life. Up to 150 other individuals who are also HIV positive receiving care in this clinic will participate in this study.

2. You are free to choose whether or not to participate. There are no penalties for not participating and the decision to decline will not affect your medical treatment in any way or your relationship with Pontificia Universidad Católica de Chile. If you decide to enroll in the research, you are free to end participation in the study at any time without consequences should you wish to do so. Your health care provider will not know whether or not you are participating in this study.

3. If you agree to enroll in the study, you will be asked to participate in two ways:

First, one of the study’s research staff, the principal investigator or the research assistant, will interview you in private about your personal background, use of antiretroviral therapy, personal networks of social support, and your perception of self-care and quality of life. Some questions that we ask may be sensitive. You may refuse to answer any questions that you prefer not to answer or end the interview at any time without penalty. The interview will last about 45 minutes.

Appendix D (continued)

- Second, you also will be asked to give permission to have the principal investigator of this study obtain health indicators from your medical record concerning your treatment and health. This will include 1) Age of HIV infection diagnosis, 2) if apply, data that antiretroviral therapy were first started, 3) latest CD4 count, 4) latest viral load level, 5) type of antiretroviral therapy taken by you, and 6) HIV stage before starting antiretroviral therapy. This information will be used to help assess how those indicators influence your perception of self-care and/or quality of life. There are no consequences should you choose not to do so.
4. Potential risks of participating in this interview are psychological discomfort and that other people may find out something that you disclosed during your interview or that appears in your medical record that you would like to keep private. We will do our best to prevent this, but there is always a slight risk with any research.
 5. To help protect your privacy, your name or other personal identifiers will never appear on any form used to record information that you tell us during your interview or that is obtained from your medical record. Instead, a confidential code number will be used to protect your privacy. Also no information about you, or provided by you during the research will be disclosed to others without your written permission, except if necessary to protect your rights or welfare as a participant in this research or if required by law. Even persons, who work here at Centro Médico San Joaquín, will not have access to the information you provide. All completed questionnaires containing raw data will be destroyed 5 years after data collection for this study has been completed.
 6. Participating in the research will not benefit you directly. However, what we will learn from you will help us to develop a prevention program to help increase self-care and to improve perceived quality of life among Chilean people who are HIV sero-positive.
 7. As compensation for your time in participating in the study, you will receive a gift card for a total amount of \$10 USD. You will receive this compensation even if you decide not to answer all the questions that are posed during your interview or change your mind about giving permission for the principal investigator to obtain and record information from your medical record.
 8. If you have a question later that you did not think of now, you can ask me at any time. You can also telephone Alejandra Araya, RN who is the principal investigator of this study or you may contact Dr Kaltwasser who is the Director of the Ethics Committee at Pontificia Universidad Católica de Chile at 56-2- 354-8173 or e-mail at etica.investigacion@med.puc.cl. Or you may contact the University of Illinois at Chicago for the Protection of Research subjects (OPRS) Office at 1-866-789-6215 or e-mail OPRS at uicirb@uic.edu. You will be reimbursed for any phone charges by submitting a receipt to EM Alejandra Araya.

Appendix D (continued)

9. By signing your name below, you agree to participate in this research. You will be given a copy of this form after you have signed it.

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.

Name of Participant

Date

Signature

I have personally explained the research to the study volunteer and answered all questions. I believe that he/she understands the information described in this informed consent and freely consents to take part.

**Name of Staff Person Obtaining
Informed Consent**

Signature

(date must be same as study volunteer's)

Date

Appendix D (continued)

Número Proyecto: 09-213

Fecha Aprobación: 01.12.2009

Fecha Expiración: 30.11.2010



“La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos Chilenos con Infección por Virus de Inmunodeficiencia Humana”

EM Alejandra Araya, Profesor Asistente

Un Proyecto de Investigación de la Pontificia Universidad Católica de Chile
y Universidad de Illinois en Chicago

DOCUMENTO DE CONSENTIMIENTO INFORMADO

1. El propósito de esta información es ayudarle a tomar la decisión de participar en esta investigación médica. Usted ha sido invitado(a) a participar en este estudio que nos ayudara a conocer mas acerca de la contribución del auto-cuidado en la calidad de vida de pacientes adultos con VIH (Virus de Inmunodeficiencia Humana). Los resultados de esta investigación serán usados para diseñar programas educativos destinados a mejorar la atención de salud. Como una persona que vive con el VIH, usted conoce una serie de factores sociales y médicos que influncian su calidad de vida. Ciento cincuenta (150) pacientes atendidos en este centro medico serán invitados a participar en este estudio.

2. Si usted esta de acuerdo en ingresar a este estudio, se le pedirá que participe de dos maneras:

Primero, el investigador o asistente de investigación, lo(a) entrevistará en una sala privada sobre datos personales, síntomas asociados al VIH, uso de terapia antirretroviral, autocuidado y calidad de vida. Algunas de estas preguntas pueden ser incómodas para usted. Usted puede negarse a contestar cualquier pregunta o puede terminar la entrevista en cualquier momento sin ninguna penalidad. La entrevista durará cerca de 30 minutos.

Segundo, también se le pedirá permiso para que el investigador de este estudio pueda obtener algunos indicadores de salud desde su ficha clínica. Los datos que serán extraídos son: 1) edad de cuando fue diagnosticado(a) con VIH, 2) Si aplica, tipo de terapia antirretroviral que se encuentra tomando, 3) clasificación del VIH antes de haber empezado la terapia antirretroviral, 4) el primero y último resultado de CD4, y 5) el primero y último resultado de su carga viral. Esta información será utilizada para ayudar a la evaluación de cómo esos aspectos pueden influenciar su autocuidado y su calidad de vida. No existe ningún tipo de consecuencia si usted no autoriza el acceso a su ficha clínica.

Appendix D (continued)

3. Usted no se beneficiará directamente por participar en esta investigación. Sin embargo, la información que se obtendrá será de utilidad para conocer más acerca de la contribución del auto-cuidado en la calidad de vida de pacientes adultos chilenos con VIH y eventualmente podría beneficiar a otras personas con su misma condición en el desarrollo de futuros programas educativos destinados a aumentar su autocuidado y para mejorar la calidad de vida de los pacientes chilenos viviendo con VIH.
4. Dentro de los potenciales riesgos de participar en este estudio se encuentran la posibilidad de sentirse incómodo(a) con las preguntas que le haremos. Además existe un pequeño riesgo, inherente a cada investigación, de que otra persona puedan descubrir que usted es VIH positivo. Sin embargo, nosotros hemos tomado las precauciones necesarias para que esto no suceda.
5. La información obtenida se mantendrá en forma confidencial. Es posible que los resultados obtenidos sean presentados en revistas y conferencias médicas, sin embargo, su nombre no será conocido. Para proteger su privacidad, su nombre y/o información personal, nunca aparecerán en ningún instrumento de recolección de datos. En reemplazo esos instrumentos se identificarán con un código. También, ninguna información que usted nos cuente o que se recolecte sobre usted durante esta investigación será revelada a otras personas sin su autorización por escrito, excepto si fuera necesario para proteger sus derechos o bienestar como participante de esta investigación o si es requerido por Ley. Incluso las personas que trabajan en este centro médico no conocerán y no tendrán acceso a la información que usted nos entregue en los cuestionarios que conteste. Todos los cuestionarios llenos serán guardados por cinco años después que este estudio haya finalizado y serán destruidos.
6. En retribución al tiempo empleado en este estudio, usted recibirá una tarjeta de regalo por la suma de \$4,000 (cuatro mil pesos). Usted recibirá este regalo incluso si usted decide no contestar el cuestionario completo o si usted cambia de opinión con respecto a autorizar al investigador a acceder a su ficha clínica.
7. Su participación en esta investigación es completamente voluntaria. No existen penalidad por no participar en este estudio y usted tiene el derecho a no aceptar participar o a retirar su consentimiento y retirarse de esta investigación en el momento que lo estime conveniente. Al hacerlo, usted no pierde ningún derecho que le asiste como paciente en este Centro Médico o con la Pontificia Universidad Católica de Chile y no se verá afectada la calidad de la atención médica que merece. Si usted retira su consentimiento, la

Appendix D (continued)

información obtenida no será utilizada. Su médico o enfermera tratante no sabrán si usted está participando de este estudio.

8. Si tiene preguntas acerca de esta investigación médica puede contactar o llamar al EM. Alejandra Araya, Investigador Responsable del estudio, al teléfono 354-5834. Si tiene preguntas acerca de sus derechos como partícipe en una investigación médica, usted puede llamar a la Dra. Sofía Salas I., Presidente del Comité de Ética en Investigación de la Escuela de Medicina, Pontificia Universidad Católica de Chile, al teléfono 354-8173, o al mail: etica.investigacion@med.puc.cl.

9. Se me ha explicado el propósito de esta investigación médica, los procedimientos, los riesgos, los beneficios y los derechos que me asisten y que me puedo retirar de ella en el momento que lo desee.

Firmo este documento voluntariamente, sin ser forzado a hacerlo.

No estoy renunciando a ningún derecho que me asista.

Se me ha informado que tengo el derecho a reevaluar mi participación según mi parecer.

Al momento de la firma, se me entrega una copia firmada de este documento.

