

## Change in Quality of Life after Being Diagnosed with HIV: A Multicenter Longitudinal Study

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### Abstract

The objective of this study was to assess in patients with HIV perceptions of life pre-HIV versus post-HIV diagnosis and examine whether such perceptions change over time. We conducted interviews and chart reviews of 347 outpatients with HIV from three cities in 2002–2004. In two interviews 12–18 months apart, patients compared their life now with their life before HIV was diagnosed. Independent variables included demographic and clinical characteristics; HIV-specific health status, symptoms, and concerns; spirituality/religion; social support; self-perception; and optimism. The patients' mean (standard deviation [SD]) age was 44.8 (8.3) years; half were minorities; and 269 (78%) were taking antiretroviral therapy. Comparing life at time 1 versus before diagnosis, 109 (31%) patients said their life was better at time 1, 98 (28%) said it was worse, and the rest said it was about the same or did not know. By time 2, approximately one fifth of the patients changed their answers to indicate life improvement and one sixth changed them to indicate life deterioration. In multivariable analysis, change in perception for the better between time 1 and time 2 (versus prediagnosis) was positively associated with time 1 positive religious coping scores, whereas change in perception for the worse was associated with study site, heterosexual orientation, a detectable viral load, shorter duration of HIV, lower spirituality scores, and lower positive religious coping scores. We conclude that many patients with HIV feel that their life is better than it was before their diagnosis, although results of such comparisons often change over time.

### Introduction

IT IS ESTIMATED THAT 1.1 million Americans are infected with HIV.<sup>1</sup> Substantial increases in life expectancy in persons with HIV have sharpened the focus on their quality of life. Many studies have examined quality of life in patients with HIV, but little information is available comparing quality of life with HIV versus quality of life before being diagnosed with HIV. Two small studies conducted in 1996–1997 at the advent of the era of highly active antiretroviral therapy (HAART) showed that, although some patients with HIV felt that their life had gotten worse since diagnosis, many patients felt that their life was better than it was before they knew they had HIV, often because they found new meaning and purpose in life or because they had stopped using injection drugs.<sup>2,3</sup> In

a cross-sectional analysis from a large multicenter study, we found that approximately one third of patients believe that their life is better than it had been before their diagnosis, and that feeling that life has improved was related in part to optimism and to the direct and indirect effects of spirituality/religion.<sup>4</sup> Another recent cross-sectional study reported that 26% of patients with HIV regarded HIV as a key positive turning point in their lives; in contrast, 11% regarded HIV as a key negative turning point in their lives.<sup>5</sup> Changes for the better in life outlook have also been noted in patients with other life-threatening conditions, such as cancer, as a result of positive coping—focusing on the positive, seeking and using social support, or searching for spiritual meaning in illness.<sup>6</sup>

If it is indeed true that many patients with HIV believe their life is better and if factors associated with such beliefs can be

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identified, it may be possible to design interventions to improve quality of life. Given that HIV is a chronic disease punctuated by various symptoms, medication side effects, and occasional opportunistic infections, a remaining question is whether comparisons between one's present quality of life and one's quality of life before diagnosis change with time. The objectives of this study were to extend our previous cross-sectional analysis<sup>4</sup> to a longitudinal analysis to determine at two time points following HIV diagnosis how patients compare their life now with their life before they knew they had HIV, and to identify factors associated with changes in opinions over time regarding whether life has improved or gotten worse relative to before HIV diagnosis. Based on our previous findings and on several conceptual models,<sup>2,7-11</sup> we hypothesized that clinical factors; HIV-specific health status, symptoms, and concerns; spirituality/religion; lifestyle; social support; self-perception; and optimism may be related to changes in beliefs regarding whether life has improved or deteriorated.

## Methods

### Patients

In 2002–2003, 450 outpatients with various stages of HIV were recruited from four sites in three cities: the University of Cincinnati and the Cincinnati Veterans Affairs (VA) Medical Center, both in Cincinnati, Ohio; George Washington University Medical Center in Washington, D.C.; and the VA Pittsburgh Healthcare System in Pittsburgh, Pennsylvania. To obtain a sample that was demographically representative of patients seeking care at each site, we enrolled minority and female patients in approximately the same proportions as their proportions at each study site's HIV clinic.

