

## Predictors of quality of life in HIV-infected rural women: Psychometric test of the chronic illness quality of life ladder

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### Abstract

The Chronic Illness Quality of Life Ladder (CIQOLL) underwent psychometric testing in a sample of 278 women with HIV disease. The CIQOLL, a self-anchoring striving scale based on Cantril's Ladder, measures seven domains (physical, emotional, financial, family and friends, spiritual well-being, peace of mind, and overall life satisfaction) across four time periods (present, past, future, life without a diagnosis of HIV). The domains were derived from focus groups with persons with HIV disease. Women with a diagnosis of HIV Infection, age 18 or older, residing in rural areas in the southeastern United States, completed questionnaires that measured physical functioning, HIV related symptom frequency and distress, depressive symptoms, social support, and quality of life. Procedures used to assess reliability included item-item, item-total, and subscale-subscale correlations, and Chronbach's coefficient  $\alpha$ . Criterion-related (concurrent) validity was assessed by correlating the CIQOLL with HIV symptoms, functional status and social support. Construct validity was estimated using factor analysis and predictive modeling. Results provide preliminary evidence that the CIQOLL is a reliable and valid scale that may provide meaningful information about persons living with a chronic illness, such as HIV disease, especially low literacy and unacculturated populations. Additional research is needed to weight the domains, test the sensitivity of the scale to changes over time, and explore the usefulness of discrepancy scores.

**Key words:** HIV, Quality of life, Reliability, Validity

**Abbreviations:** (CIQOLL) – Chronic Illness Quality of Life Ladder; (HIV) – Human Immunodeficiency Virus; (QOL) – Quality of life

### Introduction

Although no cure currently exists for HIV infection, significant advances in management and pharmacological treatments have resulted in an increased life expectancy for many people living with the disease [1, 2]. Changes in medical management from supportive care to management of a chronic disease have focused attention to issues related to quality of life (QOL) for persons with HIV infection. Living with HIV Disease presents

many physical and psychological challenges for those who are infected as well as their loved ones [3]. Women with HIV Disease, in particular, face multiple challenges in their daily lives, as they are often young, single, minority, and caring for children who also may be infected [4, 5]. The success with which they meet these challenges influences both disease progression and the quality of their lives. Attention to assessment of life quality in persons with a chronic illness, such as HIV disease, provides health care providers valuable informa-

tion on which to base treatments and interventions that may not change the course of the illness, but will improve life quality for women living with HIV. Health care professionals need sensitive, comprehensive information on which to base treatments to improve life quality. The purpose of this paper is to report the development and psychometric testing of the Chronic Illness Quality of Life Ladder (CIQOLL) and its validation for use with rural women with HIV disease.

## Background

Measures of health related quality of life (HRQOL) are commonly used to assess physical and mental functioning in AIDS clinical trials to describe the effects of treatment regimens and disease progression of HIV infection [6]. Many instruments have been developed to measure HRQOL for persons with HIV infection, including the Medical outcomes Study HIV Scale (MOS-HIV) [7], the Multidimensional Quality of Life Questionnaire for HIV and AIDS (MQOL-HIV) [8], the HIV Overview of Problems. Evaluation Scale (HOPES) [9], the Functional Assessment of HIV Scale (FAHI) [10], the HIV/AIDS Targeted Quality of Life Scale (HAT-QOL) [11], and others [12–14]. The MOS-HIV scale and two generic measures, the SF-12 or the SF-36, are the most widely used measures for HRQOL in studies of persons who are HIV Infected [7]. The number of items on HIV specific scales ranges from 21 to 165, and almost all of these scales use a Likert type (summated) format with two to eight response options. Although Likert type scales are widely used because of their simplicity, research has shown cultural variations in response styles to Likert type scales, leading to problems with interpretation of findings. In unacculturated and low literacy populations, subjects often have difficulty understanding both the directions and response choices [15–17]. Differences in response styles have also been reported in different cultures. For example Latinos and African American are more likely to use extreme responses, whereas Asian cultures tend to choose middle-range responses [18–20]. Variations in responses may reflect underlying cultural values.

In addition, health related quality of life (HRQOL) is a measure of physical and emotional

health in almost all of the HIV Disease specific instruments. Hence, these instruments are more accurately called health status scales, as they measure multiple dimensions of health to provide an assessment of the physical and mental functioning of individuals [21]. Health status instruments measure deviations from a state of health, or the absence of illness and disease [22]. Therefore, measures of QOL that focus on health domains emphasize clinical outcomes of chronic illness. This emphasis explains their usefulness in clinical trials.

