



Published in final edited form as:

AIDS Behav. 2009 April ; 13(2): 258–267. doi:10.1007/s10461-007-9297-5.

HIV Illness Representation as a Predictor of Self-care Management and Health Outcomes: A Multi-site, Cross-cultural Study

N. R. Reynolds,

The Ohio State University, 1585 Neil Ave., Columbus, OH 43210, USA

L. Sanzero Eller,

Rutgers University, Newark, USA

P. K. Nicholas,

Brigham and Women's Hospital and MGH Institute of Health Professions, Boston, USA

I. B. Corless,

MGH Institute of Health Professions, Boston, USA

K. Kirksey,

University of Texas, Houston, USA

M. J. Hamilton,

Texas A&M University, Corpus Christi, USA

J. K. Kemppainen,

University of North Carolina at Wilmington, Wilmington, USA

E. Bunch,

University of Oslo, Oslo, Norway

P. Dole,

Village Diagnostic & Treatment Center, New York, USA

D. Wantland,

University of California, San Francisco School of Nursing, San Francisco, USA

E. Sefcik,

Texas A&M University, Corpus Christi, USA

K. M. Nokes,

Hunter College, CUNY, New York, USA

C. L. Coleman,

University of Pennsylvania, Philadelphia, USA

M. Rivero,

University of Puerto Rico, San Juan, USA

G. E. Canaval,

Universidad del Valle, Cali, Colombia

Y. F. Tsai, and

Chang Gung University, Tao-Yuan, Taiwan

W. L. Holzemer

University of California, San Francisco School of Nursing, San Francisco, USA

N. R. Reynolds: reynolds.1@osu.edu

Abstract

Research has shown that the perceptions that form the cognitive representation of an illness (*illness representation*) are fundamental to how persons cope with illness. This study examined the relationship of illness representation of HIV with self-care behavior and health outcomes. Data were collected at 16 sites in the United States, Taiwan, Norway, Puerto Rico and Colombia via survey. HIV seropositive participants ($n = 1,217$, 31% female, 38% African-American/Black, 10% Asian/Pacific Islander and 26% White/Anglo) completed measures of illness representation based on the commonly accepted five-component structure: identity, time-line, consequences, cause, and cure/controllability (Weinman et al. 1996, *Psychology and Health*, 11, 431–445). Linear regression analyses were conducted to investigate relationships among illness representation, self-care behaviors and quality-of-life outcomes. Components of illness representation were associated with self-care and health outcomes, indicating that the cognitive representation of HIV has consequences for effective illness management. For example, perception that there is little that can be done to control HIV was significantly associated with fewer and less effective self-care activities ($F = 12.86$, $P < .001$) and poorer health function in the domain of quality-of-life ($F = 13.89$, $P < .001$). The concept of illness representation provides a useful framework for understanding HIV symptom management and may be useful in directing development of effective patient-centered interventions.

Keywords

HIV; Illness representation; Self-care; Self-management; Beliefs; Chronic illness

Introduction

Advances in the treatment of the human immunodeficiency virus (HIV) have dramatically improved mortality outcomes. Despite this progress, persons living with HIV are challenged to manage a host of symptoms and side effects related to the disease, its treatments, and comorbidities. Studies of symptom management (Cleary et al. 1993; Holzemer 2002) have utilized various methods and sampled individuals at different points in the course of their illness trajectory (Strauss 1990; Strauss et al. 1984). The overriding conclusion from these studies is that quality of life and productivity decrease as the number and severity of HIV-related symptoms increase. Effective management of symptoms is thus an important component of HIV health care. Although control of HIV-related symptoms may be improved with medical intervention, it is neither clinicians nor health systems that manage the symptoms on a daily basis, but rather the patients themselves; self-care activities are at the core of symptom management (Clark et al. 2001; Holzemer 2002). The individual living with HIV spends most of the time away from medical facilities and largely relies upon personal judgment and ingenuity to interpret and manage the complex vagaries of symptoms accompanying HIV (Strauss 1990).

A line of research conducted by the *HIV/AIDS International Nursing Research Network* based at the University of California, San Francisco has identified different types of self-care activities that are commonly used by persons living with HIV to self-manage symptoms. This work has demonstrated that persons living with HIV regularly use a wide range of strategies to manage symptoms including distraction techniques, dietary measures, complementary therapies, medications, exercise, and substances like alcohol and marijuana

(e.g., Chou et al. 2004; Corless et al. 2002; Kemppainen et al. 2003; Nicholas et al. 2002). Although it has been well established that quality of life diminishes as symptoms increase, it has not yet been established what factors drive use of self-care activities or whether the use of self-care strategies improves quality-of-life outcomes in persons living with HIV. A better understanding could be useful in guiding often-neglected efforts to support patient self-care management.

