

## The Will To Live among HIV-Infected Patients

Joel Tsevat, MD, MPH; Susan N. Sherman, DPA;  
Judith A. McElwee, RN; Karen L. Mandell, PharmD;  
Loretta A. Simbartl, MS; Frank A. Sonnenberg, MD;  
and Floyd J. Fowler Jr., PhD

**Background:** Patients infected with HIV value both longevity and health.

**Objective:** To understand how HIV-infected patients value their health.

**Design:** Interview study.

**Setting:** Regional treatment center for HIV.

**Patients:** 51 patients with HIV infection.

**Measurements:** Life-satisfaction, health rating, time-tradeoff, and standard-gamble scores.

**Results:** Of the 51 patients, 49% (95% CI, 35% to 63%) said that their life was better currently than it was before they contracted HIV infection; only 29% said that life was currently worse. The mean ( $\pm$  SD) time-tradeoff score was  $0.95 \pm 0.10$ , indicating that, on average, patients would give up no more than 5% of their remaining life expectancy in their current state of health in exchange for a shorter but healthy life. The average health rating score was  $71.0 \pm 18.7$  on a scale of 0 to 100, and the average standard-gamble score was  $0.80 \pm 0.27$ . Factors contributing to life satisfaction and time-tradeoff scores included spirituality and having children.

**Conclusion:** Many patients with HIV have a strong will to live, and many feel that life with HIV is better than it was before they became infected.

An estimated 650 000 to 900 000 persons in the United States are infected with HIV (1). Recognizing the enormous health burden of HIV and AIDS, researchers are more frequently studying quality of life in HIV-infected patients (2).

Two approaches can be used to measure health-related quality of life: health status assessment and health value assessment (also known as utility or preference assessment) (3). Health status measures describe function and the effect of illness on one or more aspects of health, such as physical function or mental health. Most health-related quality-of-life studies of HIV-infected patients have used health status instruments (2). In contrast, health value measures assess the desirability of a state of health by assessing one's willingness to live a shorter but healthier life (the time-tradeoff technique) or risk a bad outcome—usually death—in exchange for a chance at a healthy life (the standard-gamble technique) (3). Only a few studies have assessed the health values of patients with HIV (4–7). Despite compromised health, HIV-infected patients have been shown to exhibit a strong will to live (4, 7). Using life-satisfaction and utility measures, we examined how patients with HIV think about and value their health.

## Methods

### Study Design

On the basis of results of six focus groups that included 34 HIV-infected patients, we developed a structured questionnaire and conducted in-depth cognitive interviews (8) with 51 additional HIV-infected patients. The study took place between October 1996 and May 1997.

### Patients

Patients were recruited at the time of their physician appointment or by telephone from the University of Cincinnati Medical Center's Infectious Diseases Center, a regional center for HIV and AIDS. We recruited patients who represented various levels of severity of illness and oversampled women and persons from ethnic minority groups (understudied groups in which the prevalence of HIV infection and AIDS is increasing). We obtained informed consent and paid each patient \$25 for participating.

By reviewing medical records, we determined the year that HIV infection was diagnosed, HIV stage (asymptomatic, symptomatic but without AIDS, or AIDS), CD4 cell count, history of injection-drug use, and whether the patient was receiving protease inhibitor therapy.

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From the University of Cincinnati Medical Center and SNS Research, Cincinnati, Ohio; University of Medicine and Dentistry of New Jersey—Robert Wood Johnson Medical School, New Brunswick, New Jersey; and University of Massachusetts at Boston, Boston, Massachusetts. For current author addresses, see end of text.

## Interviews

In addition to demographic and clinical questions, the questionnaire included health rating, time-tradeoff, and standard-gamble questions; health status questions (9); a spirituality question; a religiosity question; questions addressing attitudes toward taking risks (10); questions concerning relationships with friends and family; and four life-satisfaction questions, one of which asked patients to compare their lives now with their lives before HIV infection was diagnosed (**Appendix**). All interviews were audio-taped, and audiotapes were coded for themes.

