How Do Patients with HIV/AIDS Understand and Respond to Health Value Questions?

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BACKGROUND: Utility assessment involves assigning values to experienced or unfamiliar health states. Pivotal to utility assessment, then, is how one conceptualizes health states such as “current health” and “perfect health.” The purpose of this study was to ascertain how patients with HIV think about and value health and health states.

METHODS: We conducted open-ended in-depth interviews with 32 patients with HIV infection purposefully sampled from a multicenter study of quality of life in HIV. After undergoing computer-assisted utility assessment using the rating scale, time tradeoff, and standard gamble methods, patients were asked how they thought about the utility tasks and about the terms “current health” and “perfect health.”

RESULTS: Patients understood the health valuation tasks but conceptualized health states in different ways. Many patients believed that “perfect health” was a mythical health state, and some questioned whether it was even desirable. “Current health” was variably interpreted as the status quo; deteriorating over time; or potentially improving with the hope of a cure.

CONCLUSION: Patients with HIV infection vary in the way they conceptualize health states central to utility assessment, such as perfect health and current health. Better understanding of these issues could make important methodologic and policy-level contributions.

KEY WORDS: qualitative research; HIV; acquired immunodeficiency syndrome; quality of life.

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Healthcare providers must often incorporate quality of life considerations in shaping treatment decisions. Health utility/value measures represent one type of methodology for measuring patient's quality of life by assessing the desirability of a state of health against an external standard.¹ Utilities generate quality-of-life weights, ranging from 0.0 to 1.0. When multiplied by life expectancy, they yield quality-adjusted life

years (QALYs), which in turn are incorporated as outcomes in decision analyses and cost-effectiveness analyses of health-care interventions. For example, a utility of 0.9 over 15 years yields 13.5 QALYs.

The most commonly used health value measures include the rating scale (RS) or visual analog scale, the time tradeoff (TTO), and the standard gamble (SG), all of which have been utilized with a wide spectrum of patients with various diseases. The TTO and the SG measures require the subject to compare an intermediate health state, such as their current state of health, against a worse state (e.g., “dead”) and a better state (e.g., “perfect health”) as they make a series of hypothetical choices between living in their current health versus the better or worse state. While many researchers utilize health value measures, there is no agreement on what the anchors should be or how they should be defined (if at all) for participants. Investigators have contrasted the use of different upper anchors (including perfect health) within the same sample,² or studied the effects of using different definitions or no definition for perfect health.³ Our research group has been assessing health utilities in HIV-infected patients for over a decade. In our prior studies, patients were asked to provide rating scores and utilities but were not asked how they understood the questions or formulated their answers. Many of our participants, however, did volunteer their thoughts about the tasks involved with these exercises. Some patients' comments were surprising, e.g., that perfect health is not only unrealistic but perhaps even undesirable.^{4–6} Although those comments were anecdotal, they raised a concern that patients do not use a fixed construct when conceptualizing current or perfect health. Thus, as part of a much larger, multicenter study of quality of life in 450 patients with HIV, we decided to focus our attention on how patients understand and respond to health value questions, as that would potentially affect the outcomes of studies that utilize these measures. As such, we conducted in-depth cognitive interviewing on a subset of patients in order to elucidate patients' feelings about the terminology used and to discuss at length how individuals arrive at the choices they make in the utility exercises. To our knowledge, this is the first published study that directly asked patients how they define the health states “current health” and “perfect health,” and that explored what patients think about as they consider the choices associated with the health utility tasks.

METHODS

Between January and March 2005, one author (S.N.S.) conducted individual interviews with 32 patients with HIV at the University of Cincinnati Medical Center's Infectious Diseases Center (IDC). Individuals who had participated in our larger multi-center study, and therefore, had undergone utility assessment twice, were eligible to be recruited for this study.

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We used stratified and purposeful sampling.⁷ This method is in effect, a sample within a sample. Our aim was to recruit a heterogeneous sample, one that represented minority groups and women in a similar proportion as they were represented in the U.S. HIV epidemic. Although the sample size of this study is too small to allow for generalizations or statistical representativeness, our goal was to obtain a mix of specified demographic characteristics so as not to simply represent the views of a homogeneous subgroup. Participants were recruited by IDC staff and were compensated \$30 for their time. The Institutional Review Board of the University of Cincinnati approved this extension of our previous research study.