The Self-regulation Model

Self-regulation theory provides a potentially useful framework for aiding the understanding of and directing further examination of HIV-related self-care behavior (Reynolds and Alonzo 2000; Reynolds 2003). Research guided by the *Self-regulation Model of Leventhal* and colleagues (Cameron and Leventhal 2003; Leventhal et al. 1984, 1997) has shown that individuals are active problem solvers whose behavior is a product of their cognitive processes and emotional responses to an illness. The cognitive model, *illness representation*, is constructed by individuals as they attempt to interpret bodily sensations and make sense of an illness experience. Illness representation, in turn, provides a framework for directing self-management efforts and health outcomes. This interpretive process occurs in a sociocultural context and illness representation is thought to be informed by many factors including prior bodily experiences, illness severity, intra-personal and external factors that are dynamic and modified by the observations, judgments and experiences of the individual.

Illness representation has been found to be structured around five fundamental dimensions: (1) *identity* (the label and nature of the illness and link with symptoms), (2) *cause* (beliefs about the cause of the illness), (3) *timeline* (the expected duration and course of the illness), (4) *consequences* (perceptions about the short- and long-term effects of the illness), and (5) *control* (beliefs about the degree the illness can be controlled) (Leventhal et al. 1997). Several studies across a range of clinical conditions have confirmed the consistency and validity of the five illness representation dimensions and the components have been repeatedly shown to be robust predictors of how patients conceptualize and cope with or self-manage their illness (Cameron and Leventhal 2003; Leventhal et al. 1997; Petrie and Weinman 1997). While *illness representation* has become an increasingly significant area of study across a range of chronic illnesses (e.g., diabetes, cardiovascular disease, asthma) (Cameron and Leventhal 2003; Petrie and Weinman 1997), and would seem to be of potential value in furthering an understanding of HIV self-care symptom behavior, it has received little attention in this domain to date. Therefore, guided by a model of self-regulation, this study was designed to extend previous work conducted by the *HIV/AIDS International Nursing Research Network* by exploring the relationships among *illness representation*, *self-care behavior*, and *health outcome appraisal* of a large, international sample of persons living with HIV. The research questions addressed by this analysis are: (1) What are the illness representations of persons living with HIV? (2) Are illness representations related to self-care behavior and health outcomes? (3) Does self-care behavior mediate the relationship between illness representations and health outcomes?

Method

Participants and Procedures

Study participants were enrolled in an international, multi-site study (Study III) conducted by the *HIV/AIDS International Nursing Research Network*. Data were collected in *Colombia* (Cali), *Norway* (Oslo), *Puerto Rico* (San Juan), *Taiwan* (Taipei and Tao-Yuan), and eight states (twelve cities) across the *United States* including California (San Francisco, Fresno), Massachusetts (Boston, Fall River), New York (New York City), New Jersey (Newark), North Carolina (Wilmington), Ohio (Columbus), Texas (Corpus Christi, Harlingen,

Temple), and Virginia (Richmond). The domestic and international settings included community-based organizations, university-based AIDS clinics, private practices, public and for-profit hospitals, residential and day care facilities, and home care services.

The research protocol was reviewed and approved by the institutional review board of each of the participating sites and, where applicable, the university at which the *HIV/AIDS International Nursing Research Network* investigator was based. Written informed consent was obtained from each study participant. *Certificates of Confidentiality* were obtained when requested by institutional review boards at specific sites.

Inclusion criteria for the study were that participants had to be: (a) at least 18 years of age, (b) diagnosed as having HIV, (c) able to provide informed consent, and (d) English, Spanish, or Chinese-speaking.

Measures

Survey data were collected with the *HIV/AIDS International Nursing Research Network Assessment Survey* booklet that included self-report measures of: (a) sociocultural and illness severity context, (b) illness representation, (c) self-care (frequency and effectiveness), and, (c) health outcome (quality of life). All instruments were forward- and back-translated from the original English-language instruments into Spanish and Chinese versions and pilot tested.

Sociocultural and Illness Severity Context—The survey booklet was used to collect information on sociocultural and illness severity context characteristics including age, gender, years of education, race/ethnicity, country, income, number of children, health insurance, social support, level of engagement with health care provider, year diagnosed with HIV, most recent CD4 count and plasma HIV RNA, symptom intensity, depressive symptoms, and co-morbidities.

Number of symptoms experienced was measured with *The Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev)* (Holzemer et al. 2001). The *SSC-HIVrev* checklist comprises 64 items that capture the frequency and severity of HIV signs and symptoms experienced on a given day. Items are rated on a Likert scale and summed. The instrument has been reported to have good psychometric properties (Holzemer et al. 2001; Tsai et al. 2003). Slightly different Spanish versions of the *SSC-HIVrev* were used in Texas for a predominately Mexican population, in San Juan for a Puerto Rican population, and in Cali for a Colombian population. Researchers at each site confirmed the content validity of the versions. The Cronbach's alpha coefficient was .97.