## Statistical Analysis

We classified the variables into seven categories: demographic characteristics, clinical characteristics, health status, audiotape themes (that is, factors that patients were taking into account when answering the health value questions), spirituality/religiosity, attitude toward risk, and life satisfaction. Next, we determined the univariate relations of those variables to each of four outcome variables: life-satisfaction, rating scale, time-tradeoff, and standard-gamble scores. Proportions were compared by using the chi-square test or the Fisher exact test; continuous variables were compared by using *t*-tests or Wilcoxon tests, as appropriate. We assessed univariate correlations with outcome measures using Spearman correlation coefficients. Time-tradeoff scores were compared with standard-gamble scores by using the Wilcoxon signed-rank test and Spearman correlations.

We conducted multivariable analyses with logistic regression models to determine significant predictors of whether the patient considered life better since contracting HIV. We used linear regression models to determine significant predictors of rating scale, time-tradeoff, and standard-gamble scores. The best predictors from each of the seven categories were considered candidate variables. We dichotomized the response to the spirituality question at the lowest quartile because of its skewed distribution. All analyses were performed by using SAS software, version 6.11 (SAS Institute, Inc., Cary, North Carolina).

## Role of the Funding Source

The Agency for Health Care Policy and Research funded the study but had no role in collecting, analyzing, interpreting, or reporting the data or in the decision to submit the paper for publication.

## Results

### Patients

**Table 1** shows the demographic and clinical characteristics of the 51 patients who completed the interviews.

**Table 1. Patients Who Participated in One-on-One, In-Depth Interviews**

Characteristic	Data
HIV stage, %	
Asymptomatic	31.4
Symptomatic	3.9
AIDS	64.7
Median age (25th, 75th percentile; range), y	36 (33, 40; 24–67)
Women, %	29.4
Ethnicity, %	
White	45.1
African American	49.0
Hispanic	3.9
Other	2.0
Sexual orientation, %	
Heterosexual	41.2
Gay or lesbian	39.2
Bisexual	13.7
Other or declined to answer	5.9
Past use of injection drugs, %	13.7
Married, %	35.3
Have children, %	39.2
Education, %	
Did not finish high school	19.6
High school graduate	33.3
Some college	33.3
College graduate	13.7
Median time since HIV infection was diagnosed (25th, 75th percentile), y	5 (2, 8)
Median CD4 count (25th, 75th percentile), <i>cells/mm</i> <sup>3</sup> *	185 (106, 431)
Receiving protease inhibitor therapy, %	53.1
Hospitalized in the past month, %	5.9
Health status score	
Mean disability days ( $\pm$ SD) in the past month	7.5 $\pm$ 9.1
Mean limitations in basic activities of daily living ( $\pm$ SD) <sup>†</sup>	1.1 $\pm$ 0.3
Mean limitations in intermediate activities of daily living ( $\pm$ SD) <sup>†</sup>	1.8 $\pm$ 1.0
Mean score for extreme pain ( $\pm$ SD) <sup>‡</sup>	5.1 $\pm$ 1.5
Mean score for mental health ( $\pm$ SD) <sup>‡</sup>	4.3 $\pm$ 1.2
Mean score for fatigue ( $\pm$ SD) <sup>‡</sup>	3.7 $\pm$ 1.2
Mean Jackson Personality Inventory risk scale score ( $\pm$ SD) <sup>§</sup>	2.9 $\pm$ 0.9

\* Includes one self-reported value.

<sup>†</sup> Possible range of scores is 1 (least disabled) to 5 (most disabled).

<sup>‡</sup> Possible range of scores is 1 (worst) to 6 (best).

<sup>§</sup> Possible range of scores is 1 (most risk-averse) to 6 (most risk-seeking).