A broader view of HRQOL takes into account individuals' meaning or appraisal of difference aspects of their life that are affected by the disease [23, 24]. Since meaning is an internal perception and cannot be observed, QOL is measured subjectively. The difficulty with some subjective measures is that frequently only one item or statement is used to measure QOL. For example, participants may be asked to rate how satisfied or happy they are with their current life on a scale of poor, good or excellent. The superiority of multiple item scales to single item questions has been demonstrated, as a single item may not provide clues to what may be influencing life quality [25].

The issue of general (generic) versus specific (disease oriented) measures of quality of life has been extensively debated [26] Focusing on aspects of life quality that are important to a specific patient population provides more information when the goal is to detect the effects of a treatment on quality of life. In general, disease specific instruments have been found to be more responsive than generic ones [27]. Other issues of concern in measuring QOL in chronic illness include responsiveness or sensitivity of the instrument to changes over time as well as context and cultural sensitivity, or the ability of the measure to be used or adapted for use across contexts and cultures.

Quality of life needs to be conceptually defined before it can be accurately measured. While multiple definitions exist in the literature, few are made explicit when measuring QOL in research [28]. Measures are often described without any mention of the definition of QOL guiding the scale's conceptualization. The conceptual definition that guided the construction of the CIQOLL is participants' subjective appraisal of the effects of the disease (HIV) and its treatments on the phys-

ical, mental and social aspects of their lives. In the CIQOLL, quality of life scores can be considered psychosocial and psychobehavioral markers as they assist in identifying changes in well-being that may be of prognostic importance [29].

A key issue in measuring health and psychosocial domains is to assess the perception of the impact of the disease on these domains in an individual's life. An appraisal of life satisfaction in each of the health domains moves the measurement of quality of life from a functional or health status measure to one based on the patient's perspective. The seven domains included in the CIQOLL were obtained from focus groups in which men and women with HIV disease were asked what was most important to their life quality. Seven domains related to their physical and psychosocial well-being were elicited.

Calman's theoretical perspective was considered relevant to guide the development of the CIQOLL [30]. According to Calman, quality of life depends on one's current life style, past experiences, and hopes, aspirations, and dreams for the future. A good QOL exists when one's hopes and dreams are matched with one's current life experience. The greater the gap between an individual's hopes for the future and current situation, the poorer the QOL. In a chronic illness, such as HIV disease, a gap is often created, as hopes and aspirations may no longer be attainable, or one's current situation deteriorates due to the debilitating effects of the illness. However, the gap can be decreased by realigning goals and dreams or changing one's current situation. This proposition has implications for intervening to improve QOL. For example, young persons with HIV disease may need coaching to change their future plans to make them more realistic and attainable, thereby decreasing the gap. Or, a single woman with HIV disease may need to be encouraged to live with her family rather than alone, thereby changing her current situation to improve her QOL.

### Research questions

The aim of this research was to describe the results of psychometric testing of the Chronic Illness Quality of life Ladder (CIQOLL) in a sample of

rural women who were diagnosed with HIV disease. The research questions were as follows.

1. What is the reliability of the CIQOLL assessed by item to item, item to total scale, subscale to subscale correlations and internal consistency?
2. What is the criterion-related (concurrent) validity of the CIQOLL, assessed by correlations of the CIQOLL with HIV symptoms, depressive symptoms, physical functioning and social support?
3. What is the construct validity of the CIQOLL, assessed by factor analysis and predictive modeling?

The results of psychometric testing of a disease, time, and context (HIV disease) specific measure of quality of life based on the individual's appraisal are reported. The CIQOLL was administered in a three year clinical trial in which an intervention was tested to reduce depressive symptoms, improve disease management and increase life quality in women with HIV disease. Baseline data were used for this report.

### Methods

#### *Sample*

The sample included  $n = 278$  HIV infected women, age 18 and older, residing in rural areas of three southeastern states. Criteria for participation included age 18 years or older, verified HIV positive status, English speaking, no evidence of dementia verified by medical records, residing in a town or area with a population less than 50,000, and a score of 16 or higher on the Center for Epidemiology Studies of Depression (CES-D), a screening measure for depressive symptoms. Only 7% of the women who were screened for depressive symptoms did not meet this last criterion.

#### *Procedures*

Women were accessed through local community agencies that provided services for HIV infected individuals. Trained research assistants (RAs) who lived in the local community recruited the women. Following screening to assess eligibility and informed consent, women completed an interview in their home or another place of their choice. The RAs who

conducted the interviews read all questions and recorded all responses. Instruments were presented in a random order in an interview that lasted up to two hours. The women took breaks as needed during the interview, and they were paid \$30 for their participation. The study was approved by the university institutional review board for compliance in protecting the rights of human subjects.