Illness Representation—The *Illness Perception Questionnaire (IPQ)* (Weinman et al. 1996) was used to measure illness representation. The *IPQ* was specifically developed to assess the five cognitive dimensions of illness as described by Leventhal and colleagues (Leventhal et al. 1997; Weinman et al. 1996). The instrument consists of five scales; one for each of the illness representation attributes (*identity, timeline, cause, controllability, and consequences*).

Timeline, controllability, and consequences are measured using 34-items (3 subscales). Response choices range from “strongly disagree” to “strongly agree.” Items are scored 1 to 5 with reverse scoring when appropriate. The *timeline, controllability, and consequences* subscales are summed and scored independently (scale item scores summed/# items). A higher score on the *timeline* subscale indicates stronger perceptions that HIV has a dire course (11 items). Stronger perceptions that actions can be taken to effectively manage HIV are indicated by a higher score on the *controllability* scale (12 items). Higher scores on the

consequences sub-scale indicate stronger perceptions that HIV has serious consequences for seropositive individuals (11 items).

Identity is measured using a list of symptoms that commonly accompany HIV. A higher *identity* score indicates a greater number of symptoms are attributed to HIV.

Cause is measured using a 15-item, five-point scale, ranging from “strongly agree” to “strongly disagree.” Subjects are instructed to rate their level of agreement with each item as a cause of their illness. Each item of the *cause* scale is evaluated individually.

The *IPQ* has been used with a variety of chronic illnesses and has been found to be internally consistent and reliable (Weinman et al. 1996). Concurrent, discriminant and predictive validity were not established with HIV patients at the time of the study initiation. However, the questionnaire was developed to be used across illness population groups (Weinman et al. 1996). A version adapted for use with the HIV population was used in this study. Cronbach's alphas for the adapted *timeline* (8 items), *consequences* (5 items), *control* (5 items) and *identity* (6 items) subscales used in this analysis were .78, .79, .70 and .80 respectively.

Self-care Activities—Self-care activities were measured with the *Self-care Symptom Management Scale* (Chou et al. 2004). Participants were asked to identify which six commonly occurring physical and psychological symptoms they experienced during the past week. For each symptom identified, participants were asked to identify strategies used to relieve each symptom and to rate the use (yes, no) and effectiveness (1–10) of the self-care activities performed. Items were summed and standardized on a 0–1 scale to provide a measure of *self-care frequency* and *self-care effectiveness*.

Quality of life—Quality of life was measured with the *HIV/AIDS-Targeted Quality of Life (HAT-QoL)* instrument (Holmes and Shea 1998, 1999). The *HAT-QoL* is a self-report scale that measures overall functioning, life satisfaction, health worries, HIV mastery, financial worries, and disclosure. Items are rated on a 5-point scale ranging from 1 (*low*) to 5 (*high*). The instrument has favorable psychometric properties including adequate internal consistency and evidence of construct validity (Holmes and Shea 1998, 1999). We computed an overall quality-of-life score by summing the item responses (Cronbach's alpha = .86). Negatively-worded items in the instrument were reversed scored. Higher scores indicate more favorable quality of life.

Data Analysis

Means, standard deviations, frequencies, and percents were used to provide a description of the sample. The sociocultural context variables *engagement with health care provider*, *amount of insurance*, *social support* and *psychological support* were scored so that higher scores represented *greater* engagement with health care provider, *better* insurance, and *more* social support and psychological support. The severity of illness variable year of HIV diagnosis was transformed to a new variable, years ill, with a higher score indicating more years living with a diagnosis of HIV. The illness representation variables *timeline*, *consequences*, *control*, and *identity* were scored so that a higher score represents *more serious* perceived timeline and negative consequences, *more* control, and *greater* attribution of symptoms to HIV. The self-care activities were scored so that higher scores indicate performance of more self-care activities and higher perceived effectiveness. *Quality of life* was scored so that higher scores indicate better perceived quality-of-life.

As the three outcome variables for the analysis of research question #2 [*frequency of self-care activities (self-care frequency)*, *effectiveness of self-care activities (self-care*

effectiveness) and *quality-of-life (QoL)*] are either percentages or summary scores ranging from 0 to 100, linear regression modeling was used to explore the relationship between covariates of interest and the outcome variables. The four ‘primary’ covariates of interest for the *self-care (frequency and effectiveness)* outcomes included the illness representation dimensions of *timeline, consequences, control* and *identity*.

The six ‘primary’ covariates of interest for the *quality-of-life* health outcome included the illness representation variables (*timeline, consequences, control, and identity*) and the *variables (frequency and effectiveness)*. All other potential covariates were deemed as ‘secondary’ covariates of interest. (Note: *Cause* was not included in these analyses as each item of the *cause* scale is evaluated individually).