10. FIRMAS

_____ Nombre del Participante	_____ Firma del Participante	_____ Fecha
_____ Nombre del Investigador	_____ Firma del Investigador	_____ Fecha
_____ Nombre del Director de la institución o su delegado	_____ Firma del Director de la institución o su delegado	_____ Fecha

Appendix E
Participants' Survey

Survey Instrument

***“The Contribution of Self-care to
the Perceived Quality of Life of
Chilean People who are HIV
Positive”***

**A Research Project of the Pontificia Universidad Católica de Chile &
University of Illinois at Chicago**

Principal Investigator: Alejandra Araya, R.N.
University of Illinois at Chicago, College of Nursing &
Pontificia Universidad Católica de Chile, School of Nursing

Appendix E (continued)

Participant Code _ _ _

Date _____

Time Start: _____

Interviewer Initials _____

Finish: _____

INTERVIEWER: Thank you for participating in this study. This survey will ask you basic questions about you, your perception of symptom status, self-care and quality of life. There is no right or wrong answer, please answer the questions honestly. The answers you provide will at no time be associated with your name, only a participant code number. If you have any questions feel free to ask me at any time during this survey or later. This interview will take about 45 minutes to complete.

A. BACKGROUND CHARACTERISTICS

INTERVIEWER: First, I would like to begin by asking you some questions about yourself.

A1. How old are you? (in completed years)

A2. What is your gender?

Male01
Female02
Decline to answer98

A3. What is your marital status?

Single01
Live-in-partner02
Married03
Widow or widower04
Decline to answer98

Appendix E (continued)

A4. Do you currently live with spouse or partner?

Yes01
No02
Decline to answer98

If yes, how long have you lived with your current partner? _____

A5. Do you have children?

Yes01
No02
Decline to answer98

If yes, how many children do you have? _____

A6. What is your highest level of education? (circle best answer)

Never attended school01
Elementary02
Technical school03
High school04
College05
Decline to answer98

A7. Please tell me about your work. Are you....

INTERVIEWER: READ, circle all that apply:

Employed full-time01
Employed part-time02
Working at informal jobs03
A Student04
Unemployed05
Decline to answer98

Appendix E (continued)

A8. What is your currently health insurance?

Public insurance01
Private insurance02
Institutional (army)03
Without health insurance04
Decline to answer98

A9. Do you have any other illness/disease besides HIV?

Yes01
No02
Decline to answer98

If yes, which one? _____

INTERVIEWER: Next are some questions about the support that is available to you. Now I'm going to ask you about your family members and/or friends that may help or support your HIV treatment. Even if you consider them friends, when answering these questions don't think of outreach workers, case managers, or support group members.

A10. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? _____

A11. In an emergency, do you think that there is at least one member of your family or a friend to whom you can go to for help?

No01
Yes02
Decline to answer98

B. The Self-care Management Process-Guarding (SCMP-G) Questionnaire © Jones, Linda Corson, PhD, R.N.

INTERVIEWER: Now I'd like to ask some questions about how you perceive your self-care in the past 4 weeks. As do other chronic illness, HIV may require many changes in your life. The purpose of these questions is to find out how different people with HIV deal with their illness. There are no right or wrong answers. For each statement, circle the answer that best describes your thoughts. Please answer all the questions thinking in your HIV-positive status.

Appendix E (continued)

INSTRUCTIONS: Read each one of the problems listed below. NOTE: If client refuses to respond to a statement, code “Declines to Answer” (code 98). If client states he/she does not know, (code 97).

STATEMENT	1 Strongly agree	2 Agree	3 Neither agree or disagree	4 Disagree	5 Strongly disagree
B1.I worry about being a bother because of my illness					
B2. I have made up my mind that I can control my illness					
B3. My illness does not affect my family and friends					
B4.Pleasing other people is more important than my health					
B5. I worry than I am a bother to other people					
B6. I must do all I can to control my illness					
B7. I am responsible for making sure my illness does not worry other people					
B8. I have to be careful with the way I live my life					
B9. My illness has affected my relationships with friends					
B10. I don't do certain things, because the people would worry about my health					
B11. I worry that if I don't follow my treatment plan, my illness will worsen					
B12. I am troubled that people treat me differently because of my illness					
B13. Even though I think a lot about my illness, I try not to talk about it					
B14. I try to convince other people to change the way they live so they won't develop my health problems					
B15. It is hard to plan activities, because I never know whether my illness will keep me from doing things					
B16. I must have a positive attitude about my illness for the sake of others					
B17. My illness makes other people uncomfortable					

Appendix E (continued)

STATEMENT	1 Strongly agree	2 Agree	3 Neither agree or disagree	4 Disagree	5 Strongly disagree
B18. I only think about my illness when it causes me problems					
B19. I don't think about my illness as I do daily activities					
B20. I have changed the way I live to improve my health					
B21. I tell people about my illness so they will understand if I'm out of sorts and they won't take it personally					
B22. I can control my illness if I follow my treatment plan					
B23. If I take care of myself, I can prevent further problems with my illness					
B24. I am careful about how much I tell other people about my illness, because I don't want to trouble them					
B25. I check myself for signs that my illness is changing					
B26. When I make daily plans, I think about my illness					
B27. I watch for signs that my illness is getting worse					
B28. There is a little I can do to control my illness					
B29. I think about my health a great deal					
B30. It is important to follow a routine so I can lead a normal life					
B31. I manage my illness by learning all I can about it					
B32. I have changed the way I live so that I can control my illness					
B33. My life revolves around my treatment plan					
B34. I must watch my health or it will get worse					
B35. I go out of my way to make people feel comfortable with my illness					

Appendix E (continued)

The Self-care Management Process-Guarding (SCMP-G) Questionnaire		
DOMAINS		SCORES
B36	Self-guarding	
B37	Social-guarding	
B38	TOTAL SCORE	

C. HIV/AIDS-targeted QoL (HAT-QoL) Questionnaire

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INTERVIEWER: Now I'd like to ask some questions about how you've been perceived your quality of life in the past 4 weeks. The questions in this questionnaire ask how things are going in different areas of your life. Please answer all questions, even if you do not think they are relevant to you. Before starting to answer the questions, however, there are two types of questions you need to know more about.

A. You will find some questions that ask about your job/routine daily activities. If you have a job, answer these questions thinking about your job. If you do not have a job, answer these questions thinking about the activities you usually do during most days of the week. Examples include housework, other sorts of chores, going to school or volunteering in an organization.

B. You will find some questions that ask about your doctor. If you usually see a nurse, a nurse practitioner or a physician's assistant, answer these questions thinking of this person rather than your doctor.

INSTRUCTIONS: Read each one of the problems listed below. NOTE: If client refuses to respond to a statement, code "Declines to Answer" (code 98). If client states he/she does not know, (code 97).

C1. The following questions ask about your **overall function** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C1.1. I've been satisfied with my physical activity.					
C1.2. I've been physically limited in my ability to do routine household chores.					

Appendix E (continued)

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C1.3. Pain has limited my ability to be physically active.					
C1.4. I've been worried about not being able to do my job/routine daily activities as I have in the past.					
C1.5. I've felt that having HIV has limited the amount of work I can do at my job/routine daily activities.					
C1.6. I've been too tired to be socially active.					

C2. The following questions ask about your **life satisfaction** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C2.1. I've enjoyed living.					
C2.2. I've felt in control of my life.					
C2.3. I've been satisfied with how socially active I am.					
C2.4. I've been pleased with how healthy I've been.					

C3. The following questions ask about your **health worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C3.1. I haven't been able to live the way I'd like to because I'm so worried about my health.					
C3.2. I've been worried about my CD4 count.					
C3.3. I've been worried about my viral load.					
C3.4. I've been worried about when I'm going to die.					

Appendix E (continued)

C4. The following questions ask about your **financial worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C4.1. I've been worried about having to live on a fixed income.					
C4.2. I've been worried about how to pay my bills.					
C4.3. Money has been too tight for me to care for myself the way I think I should.					

C5. The following questions ask about your **medication worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C5.1. Taking my medicine has been a burden.'					
C5.2. Taking my medicine has made it hard to live a normal life.					
C5.3. Taking my medicine has caused unpleasant side-effects.'					
C5.4. I've been worried about the effects my medicine may have on my body.'					
C5.5. I've been unsure about why I'm taking medicine.					

C6. The following questions ask about your **HIV mastery** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C6.1. I've had regrets about the way I lived my life before knowing I had HIV.					
C6.2. I've been angry about my past HIV risk behavior.					

C7. The following questions ask about your **disclosure worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C7.1. I've limited what I tell others about myself.					

Appendix E (continued)

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C7.2. I've been afraid to tell other people that I have HIV.					
C7.3. I've been worried about my family members finding out that I have HIV.					
C7.4. I've been worried about people at my job/routine daily activities finding out that I have HIV.					
C7.5. I've been worried that I'll lose my source of income if other people find out that I have HIV.					

C8. The following questions ask about your **provider trust** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C8.1. I've felt that I could see my doctor whenever I needed to.					
C8.2. I've felt that my doctor involves me in decision-making.					
C8.3. I've felt that my doctor cares about me.					

C9. The following questions ask about your **sexual function** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C9.1 It's been difficult to get sexually aroused.					
C9.2. I've had difficulty with orgasm.					

HIV/AIDS-Targeted QOL Questionnaire Domain		Scores
C10	Overall function	
C11	Life satisfaction	
C12	Health worries	
C13	Financial worries	
C14	Medication worries	

Appendix E (continued)

HIV/AIDS-Targeted QOL Questionnaire Domain		Scores
C15	HIV mastery	
C16	Disclosure worries	
C17	Provider trust	
C18	Sexual function	
C19	TOTAL SCORE	

D. SIGN AND SYMPTOM CHECK-LIST FOR PERSONS WITH HIV DISEASE

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INTERVIEWER: Now I'd like to ask some questions about how you've been feeling in the past 4 weeks. If you have any problems from those listed below, please rate the degree of **SEVERITY** from mild, moderate or severe, which best describes the extent of the problem.