## Spirituality

The mean score ( $\pm$ SD) on the spirituality question (which used a scale of 0 to 100) was 85.7  $\pm$  26.1. The median score was 100 (25th and 75th percentiles, 90 and 100), indicating that more than half of the patients said that they were fully at peace with God and the universe. Twenty-nine patients (57%) stated that religion was very important to them, and 14 patients (27%) said that religion was somewhat important.

## Living with HIV

Forty-nine percent of patients (95% CI, 35% to 63%) said that their life was better currently than it was before they were aware that they had HIV. Twenty-nine percent of patients said that life was currently worse at the time of the interview, 18% said that it was about the same, and 4% did not know. In univariate analyses, 73% of women said that their life was better currently compared with

39% of men ( $P = 0.034$ ), and 71% of persons who no longer used injection drugs said that their life was better currently compared with 45% of patients who had never used injection drugs ( $P > 0.2$ ). In addition, nonwhite patients ( $P = 0.07$ ) and unmarried patients ( $P = 0.10$ ) tended to say that life had gotten better. Feelings about whether life had improved since the patient had contracted HIV were unrelated to such factors as stage of HIV disease, number of years since diagnosis, or whether the patient was receiving protease inhibitor therapy. In multivariable analyses, patients who said that their lives were better were more likely to be at peace with God and the universe, to be female, and to have stopped using injection drugs (C-statistic, 0.8) (Table 2).

Scores on the other three life-satisfaction questions were also high. When asked how they felt their life was going, 71% of patients were mostly satisfied, pleased, or delighted; only 6% were mostly dissatisfied or unhappy. No patient felt that life was terrible. In addition, 41% of patients felt that their life was staying about the same, and 47% of patients felt that life was getting better; the remainder of patients felt that life was getting worse or did not know. Finally, when patients were asked to rate how they were feeling about their life as a whole on a scale from 0 (as bad as things could be) to 100 (as good as things could be), the mean score was  $80.0 \pm 22.2$  (median, 90 [25th and 75th percentiles, 60 and 100]).

### Health Rating Scores

On the 0 to 100 health rating scale, the mean score was  $71.0 \pm 18.7$  (median, 70 [25th and 75th percentiles, 60 and 90]). In univariate analyses, HIV-infected patients without AIDS had higher

health ratings than patients with AIDS (mean rating, 77.6 compared with 67.0;  $P = 0.058$ ). In multivariable analyses, rating scale scores were related to HIV stage: Asymptomatic patients had higher scores than symptomatic patients and patients with AIDS. Scores were also inversely related to level of fatigue ( $R^2 = 0.44$ ).

### Time-Tradeoff Scores

With a 5-year time frame, the mean time-tradeoff score was  $0.95 \pm 0.1$  (median, 0.99 [25th and 75th percentiles, 0.93 and 1.0]), indicating that, on average, patients did not have a clear preference between living 5 years in their current state of health and 4.75 years ( $0.95 \times 5$  years) in excellent health. A total of 24 patients (47%) were unwilling to trade any time at all, and 7 patients (14%) were willing to trade, at most, 9 days of life expectancy for excellent health (utility, 0.995).

Time-tradeoff scores for patients who did not have AIDS (mean score, 0.96) did not differ from scores for patients with AIDS (mean score, 0.94). Multivariable analyses showed that higher time-tradeoff scores were related to higher scores on the health rating scale, being at peace with God and the universe, male sex, and having children ( $R^2 = 0.27$ ).

### Standard-Gamble Scores

The mean standard-gamble score was  $0.80 \pm 0.27$  (median, 0.93 [25th and 75th percentiles, 0.65 and 1.0]), indicating that, on average, patients were willing to take up to a 20% risk ( $[1 - 0.80] \times 100\%$ ) for death in exchange for a chance at perfect health. Although 21 patients (41%) were willing to accept no more than 1 chance in 200 (utility  $\geq 0.995$ ), standard-gamble scores tended to be lower than time-tradeoff scores ( $P < 0.001$ ;  $r = 0.37$ ).