### *Measures*

All scales administered in the study except the CIQOLL have undergone extensive psychometric testing in prior research [31–35]. Only the scales used in this report are described.

#### *Quality of life (QOL)*

QOL was measured with the Chronic Illness Quality of Life Ladder (CIQOLL). The CIQOLL was developed by the authors for use in a prior study with women with HIV Disease. However, it had not previously undergone psychometric testing. The scale uses the concept of a self-anchoring striving scale to measure life satisfaction in seven domains: physical status, emotional status, financial status, family and friends, spiritual well-being, peace of mind, and overall satisfaction with life. Self-anchoring striving scales are useful when one is interested in responses of individuals in their own terms [31]. In the case of the CIQOLL, responses reflect how individuals evaluate their own lives, as the top of the ladder represents hopes and dreams that would indicate the best possible life, and the bottom of the ladder represents worries and fears associated with the worst possible life. According to Cantril, the ladder is symbolic of the ladder of life [31]. In addition, the ladder builds on Calman's notion of a gap between one's current situation and one's goals and aspirations. For each of the seven domains, women were asked to indicate where on a 10 step ladder they stood, if the bottom step of the ladder represented the worst possible quality of life, as defined by the woman, and the top step of the ladder represented the best possible quality of life, also as defined by the woman. Four time periods were assessed for each domain: Present QOL (seven items), Past QOL (one year ago, seven items), QOL without HIV (seven items), and Future QOL (one year from now, seven items). Scores across the seven domains

were summed for each time frame; a higher score indicating a higher QOL for that time period. In addition, a score was calculated to assess the discrepancy between Present QOL and QOL without HIV; Present QOL and Past QOL, and Present and Future QOL. Discrepancy scores refer to the absolute value of the difference between two time periods and provide information about the perceived mismatch between current perceptions of QOL and QOL at other time periods in the individual's life [32]. Discrepancy scores were calculated to assess additional information about the woman's life quality, as a greater mismatch was considered to indicate poorer adjustment and poorer QOL.

Orientation toward time is usually not explicit until a shock or disruption occurs, such as the shock of being diagnosed with HIV Infection. A diagnosis of HIV Disease is considered to end a normal life that is typically oriented toward the future in western societies [33]. Instead, the sense of time is reversed and present experience may dominate. However, the future time orientation has been measured in persons with HIV disease as well as persons with chronic pain [34, 35]. Davies interviewed persons who were HIV positive and described three forms of temporal orientation that were adopted [34]. The three categories were "living with a philosophy of the present", "living in the future", and "living in the empty present". In those who were "living with philosophy of the present" the HIV diagnosis had given them a feeling of liberation from a sense of always fighting for the future and enabled them to enjoy living in and savoring the present. Persons who were "living in the future" were determined not to let their diagnosis ruin the plans they had made for the future. Persons who were "living in the empty present" were unable to plan for the future and dwelled on the past or the way things used to be. These findings were replicated in interviews with HIV infected men who initially mourned the loss of future hopes and planned, but progressed to looking into the future and developing new plans for the future, and they began to plan for one to 2 years in the future [36, 37]. These studies provide evidence that a future orientation is salient for persons diagnosed with a serious illness, such as HIV disease. Additional evidence is found in a study of perceived future in persons with chronic

pain [35]. The future was perceived differently by different subgroups who suffered chronic pain. Adaptive copers rated highest on the future items, while those who were considered dysfunctional or interpersonally distressed perceived a more negative view of the future, providing evidence that perceived future is a useful concept in chronic illness. Hopelessness has also been correlated with a negative view of the future [38], while having hope involves having a worthwhile present and future in spite of the diagnosis [39, 40]. Hope is an expectation of a personal tomorrow [41]; therefore, measurement of expectation of the future may shed also light on the concept of hope as well.

#### *Physical functioning*

Functional status was measured with the Functional Status Questionnaire (FSQ), a scale that assesses eleven activities of daily living [42]. Women were asked to rate each activity on a 4-point response format ranging from “usually do with no difficulty” [4] to “usually do not do because of health” [1]. An additional response option was available for those who did not do the activity for other reasons (0). The total scale score measures the level of physical functional status, with higher scores indicating higher levels of physical functioning. In the current study, coefficient  $\alpha$  reliability was 0.88. Content and predictive validity was established by the original authors.