INSTRUCTIONS: Read each one of the problems listed below. If you do not have the problem, check the "not present box" box. NOTE: If client refuses to respond to a statement, code 98 "Declines to Answer". If client states he/she does not know, code 97 "Don't know."

Problem	Not present	Mild	Moderate	Severe
FATIGUE				
D1. Muscle aches				
D2. Weakness				
D3. Painful joints				
FEAR				
D4. Fatigue				
D5. Difficulty concentrating				
D6. Depression				
D7. Memory loss				
D8. Fear and/or worries				
FEVER				
D9. Fever				
D10. Chills				
D11. Day sweats				
D12. Night sweats				

Appendix E (continued)

Problem	Not present	Mild	Moderate	Severe
GASTROINTESTINAL UPSET				
D13. Loose stools				
D14. Diarrhea				
D15. Gas and/or bloating				
D16. Abdominal pain				
D17. Nausea				
D18. Vomiting				
SHORT OF BREAST				
D19. Shortness of breath at rest				
D20. Wheezing				
D21. Shortness of breath with activity				
SORE THROAT				
D22. Sore throat				
D23. Painful swallowing				
D24. Mouth ulcers				
D25. White spots in mouth and/or thrush				
NUMBNESS				
D26. Numbness/tingling of arms				
D27. Numbness/ tingling of hands and/or fingers				
D28. Numbness/ tingling of legs				
D29. Numbness/ tingling of feet and/or toes				
HEADACHE				
D30. Dizziness				
D31. Headaches				
D32. Heart racing				
D33. Chest pain				
RECTAL ITCH				
D34. Rectal itching				
D35. Rectal bleeding				
D36. Rectal discharges				
BRUISING/BLEEDINGS				
D37. Sore and/or bleedings gums				
D38. Nose bleeds				
D39. Easy bruising				

Appendix E (continued)

Problem	Not present	Mild	Moderate	Severe
D40. Blood in spit and/or sputum				
BODY CHANGES				
D41. Weight gain in stomach area				
D42. Concern over weight gain				
D43. Hump on back of neck and/or shoulders				
D44. Skinny arms and legs				
D45. Prominent leg veins				
OTHERS				
D46. Swollen glands				
D47. Swollen feet				
D48. Dry mouth				
D49. Thirst				
D50. Coughing				
D51. Lack of appetite				
D52. Constipation				
D53. Concern about weight loss				
D54. Flushing				
D55. Rash				
D56. Itchy skin				
D57. Insomnia (can't sleep)				
D58. Anxious				
D59. Blurred vision				
D60. Seizures and/or tremors				
D61. Nipple discharge				
D62. Breast pain				
D63. Sores or lumps on genitals				
D64. Burning with urination				
GYNECOLOGICAL-RELATED PROBLEMS				
D65. Vaginal discharge				
D66. Irregular period				
D67. Heavy period				
D68. Bad cramps				
D69. Vaginal itching				
GYNECOLOGICAL-RELATED PROBLEMS				
D70. Vaginal odor				
D.71 Bleeding between periods				
D72. Pelvic pain				

Appendix E (continued)

SIGN AND SYMPTOM CHECK-LIST FOR PERSONS WITH HIV DISEASE		Scores
D73	Frequency	
D74	Intensity	
D75	TOTAL SCORE	

Thank you very much for your participation in this study
If you have any further question regarding to this study, please contact the PI,
EM Alejandra Araya here at the clinic or by phone at 354-5834.

E. MEDICAL RECORD INFORMATION		
E1	Age at HIV infection Diagnosis	
E2	If apply, date that antiretroviral (ARVs) therapy were first started	
E3	CDC disease stage when patient started ARVS	
E4	Currently ARVs therapy (codes)	
E5	Were any CD4 cell counts results recorded in the patient's medical record?	
E6	CD4 cell counts before ARVs started	
E7	Latest CD4 cell counts	
E8	Were any Viral load results recorded in the patient's medical record?	
E9	HIV-1 RNA PCR before ARVs started	
E10	Latest HIV-1 RNA PCR	

Appendix E (continued)

INTERVIEWER CHECKLIST		
1	Time End	<input type="checkbox"/>
2	Informed Consent with copy to the patient	<input type="checkbox"/>
3	Completed Questionnaire (not missing data)	<input type="checkbox"/>
4	Compensation for participants	<input type="checkbox"/>
5	Scoring the survey	<input type="checkbox"/>
6	Return the questionnaire to the PI	<input type="checkbox"/>

Appendix E (continued)

Encuesta

***“La Contribución del Auto-Cuidado en
la Calidad de Vida de Adultos Chilenos
con Infección por Virus de
Inmunodeficiencia Humana”***

Investigador Responsable: EM Alejandra Araya, Profesor Asistente
Pontificia Universidad Católica de Chile, Escuela de Enfermería y
Universidad de Illinois en Chicago, Escuela de Enfermería

Appendix E (continued)

Código del participante: __ __ __

Fecha _____

Hora de Inicio: _____

Iniciales del Entrevistador __

Hora de Terminó: _____

ENTREVISTADOR: Muchas gracias por participar en este estudio. En esta encuesta se le harán preguntas acerca de sus características personales, síntomas asociados al VIH, autocuidado y calidad de vida. No hay respuestas correctas o incorrectas, por favor conteste las preguntas con sinceridad. Las respuestas que usted nos proporcione no serán en ningún momento asociadas con su nombre, sólo con su código de participante. Si usted tiene alguna consulta no dude en preguntarme, en cualquier momento, durante o después de esta encuesta. Esta entrevista dura aproximadamente 30 minutos.

A. Características Personales

ENTREVISTADOR: En primer lugar, me gustaría empezar haciéndole algunas preguntas sobre usted mismo. (Marque con un círculo la respuesta correcta).

A1. ¿Cuántos años tiene usted? (en años completos)..... _____

A2. ¿Cuál es su sexo?

Masculino01
Femenino02
No responde98

A3. ¿Cuál es su estado civil?

Soltero (a)01
Conviviente02
Casado (a)03
Separado (a)04
Viudo (a)05
No responde98

Appendix E (continued)

A4. ¿En la actualidad usted vive con su cónyuge o pareja?

Sí01
No02
No responde98

Si responde SI, ¿Cuánto tiempo hace que vive con su cónyuge o pareja actual? (en años completos) _____ años

A5. ¿Tiene usted hijos?

Sí01
No02
No responde98

Si responde SI, ¿Cuántos hijos tiene usted? _____

A6. ¿Cuál fue el último nivel de educación que usted completó?

Nunca asistió a la escuela01
Enseñanza básica02
Enseñanza media03
Enseñanza de nivel técnico04
Estudios universitarios05
No responde98

A7. Hablemos de su trabajo, ¿Cuál es su situación laboral actual?

Empleado tiempo completo01
Empleado media jornada o parcial02
Empleos temporales03
Trabajador independiente04
Estudiante05
Cesante06
No responde98

Appendix E (continued)

A8. ¿Cuál es su previsión de salud actualmente?

FONASA01
ISAPRE02
Fuerzas armadas03
Sin previsión de salud04
No responde98

A9. ¿Tiene alguna otra enfermedad o enfermedades, además del VIH?

Sí01
No02
No responde98

Si la respuesta es Sí, ¿cuál o cuáles? _____

ENTREVISTADOR: A continuación le voy a preguntar sobre los miembros de su familia y/o amigos que pueden ayudarlo(a) a apoyar su tratamiento médico asociado al VIH. Incluso si los considera sus amigos, al responder a estas preguntas no piense en los trabajadores de la salud que lo atienden.

A10. ¿Cuántos parientes o amigos cercanos tiene usted (la gente con la que usted se siente a gusto y con la que puede hablar abiertamente)? _____

A11. En una emergencia, ¿Cree usted que puede acudir a lo menos a un miembro de su familia o un amigo que lo pueda ayudar?

Sí01
No02
No responde98

B. Cuestionario sobre el Proceso de Gestión del Autocuidado: Autoprotección

© Jones, Linda Corson, PhD, R.N.

ENTREVISTADOR: Ahora me gustaría hacerle algunas preguntas acerca de su *autocuidado relacionado al VIH* en las últimas 4 semanas. El VIH, como cualquier otra enfermedad crónica, puede requerir muchos cambios en su vida. El propósito de estas preguntas es para saber cómo diferentes personas con VIH enfrentan su enfermedad. No hay respuestas correctas o incorrectas. Para cada afirmación, marque con una cruz la respuesta que mejor describe su pensamiento. Por favor, conteste todas las preguntas pensando en su condición de VIH positivo.

Appendix E (continued)

INSTRUCCIONES: Leer cada una de las afirmaciones mencionadas a continuación. **NOTA:** Si la persona no responde a la afirmación, colocar código para “no responde” (código 98). Si la persona responde que “no sabe”, colocar el código 97.