Data screening techniques were used to assess the assumptions of residual normality and linearity. Before fitting the model, the variable *self-care frequency* was transformed using a square root transformation (determined via Box–Cox power transformation) (Box and Cox 1982). Because of the large sample size and approximately symmetric residual distribution, no transformation was performed on the outcome variables *self-care effectiveness* or *quality of life*.

Linear regressions were conducted to assess relationships between variables. Guided by our conceptual model, the analysis was conducted in three parts. First, the variable *self-care frequency* was transformed and regressed against the *illness representation* components (timeline, control, consequences, identity) and the sociocultural and illness severity *context* variables (age, gender, years of education, race/ethnicity, country, income, number of children, health insurance, social support, level of engagement with health care provider, year diagnosed with HIV, most recent CD4 count and plasma HIV RNA, symptom intensity, depressive symptoms, and co-morbidities).

Next, the *self-care effectiveness* variable was regressed against the illness representation components and the context variables. Finally, the *quality-of-life* variable was regressed against both the self-care behavior variables and the illness representation and context variables. For the first two parts, the goal was to determine the effect of illness representation on the self-care activity while adjusting for the context variables. For the last part, the goal was to determine the effect of both illness representation and self-care on quality of life while adjusting for the context variables.

Model building was conducted in several steps for each outcome variable. First, simple linear regressions were fit using each of the ‘primary’ covariates. The ‘primary’ co-variables found to be significant in their individual regressions were placed together into a multiple regression model. Next, each of the ‘secondary’ variables was tested in turn as an addition to the regression model. After assessing each of these ‘secondary’ variables individually, those found to be significant were added to the model simultaneously. Next, a backward selection procedure was used to exclude insignificant ‘secondary’ covariates one by one from the model. This backward selection was conducted at an alpha level of .05. Finally, possible interaction terms between ‘primary’ covariates of interest and ‘secondary’ covariates of interest were tested.

Parameter estimates for each of the three final models were calculated and Least Square (LS) means estimates for each of the discrete variables were also estimated. Plots of outcome versus significant covariates were examined and simple summary statistics were also explored.

To answer research question #3, the regression analysis was followed by a test for mediation effects using the *Sobel* test (Sobel 1982). To conduct the test, the coefficient was calculated

for the effect of the exogenous variable (illness representation dimension) on the mediator (self-care variable) while adjusting for other moderating variables. Next, the coefficient for the effect of the mediator on the response (quality-of-life) while adjusting for other moderating variables and the effect of the exogenous variable was calculated. Based on these two coefficients and their standard errors, a mediation effect size was calculated. The *P*-value for the mediation effect size was calculated using a one-sided test since we were interested in a strictly positive effect for the mediating variable rather than a suppression effect.

Results

Participant Characteristics

Of the 1,217 participants who completed the survey, the majority were male, between 31 years and 49 years of age and non-white (see Table 1). Most had a high school education or less. Among participants with knowledge of their values, median plasma HIV-1 RNA was 57,707 (SD ± 142,034) copies/ml and the median CD4 cell count was 433 (SD ± 413) cells/mm³ (see Table 1). The survey was completed by 78% of the participants in English, 12% in Spanish, and 10% in Chinese.

The Illness Representations of Persons Living with HIV

Mean illness representation, self-care activities, and quality-of-life scores (total and by country) are reported in Table 2.

Participants' perceived reasons for becoming HIV seropositive (cause) is reported in Table 3. The greatest percentage of participants *agreed* or *strongly agreed* that “carelessness” caused him/her to become HIV+ (74.8%) followed by “belief that it could not happen to me” (51.1%), “not understanding risk” (49.4%), and “lack of concern” (46.4%). The fewest participants *agreed* or *strongly agreed* that their HIV+ status was caused by “God's will” (28.4%), “being run down” (27.4%), or “punishment” (20.4%).

The Relationship of Illness Representations to Self-care Behavior and Health Outcomes

Predictors of Self-care Frequency—Linear regression analyses were first used to examine the association between each of the *illness context* and *illness representation* variables with *self-care frequency* (the dependent variable). In the final model, after removing nonsignificant secondary effects, the significant predictors of *self-care frequency* were the covariates *symptom intensity* ($P < .001$), *engagement with provider* ($P < .001$), *country* ($P = .015$) and the illness representation dimension of *control* ($P < .001$) (see Table 4).

After adjusting for the significant effects of *symptom intensity*, *engagement with provider*, and *country*, participants with lower perceived control were found to perform fewer self-care activities. Holding the other variables constant, a decrease of one point on the scale of perceived control (less control) corresponded to an average decrease of .029 points on the 0–1 scale of frequency of self-care activities performed.

In a post hoc analysis, significant ($P < .05$) differences were found between countries in the frequency of self-care activities performed. The Taiwanese participants performed self-care activities significantly less frequently than participants from each of the other countries. Participants from Norway, the United States and Puerto Rico also performed significantly more self-care activities than participants from Colombia.