#### *HIV-related symptoms*

The HIV Symptom Distress Scale measures both frequency of 31 symptoms experienced in HIV disease and the distress (bothersome) of the reported symptoms [43]. Participants indicate the frequency of each symptom experienced in the prior month on a 5-point response format ranging from “did not have” (0) to “almost constantly have” [5]. Higher total frequency scores indicate higher symptom frequency. Participants also indicated how bothersome each symptom experienced was in the prior month on a 5-point response format ranging from “not at all bothersome”(0) to “extremely bothersome” [5]. Higher scores indicate a higher degree of symptom distress. In the present study internal consistency reliability coefficients were 0.94 for each subscale. Exploratory factor analysis resulted in two factors, frequency and bothersome, as theorized. Concur-

rent validity was evidenced by a significant positive correlation with the CES-D ( $r=0.48$ ) and a significant negative correlation with the Duke Activity Status Index ( $r=-0.73$ ).

#### *Depressive symptoms (CES-D)*

The Center for Epidemiology Scale for Depression (CES-D) was used to measure six components of depressive symptoms: depressed mood, feeling of guilt and worthlessness, feeling of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance [44]. Women rated 20 symptoms on the extent to which they had experienced the symptom in the prior week using a 4-point response format ranging from “rarely or none of the time” [1] to “most or all of the time” [4]. A total score indicates the degrees of depressive symptoms, with a higher score indicating greater depressive symptoms. Internal consistency in the present study was 0.90. The CES-D has demonstrated construct (convergent) validity by significant correlations with the Hamilton Depression Scale (0.56) and the Beck Depression Inventory (0.81). Factor analytic studies support four stable factors.

#### *Social support (MOS-SSS)*

The MOS-Social Support Scale (MOS-SSS) was used to measure the perception of availability of support along four dimensions: emotional/informational, affectionate, tangible, and positive social interaction [45]. The 19 items are rated on how often the specified support is available if needed on a 5-point response format ranging from “none of the time” [1] to “all of the time” [5]. A total score reflects the availability of social support, with higher scores indicating higher perceived availability. In the present study coefficient  $\alpha$  reliability was 0.96. Construct validity has been supported by principal components analysis with all items loading on a common factor.

#### *Data analysis procedures*

Frequency and percentage were calculated to describe demographic characteristics of the sample. Mean scores and standard deviations were calculated for each instrument. Pearson correlations and Cronbach's  $\alpha$  were used to test for reliability, including item-item, item-total scale and subscale-subscale correlations and internal consistency.

Criterion levels were  $r = 0.30$ – $0.70$  for item–item correlations,  $r > 0.65$  for item to total scale correlations, and  $r \leq 0.55$  for subscale–subscale correlations. An  $\alpha$  coefficient of 0.80 or greater was considered adequate for internal consistency reliability.

Criterion-related (concurrent) validity was assessed by correlating the Present subscale CIQOLL score with the HIV Symptom Scale, CES-D, FSQ, and MOS-SSS. It was theorized that Present CIQOLL scores would be negatively correlated with scores on the HIV Symptom Scale and the CES-D, and positive correlated with scores on the FSQ and MOS-SSS. In other words, women who reported a higher present quality of life were expected to report lower HIV symptom frequency and distress, fewer depressive symptoms, and higher physical functioning and perceived social support.

Construct validity of the CIQOLL was estimated with factor analysis and predictive modeling. A principal components factor analysis was performed with promax rotation. The optimal number of factors was determined with the minimum 80% variance criterion and scree plot [46]. Factor loadings needed to be 0.40 or higher to be retained with a difference of 0.20 if an item loaded on more than one factor. Predictive modeling, using multivariate linear regression, was performed to evaluate the theorized predictors of QOL as well as the theorized predictors of QOL incongruence. Independent variables in the model included demographic variables (age, race, marital status, educational level, and annual household income), depressive symptoms, social support, physical function, and HIV related symptoms. The independent variables were regressed on 6 dependent QOL variables separately. The dependent variables were present QOL, QOL if not infected with HIV, QOL one year ago, QOL one year from now, and two congruency variables: the discrepancy between Present QOL and QOL not infected with HIV and the difference between QOL a year ago and QOL a year from now. A sample size of  $n = 278$  was considered adequate for the factor analysis and predictive modeling, based on a rule of thumb estimate of ten times as many observations as variables [47, 48].

Participants were asked to assess their life quality for four different time points, so ANOVA with repeated measure was used to detect any

significant difference in self reported QOL among the four time subscales. A discrepancy score was calculated to describe the mismatch between Present QOL and perceived QOL if not HIV infected, and a second score to describe discrepancy between Future and Past QOL. Paired  $t$ -tests were performed to detect significant differences between the two discrepancy scores.