AFIRMACIÓN	Totalmente de acuerdo	De acuerdo	Ni de acuerdo ni en desacuerdo	En desacuerdo	Totalmente en desacuerdo
B1. Me preocupa ser una molestia por causa de mi enfermedad					
B2. He decidido que puedo manejar mi enfermedad					
B3. Mi enfermedad no afecta ni a mi familia ni a mis amigos					
B4. Agradar a otras personas es más importante que mi enfermedad					
B5. Me preocupa que este molestando a otras personas con mi enfermedad					
B6. Debo hacer todo lo que pueda para manejar mi enfermedad					
B7. Soy responsable de asegurarme que mi enfermedad no preocupe o moleste a otras personas					
B8. Tengo que ser cuidadoso con la manera en que vivo mi vida					
B9. Mi enfermedad ha afectado la relación que tengo con mis amigos					
B10. No hago ciertas cosas, porque la gente se podría preocupar por mi salud					
B11. Me preocupa mi enfermedad empeore si no sigo mi tratamiento médico					
B12. Me preocupa que la gente me trate diferente a causa de mi enfermedad					

Appendix E (continued)

AFIRMACIÓN	Totalmente de acuerdo	De acuerdo	Ni de acuerdo ni en desacuerdo	En desacuerdo	Totalmente en desacuerdo
B13. A pesar de que pienso mucho sobre mi enfermedad, trato de no hablar mucho de ella					
B14. Trato de convencer a otras personas de cambiar su forma de vida para que no adquieran mi enfermedad					
B15. Es muy difícil planificar actividades, porque nunca sé si mi enfermedad me lo permitirá					
B16. Debo tener una actitud positiva acerca de mi enfermedad, por el bien de los demás					
B17. Mi enfermedad hace que otras personas se sientan incómodas					
B18. Solo pienso en mi enfermedad cuando me causa problemas					
B19. Durante el día, pienso más en mis actividades de la vida diaria que en mi enfermedad					
B20. He cambiado mi forma de vivir para mejorar mi estado de salud					
B21. Les cuento a las personas sobre mi enfermedad, así ellas entenderán si a veces me siento mal, para que no lo tomen personal					
B22. Puedo controlar mi enfermedad, si sigo tratamiento médico					

Appendix E (continued)

AFIRMACIÓN	Totalmente de acuerdo	De acuerdo	Ni de acuerdo ni en desacuerdo	En desacuerdo	Totalmente en desacuerdo
B23. Si yo cuido de mí mismo, puedo prevenir problemas futuros asociados a mi enfermedad					
B24. Soy cuidadoso(a) sobre cuanto les hablo a la gente sobre mi enfermedad, porque no quiero molestarlos					
B25. Me examino a mí mismo(a) en busca de signos de que mi enfermedad está cambiando					
B26. Cuando planeo mis actividades diarias, pienso en mi enfermedad					
B27. Busco signos que indiquen que mi enfermedad está empeorando					
B28. Es muy poco lo que puedo hacer para controlar mi enfermedad					
B29. Pienso que mi enfermedad es muy importante					
B30. Es importante seguir una rutina para que pueda llevar una vida normal					
B31. Puedo manejar mi enfermedad, aprendiendo todo lo que puedo sobre ella					
B32. He cambiado mi forma de vivir para controlar mi enfermedad					
B33. Mi vida gira en torno de mi tratamiento médico					
B34. Debo vigilar (estar pendiente) de mi estado de salud o este va a empeorar					

Appendix E (continued)

AFIRMACIÓN	Totalmente de acuerdo	De acuerdo	Ni de acuerdo ni en desacuerdo	En desacuerdo	Totalmente en desacuerdo
B35. Hago lo que puedo para que la gente se sienta cómoda con mi enfermedad					

Cuestionario Proceso de Gestión Autocuidado: Autoprotección		PUNTAJE
B36	Auto-protección	
B37	Protección social	
B38	Puntaje Total (Auto-protección + Protección social)	

C. Cuestionario de calidad de vida para pacientes con VIH/SIDA

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ENTREVISTADOR: Ahora me gustaría hacerle algunas preguntas acerca de cómo usted a percibido su *calidad de vida* en las últimas 4 semanas. En este cuestionario se le preguntará sobre diferentes áreas de su vida. Por favor, conteste todas las preguntas, aunque no crea que estas preguntas sean importantes para usted. En este cuestionario hay dos tipos de preguntas que usted necesita mayor explicación de cómo contestarlas:

Primero, usted encontrará algunas preguntas relacionadas con su trabajo y/o actividades diarias. Si usted tiene un trabajo, responda estas preguntas pensando en su trabajo. Si usted no tiene un trabajo, responda a estas preguntas pensando en las actividades de la vida diaria que usualmente hace la mayoría de los días de la semana. Por ejemplo, tareas domésticas, ir a la escuela o el trabajo voluntario en una organización, etc.

Segundo, usted encontrará algunas preguntas acerca de su médico. Si suele ver a una enfermera, responda estas preguntas pensando en esta persona en lugar de su médico.

INSTRUCCIONES: Leer cada una de las afirmaciones enumeradas continuación. NOTA: Si el cliente se niega a contestar una pregunta, codifique como “no responde” (código 98). Si la persona no sabe, codifique como “No Sabe” (código 97).

Appendix E (continued)

C1. Las siguientes preguntas son sobre su **“funcionamiento general”** en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C1.1. He estado satisfecho(a) con mi nivel de actividad física					
C1.2. He estado físicamente limitado(a) en mi capacidad para hacer las tareas del hogar y/o las actividades del día a día					
C1.3. El dolor ha limitado mi capacidad de practicar actividades físicas					
C1.4. He estado preocupado(a) por no poder hacer mi trabajo o actividades de la vida diaria como lo he hecho en el pasado					
C1.5. El hecho de tener VIH ha limitado la cantidad de trabajo o actividades de la vida diaria que puedo hacer					
C1.6. He estado demasiado cansado(a) para hacer actividades sociales					

C2. Las siguientes preguntas son sobre su **“satisfacción con su vida”** en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C2.1. He estado disfrutando de la vida					
C2.2. He sentido que controlo/manejo mi vida					
C2.3. He estado satisfecho(a) con mi nivel de actividad(es) social(es)					
C2.4. He estado contento(a) con lo saludable/sano que me he sentido					

C3. Las siguientes preguntas son sobre su **“preocupaciones sobre mi salud”** en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C3.1. No he sido capaz de vivir en la forma en que me gustaría porque estoy muy preocupado(a) sobre mi salud					

Appendix E (continued)

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C3.2. He estado preocupado(a) sobre mi nivel de CD4.					
C3.3. He estado preocupado(a) por mi carga viral					
C3.4. He estado preocupado(a) sobre cuando moriré					

C4. Las siguientes preguntas son sobre su “preocupaciones económicas” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C4.1. He estado preocupado(a) por tener que vivir en un ingreso económico fijo					
C4.2. He estado preocupado(a) sobre como voy a pagar mis cuentas					
C4.3. El dinero ha sido muy escaso para cuidar de mi mismo(a) en la manera en que pienso que debería cuidarme					

C5. Las siguientes preguntas son sobre su “preocupaciones sobre los medicamentos” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C5.1. Tomar mis medicamento ha sido una carga					
C5.2. Tomar mis medicamentos ha hecho que sea difícil vivir una vida normal					
C5.3. Tomar mis medicamentos me ha causado efectos secundarios desagradables					
C5.4. He estado preocupado(a) por los posibles efectos que mis medicamentos pueden tener en mi cuerpo					

Appendix E (continued)

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C5.5. He estado inseguro(a) de por qué estoy tomando medicamentos					

C6. Las siguientes preguntas son sobre su “**experiencia de VIH**” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C6.1. Me he lamentado sobre la manera en que yo vivía antes de saber que era VIH (+)					
C6.2. He estado enojado(a) sobre mis conductas de riesgo del pasado					

C7. Las siguientes preguntas son sobre su “**preocupaciones de divulgación del estado VIH positivo**” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C7.1. He reducido lo que le cuento a otras personas sobre mi mismo(a)					
C7.2. He estado asustado(a) de hablar con otras personas de que tengo VIH					
C7.3. He estado preocupado(a) de que mis familiares descubran que tengo VIH					
C7.4. He estado preocupado(a) de que personas relacionadas con mi trabajo o actividades diarias descubran que tengo VIH					
C7.5. He estado preocupado(a) de perder mi fuente de ingresos en caso de que otras personas descubran que tengo VIH					

Appendix E (continued)

C8. Las siguientes preguntas son sobre su “**confianza en los trabajadores de la salud**” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C8.1. He sentido de que puedo ver a mi médico o enfermera en cualquier momento, si lo necesito					
C8.2. He sentido que mi médico o enfermera me involucra en la toma de decisiones sobre mi salud					
C8.3. He sentido que mi médico o enfermera se preocupa por mí					

C9. Las siguientes preguntas son sobre su “**funcionamiento sexual**” en las últimas 4 semanas:

AFIRMACIÓN	Siempre	La mayoría del tiempo	Parte del tiempo	Un poco del tiempo	Nunca
C9.1 Me ha sido difícil excitarme sexualmente					
C9.2. He tenido problemas con alcanzar el orgasmo					

Cuestionario de calidad de vida para pacientes con VIH/SIDA		PUNTAJE
C10	Funcionamiento general	
C11	Satisfacción con su vida	
C12	Preocupaciones sobre mi salud	
C13	Preocupaciones económicas	
C14	Preocupaciones sobre mis medicamentos	
C15	Experiencia de VIH	
C16	Preocupaciones de divulgación del estado VIH positivo	
C17	Confianza en los trabajadores de la salud	
C18	Funcionamiento sexual	
C19	Calidad de Vida: Puntaje total	

Appendix E (continued)

D. Lista de Signos y Síntomas para personas con VIH

© Holzemer and Bakken, 1999

ENTREVISTADOR: Ahora me gustaría hacerle algunas preguntas acerca de cómo usted se ha sentido en las últimas 4 semanas. Si usted tiene algún problema de los que se enumeran a continuación, por favor calificar el grado de **INTENSIDAD** entre leve, moderado o severo, que mejor describe su problema.