The structure of the interviews can be described as standardized open-ended, meaning that all participants were asked the same body of questions in the same order. However, since the nature of the questioning was open-ended, we employed extensive probes that differed in content depending on the type of responses elicited. Participants were asked to describe in their own words what perfect health and current health means to them in the context of the utility tasks. Those questions were followed by a simulated "walk-through" of the interactive utility exercise using a laptop computer and U-Maker software (Frank Sonnenberg, New Brunswick, NJ). Participants were asked to "talk aloud" as they worked through the health value exercises and to explain why they made the choices they did. They were also asked to notify the interviewer if they did not understand the tasks at hand.

Because of the small sample size and to ensure consistency in how the questions were posed, the 3 health value questions were always presented in the same order: RS, TTO and SG. The RS asked the subject to rate his or her current health state on a "feeling thermometer" anchored by 0 (dead) and 100 (perfect health). The next exercise was the TTO, which began with a choice between living 15 more years in his or her current health versus 15 years in perfect health. If the participant preferred 15 years in perfect health, he or she was then offered a choice between 15 years in current health or immediate death. If 15 years in current health was selected, the amount of time in perfect health was varied systematically in a ping-pong fashion until the participant did not have a clear preference between living 15 more years in current health or living the given amount of time in perfect health. For the TTO, we used 15 years as the time horizon to approximate the life expectancy of patients with HIV/AIDS. In the SG, the participant was offered a choice between living the remainder of his or her life in current health (duration not specified) or taking a gamble involving 2 possible outcomes, perfect health for the rest of their lives versus immediate death. Here, too, we used a ping-pong approach to systematically vary the probabilities of perfect health and death until the participant had no preference between the certainty of life in current health or the gamble. During the course of the interview, participants were also asked to describe how they currently value and define health and illness.

To summarize, we used a combination of cognitive and expansive questions and clarifying probes to enhance and extend our comprehension of how participants understand and respond to health value questions (see online Appendix). The objective was to probe for clarity, that is, to elucidate the participant's understanding of the meaning of certain terminology and concepts.⁸ We asked questions to determine what the concepts meant to the participant and to identify the indi-

vidual's contextual background.⁷ In addition, we explored the individual's set of assumptions in an effort to understand how each person approached the utility exercises.

All interviews were held at the IDC in a private room where confidentiality could be assured. Interviews lasted 45 to 60 minutes, were tape-recorded with the participant's permission, and were transcribed. In addition, the interviewer read and reviewed all of the transcripts and recorded field notes indicating any special circumstances of the interviews. A subset of transcripts was read by 2 other authors (M.S.Y., J.T.).

An informal interpretative style of analysis was used to examine and explore participants' answers to the cognitive and expansive questions.⁸ This approach is most appropriate for analyzing the results of heavily probed interviews when the questions are standardized but the probes are not. Responses to specific questions were organized in a tabular fashion for comparison purposes, then analyzed and discussed by the 3 transcript reviewers (S.N.S., M.S.Y., J.T.). Items addressed included: patients' definitions of current health and perfect health, stability of those definitions throughout the course of the interview, belief in the existence of perfect health, referents for the RS scores, thought processes during the TTO and SG exercises, and opinions on an alternative upper anchor. Our purpose was to complete a cognitive assessment of how patients approached these exercises, then look for patterns across certain categories of responses and summarize the results. We report the types of responses along with representative quotes.

RESULTS

Subjects

The 32 participants ranged in age from 28 to 63 years; the average age was 45. Reflecting the current HIV epidemic,⁹ 6 (19%) participants were women and 15 (47%) were minorities. Sixteen (50%) had completed some or all of high school, 8 (25%) had completed some college, and the remaining 8 (25%) had graduated from college or had obtained a graduate degree. On average, patients had been known to have HIV infection for 11 years (range: 3 to 20 years) before this study. (Many participants noted that the time of diagnosis postdated the onset of symptoms, so that, in actuality, they may have been living with HIV/AIDS longer.) Several patients had comorbidities such as chronic hepatitis C virus infection or cancer.

Overall Experience with Health Values Assessment

Nearly all participants seemed to readily understand the individual tasks required for each of the health value tasks; misunderstanding was determined by the interviewer (experienced in assessing health utilities in hundreds of patients) when she detected confusion through facial expressions or was asked directly by participants for further explanation. A few individuals needed additional explanations in order to complete the exercises. Many felt that these exercises mirrored choices that they faced in terms of managing their disease but others felt that their answers to the TTO and SG did not reflect the extent to which HIV impacted them. For example, some participants who reported having debilitating HIV-related symptoms, disability, or co-morbidities were nevertheless unwilling to trade time or gamble. They revealed that they had already "faced death" and were not ready to succumb; they

would choose life rather than face a shortened lifespan (TTO) or risk immediate death (SG).