## Results

### *Sample*

Women who participated in the study were predominantly poor, African-American (84%), and single mothers living with children (83%). Almost all (89%) reported annual household incomes below \$10,000. Close to half (42%) of the women did not complete high school and over three fourths (77%) were not working. Most women (84%) had been diagnosed with the disease within the prior 5 years, and one fourth had been diagnosed with AIDS. The average age of the women was 40 years ( $SD = 10$  years). About half (51%) were between 31 and 45 years, almost one fourth (22%) were between 18 and 30 years, and one fourth (26%) were older than 45 years.

The CIQOLL subscale item means were as follows. Present QOL 52.42 ( $SD = 12.92$ ), QOL without HIV 60.95 ( $SD = 9.50$ ), Past QOL 46.78 ( $SD = 16.44$ ), and Future QOL 58.75 ( $SD = 13.56$ ). Women perceived their past life quality to be worse than their present QOL, and perceived that their future life quality would be higher than the present. As expected, QOL was perceived to have been higher if they had not been diagnosed with HIV.

### *Reliability*

The subscale means, standard deviations, and Cronbach's  $\alpha$  of all of the measures are displayed in Table 1.

For the CIQOLL, all internal consistency ( $\alpha$ ) coefficients exceeded the criterion level of 0.80. Cronbach's  $\alpha$  coefficients ranged from 0.91–0.95 for the four subscales.

All inter-item correlations for the Present QOL subscale except two met the preset criterion level ( $r = 0.30$ – $0.70$ ): financial state with family friends

**Table 1.** Description of measures

| Instrument          | Number of items | Range | Scale Mean | SD    | Sample size | $\alpha$ |
|---------------------|-----------------|-------|------------|-------|-------------|----------|
| CIQOLL              |                 |       |            |       |             |          |
| Present             | 7               | 11–70 | 52.42      | 12.92 | 278         | 0.91     |
| If not HIV +        | 7               | 12–70 | 60.95      | 9.50  | 278         | 0.90     |
| A year ago          | 7               | 7–70  | 46.78      | 16.44 | 278         | 0.94     |
| A year from now     | 7               | 7–70  | 58.76      | 13.56 | 278         | 0.95     |
| Depressive symptoms | 20              | 0–56  | 23.66      | 12.61 | 277         | 0.90     |
| Social Support      | 19              | 19–95 | 67.49      | 18.35 | 278         | 0.96     |
| Physical Function   | 11              | 0–44  | 36.12      | 7.76  | 278         | 0.89     |
| HIV symptoms        |                 |       |            |       |             |          |
| Frequency           | 31              | 0–108 | 37.22      | 25.62 | 278         | 0.94     |
| Bothersome          | 31              | 0–111 | 37.15      | 25.98 | 273         | 0.94     |

( $r=0.28$ ) and financial state with spiritual well-being ( $r=0.29$ ). A correlation between 0.30 and 0.70 indicates the items are similar, but not redundant. All item–total correlations except one met the criterion level of at least  $r=0.65$  ( $r=0.62$ – $0.84$ ). All item–item and item to total scale correlations for QOL if not HIV infected subscale met preset criterion levels. Item to item correlations indicated that four Past QOL item–item correlations and four Future QOL item–item correlations were above 0.70. On the Past subscale, the correlations were physical functioning with emotional health ( $r=0.72$ ), peace of mind with emotional health ( $r=0.74$ ), peace of mind item with overall satisfaction with life ( $r=0.75$ ), and peace of mind with overall life satisfaction ( $0.81$ ). On the Future subscale, the items included physical health with emotional health ( $r=0.74$ ), emotional health with family and friends ( $r=0.75$ ), emotional health with peace of mind ( $r=0.76$ ) and peace of mind with financial situation ( $r=0.74$ ). The decision was made to retain the items in the subscale as all except one correlation was less than 0.80.

Subscale to subscale correlation results are displayed in Table 2. These correlations were obtained for the four subscales following factor analysis of the CIQOLL. The subscale to subscale correlations ranged from 0.28 (Present QOL with QOL If not HIV positive) to 0.40 (Present QOL with Past QOL), indicating that the subscales were measuring different components of QOL and validated the decision that had been made not to combine the subscale scores for a total scale score.

Results of ANOVA with repeated measure analysis also provided evidence that the four QOL time frames were significantly different from each other. ( $F=125.99$ ,  $p<0.0001$ ). Paired  $T$ -test results showed the difference between Present QOL and QOL if not infected by HIV was also significant. ( $T=14.22$ ,  $p<0.001$ ), and the difference between Past QOL and Future QOL was significant ( $T=11.40$ ,  $p<0.0001$ ).