INSTRUCCIONES: Leer cada uno de los problemas enumerados a continuación. Si la persona no tiene el problema enunciado, marque la casilla “ausente”. NOTA: Si el paciente se niega a contestar una pregunta, codifique como “no responde” (código 98). Si la persona no sabe, codifique como “No Sabe” (código 97).

PROBLEMA	AUSENTE	PRESENTE: Intensidad		
		Leve	Moderado	Severo
FATIGA				
D1. Dolores musculares				
D2. Debilidad general				
D3. Articulaciones dolorosas				
D4. Fatiga				
MIEDOS				
D5. Dificultad para concentrarse				
D6. Depresión				
D7. Pérdida de memoria				
D8. Miedos y/o preocupaciones				
FIEBRE				
D9. Fiebre				
D10. Escalofríos				
D11. Transpiración durante el día				
D12. Transpiración durante la noche				
MOLESTIAS GASTROINTESTINALES				
D13. Deposiciones líquidas o frecuentes				
D14. Diarrea				
D15.Gases y/o hinchazón				
D16. Dolor abdominal				
D17. Náuseas				
D18. Vómitos				
FALTA DE LA RESPIRACIÓN				
D19. ¿Le falta la respiración al descansar?				
D20. Silbidos en el pulmón				

Appendix E (continued)

PROBLEMA	AUSENTE	PRESENTE: Intensidad		
		Leve	Moderado	Severo
FALTA DE LA RESPIRACIÓN				
D21. ¿Le falta la respiración al realizar alguna actividad?				
DOLOR DE GARGANTA				
D22. Dolor de garganta				
D23. Deglución (tragar) dolorosa				
D24. Úlceras en la boca				
D25. Áreas blancas en la boca o candidiasis				
ADORMECIMIENTO/ HORMIGUEO				
D26. Adormecimiento/ hormigueo de brazos				
D27. Adormecimiento / hormigueo de los dedos de la mano				
D28. Adormecimiento / hormigueo de las piernas				
D29. Adormecimiento / hormigueo de los pies o dedos de los pies				
DOLOR DE CABEZA				
D30. Mareo				
D31. Dolor de Cabeza				
D32. Palpitaciones en el corazón				
D33. Dolor en el pecho				
PICAZÓN RECTAL				
D34. Picazón rectal				
D35. Sangramiento rectal				
D36. Salida de flujo o líquido rectal				
HEMATOMAS / HEMORRAGIAS				
D37. Encías dolorosas o sangrantes				
D38. Sangramiento de nariz				
D39. Moretones en la piel fáciles				
D40. Sangre con el escupo o con la expectoración (flema)				
CAMBIOS CORPORALES				
D41. ¿Ha engordado en el área del estomago?				
D42. ¿Esta preocupado por el peso que ha aumentado?				

Appendix E (continued)

PROBLEMA	AUSENTE	PRESENTE: Intensidad		
		Leve	Moderado	Severo
CAMBIOS CORPORALES				
D43. ¿Crecimiento (joroba) detrás del cuello o en los hombros/				
D44. ¿Tiene brazos y piernas más delgadas?				
D45. ¿Tiene venas prominentes en las piernas?				
D46. Crecimiento/inflamación de glándulas salivales				
D47. Crecimiento/ inflamación de los pies				
D48. Boca seca				
D49. Sed				
D50. Tos				
D51. Falta de apetito				
D52. Estitiquez (constipación)				
D53. Preocupación sobre el peso perdido				
D54. Bochorno				
D55. Eritema o enrojecimiento				
D56. Picazón en la piel				
D57. Insomnio (no poder dormir))				
D58. Ansiedad				
D59. Visión borrosa				
D60. Convulsiones y/o temblores				
D61. Salida de flujo o líquido del pezón				
D62. Dolor mamario				
D63. Dolor o nódulos en genitales				
D64. Sensación de ardor (dolor) al orinar				
D73. Orina con sangre				
D74. Deposiciones con sangre				
PROBLEMAS GINECOLÓGICOS				
D65. Descarga vaginal				
D66. Periodos menstruales (reglas) irregulares				
D67. Periodo menstrual (reglas) con mucho flujo y/o dolor				
D68. Calambres abdominales intensos y dolorosos				

Appendix E (continued)

PROBLEMA	AUSENTE	PRESENTE: Intensidad		
		Leve	Moderado	Severo
PROBLEMAS GINECOLÓGICOS				
D69. Picazón vaginal				
D70. Mal olor vaginal				
D.71 Sangramiento entre periodos menstruales (reglas)				
D72. Dolor pélvico (en la región baja del abdomen y/o genitales)				

Lista de Signos y Síntomas para personas con VIH		PUNTAJE
D73	Frecuencia	
D74	Intensidad	
D75	Puntaje Total	

ENTREVISTADOR: *Muchas gracias* por su participación en este estudio, si usted tiene alguna pregunta respecto a este estudio, por favor, póngase en contacto con la investigadora responsable, EM Alejandra Araya aquí en la clínica o por teléfono al 354-5834.-

LISTA DE CHEQUEO PARA EL ENTREVISTADOR		
1	Colocar la hora de inicio y termino de la entrevista	<input type="checkbox"/>
2	Consentimiento Informado con copia para el paciente	<input type="checkbox"/>
3	Cuestionario completo (No faltan datos)	<input type="checkbox"/>
4	Entregar la retribución al paciente	<input type="checkbox"/>
5	Calcular cada uno de los puntajes del cuestionario	<input type="checkbox"/>
6	Devolver el cuestionario al investigador responsable	<input type="checkbox"/>

Appendix E (continued)

E. INFORMACIÓN DE LA FICHA CLÍNICA		RESULTADO
E1	Edad al diagnóstico de infección por el VIH	
E2	Si es aplicable, fecha en la que se comenzó la terapia antirretroviral	
E3	Etapas de la enfermedad según CDC antes de que el paciente comenzara con la terapia antirretroviral	
E4	Terapia antirretroviral actual (códigos)	
E5	¿Existe registro en la ficha clínica de los resultados del CD4?	
E6	CD4 antes de que se comenzará la terapia antirretroviral	
E7	El último CD4 registrado en la ficha clínica	
E8	¿Existe registro en la ficha clínica de los resultados de la carga viral?	
E9	Carga viral antes de que se comenzará la terapia antirretroviral	
E10	La última carga viral registrada en la ficha clínica	

Appendix F
Medical Record Abstraction Form

“The Contribution of Self-care to the Perceived Quality of Life of Chilean People who are HIV Positive”

A Research Project of the Pontificia Universidad Católica de Chile &
 University of Illinois at Chicago
 Principal Investigator: Alejandra Araya, R.N.

MEDICAL RECORD ABSTRACTION INSTRUMENT

A. ABSTRACTION INFORMATION

A1. Participant Name: _____

A2. Participant ID Number: _____

A3. Date of Abstraction: ____/____/____

Month/Day/Year

A4. Name of Abstractor: _____

B. HIV STAGE WHEN ANTIRETROVIRAL THERAPY (ARVS) INITIATED

B1. Date of HIV infection diagnosis ____/____/____

Month/Day/Year

B2. Age at HIV infection Diagnosis: ____ years

B3. Date that ARVs were first started ____/____/____

Month/Day/Year

B4. CDC disease stage when patient started ARVS (Circle the correct stage):

1. Clinical Stage	A1	A2	A3
2. Clinical Stage	B1	B2	B3
3. Clinical Stage	C1	C2	C3

Appendix F (continued)

C. CURRENTLY ANTIRETROVIRAL (ARVS) THERAPY

Enter all HIV treatment medications (ARVs and/or Medications for Prophylaxis against Opportunistic Infections) given to patient before enrollment

Section C: Anti-Retroviral (ARV) Medication History Form

C1. ARV Taken	C2. ARV Code	C1. ARV Taken	C2. ARV Code
1 _____	1 _____	4 _____	4 _____
2 _____	2 _____	5 _____	5 _____
3 _____	3 _____	6 _____	6 _____

D. LABORATORY MONITORING: CD4 CELL COUNTS AND VIRAL

LOAD Record CD4 CELL COUNT and VIRAL LOAD results obtained before ARVs started and the latest results reported in medical records.

CD4 CELL COUNTS		VIRAL LOAD	
D1. Date of Result	D2. CD4 Absolute Count (per mm ³)	D3. Date of Result	D4. Raw Copies/ml
1. ____-____-____ Month/ Day/ Year (CD4 cell counts before ARVs started)	_____	2. ____-____-____ Month/ Day/ Year (HIV-1 RNA PCR before ARVs started)	_____ —
3. ____-____-____ Month/ Day/ Year (Latest CD4 cell counts)	_____	4. ____-____-____ Month/ Day/ Year (Latest HIV-1 RNA PCR)	_____ —

D5. Were any CD4 cell counts results recorded in the patient's medical record? YES NO

D6. Were any Viral load results recorded in the patient's medical record? YES NO

Appendix F (continued)

**“La Contribución del Auto-Cuidado en la Calidad de Vida de Adultos
Chilenos con Infección por Virus de Inmunodeficiencia Humana”**

EM Alejandra Araya, Profesor asistente

Un Proyecto de Investigación de la Pontificia Universidad Católica de Chile
y Universidad de Illinois en Chicago

INSTRUMENTO: RECOLECCIÓN DE DATOS DESDE FICHA CLÍNICA

A. INFORMACION DE LA RECOLECCION DE DATOS

A1. Nombre del Participante: _____

A2. Código del Participante: _____

A3. Fecha de la Recolección de Datos: ____ / ____ / ____

Día/Mes/Año

**B. ESTADO DEL VIH ANTES DE INICIAR LA TERAPIA
ANTIRRETROVIRAL**

B1. Edad del paciente al momento de ser diagnosticado con VIH ____ años

B2. Si aplica, fecha de cuando fue iniciada la terapia antirretroviral ____
Día/Mes/Año

B3. Estadio del VIH según la CDC antes que el paciente iniciara terapia
antirretroviral (marque con un círculo la alternativa correcta):

1. Estadio Clínico	A1	A2	A3
2. Estadio Clínico	B1	B2	B3
3. Estadio Clínico	C1	C2	C3

Appendix F (continued)

C. TERAPIA ANTIRRETROVIRAL (ARV) ACTUAL

Coloque todos los medicamentos relacionados al VIH (terapia ARV y/o medicamentos de profilaxis para infecciones oportunista) que el paciente esta recibiendo antes de su ingreso a este estudio.