Predictors of Self-care Effectiveness—Linear regression analyses were next used to examine the association between each of the *illness context* and *illness representation* variables with *self-care effectiveness* (the dependent variable). After removing nonsignificant secondary effects, significant predictors of *self-care effectiveness* were the covariates *engagement with provider* ($P \leq .001$), general *physical condition* ($P < .001$), *country* ($P < .001$) and the illness representation dimensions of *timeline* ($P < .05$), *identity* ($P < .01$) and *control* ($P < .001$) (see Table 4).

After adjusting for the significant effects of *engagement with provider*, *physical condition*, and *country*, there were significant relationships between the patient's perception of the HIV *timeline* and *self-care effectiveness* and the patient's perception of severity of *consequences* and *self-care effectiveness*. Perceptions of a more dire illness trajectory were associated with lower *self-care effectiveness*; a 1 unit increase on the timeline scale (more dire) was associated with an average of .02 decrease in the 0–1 scale of *self-care effectiveness*. Greater perception of *control* was associated with greater *self-care effectiveness*; a 1 unit increase on the control scale (more control) was associated with an average of .04 increase in *self-care effectiveness*.

In a post hoc analysis, significant ($P < .05$) differences were found between countries in the perceived effectiveness of self-care activities performed. Taiwanese participants perceived self-care activities to be significantly less effective than participants from Columbia, Puerto Rico, and the United States. Norwegian and United States participants perceived self-care activities to be significantly less effective than participants from Columbia and Puerto Rico.

Quality of life—Linear regression analyses were next used to examine the association between each of the *illness context*, *illness representation*, and *self-care* variables with *quality of life* (the dependent variable). After removing nonsignificant secondary effects, significant predictors of *quality of life* were the covariates *social support*, *depression*, number of *symptoms*, *years ill*, *insurance adequacy*, and *country*, the self-care measure of perceived *effectiveness*, and the illness representation dimensions of *consequences* and *control* (see Table 4).

After adjusting for the significant effects of the illness context variables, significant relationships were demonstrated between *quality of life* and the patient's perception of the severity of *consequences*, *control*, and *self-care effectiveness*. Higher *self-care effectiveness* was associated with better *quality of life*; a 1 unit increase on the effectiveness scale was associated with an average of 4.96 increase on the quality-of-life scale. Perception of more serious *consequences* was associated with worse *quality of life*; a 1 unit increase on the consequences scale (more serious) was associated with an average of 3.89 decrease in quality-of-life. Higher perception of *control* was associated with higher *quality of life*; a 1 unit increase on the control scale (more control) was associated with an average of 2.71 decrease in *quality of life*.

In a post hoc analysis significant ($P < .05$) differences were again found between countries in quality of life. The Norwegian participants had significantly lower perceived quality of life than participants from each of the other countries. The Taiwanese participants had lower perceived quality-of-life than the Puerto Rican and U.S. participants.

Mediational Effects of Self-care Behavior—Mediation effects tests using the Sobel test (Sobel 1982) were performed for the variables *control*, *identity*, and *timeline*. A P-value of .04 ($z = 1.75$) for *control* indicates that *self-care effectiveness* has a significant mediating effect on the relationship between *control* and *quality of life*. The P-values of .82 ($z = -.91$) for *identity* and .92 ($z = -1.40$) for *timeline* suggest that there is no evidence that self-care

effectiveness has a significant positive mediating effect on the relationship between either variable and *quality of life*. The Sobel test was not performed for *consequences* because assumptions were not met; no significant link was found between *consequences* and *self-care effectiveness*.

Discussion

Self-management of symptoms accompanying HIV and its treatments is an important component of HIV health care. Although it has been well established that quality-of-life diminishes as symptoms increase, there has been little consideration of what factors drive the self-care activities of persons living with HIV or whether the use of self-care strategies improves their quality-of-life outcomes. Our study, guided by self-regulation theory, extended previous work by validating the nature of illness representations and their relationship to self-care symptom management behaviors and quality-of-life health outcomes among a large, international sample of HIV+ individuals.

Results from this study indicate that consideration of illness representations can enhance an understanding of self-care symptom management behavior and quality of life outcomes among persons living with HIV. Our findings indicated that perceptions of the seriousness, consequences and ability to control HIV day-to-day are associated with the frequency and perceived effectiveness of self-care activities and quality-of-life outcomes. They also suggest that the effectiveness of self-care activities may mediate the link between illness representation and quality-of-life outcomes. This provides some explanation concerning how illness representations affect quality of life outcomes. Perception of illness controllability appears to be a particularly important dimension of illness representation with respect to frequency and perceived effectiveness of self-care activities and quality-of-life outcomes. Our findings illustrate that individuals with a greater sense of control are likely to perform more self-care activities, find the self-care activities more effective and report greater quality of life, while individuals with less control are likely to perform fewer activities, perceive activities performed to be less effective, and experience lower quality of life.