#### *Criterion-related validity*

Concurrent validity was addressed by correlating the four CIQOLL subscales with the HIV Symptom Scale, CES-D, FSQ and MOS-SSS. Significant negative correlations were found between the CIQOLL and the HIV Symptom Scale and the CES-D as predicted. Correlations between the Symptom Frequency subscale and the four CIQOLL subscales ranged from  $-0.22$  (QOL without HIV) to  $-0.36$  (Present QOL), and all were significant ( $p=0.0001$ ). Significant correlations for the Symptom Bothersome subscale ranged from  $-0.17$  (QOL without HIV) to  $-0.35$  (Present QOL). Correlations between depressive symptoms and the four CIQOLL subscales ranged from  $-0.11$  (If not HIV positive) to  $-0.47$  (Present

**Table 2.** Subscale–subscale correlations for QOL time periods

| QOL          | Present | Not HIV + | Past | Future |
|--------------|---------|-----------|------|--------|
| Present      | 1.00    | 0.28      | 0.40 | 0.37   |
| If not HIV + |         | 1.00      | 0.35 | 0.34   |
| Past         |         |           | 1.00 | 0.36   |
| Future       |         |           |      | 1.00   |

**Table 3.** Factor loadings of CIQOLL items (Principal Components Analysis,  $n = 278$ )

| Item                    | Factor loading |       |       |       |
|-------------------------|----------------|-------|-------|-------|
|                         | 1              | 2     | 3     | 4     |
| Future friends          | 0.87           |       |       |       |
| Future overall QOL      | 0.84           |       |       |       |
| Future family           | 0.78           |       |       |       |
| Future health           | 0.79           |       |       |       |
| Future peace of mind    | 0.79           |       |       |       |
| Future financial        | 0.74           |       |       |       |
| Future spiritual        | 0.50           |       |       |       |
| Past overall QOL        |                | 0.83  |       |       |
| Past peace of mind      |                | 0.82  |       |       |
| Past health             |                | 0.80  |       |       |
| Past friends            |                | 0.80  |       |       |
| Past family             |                | 0.74  |       |       |
| Past financial          |                | 0.71  |       |       |
| Past spiritual          |                | 0.56  |       |       |
| No HIV friends          |                |       | 0.79  |       |
| No HIV peace of mind    |                |       | 0.74  |       |
| No HIV overall QOL      |                |       | 0.71  |       |
| No HIV health           |                |       | 0.69  |       |
| No HIV family           |                |       | 0.62  |       |
| No HIV finances         |                |       | 0.59  |       |
| No HIV spiritual        |                |       | 0.52  |       |
| Present spiritual       |                |       |       | 0.72  |
| Present overall QOL     |                |       |       | 0.53  |
| Present peace of mind   |                |       |       | 0.50  |
| Present financial       |                |       |       | -     |
| Present physical health | 0.52           |       |       |       |
| Present friends         | 0.54           |       |       |       |
| Present family          | 0.44           |       |       |       |
| Eigenvalues             | 9.978          | 2.997 | 2.308 | 1.262 |
| % Explained variance    | 52.45          | 15.76 | 12.14 | 6.63  |

QOL). Significant correlations between the four CIQOLL subscales and the FSQ ranged from 0.16 (If not HIV Positive) to 0.40 (Present QOL). Correlations between the four CIQOLL subscales and the social support scale ranged from 0.11 (NS) (If not HIV Positive) to 0.34 (Present QOL). These correlations indicated that women who reported a higher QOL also reported fewer and less bothersome HIV symptoms and fewer depressive symptoms as well as a higher functional status and greater social support.

#### *Construct validity*

##### *Factor Analysis*

As stated earlier an iterated principal components factors analysis was performed using promax rotation. Initially five factors were obtained with

eigenvalues greater than 1.00. However, only one item loaded on the fifth factor, so a four factor solution was analyzed. Four meaningful factors, corresponding to the four time periods (Future QOL, Past QOL, QOL without HIV, Present QOL), were extracted accounting for 87% of the variance. Factor loadings ranged from 0.50 to 0.87 for items on all of the factors except Factor 4 (Present QOL). Factor 4 contained three meaningful items, while three of the Present items loaded on Future QOL. The first factor, Future QOL, explained the greatest amount of variance (52%), with Present QOL explaining the least amount (7%).