Sección C: Registro de la terapia antirretroviral tomada por el paciente al momento del estudio

C1. Terapia ARV	C2. Código Terapia ARV	C1. Terapia ARV	C2. Código Terapia ARV
1 _____	1 _____	4 _____	4 _____
2 _____	2 _____	5 _____	5 _____
3 _____	3 _____	6 _____	6 _____

D. ESTUDIOS DE LABORATORIO: CD4 Y CARGA VIRAL

Registre los resultados del CD4 y de la CARGA VIRAL antes de que el paciente haya iniciado la terapia ARV y el último resultado disponible.

CD4		CARGA VIRAL	
D1. Fecha de los resultados	D2. Valor del CD4 (per mm ³)	D3. Fecha de los resultados	D4. Valor de la Carga viral (Copies/ml)
5. _____ Día/ Mes/ año (CD4 antes de comenzar terapia ARV)	_____	1. _____ Día/ Mes/ año (Carga viral antes de comenzar terapia ARV)	_____
1. _____ Día/ Mes/ año (Último resultado de CD4)	_____	1. _____ Día/ Mes/ año (Último resultado de carga viral)	_____

D5. ¿Había registro en la ficha clínica de los resultados del CD4 del paciente? SI NO

D6. ¿Había registro en la ficha clínica de los resultados de la carga viral del paciente? SI NO

Appendix G
Institutional Review Boards approval at University of Illinois at Chicago

UNIVERSITY OF ILLINOIS
 AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
 Office of the Vice Chancellor for Research (MC 672)
 203 Administrative Office Building
 1737 West Polk Street
 Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

December 7, 2009

Alejandra Araya, BS
 Health Systems Science
 845 South Damen Avenue
 11th Floor, M/C 802
 Chicago, IL 60612-1350
 Phone: (507) 206-1138 / Fax: (312) 996-8945

RE: **Protocol # 2009-0991**
"The Contribution of Self-Care to the Perceived Quality of Life of Chilean People Who are HIV Positive"

Dear Ms. Araya:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on November 23, 2009. You may now begin your research.

Please note the following information about your approved research protocol:

Please remember to submit Spanish translations of all recruitment and consent documents prior to recruiting and enrolling subjects at Chilean sites. Spanish translations must be accompanied by an Amendment form when submitted to the UIC IRB.

Please remember to submit a copy of IRB approval from the Chilean site prior to recruiting and enrolling subjects at that site. A copy of the IRB approval must be accompanied by an Amendment form when submitted to the UIC IRB.

<u>Protocol Approval Period:</u>	November 23, 2009 - November 22, 2010
<u>Approved Subject Enrollment #:</u>	150
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Site:</u>	UIC
<u>Sponsor:</u>	Fogarty International Center
<u>PAF#:</u>	Not applicable
<u>Grant/Contract No:</u>	D43 TW01419
<u>Grant/Contract Title:</u>	UIC AIDS International Training and Research Program

Appendix G (continued)

2009-0991

Page 2 of 3

12/7/2009

Research Protocol:

- a) The Contribution of Self-Care to the Perceived Quality of Life of Chilean People Who are HIV Positive; Version 1; 10/29/2009

Recruitment Materials:

- a) Health Care Providers Referral Script; Version 1; 10/29/2009
- b) Letter of Invitation; Version 1; 10/29/2009

Informed Consents:

- a) Informed Consent; Version 2; 11/11/2009
- b) A waiver of informed consent has been granted under 45 CFR 46.116(d) for recruitment purposes only

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

- (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis),
- (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
10/29/2009	Initial Review	Expedited	11/05/2009	Modifications Required
11/12/2009	Response To Modifications	Expedited	11/23/2009	Approved

Please remember to:

→ Use your **research protocol number** (2009-0991) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Appendix G (continued)

2009-0991

Page 3 of 3

12/7/2009

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosures:

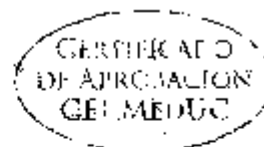
- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 2. Informed Consent Document:**
 - a) Informed Consent; Version 2; 11/11/2009
- 3. Recruiting Materials:**
 - a) Health Care Providers Referral Script; Version 1; 10/29/2009
 - b) Letter of Invitation; Version 1; 10/29/2009

cc: Arlene Miller, PhD, RN, Health Systems Science, M/C 802
Beverly J. McElmurry, Health Systems Science, M/C 802

Appendix H
Institutional Review Boards approval at Pontificia Universidad Católica de Chile



PONIFICIA UNIVERSIDAD CATÓLICA DE CHILE
FACULTAD DE MEDICINA
ESCUELA DE MEDICINA CLÍNICA Y DE ESPECIALIZACIÓN



SE APROBÓ EL SIGUIENTE PROYECTO

Número Proyecto: 09-213
Fecha Aprobación: 01.12.2009
Fecha Expiración: 30.11.2010

Investigador: Araya, Alejandra (Escuela de Enfermería)

Título Proyecto: La contribución del auto-cuidado en la calidad de vida en adultos chilenos con infección por virus de inmunodeficiencia humana."

Patrocinador: Este proyecto no requiere financiamiento institucional.

Se acusa recibo de los siguientes documentos:

- Carta de presentación del proyecto en referencia.
- Carta de apoyo del Director médico del Centro Médico San Joaquín, Dr. Enrique Donoso.
- Guion trabajadores de la Salud, versión 11 de noviembre de 2009, versión 1.
- Carta de invitación, 11 de noviembre de 2009, versión 1.
- Formulario de evaluación criterios de inclusión, 11 de noviembre de 2009, versión 1.
- Carta respaldo jefe del Departamento.
- Carta respaldo del Jefe de Programa de Enfermedades Infecciosas.

Documentos para revisión por el comité :

- Encuesta, versión del 11 de noviembre de 2008, versión 1.
- Documento de recolección datos ficha clínica.. 11 de noviembre del 2008, versión 1.
- Documento de consentimiento informado. versión del 11.11.2009, versión 1.

Condiciones de la aprobación:

Si aprueba. Se le solicita cambios mínimos al consentimiento informado, debe señalar que no habrán muestras de sangre adicionales, y redactar en positivo lo de la confidencialidad (que se harán los máximos esfuerzos para asegurar la confidencialidad...)

Se le solicita en toda futura correspondencia hacer referencia al número del Proyecto as grado
09-213

EN CASO DE EMERGENCIA SE LE SOLICITA CONTACTARSE CON EL CENTRO

Se afirma que la información contenida en el presente documento es confidencial y que el ejemplar de Contrato de Egreso en Investigación de la Universidad de Medicina (CE-UMed) que la Comisión de Egreso y las principales Oficinas de Egreso de Medicina de la Facultad de Medicina Central, se conservará como un documento confidencial en la Facultad de Medicina Central, y no se permitirá su divulgación, desde el momento de la emisión de la hasta la muerte natural. Este contrato es el resultado de la negociación entre la Universidad de Medicina Central y la Comisión de Egreso de Medicina Central, y no se permite su divulgación a terceros (CE-UMed) y por las leyes de 1973 y 1974, la información de la vida privada y protección de datos de cualquier nacional.

Elaborado por el autor

DR. SOFIA SUZUKI President



10.1 DEC. 2009

Fraser

Appendix I
Study's Letters of Support



Red Salud UC
Facultad de Medicina
Medicina de Confianza

October 16th, 2009
100/2009

Alejandra Araya, RN
Assistant Professor, School of Nursing,
Pontificia Universidad Católica de Chile.
PhD Candidate, College of Nursing,
University of Illinois at Chicago.

Dear Alejandra Araya:

As Director of the Centro Médico San Joaquín Clinic, I am pleased to support the implementation of the dissertation study "The Contribution of Self-care on Quality of Life among HIV Positive Chilean People" in this outpatient clinic. I believe that our institution is in an adequate position to collaborate improving the research in HIV and AIDS in Chile.

Please be assured that I give full support from our clinic and we stand willing to facilitate this dissertation study in whatever way we can as it is moved forward.

I wish you great success in the proposed dissertation study.

Sincerely,

Dr. Enrique Donoso
Director of Centro Médico San Joaquín Clinic
Faculty of Medicine
Pontificia Universidad Católica de Chile

Appendix I (continued)

**PONTIFICIA UNIVERSIDAD CATOLICA DE CHILE
DIRECCION
HOSPITAL CLINICO U.C.**

October 16th, 2009

**Alejandra Araya, RN
Assistant Professor, School of Nursing,
Pontificia Universidad Católica de Chile.
PhD Candidate, College of Nursing,
University of Illinois at Chicago.**

Dear Alejandra Araya,

As Head of the Program of Infectious Diseases at Centro Médico San Joaquín Clinic, I am delighted to support the implementation of the dissertation study "The Contribution of Self-care on Quality of Life among HIV Positive Chilean People" in our program. I believe the proposed study is greatly needed among Chilean HIV-infected persons to improve patient's quality of life as well as contribute to the research of HIV and AIDS in Chile.

