

## ABSTRACT

**OBJECTIVE:** The objective of this study is to elicit preferences for hypothetical risks and benefits of antiretroviral treatment among treatment-naïve HIV-positive African Americans using a stated-choice (SC) survey with probabilistic attribute levels.

**BACKGROUND:** SC surveys often include attributes that describe disease outcomes and treatment features as discrete levels. Rarely do studies describe attributes in probabilistic terms. Understanding and conceptualizing numerical probabilities is often cognitively challenging. Researchers have experimented with various graphical representations to assist subjects in understanding quantitative risks, but there is no general consensus about the most effective approach.

**METHODS:** In a recent study to estimate the willingness of treatment-naïve HIV-positive African Americans to accept adverse event risks in exchange for improvements in treatment efficacy, four of the five attributes were described as probabilities. We relied on a format that portrays absolute risks using a risk grid in which each square of the grid represents one person. Subjects completed an online survey instrument that included a series of 10 SC tasks. Each hypothetical treatment alternative included different probabilities of virologic failure, allergic reaction, bone damage, and kidney damage. The fifth attribute described discrete outcomes of bone or kidney damage (degree to which the problem could be treated successfully). We included four questions that tested subjects' understanding of the risk grid format prior to completing the choice questions.

**RESULTS:** One hundred fifty-three subjects completed the survey. The mean age was 42, with a standard deviation of 8.6. There were slightly more males (58%) than females (42%). Seventy-four percent of subjects answered the first risk question correctly, and 89% answered the fourth question correctly, indicating a high level of comprehension of risk levels.

**CONCLUSION:** Our risk grid approach, which included both a numerical and graphical representation of absolute risk levels, is an appropriate method for including probabilistic attribute levels in SC surveys.

## BACKGROUND

- Stated-choice (SC) surveys often include attributes that describe disease outcomes and treatment features as discrete levels.
- Rarely do SC studies describe attributes as probabilistic outcomes.
- Understanding and conceptualizing numerical probabilities is often cognitively challenging for subjects.
- Researchers have experimented with various graphical representations to assist subjects in understanding quantitative risks.<sup>1,2</sup>
- There is no general consensus about the most effective approach.

## OBJECTIVE

To elicit preferences for hypothetical risks and benefits of antiretroviral therapy (ART) among treatment-naïve HIV-positive African Americans using an SC survey in which nearly all treatment attributes are expressed as probabilistic outcomes, using a risk grid approach to assist subjects with understanding quantitative risks.

## METHODS

- In a recent study to estimate the willingness of treatment-naïve HIV-positive African Americans to accept treatment-related risks in exchange for improvements in treatment efficacy, four of the five treatment attributes included in the SC questions were described as outcome probabilities.<sup>3</sup>
- Risks were expressed using a risk grid in which each square of the grid represents one person and each shaded square represents a person who will experience the treatment-related risk event (Figure 1).
- Four questions were included in the survey instrument to test subjects' understanding of the risk grid format prior to presenting the choice questions (Figure 2).

## Subjects

### Inclusion Criteria

- Aged 18 years or older,
- United States resident,
- Self-reported African American or black,
- HIV-positive but ART-naïve,
- Able to read and understand English at the sixth-grade level.

### Recruitment

- Participants were recruited through clinical sites.
- All subjects provided online informed consent.
- The final sample was 153.

### Survey Instrument

- The survey instrument was developed using focus groups, face-to-face interviews, and consultation with clinical experts.
- Participants completed the Web-enabled survey instrument at study clinics.
- Participants chose between 10 pairs of treatment options (Figure 3).
  - Choices were characterized by varying probabilistic levels of benefit, short-term and long-term adverse event (AE) risks, and the outcome associated with the long-term AE risks (Table 1).
  - Probabilistic attribute levels were chosen to encompass the range over which events might plausibly occur (based on published studies) and over which subjects are expected to have preferences, even if the level is clinically implausible.
  - The benefit outcome constituted changes/reductions in the chance that the medicine does not work (virologic failure) within 1 year of starting treatment.<sup>4</sup>
  - AE risks included:
    - Chance of a serious allergic reaction within 6 weeks of starting treatment,
    - Chance of bone damage (decreased bone mineral density or osteoporosis) within 5 years of starting treatment,
    - Chance of kidney damage within 5 years of starting treatment,
  - Outcomes associated with long-term serious AEs (bone and kidney damage) included:
    - AE can be treated successfully if detected,
    - Do not know if AE can be treated successfully if detected,
    - AE cannot be treated successfully if detected,
- The survey instrument also collected demographic information (age, sex, education, and employment status) and the year in which the subject learned he or she was HIV-positive.