**Table 2. Predictors of Life Satisfaction and Health Values**

Outcome Measure	Significant Multivariable Predictors	Odds Ratio (95% CI)	$\beta$ -Coefficient	P Value	C-Statistic*	$R^2$ †
Life is better currently than it was before HIV infection	Being at peace with God and the universe	28.4 (5.5–147.4)	–	0.008	0.8	–
	Female sex	9.0 (2.4–33.9)	–	0.015		–
	Past use of injection drugs	13.6 (2.4–77.8)	–	0.059		–
Health rating score	Stage of HIV disease	–	–6.7	0.005	–	0.44
	Fatigue	–	2.4‡	<0.001	–	
Time-tradeoff score	Health rating	–	0.002	0.029	–	0.27
	Being at peace with God and the universe	–	0.001	0.046	–	
	Male sex	–	0.114	0.005	–	
	Having children	–	0.093	0.012	–	
Standard-gamble score	Disability	–	–0.01	0.01	–	0.33
	Risk aversion	–	–0.023	<0.001	–	

\* Mathematically equivalent to the area under the receiver-operating characteristic curve, which is a measure of how well the model discriminates (correctly identifies) patients who report that their lives have improved compared with those who report that their lives have not improved. A C-statistic of 1.0 indicates perfect discrimination; a C-statistic of 0.5 indicates discrimination no better than chance.

† Proportion of variability in the outcome measure that is explained by the predictors.

‡ Indicates an inverse relationship.

Mean standard-gamble scores tended to be higher among patients without AIDS than among patients with AIDS (mean score, 0.90 compared with 0.74;  $P = 0.1$ ). Multivariable analyses showed that standard-gamble scores were inversely related to level of disability and to risk aversion ( $R^2 = 0.33$ ).

## Discussion

Despite advances in treatment, HIV infection and AIDS remain chronic and debilitating, and no cure or vaccine is expected soon. Consequently, two findings from our study are particularly noteworthy. First, half of the patients interviewed indicated that their life with HIV is better than it was before they contracted HIV. Only 29% of patients said that their life was worse. Second, time-tradeoff utilities were especially high; this result indicates that despite their compromised health, patients strongly preferred longevity to excellent health. Factors unrelated to health that contributed to (and confounded) health values included spirituality (11, 12) and concern and love for one's children.

Several studies have assessed health values in HIV-infected patients (4–7). Although our standard-gamble scores were similar to those found in other studies, the time-tradeoff scores in our study were substantially higher, indicating a strong preference for quantity of life over quality of life. The time-tradeoff scores for current health reported by patients in our study (mean, 0.95; median, 0.99) are at least as high as those of persons without HIV (13–16). Other studies have found mean time-tradeoff scores of 0.73 for seriously ill hospitalized patients (14) and 0.87 for survivors of myocardial infarction (15) and a median utility of 0.92 for patients with cancer (16). It is important to note that the time-tradeoff scores of the patients in our study were much higher than those previously obtained from a sample of physicians caring for HIV-infected patients (18); for example, the median utility for AIDS in that study was only 0.167 (17). Such huge disparities in scores can substantially affect decision analyses and cost-effectiveness analyses. They also indicate the importance of involving patients in decisions that involve quality of life (3).

Our study is one of the first studies of health-related quality of life in patients with HIV to be conducted in the era of highly active antiretroviral therapy. Except for level of fatigue, the health status of patients in our study was better than that of patients in previous studies (9). Our findings regarding life satisfaction and the will to live may be attributable to improvements in therapy and prognosis, but protease inhibitor use in itself was not associated with patient perceptions. Instead, factors

unrelated to health were often more important in predicting satisfaction with life and will to live.

Our findings should be considered preliminary. The small study sample is not necessarily representative of all HIV-infected patients. We could not determine whether patients attributed their life improvement to HIV infection or to some other factor. Discontinuing illicit drug use, qualifying for social services, or some other coincident event could explain improved life satisfaction.