Six multiple regression models were analyzed. Since all of the models showed similar results, only two are used to describe the significant relationships between the set of independent variables and QOL measures: [1] the model predicting Present QOL as



**Table 4.** Multiple regression analysis for significant predictors of Present QOL

| Analysis of variance |     |                |              |          |          |                       |
|----------------------|-----|----------------|--------------|----------|----------|-----------------------|
| Source               | DF  | Sum of squares | Mean squares | <i>F</i> | <i>p</i> | <i>R</i> <sup>2</sup> |
| Model                | 13  | 16984          | 1237.26      | 10.93    | < 0.0001 | 0.32                  |
| Error                | 257 | 29091          | 113.19       |          |          |                       |
| Total                | 270 | 45175          |              |          |          |                       |

  

| Parameter estimates for significant predictors |                    |                |
|------------------------------------------------|--------------------|----------------|
| Variable                                       | Parameter estimate | <i>p</i> value |
| Intercept                                      | 40.43              | < 0.0001       |
| Physical function                              | 0.35               | 0.0004         |
| Depression                                     | -0.29              | 0.0001         |
| Social support                                 | 0.13               | 0.0007         |
| Race group                                     | -4.41              | 0.02           |
| Age                                            | 6.61               | 0.0007         |

the outcome and [2] the model with a discrepancy score between Present QOL and QOL if not infected with HIV as an outcome. Findings from the other three models with QOL if no HIV, Past QOL, and Future QOL as dependent variables were similar to the model with Present QOL as the dependent variable. A total of 32% of the variation in Present QOL was explained by functional status, depressive symptoms, social support, and age.

A total of 56% of the variance in the degree of discrepancy or mismatch of Present QOL and QOL if not infected with HIV was explained by Present QOL, HIV symptom frequency, HIV symptom distress, depressive symptoms, marital status, and educational level.

## Discussion

The maintenance and improvement of life quality are important goals in the treatment of HIV disease. QOL measurement has been used as an end point to measure the effectiveness of therapeutic interventions in HIV disease. When used appropriately, these measures offer important information about the impact of treatment on perceived well-being and inform clinicians about treatment effects and potential interventions.

Results of psychometric tests of the CIQOLL provide preliminary evidence for a reliable and valid scale. The internal consistency was high for the four QOL subscales, as Cronbach's  $\alpha$  ranged between

0.91 and 0.95. Item to item and item to total scale correlations were moderately correlated. Correlation coefficients ranged between 0.28 and 0.86, providing further evidence for the reliability of the scale.

The women perceived a higher future QOL than their present life quality, indicating an orientation toward the future. This might be extrapolated to represent hopefulness and optimism, in spite of the diagnosis. The majority of the women were young with children, and this may reflect their need to be hopeful for a future with their children. A negatively perceived future QOL would indicate hopelessness and distress, pointing to the need for further assessment and intervention.

The correlations to assess criterion-related (concurrent) validity indicate the CIQOLL measures a distinctly different, positive construct. In addition, principal components factor analysis provided evidence for construct validity of the CIQOLL, as almost all items loaded on the four time periods as theorized, explaining 87% of the variance.

In the regression model, 32% of the variance that predicted Present QOL was explained by functional status, social support, age and race. As theorized, women who reported higher physical functioning and perceived greater availability of support also reported a higher Present quality of life. This finding documents the positive relationship of support with QOL for these women and suggests the need to pay attention to this component, as it is amenable to interventions. HIV symptom frequency and bothersome were not

significant predictors of Present QOL. The finding substantiates the need to assess the individual's perception of QOL, as a clinical assessment based on objective indicators, such as symptoms, may not accurately reflect one's perceived life quality. Depressive symptoms were negatively associated with Present QOL, and social support was a positive predictor of Present QOL. As supported in the literature persons with higher depressive symptoms report a poorer QOL, while social support is associated with a more positive QOL [49, 50] Race was also a significant predictor of QOL. However the majority of subjects were African-American, so this result needs to be replicated in a heterogeneous racial sample. Age was also a significant predictor of Present QOL. Age was grouped as: 18–30, 30–45, and over 45 years. Older age predicted a higher Present QOL. Older women were more likely to have a stable home environment and fewer home responsibilities, such as taking care of small children, than younger women. In addition they were more likely to perceive fewer lost opportunities in pursuing their career goals because of the HIV status. In other words, the gap between aspirations and current life circumstances was not as great as for younger women with HIV disease.

The regression model for the discrepancy between Present QOL and QOL if not HIV infected as an outcome explained 56% of the variance. Present QOL was a negative predictor, meaning that the higher the present QOL, the less the discrepancy

between Present QOL and QOL if not infected. A positive Present QOL was associated with a smaller gap between the two time periods. HIV symptom frequency and distress were both positive predictors of QOL discrepancy between the two time periods. More frequent and distressful HIV symptoms were associated with a greater discrepancy or mismatch between present QOL and perceived QOL without HIV. As women experienced more frequent and bothersome symptoms, they perceived, rightly so, their Present QOL was much worse. Increased depressive symptoms were also associated with a greater mismatch or gap between present QOL and QOL with out HIV. Education was a predictor with lower education being associated with a greater discrepancy score as well. Martial status was also a significant predictor, but as with race, this needs to be replicated due to the small number of married women.