We interviewed subjects twice, with follow-up interviews taking place 12–18 months after initial interviews. A total of 347 (77%) patients completed both interviews, and those patients formed our analytic sample for this article. There were no significant differences between the 347 patients interviewed twice and the 103 patients interviewed only once with respect to demographic, clinical, and psychosocial characteristics, except that patients interviewed twice were more likely at baseline to have a viral load below detectable levels ( $\leq 400$  copies per milliliter), to be Caucasian, and to be less worried about disclosing their health. Subjects were paid \$30 per interview. The Institutional Review Boards at each site approved the study.

### Measures

We collected extensive demographic and clinical data from chart review and patient interviews. Clinical data included year diagnosed with HIV; current and nadir CD4 cell count; and current and peak viral load. Information regarding current antiretroviral therapy was ascertained both by chart review and patient interview.

Our outcome measure was a question addressing whether patients felt that global quality of life had improved since being diagnosed with HIV: "I wonder if you could think back to the time before you knew you were HIV-positive. If you compare your life now with your life then, would you say your life is: (1) better now, (2) worse now, (3) about the same as before you knew you were HIV-positive, [or] (4) don't know."<sup>2</sup>

To assess health status and concerns, we administered the HIV/AIDS-Targeted Quality of Life (HAT-QoL) measure, a 34-item health status scale addressing nine domains identified previously by patients with HIV as being important: overall functioning; sexual functioning; disclosure worries; medication worries; health worries; financial worries; HIV mastery, or level of comfort with how the patient contracted HIV; life satisfaction; and provider trust.<sup>12</sup> Each subscale is scored from 0 (worst) to 100 (best); in our full sample, the Cronbach  $\alpha$  of the HAT-QoL subscales ranged from 0.80–0.90. Because feelings regarding life improvement can be associated with depression and because depression is common in patients with HIV,<sup>13</sup> we assessed depressive symptoms using the 10-item version of the Center for Epidemiologic Studies–Depression (CESD-10) scale (range, 0–30, with scores  $\geq 10$  indicating significant depressive symptoms).<sup>14</sup> In our sample, the CESD-10 had a Cronbach  $\alpha$  of 0.87.<sup>4</sup>

We used the HIV Symptom Index to assess the presence and degree of both of 20 symptoms, including fatigue, fever, pain or numbness, difficulty with memory, rash, headache, stomach pain or gas/bloating, changes in body appearance such as fat deposits, and changes in weight over the past 4 weeks.<sup>15</sup> For each symptom that the patient reported, he/she rated its degree of bother on a 4-point Likert scale ("it doesn't bother me"; "it bothers me a little"; "it bothers me"; or "it bothers me a lot"). We counted the number of symptoms the patient reported as bothering him/her or bothering him/her a lot. Because several questions on the HIV Symptom Index pertaining to depression have similar counterparts on the CESD-10, we scored only the 15 questions on the HIV Symptom Index having no CESD-10 counterparts, as advocated by Kilbourne and colleagues.<sup>16</sup> In our sample, the HIV Symptom Index had a Cronbach  $\alpha$  of 0.91.<sup>4</sup>

Next, we assessed multidimensional aspects of spirituality and religion with three measures: the Duke Religion Index, the Functional Assessment of Chronic Illness Therapy–Spirituality-Expanded (FACIT-SpEx) scale, and the Brief RCOPE measure. The Duke Religion Index assesses organized religious activity (frequency of attending services; range: 1 [never]–6 [more than once a week]), nonorganized religious activity (frequency of praying, meditating, studying Bible, etc.; range, 1 [rarely or never]–6 [more than once a day]), and intrinsic religiosity (the degree to which one "lives" his/her religion; range: 3 [low]–15 [high]; Cronbach  $\alpha$  in our sample = 0.88).<sup>4,17</sup> The FACIT-SpEx is a 23-item measure of spiritual well-being addressing faith, meaning, and peace, with overall scale scores ranging from 0 (low) to 92 (high) [Cronbach  $\alpha$  in our sample = 0.95].<sup>18</sup> The Brief RCOPE is a 14-item measure that addresses both positive religious coping (spiritual connection, seeking spiritual support, religious forgiveness, collaborative religious coping, benevolent religious reappraisals, religious purification, and religious focus [Cronbach  $\alpha$  in our sample = 0.92]<sup>4</sup> and negative religious coping (spiritual discontent, punishing God reappraisals, interpersonal religious discontent, demonic reappraisals, and reappraisals of God's powers; Cronbach  $\alpha$  in our sample = 0.82)<sup>4</sup>; scores on each subscale range from 7 (low) to 28 (high).<sup>11</sup>