## RESULTS

Table 2. Demographic Information for Survey Subjects

Variable	N	Percentage
<b>Age</b>	<b>146</b>	
Years, mean (SD)	41.8 (8.6)	NA
<b>Sex</b>	<b>151</b>	
Male	88	58.3%
Female	63	41.7%
<b>Highest education level</b>	<b>151</b>	
Less than high school	15	9.9%
High school	67	44.4%
Some college	55	36.4%
Bachelor's degree or higher	14	9.3%
<b>Employment status</b>	<b>149</b>	
Full-time	23	15.5%
Part-time	15	10.1%
Self-employed	14	9.4%
Homemaker	10	6.7%
Student	3	2.0%
Retired	2	1.3%
Disabled/unable to work	48	32.2%
Unemployed but looking for work	28	18.8%
Unemployed and not looking for work	6	4.0%
<b>Years of HIV-positive status</b>	<b>139</b>	
Years, mean (SD)	7.6 (6.8)	NA

NA = not applicable; SD = standard deviation.

## Risk Grid Questions

- Seventy-four percent of subjects answered the first risk grid question correctly, indicating a high level of initial comprehension of risk levels.
- The percentage of subjects answering the risk grid questions correctly steadily increased from 74% on the first question to 89% on the fourth question (Table 3).
- Six percent of subjects did not answer any risk grid question correctly (Table 4).
- Deleting subjects who did not answer any of the risk grid questions correctly did not have a statistically significant effect on the preference estimates.

Table 3. Percentage of Subjects Who Answered the Risk Grid Questions Correctly

Risk Grid Question*	N	Percentage
1	113	73.9%
2	115	75.2%
3	124	81.1%
4	136	88.9%

\*See Figure 2

Table 4. Number of Risk Grid Questions Subjects Answered Correctly

Number of Risk Grid Questions Answered Correctly	N	Percentage
0	9	5.9%
1	14	9.1%
2	11	7.2%
3	24	15.7%
4	95	62.1%
Total	153	100%

## CONCLUSION

- The risk grid approach, which included both a numerical and graphical representation of absolute risk levels, is an appropriate method for including probabilistic attribute levels in SC surveys.

Figure 1. Examples of Risk Grids Used in the Study

**Side Effects of HIV Medicines**

Most medicines for HIV can cause side effects. Some of these side effects can be serious. Some of these side effects happen to a lot of people who take the medicine. Other side effects happen to only a few people who take the HIV medicine.

The following pictures may help you think about how many people might be affected by side effects.

Each square in these boxes represents one person who takes an HIV medicine. There are 100 squares in each box. The filled-in squares represent people who will have a serious side effect from taking an HIV medicine. The blank squares represent people who take an HIV medicine and do not have a serious side effect.

- 1 person out of 100 (1%) who takes this HIV medicine will have a serious side effect
- 5 people out of 100 (5%) who take this HIV medicine will have a serious side effect
- 7 people out of 100 (7%) who take this HIV medicine will have a serious side effect
- 8 people out of 100 (8%) who take this HIV medicine will have a serious side effect

Figure 2. Questions Testing Subjects' Understanding of the Risk Grid Format

- 1 out of 100 (1%)
  - 7 out of 100 (7%)
  - 10 out of 100 (10%)
  - 15 out of 100 (15%)
- 1 out of 100 (1%)
  - 5 out of 100 (5%)
  - 7 out of 100 (7%)
  - 8 out of 100 (8%)
- 10 out of 100 (10%)
  - 12 out of 100 (12%)
  - 15 out of 100 (15%)
  - 21 out of 100 (21%)
- 1 out of 100 (1%)
  - 5 out of 100 (5%)
  - 7 out of 100 (7%)
  - 10 out of 100 (10%)

Figure 3. Example of Choice Question Comparing HIV Treatment Options

Medicine Feature	Medicine A	Medicine B
CHANCE THAT MEDICINE DOES NOT WORK	15 people out of 100 (15%)	7 people out of 100 (7%)
CHANCE OF ALLERGIC REACTION	12 people out of 100 (12%)	1 person out of 100 (1%)
CHANCE OF BONE DAMAGE	10 people out of 100 (10%)	5 people out of 100 (5%)
CHANCE OF KIDNEY DAMAGE	1 person out of 100 (1%)	10 people out of 100 (10%)
WHAT HAPPENS IF YOU HAVE BONE OR KIDNEY DAMAGE	Don't know if problem can be treated successfully	Problem can be treated successfully

Table 1. Treatment Attributes and Levels Used in the Survey Instrument

Treatment Attribute	Levels
Chance that medicine does not work	<ul style="list-style-type: none"> <li>7%</li> <li>15%</li> <li>21%</li> </ul>
Chance of having an allergic reaction	<ul style="list-style-type: none"> <li>None</li> <li>1%</li> <li>8%</li> <li>12%</li> </ul>
Chance of bone damage	<ul style="list-style-type: none"> <li>None</li> <li>1%</li> <li>5%</li> <li>10%</li> </ul>
Chance of kidney damage	<ul style="list-style-type: none"> <li>None</li> <li>1%</li> <li>5%</li> <li>10%</li> </ul>
What happens if you have bone damage or kidney damage	<ul style="list-style-type: none"> <li>You don't know if the problem can be treated successfully.</li> <li>The problem can be treated successfully.</li> <li>The problem cannot be treated successfully.</li> </ul>

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