#### Limitations

Four limitations are acknowledged. First, the results are based on cross-sectional rather than longitudinal data. The responsiveness or sensitivity of the CIQOLL to change was not assessed, as cross sectional data does not provide a dynamic picture of the women's perceived quality of life as it changes over time. Plans are underway to test the sensitivity of the scale to change, when longitudinal data in the ongoing study are available. Additional measures of HRQOL will be obtained at three months and six months in the control

**Table 5.** Multiple regression analysis for significant predictors of QOL incongruency (present QOL and QOL without HIV)

| Analysis of variance                           |                    |                |                |          |          |                       |
|------------------------------------------------|--------------------|----------------|----------------|----------|----------|-----------------------|
| Source                                         | DF                 | Sum of squares | Mean squares   | <i>F</i> | <i>p</i> | <i>R</i> <sup>2</sup> |
| Model                                          | 14                 | 23406          | 1671.88        | 20.38    | < 0.0001 | 0.56                  |
| Error                                          | 256                | 18308          | 71.52          |          |          |                       |
| Total                                          | 270                | 41714          |                |          |          |                       |
| Parameter estimates for significant predictors |                    |                |                |          |          |                       |
| Variable                                       | Parameter estimate |                | <i>p</i> value |          |          |                       |
| Intercept                                      | 42.89              |                | 0.0001         |          |          |                       |
| Present QOL                                    | −0.64              |                | 0.0001         |          |          |                       |
| Freq of HIV symptom                            | 0.20               |                | 0.002          |          |          |                       |
| Bothersome of symptom                          | 0.13               |                | 0.03           |          |          |                       |
| Depression                                     | 0.16               |                | 0.003          |          |          |                       |
| Martial status                                 | 3.02               |                | 0.04           |          |          |                       |
| Education                                      | −2.42              |                | 0.05           |          |          |                       |

group of a clinical trial for women with HIV disease. Second, the population was self selected. Since the purpose was to test the CIQOLL, the sample was considered adequate. However, further testing is needed in different age groups and across ethnic and cultural groups, and as well as in men. Test–retest reliability was not conducted as there is increasing evidence that in chronic diseases persons do not assess their quality of life against a fixed reference point, but one which shifts in the light of experiences [51]. In other words, quality of life is a dynamic construct that changes across the disease and its treatments. However, it will be useful to assess test–retest reliability for the Past subscale and Life without HIV subscales in the CIQOLL to see if these time frames remain stable. The temporal dimensions of the scales may provide additional information on which to intervene when large discrepancies between the time periods are observed, so further work is warranted. Third the CIQOLL does not weight the domains measured. The scale needs to be expanded so that participants are first asked to rate the importance of each of the seven domains to their QOL prior to rating the items in each domain. A weighed summary score may be a more sensitive measure of QOL. Last, while discrepancy scores are theoretically appealing based on Calman's theory, more work and additional tests of the CIQOLL in multiple populations are needed to gain a better understanding of the meaning of these scores.

## Conclusion

The number of women, particularly minority women, with HIV/AIDS is steadily increasing and is a major public health problem [52]. Understanding the effects of the disease and its treatment on the lives of these women is critical in order to meet their needs and improve their life quality. HRQOL instruments are needed that are easy to administer, understandable, sensitive, and assess perceived life quality across domains thought to be important.

The CIQOLL is easy to administer and well-suited for groups who may find Likert type scales difficult to understand, such as those with limited education or ethnic minorities who have not been exposed to Likert response formats. Although

many scales are available to measure HRQOL in HIV populations, the CIQOLL is not redundant, as it using a self anchoring scale to measure the HRQOL domains across four time periods. In addition the seven domains are based on input from persons with HIV-Infection. The scale is a useful adjunct to current instruments, such as the MOS-HIV or the SF-36, as the CIQOLL offers additional information related to how one is presently adjusting to living with the disease, as well as appraisal of their life quality, or hope for the future. In addition, inspection of the seven domains may enable health care providers to identify areas where interventions are needed, such as financial, social support, or physical or emotional health.

The CIQOLL was tested in a sample of rural women who were diagnosed with HIV disease. Although results of psychometric testing provide preliminary evidence that the scale is reliable and valid, additional analysis is needed to further understand the significance of discrepancy scores as well as the sensitivity of the scale to changes in QOL over the illness trajectory. In addition further work is needed to explore the feasibility of weighting the items. However, the scale can be used in its current form to provide important information about the QOL of persons who are living with a chronic illness such as HIV Disease.

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