The findings from this study also suggest that perceptions of HIV differ among the ethnic groups represented. Of note, the perceptions that characterize the Taiwanese participants tend to be associated with fewer self-care activities performed and lower perceived effectiveness while the Norwegian participants had significantly poorer quality of life outcomes.

These findings underscore the potential importance of illness representations for self-care behavior and health outcomes and raise the question of to what extent health care providers can intervene to enhance self-care and quality of life outcomes. Level of engagement with health care providers was one of the illness context variables found to be significantly associated with self-care activities in this study. Persons with greater provider engagement performed fewer self-care activities, but perceived greater effectiveness of self-care activities performed. This suggests providers with whom patients were more engaged may have been more successful in directing their patients to self-care activities that were more useful. A voluminous literature on patient-provider relationships has accumulated describing the interactions between the two. In recent years, the special role of the clinician, and the particular set of clinical skills needed to enable patients to successfully manage chronic disease have been acknowledged. Essential to chronic disease management is a partnership between the patient and the clinician, and a central role for most clinicians is to encourage and facilitate effective management by their patients.

A self-regulation model of symptom management helps to clarify how a patient decides to take certain actions and reject others. Intrapersonal and external factors give rise to and are modified by the observations, judgments and reactions of the individual leading him or her to undertake self-management strategies to achieve a desired endpoint. Self-management strategies comprise the individual's means to keep the illness and its effects under control. These strategies may be effective or ineffective and may or may not be consistent with clinician's recommendations. One's ability to be self-regulating comprises abilities that are applied to a specific goal and problem within a given context. Endpoints of priority to patients typically include day-to-day functioning and perceptions of quality of life (Clark et al. 2001; Reynolds and Alonzo 2000).

Findings from this study support a growing body of research that demonstrates that elements of the self-regulation model give rise to symptom management strategies that are associated with positive health outcomes. However, interventions designed to enhance self-management are still limited. The basic precepts of self-regulation offer an explanation for the development of self-care strategies and may constitute a promising emphasis for interventions (Alonzo and Reynolds 1998; Reynolds and Alonzo 2000; Reynolds 2003).

The use of a cross-sectional design and correlational nature of the study data have important implications for the inferences that can be made. Assumptions of a causal link between illness representations and outcome are tentative. There is need for future research to use longitudinal designs so the nature of the relationship between illness representation and outcome can be explored more fully. Despite this limitation, this study suggests the importance of understanding the illness representations of persons with HIV and the contribution of these beliefs to self-care behavior and health outcomes. The concept of illness representation provides a useful framework for understanding HIV health outcomes and may prove useful in directing effective therapeutic interventions. Asking patients about their illness and cultural beliefs may provide medical practitioners with an avenue to address poor self-care and health outcomes.

Acknowledgments

Support: U.S. NIH, NIAID, AIDS Clinical Trials Group (U01AI68636), The Ohio State University (U01AI069474), NIH, NINR (R01 NR05108) nrr. We wish to thank the study volunteers for their contribution to this project and Christopher Holloman, PhD, Director Statistical Consulting Service, The Ohio State University, for his consultation.

References

- Alonzo AA, Reynolds NR. The structure of emotions during acute myocardial infarction: A model of coping. *Social Science & Medicine*. 1998; 46:1099–1110. [PubMed: 9572601]
- Cameron, LD.; Leventhal, H. *The self-regulation of health and illness behaviour*. New York: Routledge; 2003.
- Chou FY, Holzemer WL, Portillo CJ, Slaughter R. Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research*. 2004; 53:332–339. [PubMed: 15385870]
- Clark NM, Gong M, Kaciroti N. A model of self-regulation for control of chronic disease. *Health Education and Behavior*. 2001; 28(6):769–782. [PubMed: 11720277]
- Cleary PD, Fowler FJ Jr, Weissman J, Massagli MP, Wilson I, Seage GR 3rd, Gatsonis C, Epstein A. Health-related quality of life in persons with acquired immune deficiency syndrome. *Medical Care*. 1993; 31:569–580. [PubMed: 8326772]
- Corless IB, Bunch EH, Kempainen JK, Holzemer WL, Nokes KM, Eller LS, Portillo CJ, Butensky E, Nicholas PK, Bain CA, Davis S, Kirksey KM, Chou FY. Self-care for fatigue in patients with HIV. *Oncology Nursing Forum*. 2002; 29:E60–E69. [PubMed: 12064325]