We assessed healthy lifestyle by examining history of injection drug use (never, past, or current) and alcohol consumption (frequency of drinking in the past 30 days and typical number of drinks ingested each time). We assessed

social support by using the Brief Interpersonal Support Evaluation List, which captures appraisal, belonging, and tangible support (range: 12 [low]–48 [high]; Cronbach  $\alpha$  in our sample = 0.90)<sup>4,19</sup>; self-perception, by using the 6-item Rosenberg Global Self-esteem Measure (range: 6 [low]–24 [high]; Cronbach  $\alpha$  in our sample = 0.81)<sup>4,20</sup>; and optimism by using the 12-item Life Orientation Test (range: 0 [low]–32 [high]; Cronbach  $\alpha$  in our sample = 0.83).<sup>4,21</sup>

### Statistical analysis

Descriptive statistics included means and standard deviations. Alcohol use was expressed as a number of drinks per month, calculated from the responses to the frequency and amount of drinking questions. We compared independent proportions by using exact tests and independent means by using *t* tests or Wilcoxon tests, as appropriate. To assess consistency of time 1 and time 2 responses on the question regarding whether life is better, we calculated a weighted kappa statistic. Here, we combined “about the same” responses with “don’t know” responses and assigned weights to the  $\kappa$  statistic based on degree of change from time 1 to time 2 (a change of 0, 1, or 2 categories). For bivariate analyses, *p* values are two-tailed and use a Bonferroni-corrected level of significance of  $p < 0.00135$ .

We constructed two logistic regression models predicting changes in quality of life from time 1 (versus prediagnosis) to time 2 (versus prediagnosis). As with the kappa statistic calculation above, for both models, we combined “about the same” and “don’t know” responses. For the first model, we used only those patients whose time 1 response allowed them to move into a better category (improve) at time 2, i.e., patients who answered “worse” or “about the same”/“don’t know” at time 1. A logistic model then predicted whether, going from time 1 to time 2, patients moved into a better quality of life category, treating a change of 1 or 2 categories equally. A second model was constructed in an analogous fashion, this time using only patients whose time 1 responses allowed them to change into a worse category (deteriorate) by time 2, then predicting which of those patients did actually change responses to a worse quality of life category. For each of the models, potential independent variables included time 1 measures related in bivariate analyses to the outcome at  $p < 0.10$ ; those variables were entered in the multivariable models, then subjected to backwards selection until all remaining independent variables were significant in the presence of the others at  $p < 0.05$ . Because the HAT-QoL Life Satisfaction subscale so closely mirrors our outcome measure, we did not include it in these models. All analyses were performed by using SAS, version 8.02 (SAS Institute, Cary, NC).

### Results

The 347 subjects comprised a diverse group of patients with HIV (Table 1). Reflecting the current trends in the U.S. HIV epidemic,<sup>1</sup> half were ethnic minorities. The patients’ mean (standard deviation [SD]) age was 44.8 (8.3) years; 302 (87%) were male; 201 (58%) had more than a high school education; and 273 (79%) identified themselves with a particular religion, most commonly Roman Catholic, Baptist, or Southern Baptist. At time 1, patients had known they had HIV infection a mean (SD) of 8.5 (5.3) years; 269 (78%) were taking HAART, and 151 (44%) had undetectable viral loads ( $\leq 400$  copies per milliliter).

At time 1, comparing life now with their life before they knew they had HIV, 109 (31%) patients said life now was better, 98 (28%) said it was worse, 90 (26%) said it was about the same, and 50 (14%) didn’t know (Table 2). Of the 238 patients who did not report at time 1 that life is better, by the second interview, 70 (29% of those who could improve; 20% of the full sample) reported at least a 1-category improvement, that is, those who had said “worse now” at time 1 (versus prediagnosis) said either “about the same,” “don’t know,” or “better now” at time 2 (versus prediagnosis), and those who said “about the same” or “don’t know” at time 1 said “better now” at time 2. Conversely, of 249 patients saying “better now,” “about the same,” or “don’t know” at time 1 (versus prediagnosis), 58 (23% of those who could deteriorate; 17% of the full sample) reported a 1- to 2-category deterioration at time 2 (weighted  $\kappa = 0.49$ ).