Concepts of Health States

Current health was commonly defined as a health state experienced on a particular day. A portion of participants perceived current health as constant over the 15-year life expectancy, while others saw it as deteriorating to full-blown AIDS or improving with the hope of a cure. Participants described how they typically assess how they are feeling when they awaken each day. Important barometers of current health included the amount of energy, fatigue, and pain experienced by the individual:

- Do you have a fever, is your nose running, do you have diarrhea? . . . your ability to function in the day-to-day tasks.
- What needs to get done and you have to figure out which can I do feeling this way or that way . . .
- What I felt like when I woke up . . . your normal bodily functions, is it all going right, no pain?
- Do I feel sluggish, light-headed, do I have aches and pains, how long has it been going on?

Participants' definitions of the perfect health anchor formed a continuum ranging from acceptance of the concept to outright rejection of the existence of perfect health. Representative quotes of patients not believing in perfect health included:

- It is like the concept of heaven . . . there's no proof and it's just a state of mind, it's not a real thing . . . it doesn't exist.
- It doesn't exist. Perfect is not a word in our vocabulary anymore.
- I don't understand what perfect health means and I don't think that anyone does . . . no one has perfect body temperature, perfect blood pressure, perfect everything with them, 'cause then they would be bionic.
- I don't think that there's actually a thing called perfect health because you've always got something that goes wrong each and every day . . . and sometimes the doctor can't even tell you what it is and that's bad.

Many struggled with defining the concept, and one participant began by labeling it as "so-called perfect health." Some expressed an opinion that perfect health represents an ideal health state and that it does not exclude persons affected by HIV/AIDS, while others indicated that being HIV-positive automatically excluded one from ever attaining perfect health. Some imagined perfect health as removing their HIV infection while others did not. Definitions of perfect health ranged from a rigid one—the absence of any acute or chronic medical condition, including the common cold—to a more elastic definition adjustable for age and circumstance. Several participants defined perfect health as entirely subjective and personal (i.e., in the eye of the beholder), and were thus unable to judge if it existed for other people.

Characterizations of perfect health for those accepting the concept included the absence of symptoms; lack of limitations or side-effects from medications; normal physical functioning; absence of health behaviors such as smoking or alcohol use; and normal physical condition and energy level. Some descriptions took a more global perspective that included emotional well-being, as well as success at work and in family life. A few individuals made adjustments to their conceptualization of

perfect health during the course of the long interview. Several viewed perfect health as ephemeral; even if they obtained it, it would most likely be endangered by some other crisis. Many participants were solely able to define perfect health through an HIV/AIDS lens. Even when asked to respond to questions about definitions of perfect health in a general sense, they responded through the filter of their own experience with HIV. Some verbatim definitions provided by participants believing in perfect health included:

- Going through a day without any pain, any suffering, any guilt, with a smile on your face, being happy.
- Not taking 38 pills a day.
- Able to function, work, do whatever, to get through the day feeling good and not feeling impacted in any sort of way.
- Not having to feel ill, not having to feel fatigue and along with that there is a lot of depression that goes with it as well.
- Initially, perfect health meant never having to take an aspirin, whereas now, I understand that in order to achieve perfect health based on some medical ailment . . . you may have to take medication.
- Functioning at your optimal level, financially as well as your emotional side, which would include your relationship as well as your HIV status being nominal.
- Doing the best they can with what they got and making the best of it, that's perfect health 'cause that's the best for that person.
- Being able to jump out of bed in the morning and go be very physical, go to their job, finish their job . . . skin looks good, hair looks good, nails look great . . .

Alternative Upper Anchor

Many participants volunteered that they prefer the terms "manageable health" or "functional health" as upper anchors when assessing their health state, because those anchors served as a personal benchmark against which they actively assess their own level of functioning with HIV and their own wellness: Were they able to manage life in the context of their disease? Did they have functional limitations? Those were the relevant questions for such individuals, not whether they had perfect health.

- I'm not in perfect health as far as [being] disease-free. But, with the disease, I am at peak performance.
- You can have a better quality of your illness but maybe not perfect health, you might be able to manage your illness.

When asked specifically if they preferred "excellent" or "optimal" health as substitutes for perfect health, no consensus was reached. A majority of participants did not understand what optimal health means. Opinions were mixed as to whether an "excellent health" rating of 100 was superior to a "perfect health" rating of 100.