- Holmes WC, Shea JA. A new HIV/AIDS-targeted quality of life (HAT-QoL) instrument: Development, reliability, and validity. *Medical Care*. 1998; 36:138–154. [PubMed: 9475469]
- Holmes WC, Shea JA. Two approaches to measuring quality of life in the HIV/AIDS population: HAT-QoL and MOS-HIV. *Quality of Life Research*. 1999; 8(6):515–527. [PubMed: 10548867]
- Holzemer WL. HIV and AIDS: The symptom experience. What cell counts and viral loads won't tell you. *American Journal of Nursing*. 2002; 102:48–52. [PubMed: 11943923]
- Holzemer WL, Hudson A, Kirksey KM, Hamilton MJ, Bakken S. The revised sign and symptom check-list for HIV (SSC-HIVrev). *Journal of the Association of Nurses in AIDS Care*. 2001; 12:60–70. [PubMed: 11565239]
- Kemppainen JK, Holzemer WL, Nokes K, Eller LS, Corless IB, Bunch EH, Kirksey KM, Goodroad BK, Portillo CJ, Chou FY. Self-care management of anxiety and fear in HIV disease. *Journal of the Association of Nurses in AIDS Care*. 2003; 14:21–29. [PubMed: 12698763]
- Leventhal, H.; Benyamini, Y.; Brownlee, S.; Diefenbach, M.; Leventhal, EA.; Patrick Miller, L.; Robitaille, C. Illness representations: Theoretical Foundations. In: Petrie, KJ.; Weinman, JA., editors. *Perceptions of health and illness: Current research and applications*. Singapore: Harwood Academic Publishers; 1997.
- Leventhal, HL.; Nerenz, DR.; Steele, DJ. Illness representations and coping with health threats. In: Baum, A.; Taylor, SE.; Singer, JE., editors. *Handbook of psychology and health*. Hillsdale, NJ: Lawrence Erlbaum; 1984.
- Nicholas PK, Kemppainen JK, Holzemer WL, Nokes KM, Eller LS, Corless IB, Bunch EH, Bain CA, Kirksey KM, Davis SM, Goodroad BK. Self-care management for neuropathy in HIV disease. *AIDS Care*. 2002; 14:763–771. [PubMed: 12511209]
- Petrie, KJ.; Weinman, J. *Perceptions of health and illness: Current research and applications*. Amsterdam: Harwood Academic Publishers; 1997.
- Reynolds, N.; Alonzo, AA. Self-regulation theory: Review and analysis. In: Rice, V., editor. *Handbook of stress, coping and health*. Thousand Oaks: Sage; 2000.
- Reynolds NR. The problem of antiretroviral adherence: A self-regulatory model for intervention. *AIDS Care*. 2003; 15:117–124. [PubMed: 12655839]
- Strauss, A. A trajectory model for reorganizing the health care system, perspectives in nursing 1989-1991. New York: National League for Nursing; 1990.
- Strauss, AL.; Corbin, J.; Fagerhaugh, S.; Glaser, BG.; Maines, D.; Sucek, B.; Wiener, CL. *Chronic illness and the quality of life*. 2. St. Louis: Mosby; 1984.
- Tsai YF, Hsiung PC, Holzemer WL. Validation of a Chinese version of the sign and symptom checklist for persons with HIV diseases. *Journal of Pain and Symptom Management*. 2003; 25:363–368. [PubMed: 12691688]
- Weinman J, Petrie KJ, Moss-Morris R, Horne R. The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*. 1996; 11:431–445.

Table 1
Characteristics of sample (*n* = 1,217)

	Mean (SD)	Percentage (<i>n</i>)	Range
Sociodemographic characteristics			
<i>Age</i>	41.7 (9.1)		(20–84)
<i>Gender</i>			
Male		67.5 (821)	
Female		31.4 (382)	
<i>Education level</i>			
Less than high school		29.2 (355)	
High school		33.1 (403)	
Greater than high school		37.5 (456)	
<i>Race/ethnicity</i>			
African-American/Black		37.9 (461)	
Hispanic/Latino		26.0 (316)	
White/Anglo (non-Hispanic)		22.7 (276)	
Asian/Pacific Islander		10.4 (126)	
Other		2.7 (33)	
<i>Income</i>			
Inadequate		24.4 (297)	
Barely adequate		51.4 (626)	
Adequate		23.4 (285)	
<i>No. children at home</i>			
0		27.5 (335)	
1–2		16.8 (205)	
≥3		6.8 (83)	
Do not have children		51.2 (623)	
<i>Insurance</i>			
Totally inadequate		10.6 (129)	
Barely possible		21 (255)	
Enough		43.9 (534)	
<i>Social Support</i>	7.25 (2.6)		0–10 (higher more)
<i>Engagement with Health Care Provider</i>	18.1 (17.8)		0–52 (higher more)
Illness characteristics			
<i>Years ill</i>	9.8 (5.5)		1–20
<i>CD4</i>	433 (413)		0–1,580
<i>Plasma HIV RNA</i>	57,707 (1420)		0–750,000
<i>Comorbidities</i>			
No		45.3 (551)	
Yes		53.8 (655)	
<i>Depressive symptoms</i>	21.3 (12.4)		0–58 (higher more)
<i>Symptom intensity</i>	33.6 (32)		0–192 (higher more)