In bivariate analyses, no variable was associated (at a Bonferroni-adjusted *p* value  $< 0.00135$ ) with improvement in quality of life from time 1 (versus prediagnosis) to time 2 (versus prediagnosis). Change in quality of life for the worse was associated only with low levels of spirituality/religion. Specifically, patients whose quality of life comparisons for the present versus prediagnosis changed for the worse between time 1 and time 2 had lower FACIT-SpEx scores at time 1.

In multivariable analysis, a 1- to 2-category improvement from time 1 (versus prediagnosis) to time 2 (versus prediagnosis) was positively associated only with baseline positive religious coping scores (area under the receiver operating characteristic curve = 0.61; Table 3A). A 1- to 2-category deterioration from time 1 (versus prediagnosis) to time 2 (versus prediagnosis) was associated with VA study site, heterosexual orientation, a detectable viral load, shorter duration of HIV infection, lower FACIT-SpEx spirituality scores, and lower positive religious coping scores (area under the receiver operating characteristic curve = 0.76; Table 3B).

### Discussion

In a multicenter cohort study of patients with various stages of HIV, we reported previously that approximately one third of patients felt that their life had improved compared with their life before they were diagnosed with HIV. A slightly smaller proportion felt that their life was now worse, with the rest indicating that it was about the same or that they didn’t know.<sup>4</sup> In the present study, however, we found that, 12–18 months later, approximately one fifth of the patients changed their answer to a more favorable category, and one sixth changed to a less favorable category. The weighted  $\kappa$  between the two assessments (0.49) indicates that responses were approximately midway along a continuum between completely stable and completely unstable. In multivariable analysis, improvement in quality of life from time 1 (versus prediagnosis) to time 2 (versus prediagnosis) among patients not reporting that quality of life was better at time 1 was associated only with positive religious coping scores. Deterioration in quality of life from time 1 (versus prediagnosis) to time 2 (versus prediagnosis) among patients not reporting that quality of life was worse at time 1 was associated with subject recruitment site, sexual orientation, and viral load, and inversely with duration since HIV diagnosis, FACIT-SpEx spirituality score, and positive religious coping score.