Experiences with Using the Rating Scale

Many individuals reported that they rate their own current health as close to perfect. Frequently, participants deducted 5 or 10 points for their HIV status. Many participants did not like to label themselves as "HIV/AIDS-infected": in the words of one subject, "HIV doesn't define my life." Others described concomitant medical conditions such as heart and kidney disease, diabetes, speech and hearing deficits, and a leg deformity

as more problematic than HIV. Many commented that the side-effects from their medications represented more of a burden than their illness and attributed deductions from their RS score accordingly. "I'm in perfect health but I can't control my bowels. I'm more limited by the side-effects than by the disease."

Most individuals considered an array of psychosocial factors when computing a RS score, while others focused solely on physical symptoms. A large number included ratings of satisfaction with jobs and relationships while 2 mentioned spiritual health or well-being. Some reported giving an equal weight to physical and emotional factors. Others felt differently: "A little more weight to the mental health because if you're not feeling good mentally you will be sick physically." Most participants found it difficult to assess how changeable their score was. Those who currently had good health tended to believe that their RS score was generally stable.

Finally, when individuals were asked whether they compare themselves with others with HIV/AIDS or with others their age (who are HIV-negative) when assessing their own RS score, a majority reported that they consider the RS to be custom-tailored, i.e., that the RS does not represent "how they are doing" relative to anyone else. However, when assigning their rating score, some participants compared themselves with how *they* were feeling at another point in time, usually when they were worse off. A few others did compare themselves with others with HIV: "There are other people who are HIV-positive and have been as long as I have and they look like [expletive]. I think that may be the ravages of the disease 'cause you never know when it will rear its ugly head."

Experiences with Completing the Time Tradeoff and Standard Gamble Exercises

Patients' reactions to the constructs of the TTO and SG exercises varied. The actual act of (hypothetically) exchanging health states was construed in several manners. For some, obtaining perfect health was envisioned as partaking in "time travel," i.e., returning to a previous place in their lives where they will have to relive bad experiences and choices. Others perceived it as being given a "clean slate" in life—a new start. Several participants, however, feared that a new start might precipitate a relapse of their risky behavior: "I'm just going to do something stupid so I'm not going to make it through the 15 years."

Some individuals commented on the brevity of the life they were being offered in the TTO. Thus, for them, the perfect health option was not attractive or not attractive enough, because it (like current health) would last at most for 15 years.

- Well, if it's 15 years either way, then why, you know? Current health is good right now . . . but if I were HIV-negative and only had 15 years to live, what would be the difference? HIV has become a chronic condition, not the death sentence.

Many individuals calculated how old they would be 15 years from now and gauged whether they wished to forgo any of those later years when they might be infirm or incapacitated. The perfect health option in the SG exercise provided greater potential longevity than in the TTO because life expectancy was not specified, but many were not eager to entertain the risk of immediate death.

With regard to the quantitative aspect of the exercises, many participants were not willing to trade much time or take on much risk of death.¹⁰ For those individuals, 3 primary underlying themes explained their unwillingness to exchange health states: (1) belief that adversity enhances one's life, (2) contentment with the status quo, and (3) unwillingness to truncate relationships with family and friends.

Adversity enhances one's life

- My current health reminds me that I am human and if everything was perfect, life would be boring. You need those adversities in life to keep you growing, at least I do . . . I like my little issues, they're all mine.
- I wouldn't want the perfect health. "Cause I don't know who I would be, I'm kinda liking who I'm becoming. I don't want to give that up.

Contentment with the status quo

- I like life, I like being alive and being here.
- I have come a long way in the 20 years since I found out so no, I don't really want to change . . . I'm happy and content with where I am in my life right now.
- I'm used to this trouble . . .

Relationships with family and friends

- I have a fairly decent life. I work, I enjoy what I do, I have a lot of friends, you know, so I really wouldn't be prepared today to jeopardize that.
- My current health isn't so bad that I want to cut myself short . . . and I still have a life to look forward to. I have 2 nephews and 2 twin nieces that I'd like to still see into their early teenage years or adulthood . . . and I still have both of my parents.

There was only one underlying theme for those individuals who did trade time or engage in a gamble: the burden of their disease and impact on their quality of life.