Health value scores can influence the results of cost-effectiveness (cost-utility) analyses of prevention, screening, diagnosis, and treatment for HIV. From a clinical standpoint, if it could be determined why patients thought that their life had improved and how they got to that point, other patients who are not at that stage could be helped. Potential mechanisms could include spiritual or psychological counseling, medications, support groups, or access to social services. Further study is needed to corroborate and expand on our findings so that effective interventions can be designed.

## Appendix: Health Values, Life-Satisfaction, Spirituality, and Religiosity Questions

### Health Values

By using U-Maker, a computer-assisted utility assessment software program (Pratt Medical Group, Boston, Massachusetts), the patient was first asked to rate his or her current state of health on a rating scale (or feeling thermometer) that was anchored by 0 (representing death) and 100 (representing perfect health). Next, the patient was presented with a time-tradeoff task; the series began with a choice between living 5 more years in his or her current state of health or living 5 more years in perfect health. If the patient preferred 5 years in perfect health, he or she was offered a choice between 5 years in current health or 0 years in perfect health (that is, immediate death). If 5 years in current health was preferred, the amount of time in perfect health was varied systematically in a "Ping-Pong" fashion until the patient did not have a clear preference between living 5 more years in current health or living the given amount of time in perfect health. The final utility task was the standard gamble, in which the patient was offered a choice between living the remainder of his or her life in his or her current health or taking a gamble; the possible outcomes of the gamble were perfect health for the remainder of life or immediate death. As with the time tradeoff, the probabilities of the two outcomes of the gamble were varied systematically until the patient had no preference between the certainty of life in his or her current state of health or the gamble.

### Life Satisfaction

1. 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:

- Better now  
Worse now  
About the same as before you knew you were HIV positive  
Don't know
2. Please look at this card and tell me which answer best describes the way you feel about the way your life is going now. Would you say you are:
- Delighted  
Pleased  
Mostly satisfied  
Mixed  
Mostly dissatisfied  
Unhappy  
Terrible  
Don't know/can't say
- (Question 2 was adapted from reference 18.)
3. Overall, at the moment, would you say your life is:
- Getting better  
Getting worse  
Staying about the same  
Don't know
4. We would like you to use a scale from 0 to 100, where 0 is as bad as things could be and 100 is as good as things could be. What number would you give for how you've been feeling about your life a whole?

### Spirituality

We would like you to use a scale from 0 to 100, where 0 is as bad as things could be and 100 is as good as things could be. What number would you give for the extent to which you feel at peace with your God and the universe?

### Religiosity

- How important is religion in your life?
- Very important  
Somewhat important  
Not important  
Don't know

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*Requests for Reprints:* Joel Tsevat, MD, MPH, Section of Outcomes Research, Division of General Internal Medicine, University of Cincinnati Medical Center, Cincinnati, OH 45267-0535; e-mail, Joel.Tsevat@uc.edu.

*Current Author Addresses:* Drs. Tsevat and Mandell and Ms. Simbartl: Section of Outcomes Research, Division of General

Internal Medicine, Box 670535, University of Cincinnati Medical Center, Cincinnati, OH 45267-0535.

Dr. Sherman: SNS Research, 11120 Sycamore Grove Lane, Cincinnati, OH 45241.

Ms. McElwee: Infectious Diseases Center, Box 670405, University of Cincinnati Medical Center, Cincinnati, OH 45267-0405.

Dr. Sonnenberg: Division of General Internal Medicine, Department of Medicine, University of Medicine and Dentistry of New Jersey—Robert Wood Johnson Medical School, 125 Paterson Street, Room 2312, New Brunswick, NJ 08903.

Dr. Fowler: Center for Survey Research, University of Massachusetts at Boston, 100 Morrissey Boulevard, Boston, MA 02125-3393.

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