I wish great success in this dissertation study.

Sincerely,

**Carlos M. Pérez, M.D., F.A.C.P.
Head Program of Infectious Diseases
Centro Médico San Joaquín Clinic
Pontificia Universidad Católica de Chile**

Appendix J
HIV/AIDS-Targeted QOL (HAT-QOL) Questionnaire

C1. The following questions ask about your **overall function** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C1.1. I've been satisfied with my physical activity.					
C1.2. I've been physically limited in my ability to do routine household chores.					
C1.3. Pain has limited my ability to be physically active.					
C1.4. I've been worried about not being able to do my job/routine daily activities as I have in the past.					
C1.5. I've felt that having HIV has limited the amount of work I can do at my job/routine daily activities.					
C1.6. I've been too tired to be socially active.					

C2. The following questions ask about your **life satisfaction** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C2.1. I've enjoyed living.					
C2.2. I've felt in control of my life.					
C2.3. I've been satisfied with how socially active I am.					
C2.4. I've been pleased with how healthy I've been.					

C3. The following questions ask about your **health worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C3.1. I haven't been able to live the way I'd like to because I'm so worried about my health.					
C3.2. I've been worried about my CD4 count.					
C3.3. I've been worried about my viral load.					

Appendix J (continued)

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C3.4. I've been worried about when I'm going to die.					

C4. The following questions ask about your **financial worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C4.1. I've been worried about having to live on a fixed income.					
C4.2. I've been worried about how to pay my bills.					
C4.3. Money has been too tight for me to care for myself the way I think I should.					

C5. The following questions ask about your **medication worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C5.1. Taking my medicine has been a burden.'					
C5.2. Taking my medicine has made it hard to live a normal life.					
C5.3. Taking my medicine has caused unpleasant side-effects.'					
C5.4. I've been worried about the effects my medicine may have on my body.'					
C5.5. I've been unsure about why I'm taking medicine.					

C6. The following questions ask about your **HIV mastery** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C6.1. I've had regrets about the way I lived my life before knowing I had HIV.					
C6.2. I've been angry about my past HIV risk behavior.					

Appendix J (continued)

C7. The following questions ask about your **disclosure worries** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C7.1. I've limited what I tell others about myself.					
C7.2. I've been afraid to tell other people that I have HIV.					
C7.3. I've been worried about my family members finding out that I have HIV.					

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C7.4. I've been worried about people at my job/routine daily activities finding out that I have HIV.					
C7.5. I've been worried that I'll lose my source of income if other people find out that I have HIV.					

C8. The following questions ask about your **provider trust** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C8.1. I've felt that I could see my doctor whenever I needed to.					
C8.2. I've felt that my doctor involves me in decision-making.					
C8.3. I've felt that my doctor cares about me.					

C9. The following questions ask about your **sexual function** in the past four weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the time
C9.1. It's been difficult to get sexually aroused.					
C9.2. I've had difficulty with orgasm.					

Appendix K
The Self-Care Management Process-Guarding (SCMP-G) Questionnaire

STATEMENT	1 Strongly agree	2 Agree	3 Neither agree or disagree	4 Disagree	5 Strongly disagree
B1.I worry about being a bother because of my illness					
B2. I have made up my mind that I can control my illness					
B3. My illness does not affect my family and friends					
B4.Pleasing other people is more important than my health					
B5. I worry than I am a bother to other people					
B6. I must do all I can to control my illness					
B7. I am responsible for making sure my illness does not worry other people					
B8. I have to be careful with the way I live my life					
B9. My illness has affected my relationships with friends					
B10. I don't do certain things, because the people would worry about my health					
B11. I worry that if I don't follow my treatment plan, my illness will worsen					
B12. I am troubled that people treat me differently because of my illness					
B13. Even though I think a lot about my illness, I try not to talk about it					
B14. I try to convince other people to change the way they live so they won't develop my health problems					
B15. It is hard to plan activities, because I never know whether my illness will keep me from doing things					
B16. I must have a positive attitude about my illness for the sake of others					
B17. My illness makes other people uncomfortable					
B18. I only think about my illness when it causes me problems					

Appendix K (continued)

STATEMENT	1 Strongly agree	2 Agree	3 Neither agree or disagree	4 Disagree	5 Strongly disagree
B19. I don't think about my illness as I do daily activities					
B20. I have changed the way I live to improve my health					
B21. I tell people about my illness so they will understand if I'm out of sorts and they won't take it personally					
B22. I can control my illness if I follow my treatment plan					
B23. If I take care of myself, I can prevent further problems with my illness					
B24. I am careful about how much I tell other people about my illness, because I don't want to trouble them					
B25. I check myself for signs that my illness is changing					
B26. When I make daily plans, I think about my illness					
B27. I watch for signs that my illness is getting worse					
B28. There is a little I can do to control my illness					
B29. I think about my health a great deal					
B30. It is important to follow a routine so I can lead a normal life					
B31. I manage my illness by learning all I can about it					
B32. I have changed the way I live so that I can control my illness					
B33. My life revolves around my treatment plan					
B34. I must watch my health or it will get worse					
B35. I go out of my way to make people feel comfortable with my illness					

Appendix L
Sign and Symptom Check-list for Persons with HIV Disease (SSC-HIVrev) Instrument

Problem	Not present	Mild	Moderate	Severe
FATIGUE				
D1. Muscle aches				
D2. Weakness				
D3. Painful joints				
D4. Fatigue				
FEAR				
D5. Difficulty concentrating				
D6. Depression				
D7. Memory loss				
D8. Fear and/or worries				
FEVER				
D9. Fever				
D10. Chills				
D11. Day sweats				
D12. Night sweats				
GASTROINTESTINAL UPSET				
D13. Loose stools				
D14. Diarrhea				
D15. Gas and/or bloating				
D16. Abdominal pain				
D17. Nausea				
D18. Vomiting				
SHORT OF BREAST				
D19. Shortness of breath at rest				
D20. Wheezing				
D21. Shortness of breath with activity				
SORE THROAT				
D22. Sore throat				
D23. Painful swallowing				
D24. Mouth ulcers				
D25. White spots in mouth and/or thrush				
NUMBNESS				
D26. Numbness/tingling of arms				
D27. Numbness/ tingling of hands and/or fingers				
D28. Numbness/ tingling of legs				

Appendix K (continued)

Problem	Not present	Mild	Moderate	Severe
HEADACHE				
D29. Numbness/ tingling of feet and/or toes				
D30. Dizziness				
D31. Headaches				
D32. Heart racing				
D33. Chest pain				
RECTAL ITCH				
D34. Rectal itching				
D35. Rectal bleeding				
D36. Rectal discharges				
BRUISING/BLEEDINGS				
D37. Sore and/or bleedings gums				
D38. Nose bleeds				
D39. Easy bruising				
D40. Blood in spit and/or sputum				
BODY CHANGES				
D41. Weight gain in stomach area				
D42. Concern over weight gain				
D43. Hump on back of neck and/or shoulders				
D44. Skinny arms and legs				
D45. Prominent leg veins				
OTHERS				
D46. Swollen glands				
D47. Swollen feet				
D48. Dry mouth				
D49. Thirst				
D50. Coughing				
D51. Lack of appetite				
D52. Constipation				
D53. Concern about weight loss				
D54. Flushing				
D55. Rash				
D56. Itchy skin				
D57. Insomnia (can't sleep)				
D58. Anxious				
D59. Blurred vision				

Appendix K (continued)

Problem	Not present	Mild	Moderate	Severe
D60. Seizures and/or tremors				
D61. Nipple discharge				
D62. Breast pain				
OTHERS				
D63. Sores or lumps on genitals				
D64. Burning with urination				
GYNECOLOGICAL-RELATED PROBLEMS				
D65. Vaginal discharge				
D66. Irregular period				
D67. Heavy period				
D68. Bad cramps				
D69. Vaginal itching				
GYNECOLOGICAL-RELATED PROBLEMS				
D70. Vaginal odor				
D.71 Bleeding between periods				
D72. Pelvic pain				

VITA

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Education

- 2010 PhDc (Doctor of Philosophy in Nursing Research)
University of Illinois at Chicago, College of Nursing, Chicago, IL, USA.
- 2001 Clinical Specialist in Gerontology Neuroscience
Pontificia Universidad Católica de Chile, School of Nursing, Santiago, Chile.
- 1999 BSN in Nursing
Pontificia Universidad Católica de Chile, School of Nursing, Santiago, Chile.

Continuing Education/Training

- 2003 Teaching in Nursing, Pontificia Universidad Católica de Chile, School of
Nursing, Santiago, Chile.

Positions

- 2006 to date Assistant Professor, School of Nursing, Pontificia Universidad Católica de Chile.
- 2002–2005 Associate Instructor, School of Nursing, Pontificia Universidad Católica de Chile.
- 2001–2006 Associate Professor, Gerontology Certificate Program. College of Medicine.
Pontificia Universidad Católica de Chile.
- 2001–2004 Staff nurse, Surgical Unit. Clínica San Carlos. Pontificia Universidad Católica
de Chile.
- 2001–2002 Staff nurse, Geriatric Program. Pontificia Universidad Católica de Chile.
- 2000–2000 Staff nurse Medicine and Surgical Unit. San Joaquín Medical Center.
Pontificia Universidad Católica de Chile.