- I would factor in the days that I feel horrible . . . I would factor in all the great things I feel I could do which I don't think I could do now. Having been [HIV-] positive for 20 years, there's definitely things that have happened to my body. I am not gonna live to my full life expectancy because of the toxicity of the medications I'm on . . . The medications have affected my sexual function dramatically and I think that has a huge impact on a 45-year-old man's life. I hate being on disability, just hate it. And there's this huge disappointment in myself as to what I could of [sic] done in life.
- In 7 to 10 years my health is not gonna be where it's at [now] . . . I'd rather go early and have a short life than live to be 60 and the last 10 years are on a machine.
- HIV meds is not a way to live, even if you had the choice to live it. I mean you can live 45, 50 extra years, but taking all those pills, it gets to be structure, it's too much structure.

DISCUSSION

Health values, or utilities, ascertain the desirability of health states and serve as quality-of-life weights for decision analyses and cost-effectiveness analyses. Central to utility assessment is the valuation of "intermediate" experienced or described health states against anchor states, often presented as "dead" on the

one end and “perfect health” on the other. In theory, the anchor states should be clearly understood so that the intermediate state(s) can be valued against fixed constants. In this qualitative study, we found that “perfect health” as an anchor in utility assessment was far from perfect. Rather, its use was fraught with complications. First, there was no consensus among participants with HIV/AIDS about its definition and some individuals believed that perfect health is either unrealistic or undesirable. Second, the hypothetical exchange of current health for perfect health in the TTO and SG was also interpreted in multiple ways. Some participants perceived of trading time as participating in time travel, returning to a time in their lives when they had perfect health, while others perceived of the trade as starting anew with a clean slate. Some saw perfect health as ephemeral, fearing that it could be endangered at any time. A few of our participants adjusted their initial definition of perfect health during the course of the interview.

Like perfect health, current health was also perceived inconsistently: as stable over time, deteriorating, or improving. A majority of our study participants assigned a relatively high rating to their current health in spite of having HIV and other problems: medication cost, disclosure issues, fatigue, depression, the burden and side-effects associated with taking medications, and for some, serious co-morbidities. Further, many were unwilling to trade much time (if any) or engage in a gamble to achieve perfect health.

Although one may have expected all participants to value having perfect health, not all did. Why not? Researchers who have encountered such an unexpected response in the past have labeled it as nonsensical or paradoxical.² But by using open-ended interviews, we learned that some participants prefer current health to perfect health because current health represents “choosing life,” not sacrificing any time or not risking immediate death. Others felt that they already have perfect health or are comfortable with the status quo. Many reported that they have manageable and functional health and that was the context in which they prefer to assess their own health. Many of our participants no longer thought of HIV as a disease with impending death, but as a chronic illness, citing other diseases as more life-threatening than HIV/AIDS. Patients with HIV, then, seemed to adapt to their seemingly undesirable health state. In fact, in our full sample of 450 patients, approximately one-third felt that their life is better now than it was before they had been diagnosed with HIV.¹¹ Our findings are also consistent with other work about adaptation to health states.¹²

By talking directly with patients participating in health value assessments, we confirmed that individuals used a variety of referents. This lack of a fixed frame of reference for the upper anchor is similar to Krause and Jay’s finding that participants utilize multiple referents for self-ratings of overall health (excellent, good, fair or poor).¹³ Ubel’s group found that some people interpret perfect health in the RS exercise as “perfect health for someone your age” even when that definition is not provided in the exercise.³ There is some evidence, then, that participants interpret health value questions in an individualized fashion and accordingly, that responses to health value questions may not be readily comparable across individuals or populations.

If confirmed by other studies, our findings regarding varying conceptualizations of such fundamental health states as current health and perfect health have implications for deci-

sion analyses and cost-effectiveness analyses. That is, in much the same way as 100 °F is not the same as 100 °C because the boiling points on the 2 thermometers are different, so too would a utility of 1.0 not necessarily equal another utility of 1.0 if the upper anchors of the scale are different (say, disease free vs perfect health). And yet, even if the anchor is assumed to be fixed as say, perfect health, if perfect health is murky, unrealistic, or undesirable, then one person’s utility of 1.0 may not be the same as another’s. By extension, one person’s utility of anything less than 1.0 (e.g., 0.7) may not be the same as another’s if they do not agree on what it is they are gambling for or trading against.

Future research should also focus on several other issues related to health state descriptions and scale anchors. For example, what should the lower anchor be? Most commonly, the lower anchor is “dead,” but alternatives include “disease free,” “worst possible health state,” “worst state you could imagine,” etc. A label such as “worst possible imaginable health state” allows for states worse than “dead,” but is more ambiguous than “dead.” In our previous research, patients indeed thought that “dead” was “black and white,” but some found it startling to think about.⁴ With regards to the upper anchor, future research might experiment with comparing some of the labels our patients suggested, such as “manageable health,” “functional health,” or “peak performance” versus the more traditional labels of “perfect health” or “best possible imaginable health state.” In addition, future studies could randomize the presentation order of the RS, TTO, and SG to eliminate any potential bias in question order. Finally, future research could examine how people conceptualize “perfect health” and “current health” outside of the context of a utility assessment exercise.