TABLE 1. PATIENT CHARACTERISTICS

| Variable   | Value at Time 1 | Variable  | Value at Time 1 |
|--|-----------------|---|-----------------|
| Mean (SD) age, y   | 44.8 (8.3)      | Lack of stable housing, n (%)   | 24 (7)          |
| Mean (SD) time since diagnosis, y                            | 8.5 (5.3)       | Married or living with significant other, n (%)                           | 97 (28)         |
| Male, n (%)  | 302 (87)        | Has one or more children, n (%)   | 105 (30)        |
| Race/ethnicity   |                 | Has financial dependent(s), n (%)   | 98 (28)         |
| Caucasian, n (%)   | 172 (50)        | Has a religion, n (%)   | 273 (79)        |
| African American, n (%)                                      | 159 (46)        | Mean (SD) CD4 count, cells/ $\mu$ L                                       | 420 (305)       |
| Hispanic, n (%)  | 13 (4)          | Viral load $\leq$ 400 copies/mL, n (%)                                    | 151 (44)        |
| Other, n (%)   | 54 (16)         | Mean (SD) HAT-QoL Overall Functioning score <sup>a</sup>                  | 70.9 (22.3)     |
| VA patient, n (%)  | 81 (23)         | Mean (SD) HAT-QoL Life Satisfaction score <sup>a</sup>                    | 67.5 (24.0)     |
| Sexual orientation   |                 | Mean (SD) HAT-QoL Health Worries score <sup>a</sup>                       | 70.8 (26.2)     |
| Heterosexual, n (%)  | 102 (29)        | Mean (SD) HAT-QoL Financial Worries score <sup>a</sup>                    | 57.5 (34.6)     |
| Gay or lesbian, n (%)  | 182 (52)        | Mean (SD) HAT-QoL Medication Worries score <sup>a</sup>                   | 76.6 (22.5)     |
| Bisexual, n (%)  | 39 (11)         | Mean (SD) HAT-QoL HIV Mastery score <sup>a</sup>                          | 68.5 (32.1)     |
| Asexual, n (%)   | 8 (2)           | Mean (SD) HAT-QoL Disclosure Worries score <sup>a</sup>                   | 58.9 (27.2)     |
| Refused to answer, n (%)                                     | 16 (5)          | Mean (SD) HAT-QoL Provider Trust score <sup>a</sup>                       | 80.4 (23.5)     |
| Injection drug use history                                   |                 | Mean (SD) HAT-QoL Sexual Functioning score <sup>a</sup>                   | 63.6 (35.4)     |
| Never used, n (%)  | 284 (82)        | Mean (SD) number of bothersome symptoms on HIV Symptom Index <sup>b</sup> | 3.1 (3.2)       |
| Past use, n (%)  | 48 (14)         | Mean (SD)   | 11.0 (6.9)      |
| Current use, n (%)   | 6 (2)           | Scores $\geq$ 10, n (%)   | 186 (54)        |
| Refused to answer, n (%)                                     | 9 (3)           | Mean (SD) Interpersonal Support Evaluation List score <sup>d</sup>        | 37.9 (8.1)      |
| Number of alcoholic drinks per month, mean (SD)              | 12.9 (30.7)     | Mean (SD) Rosenberg Global Self-esteem Measure score <sup>e</sup>         | 19.6 (3.6)      |
| Education level  |                 | Mean (SD) Life Orientation Test score <sup>f</sup>                        | 19.3 (6.2)      |
| Did not graduate from high school, n (%)                     | 43 (12)         | Mean (SD) DUREL-ORA score <sup>g</sup>                                    | 2.9 (1.6)       |
| Graduated from high school but did not attend college, n (%) | 103 (30)        | Mean (SD) DUREL-NORA score <sup>h</sup>                                   | 2.9 (1.9)       |
| Attended college, n (%)                                      | 201 (58)        | Mean (SD) DUREL-IR score <sup>i</sup>                                     | 11.2 (3.5)      |
| Taking highly active antiretroviral therapy, n (%)           | 269 (78)        | Mean (SD) FACIT-SpEx score <sup>j</sup>                                   | 63.1 (19.1)     |
| Employment status  |                 | Mean (SD) RCOPE-Positive score <sup>k</sup>                               | 17.4 (6.3)      |
| Working full-time, n (%)                                     | 130 (37)        | Mean (SD) RCOPE-Negative score <sup>k</sup>                               | 10.6 (4.2)      |
| Working part-time, n (%)                                     | 41 (12)         |   |                 |
| Not working, n (%)   | 176 (51)        |   |                 |

<sup>a</sup>HAT-QoL, HIV/AIDS-Targeted Quality of Life scale (range on each subscale: 0 [worst]–100 [best]).

<sup>b</sup>Number of symptoms from a list of 15 in which the respondent said that “it bothers me” or “it bothers me a lot.”

<sup>c</sup>CESD-10, Center for Epidemiologic Studies–Depression scale, 10-item version (range of scores: 0–30, with scores >10 indicative of significant depressive symptoms).

<sup>d</sup>Range: 12 (low)–48 (high).

<sup>e</sup>Range: 0 (low)–24 (high).

<sup>f</sup>Range: 0 (low)–32 (high).

<sup>g</sup>DUREL-ORA, Duke Religion Index–Organized Religious Activity subscale (range: 1 [never]–6 [more than once a week]).

<sup>h</sup>DUREL-NORA, Duke Religion Index–Non-Organized Religious Activity subscale (range: 1 [rarely or never]–6 [more than once a day]).

<sup>i</sup>DUREL-IR, Duke Religion Index–Intrinsic Religiosity subscale (range: 3 [low]–15 [high]).

<sup>j</sup>FACIT-SpEx, Functional Assessment of Chronic Illness Therapy–Spirituality-Expanded scale (range: 0 [low]–92 [high]).

<sup>k</sup>Range: 7 (low)–28 (high).