Table 2
Comparison of mean illness representation, self-care and quality-of-life by country (\pm standard deviation for total sample)

	Total sample <i>n</i> = 1,217	Norway <i>n</i> = 77	Taiwan <i>n</i> = 118	United States <i>n</i> = 876	Colombia <i>n</i> = 101	Puerto Rico <i>n</i> = 44
Timeline (Scale 1–5, higher = more serious)	3.7 \pm .68	3.9	3.6	3.7	3.5	3.3
Consequences (Scale 1–5, higher = more severe)	3.4 \pm .88	3.6	3.5	3.5	3.2	2.8
Control (Scale 1–5, higher = more control)	3.9 \pm .66	3.6	3.8	3.9	3.9	4.1
Identity (Scale 1–6, higher = HIV associated with more symptoms)	2.1 \pm 1.7	2.3	2.1	2.2	1.6	1.7
Self-care frequency (Scale 0–1, higher = more SC activities performed)	.34 \pm .16	.36	.17	.36	.29	.42
Self-care effectiveness (Scale 0–1, higher = SC activities more effective)	.63 \pm .21	.52	.50	.64	.73	.82
Quality-of-life (Scale 1–100, higher = better qol)	61 \pm 18.4	45	58	64	64	73

Table 3
Perceived reasons for acquiring HIV (*cause*)

	Strongly agree/agree percentage (<i>n</i>)	Neutral percentage (<i>n</i>)	Disagree/strongly disagree percentage (<i>n</i>)
Carelessness	74.8 (910)	9.3 (113)	13.4 (163)
Belief it could not happen to me	49.4 (601)	17.1 (208)	30.1 (367)
Not understanding risk	49.4 (602)	15.4 (188)	32.5 (395)
Lack of concern	46.4 (564)	18.2 (222)	32.8 (399)
Chance/bad luck	44.4 (540)	18.7 (228)	34.1 (416)
Being deceived	41.5 (506)	18.7 (228)	37.1 (452)
Love for another person	40.6 (494)	17.7 (215)	38.9 (474)
Alcohol/drug use	37.3 (454)	14.2 (173)	45.3 (551)
Human nature	35.5 (431)	25.9 (315)	35.9 (437)
Weak immune system	33.5 (408)	19.6 (239)	44.0 (535)
Depression	28.7 (349)	17.7 (216)	51.1 (622)
God's will	28.4 (346)	18.4 (224)	50.4 (614)
Being run down	27.4 (333)	22.0 (268)	47.8 (582)
Punishment	20.4 (248)	31.4 (382)	57.3 (697)

Table 4
Regression analyses for prediction of self-care frequency, effectiveness and quality-of-life

Model	R ²	F	df	Parameter estimates (B)	Standardized parameter estimates (Beta)
Predictors self-care frequency	.21	35.31	***	7, 935	
Control				.029 ***	.134 ***
Symptom intensity				5.69 × 10 ⁻⁴ ***	.128 ***
Engagement with provider				- 1.37 × 10 ⁻³ *	-.073 *
Country					
United States				-.016	NA
Colombia				-.070 **	NA
Puerto Rico				.048	NA
Taiwan				-.197 ***	NA
Norway				0 (Baseline)	NA
Predictors self-care effectiveness	.20	21.04	***	9, 742	
Timeline				-.024 *	-.080 *
Control				.037 **	.118 **
Identity				-4.00 × 10 ⁻³	-.034
Engagement with provider				2.91 × 10 ⁻³ **	.110 **
Physical condition				.016 ***	.164 ***
Country					
United States				.032	NA
Colombia				.122 ***	NA
Puerto Rico				.198 ***	NA
Taiwan				-.084 *	NA
Norway				0 (Baseline)	NA
Predictors quality-of-Life	.59	57.31	***	15, 595	
Self-care effectiveness				4.96 *	.056 *
Consequences				-3.89 ***	-.186 ***

Model	R ²	F	df	Parameter estimates (B)	Standardized parameter estimates (Beta)
Control				2.71***	.098***
Identity				-.513	-.048
Social support				.425*	.061*
Depression				-.593***	-.400***
Symptom intensity				-.070***	-.126***
Years ill				.255**	.080**
Insurance					
Not applicable				-2.89	NA
Totally inadequate				-.788	NA
Barely possible				-2.98**	NA
Enough				0 (Baseline)	NA
Country					
United States				60.96***	NA
Colombia				58.43***	NA
Puerto Rico				63.30***	NA
Taiwan				54.10***	NA
Norway				0 (Baseline)	NA

* P < .05

** P < .01

*** P < .001