Honors

- 2008 to date Presidente de la República de Chile Award.
- 2007 to date John E. Fogarty International Center AIDS International Training and Research Program at the University of Illinois at Chicago (D43 TW001419).

Professional memberships

- 2009 to date Sigma Theta Tau International. Honor Society of Nursing
- 2008 to date International AIDS Society. USA.
- 2007 to date Midwest Nursing Research Society Member, USA.
- 2004 to date Geriatric and Gerontology Society Member, Chile.

Selected Publications

Journals

- Urrutia, M. T., Araya, A., & Poupin, L. (2010). ¿Por qué las mujeres no se toman el Papanicolaou? respuestas entregadas por los profesionales del programa cáncer cervicouterino – AUGE del Servicio de Salud Metropolitano Sur Oriente [Why women do not take the Pap smear? Answers delivered by professionals from the cervical cancer program - AUGE Metropolitan Health Service South East] *Revista Chilena de Obstetricia y Ginecología*, 75(5), 284–289.
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Selected Published Abstracts and Professional Meeting Presentations

Araya, A., Pérez, C., Scrivanti, M., & Soto, P. (2010, December). Introducción del concepto de “protección” en población Chilena con VIH y su relación con síntomas/signos de la enfermedad [Introduction of the concept of “guarding” in Chilean people living with HIV and its relationship with HIV-related symptoms]. Poster session presented at the II Encuentro Internacional de Autocuidado en Salud [International Self-care meeting]. Santiago, Chile.

Araya, A., Ferrer, L., Cianelli, R., Bernales, M., Lara, L., Irarrazaval, . . . Norr, K. (2010, April). Peer group intervention decreases HIV stigmatization Chilean health care workers. Paper presented at the 34th Annual MNRS Research Conference. Kansas City, MO, EEUU.

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Araya, A., Norr, K., Norr, J., Ferrer, L., Bernales, M., Cabieses, B. . . . Lara, L. (2009, March).

Chilean health care workers: Beyond the AIDS law in primary health care settings. Paper presented at the ation, 33rd Annual MNRS Research Conference. Minneapolis, MN, EEUU.

Araya, A., Norr, K., Norr, J., Ferrer, L., Bernales, M., Cabieses, B., . . . Lara, L. (2008,

November). Profesionales de la salud y legislación sobre el VIH/SIDA en Chile: Un desafío para la atención primaria de salud [Health care providers and HIV law: A challenge for primary care]. Paper presented at the 10th Conferencia Iberoamericana de Educación en Enfermería [10th Conference on Nursing Education of ALADEFE]. Quito, Ecuador.

Araya, A., Norr, K. F., Norr, J. L., Ferrer, L., Bernales, M., Cabieses, B., . . . Irarrazabal, L.

(2008, August). Health care workers and AIDS law: Regulation and practice gaps? Poster session presented at the 17th International AIDS Conference. Mexico City, Mexico.

Cianelli, R., Ferrer, L., Norr, K. F., Norr, J. L., Crittenden, K. S., Villegas, N., . . . Araya, A.

(2008, August). Intervention improves HIV prevention knowledge, attitudes and behaviors for Chilean health care workers. Poster session presented at the 17th International AIDS Conference. Mexico City, Mexico.

Araya, A., Ferrer, L., Cianelli, R., Norr, K., Bernales, M., Irarrazabal, L., & Cabieses, B. (2008,

April). The effectiveness of an HIV and AIDS prevention training program for Chilean health care workers. The Annual UIC Student Research Forum. Chicago, IL, EEUU.

Araya, A., Ferrer, L., Cianelli, R., Norr, K., Bernales, M., Irarrazabal, L., & Cabieses, B. (2008,

March). HIV/AIDS prevention training program effectiveness for Chilean health care workers (HCW). Poster session presented at the 32nd Annual MNRS Research Conference. Indianapolis, IN, EEUU.

Araya, A., Ferrer, L., Cianelli, R., Bernales. M., Irarrazabal, L., Cabieses, B., & Norr, K.(2007,

October). Mano a Mano: Una capacitación efectiva para trabajadores de la salud en prevención de VIH/SIDA [Mano a Mano: An effective HIV prevention intervention for health care workers]. Paper presented at the Ninth Conferencia Iberoamericana de Educación en Enfermería y I Encuentro Latinoamericano-Europa. Toledo, Spain,

Ferrer, L., Cianelli, R., Urrutia, M. T., Peragallo, N., & Araya, A. (2007, October).

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Araya, A., Cianelli, R., Ferrer, L., Irarrazabal, L., Cabieses, B., Bernales, M., & Miner, S. (2006, May). Conocimientos y actitudes de trabajadores de salud (TS) frente al VIH/SIDA en un contexto rural. (Knowledge and attitudes of HIV/AIDS among rural health care workers]. Paper presented at the Encuentro Internacional de Autocuidado en Salud. Santiago, Chile.

- Cianelli, R., Norr, K., Ferrer, L., Cabieses, B., Araya, A., Irarrazabal, L. & Bernales, M. (2006, May). HIV/AIDS-related stigma and discrimination affecting Chileans' self-care. Paper presented at the Encuentro Internacional de Autocuidado en Salud. Santiago, Chile.
- Bernales, M., Ferrer, L., Cianelli, R., Cabieses, B., Araya, A. & Ferrer, X. (2006, May). Experiencia de capacitación en VIH/SIDA para Trabajadores Salud Rural (TSR): Recomendaciones para el fortalecimiento del Autocuidado (Experience of HIV/AIDS training program for rural health care workers: Recommendations for the fortifications of self-care). Poster session presented at the Encuentro Internacional de Autocuidado en Salud. Santiago, Chile.
- Cabieses, B., Bernales, M., Ferrer, L., Cianelli, R., Ferrer, X., Triviño, X... Irarrázaval, L. (2006, May). Evaluación de Programa de Capacitación en Prevención de VIH/SIDA a Futuros Profesionales de la Salud (FPS) como estrategia de Autocuidado [Evaluation of HIV/AIDS training program for future health care providers as strategy of self-care]. Poster session presented at the Encuentro Internacional de Autocuidado en Salud. Santiago, Chile.
- Urrutia, M. T., Araya, A., Orellana, C., Medina, C., Navia, P., & Rivera, S. (2005, November). Modelo predictivo de sexualidad en la mujer histerectomizada: Estrategia para enseñar multicausalidad en salud [Predictive model of sexuality among hysterectomized women: An strategy to teach multicausality in health]. Paper presented at the Eighth Conferencia Iberoamericana de Educación en Enfermería. Concepción, Chile.
- Urrutia, M. T., Riquelme, P., & Araya, A. (2005, November). Satisfacción con la educación recibida en mujeres histerectomizadas: Tópico a considerar en la enseñanza de enfermería [Satisfaction with the education received among hysterectomized women: Topic to consider in the nursing education] at the Eighth Conferencia Iberoamericana de Educación en Enfermería. Concepción, Chile.
- Cianelli, R., Cabieses, B., Matsumoto, C., Ferrer L., & Araya, A. (2005, October). HIV/AIDS prevention among disadvantaged groups in Chile: Experience in two training programs. Poster session presented at the Optimizing Global Health Through Nursing Science Conference. Chicago, IL, USA.

Araya A., Marin P. P., & Guzman, J. M. (2003, September). Adultos mayores institucionalizados en Chile. [Institutionalized older people in Chile]. Poster session presented at the Fourth Congreso Latinoamericano de Geriatria y Gerontologia (COMLAP-IAG), Santiago, Chile.

Araya A. (2003, September). Manejo de enfermería del paciente con demencia [Nursing care among patients with dementia]. Paper presented at the Fourth Congreso Latinoamericano de Geriatria y Gerontologia (COMLAP-IAG), Santiago, Chile.

Rivera S., Araya A. (2001, August). Ser adulto mayor saludable: Construyendo una nueva conciencia [Healthy older adults: Making a new conscience]. Poster session presented at the 17th Conferencia Mundial de la Promoción de la Salud y Educación para la salud. Paris, France.

Arechabala C., Lange, I., & Araya A. (2000, April). Encuentro educativo y de apoyo con los adultos mayores: Creando vínculos para ser saludables [Education with older adults: Making relationships for being healthy]. Poster session presented at the Sixth Jornadas Nacionales de la Sociedad Española de Enfermería Geriátrica y Gerontológico, Logroño, Spain.

RESEARCH SUPPORT

Title: Generando una intervención interdisciplinaria para mujeres histerectomizadas desde la perspectiva de la mujer, su pareja y el profesional que los atiende [Generating an interdisciplinary intervention for hysterectomized women from the perspective of the women, their partners, and their health care providers] 2010–2011.

Institution: Pontificia Universidad Católica de Chile

Purpose: Elaborar una intervención culturalmente apropiada para mujeres histerectomizadas del Complejo Asistencial Dr. Sotero del Rio [To develop a culturally appropriate intervention for women hysterectomized who receive care at the outpatient clinic Dr. Sotero del Rio].

Role: Co-I.

Title: Mobilizing Health Workers for Community HIV Prevention in Chile.

Institution: National Institutes of Health, USA (NIH) Grant # 1 R03 TW006980-01 2004-2008

Purpose: Modify and test an HIV/AIDS training program for health care workers at the primary level in Chile.

Role: Co-I.

Title: Percepción de la mujer sobre el impacto de la histerectomía en su vida sexual [Chilean women's perceptions of the impact of hysterectomy on their sexual lives].

Institution: Dirección de Investigación, Escuela de Enfermería. Proyecto DIEE/2002

Role: Co-I.