SD, standard deviation; VA, Department of Veterans Affairs.

TABLE 2. OPINIONS COMPARING LIFE AT TIME 1 AND AT TIME 2 VERSUS LIFE BEFORE HIV DIAGNOSIS

| Time 1 vs. before diagnosis | Time 2 vs. before diagnosis |                   |               |              | Total, n (%) |
|-----------------------------|-----------------------------|-------------------|---------------|--------------|--------------|
|                             | Better now, n               | About the same, n | Don't know, n | Worse now, n |              |
| Better now                  | 80                          | 14                | 5             | 10           | 109 (31)     |
| About the same              | 20                          | 46                | 9             | 15           | 90 (26)      |
| Don't know                  | 12                          | 13                | 11            | 14           | 50 (14)      |
| Worse now                   | 14                          | 17                | 7             | 60           | 98 (28)      |
| Total, n (%)                | 126 (36)                    | 90 (26)           | 32 (9)        | 99 (29)      | 347 (100)    |

Several studies have described factors affecting quality of life in patients with HIV. Those factors include physical functioning; psychological well-being and psychiatric comorbidities; substance abuse; antiretroviral therapy; symptoms related to HIV or its treatment; sexual functioning; body image; cognitive function; sociodemographic variables, such as age, gender, income, and employment status; social support systems; concerns about finances, medications, and disclosure of HIV infection; HIV mastery; illness-related discrimination; access to care; trust in one's health care provider; hospitalization; death and dying; CD4 count; coping strategies; forgiveness; sense of coherence; and spiritual well-being.<sup>12,22-37</sup> In a small study that we conducted in 1996-1997 at the advent of the HAART era, 51 patients with HIV compared their life at present with their life before HIV. In that study, 49% said that their life is better now than before they knew they had HIV; 29% said it is worse now, 18% said it is about the same, and 4% did not know; factors associated with

feeling that life had improved included spirituality (defined in that study as being at peace with God and the universe), female gender, and having discontinued injection drug use.<sup>2</sup> In another study conducted in 1997, Honiden and coauthors<sup>3</sup> found that, among 66 patients with HIV, 47% reported that being diagnosed with HIV decreased their quality of life, but 35% felt that their quality of life improved with the diagnosis. Health utilities (which assess the desirability of health states), assessed retrospectively, decreased transiently after diagnosis before returning to their prediagnosis levels.<sup>3</sup> The finding that health utilities return to prediagnosis levels over time supports our finding of adapting to living with HIV; specifically, we found that among patients who reported that quality of life at time 1 was not worse compared with prediagnosis, the longer it had been since HIV diagnosis, the less likely they were to change their response to "worse now" [than before diagnosis] at the next interview.

In a study of 189 lower socioeconomic status women with HIV, Updegraff and colleagues<sup>38</sup> assessed positive and negative changes associated with HIV infection. Overall, participants reported a greater number of HIV-related positive changes than negative changes. Women's life priorities and self-image tended to change for the better, while their romantic relationships and body image tended to change for the worse after developing HIV. Positive changes tended to be associated with higher educational levels and greater income, while negative changes were inversely related to health status and level of optimism. In a study of 147 patients with HIV, Kremer and coauthors<sup>5</sup> found that an HIV diagnosis is often the major turning point in one's life. For 26% of patients, it was a positive turning point, associated with having survived a near-death experience, with becoming more spiritual, and with feeling hand-picked by a higher power to have HIV. For 11% of patients, HIV was a negative turning point, associated with becoming less spiritual.<sup>5</sup>

A cross-sectional analysis of our full cohort combining path analysis and logistic regression found that the two main factors associated with feeling that life is better, relative to prediagnosis, were healthy beliefs (optimism) and spirituality/religion.<sup>4</sup> Specifically, a 1-standard deviation increase in healthy beliefs resulted in a 109.75% increase in the odds of feeling that life has improved relative to prediagnosis, and a 1-standard deviation change in spirituality/religion was associated with a 68.50% increase in the odds: 29.97% due to a direct effect, and 38.54% due to indirect effects through healthy beliefs (29.15%) and health status/health concerns (9.39%). In sum, while research has shown that diseases such as HIV or cancer often confer new meaning and purpose in life,<sup>6,39-46</sup> no other large-scale studies have directly asked patients to compare their quality of life at two time points following diagnosis with their quality of life before they were aware they had HIV. Our findings corroborate cross-sectional research and suggest that spirituality/religion persists as an important factor in how patients perceive their quality of life with HIV.