Our study has several limitations. First and foremost, the number of subjects was small and the sample, although demographically representative of patients with HIV in the U.S., came from one site. Our participants were generally well educated and had prior experience with utility assessment. For our participants, the average number of years since diagnosis was 11; thus our findings might not generalize to people who have been recently diagnosed. And although our findings were similar to those from a study we conducted among patients with HIV/AIDS in 1996–1997,⁴ it is unclear whether they extend to patients with diseases other than HIV/AIDS. Finally, although one may be tempted to infer from our results that varying conceptualizations of health states could affect results of decision analyses and cost-effectiveness analyses, our study did not examine that issue directly.

Those limitations notwithstanding, our findings call into question the use of “perfect health,” and perhaps also “current health,” in assessing utilities in patients with HIV. At the very least, the term “perfect health” should be used with caution. We agree with the recommendations by Ubel and colleagues that upper anchors be defined for specific age groups but we suggest an additional step: specifying the referent age and presence/absence of disease with regards to the upper anchor. For example, for a study of patients with HIV, the upper anchor might specify the absence of HIV and other diseases and specify an age group referent. In addition, “current health” should be defined, as should the “rules” governing the hypothetical act of exchanging current health for an upper anchor. Health values obtained directly from individuals will become more generalizable for medical decision and cost-effectiveness analyses once the ambiguity surrounding the

terminology and the exercises is eliminated to the greatest extent possible.

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REFERENCES

1. **Torrance GW.** Measurement of health state utilities for economic appraisal. *J Health Econ.* 1986;5:1-30.
2. **King JT, Styn MA, Tsevat J, Roberts MS.** "Perfect health" versus "disease free": the impact of anchor point choice on the measurement of preferences and the calculation of disease-specific disutilities. *Med Decis Making.* 2003;23:212-25.
3. **Ubel PA, Jankovic A, Smith D, Langa KM, Fagerlin A.** What is perfect health to an 85-year-old? Evidence for scale recalibration in subjective health ratings. *Med Care.* 2005;43:1054-7.
4. **Tsevat J, Sherman SN, Sanchez-McElwee JA, Mandell KL, Sonnenberg FA, Fowler FJ.** Understanding health values of HIV-infected patients: results from focus groups (abstract). *J Gen Intern Med.* 1997;12(suppl 1):64.
5. **Mrus JM, Sherman KE, Leonard AC, Sherman SN, Mandell KL, Tsevat J.** Health values of patients coinfecting with HIV/hepatitis C: are two viruses worse than one? *Med Care.* 2006;44:158-66.
6. **Mrus JM, Yi MS, Leonard AC, et al.** Multi-center study of utilities in patients with HIV/AIDS in the era of highly-active antiretroviral therapy (HAART) (abstract). *Med Decis Making.* 2003;23:568.
7. **Patton MQ.** *Qualitative Evaluation and Research.* 3rd edition. Thousand Oaks, CA: Sage Publications; 2002.
8. **Willis GB.** *Cognitive Interviewing.* Thousand Oaks, CA: Sage Publications; 2005.
9. **Centers for Disease Control and Prevention.** A glance at the HIV/AIDS epidemic. Available at: <http://www.cdc.gov/hiv/PUBS/FACTS/AT-A-GLANCE.htm>. Accessed January 3, 2006.
10. **Mrus JM, Leonard AC, Yi MS, et al.** Health-related quality of life in veterans and non-veterans with HIV/AIDS. *J Gen Intern Med.* 2006;21:S39-47.
11. **Szaflarski M, Ritchey PN, Leonard AC, et al.** Modeling the effects of spirituality/religion on patients' perceptions of living with HIV/AIDS. *J Gen Intern Med.* 2006;21:S28-38.
12. **Radley A.** *Making Sense of Illness.* Thousand Oaks, CA: Sage Publications; 1994.
13. **Krause NB, Jay GM.** What do global self-rated health items measure? *Med Care.* 1994;32:930-42.

Supplementary Material

The following supplementary material is available for this article online at www.blackwell-synergy.com

Appendix: Examples of questions used during cognitive interview.