Our findings should be interpreted with caution. First, quality of life was assessed retrospectively and responses reflect only patients' current perceptions of their present versus past quality of life. Any recall bias may have been exacerbated by the second round of interviews, which took place 12-18 months further from the time of HIV diagnosis than did the first round. Importantly, because of variation in length of time since HIV diagnosis, life with HIV encompassed relatively

TABLE 3. MULTIVARIABLE ANALYSES

| A: Improvement in Quality of Life from Time 1 (versus Prediagnosis) to Time 2 (versus prediagnosis) among Patients Not Reporting That Quality of Life Was Better at Time 1 (versus prediagnosis; n = 238)  |      |           |         |  |
|--|------|-----------|---------|--|
|  | OR   | 95% CI    | p value |  |
| RCOPE-Positive score at time 1   | 1.07 | 1.02-1.12 | 0.008   |  |
| Area under the receiver operating characteristic curve = 0.61.   |      |           |         |  |
| B: Deterioration in Quality of Life from Time 1 (versus Prediagnosis) to Time 2 (versus Prediagnosis) among Patients Not Reporting That Quality of Life Was Worse at Time 1 (versus Prediagnosis; n = 249) |      |           |         |  |
|  | OR   | 95% CI    | p value |  |
| VA patient   | 2.29 | 1.10-4.76 | 0.03    |  |
| Heterosexual orientation   | 2.34 | 1.13-4.86 | 0.02    |  |
| Detectable viral load at time 1  | 2.05 | 1.07-3.96 | 0.03    |  |
| Years since HIV diagnosis  | 0.90 | 0.84-0.96 | 0.002   |  |
| FACIT-SpEx score at time 1   | 0.98 | 0.95-1.00 | 0.02    |  |
| RCOPE-Positive score at time 1   | 0.93 | 0.88-0.99 | 0.03    |  |

OR, odds ratio; CI, confidence interval. VA, Department of Veterans Affairs. FACIT-SpEx, Functional Assessment of Chronic Illness Therapy-Spirituality-Expanded scale.

Area under the receiver operating characteristic curve = 0.76.

small proportions of lifetime for some and relatively large proportions for others. Further, such “transition questions” may reflect response shift resulting from a change in underlying health,<sup>47</sup> may or may not mirror serially assessed measures obtained before and after diagnosis, and may mean different things to different people<sup>47–50</sup>—and yet such retrospective assessment may be preferable to serial assessment.<sup>3,51</sup> Next, although we explored many potential factors that may be related to feeling that life has improved or gotten worse, the closed-ended format of the questionnaire did not allow for direct explanation of responses to this question. Potential factors that we did not explore include legal problems, threats of violence, and environment/milieu. To wit, many patients who thought that their lives had gotten better mentioned during the interview that they attributed that to career success, contentment with relationships, other accomplishments, or maturation, factors that we did not directly measure.

Another limitation is that we studied outpatients who had access to state-of-the-art treatment for HIV; over three fourths of patients were receiving HAART and nearly half had undetectable viral loads. Our findings regarding quality of life improvement are not generalizable to newly-diagnosed patients, to patients with terminal AIDS, or to patients in parts of the world where state-of-the-art care is either not available or not affordable.<sup>52</sup> Also, this degree of adaptation or coping may not be unique to patients with HIV<sup>53,54</sup>; further research among patients with other diseases is warranted.

The results of this study have several implications. First, the finding that many patients not only can cope and adapt to such a serious illness—but actually reach a point where they believe that life is better than before being diagnosed with HIV—offers hope for numerous people infected with a virus that once portended only suffering and death.<sup>55</sup> Second, the findings point the way to potential interventions to improve quality of life for patients. For instance, our finding of a positive association between spirituality/religion and quality of life improvement corroborates our previous finding<sup>2</sup> and implies that some type of spiritual intervention might be helpful for some patients. Future work should explore whether interventions can improve quality of life among those with a less favorable view of life with HIV.

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