

Lessons from Cognitive Testing of Self-report Adherence Items

Ira Wilson, Jack Fowler, Carol Cosenza, William Rogers, Joanne Michaud, Judith Bentkover, Laura Kogelman, Aadia Rana



BROWN

Disclosures

- Adherence Advisory Boards for Merck and Gilead

Background

- Adherence measurement is a challenge in research and in clinical practice
- “Objective” measures: expensive and impractical
- No “gold standard”
- Administrative measures (pharmacy claims): indirect and often unobtainable
- Self-report: prone to upward bias and ceiling effects
 - Many SR measures
 - All seem to work to some extent
 - None have been rigorously developed and tested



Goals of this Research

- Previous work¹
 - Time frame: 30 days
 - Response task: E/VG/G/F/P/VP Likert scale
- Characteristics of the event: frequent, regular, non-salient, identical
- Marketing literature:² enumeration vs. estimation
- Understand cognitive process
- Match item content and response task to cognitive process

¹Lu et al, AIDS Behav 2008 Jan;12(1):86-94.

²Blair E, Burton S. Cognitive Processes Used by Survey Respondents to Answer Behavioral Frequency Questions. *Journal of Consumer Research*. 1987;14:280-288.



Goals of this Research

- Goal: rigorously develop and test SR items
- Conceptual Framework: Tourangeau's 4 phases of survey response:
 - Comprehension
 - Retrieval
 - Judgment
 - Response
- First phase: cognitive testing



Methods

- Literature review: HIV and non-HIV
- Preliminary item reduction based on basic principles of survey design
 - For example, the problem of attribution
- 4 iterative rounds of cognitive testing: 66 people
- 2 sites: Boston and Providence
- Patients: using ART
 - Diversity of gender, race/ethnicity, educational level
 - Detectable viral loads
 - When possible, multiple medications



Methods: Cognitive Interviews

- Highly experienced interviewing team
- Participants completed questionnaires
- “Think aloud” method: how they decided on the answer they gave
- Focus on Tourangeau’s 4 phases or components
- Interviews audio recorded
- 4 rounds of interviews



Methods: Cognitive Interviews

- How to decide when an one item stem or response set is “better” than another one
- Reliability
 - amount of participant to participant variation in understanding, interpretation, and response
 - Judgment of interviewing team
- Validity: how close does it seem to the “true behavior”
 - Assessment of patterns of response among respondents



Methods: Response Patterns

In the last 30 days, on how many days did you take all of your MED1 exactly as your doctor prescribed?

Days	100% Compliant	<100% Compliant
1		1
20		2
24		1
25		1
26		1
27		2
28		2
29		
30	8	
31	1	
100%	1	
“all days”	1	



Results: Participant Characteristics

- N=66
- Gender: 30% female
- Education: 71% had high school or less
- Race/ethnicity: 59% non-white

Results

- Medication lists
- Item stem
- Response options



Medication lists

- Most patients unable to construct a medication list
- Spelling medication names intimidating
- Confusion about HIV vs. non-HIV related medications
- Pills vs. non-pills caused confusion
- Difficulty knowing how to report pills taken “as needed”



Item Stem: Reference Period

- No consistent understanding of “the last week” or “the last month”
- The last week could mean:
 - The last seven days
 - The previous Monday to Sunday interval
 - The previous Sunday to Saturday interval
- Consistent understanding of:
 - The last 7 days
 - The last 30 days



Item Stem: Reference Period

- Attention to the reference period
 - Poor overall
 - Whether 7 days or 30 days, patients seemed to estimate rather than actually count or enumerate
 - There was some, limited, evidence that patients recall better for 7 than 30 days



Item Stem: Taking vs. missing

- Recall seemed better when we asked about missing
- Responding about taking often involved a subtraction

Item Stem: As Prescribed

- Original formulation: “Exactly as doctor subscribed”
- Doctors differ in the extent to which they describe how the medications should be taken
- If instructions were general the phrase is unclear
- If instructions were specific the phrase also proved unclear
- Better: “the way you are supposed to take”



Item Stem: Dose

- Consistent understanding of the concept of dose
- Inconsistent application of the concept to actual survey questions



Response options

- Visual analogue scales
- Percents
- Frequency
- Rating scales



Response options: Percents

- Visual analogue scales and percents worked poorly
- Most people have to do some math to do this, and they often make errors
- Some make a guess or estimate without doing math
- Some treat it as a 0-100 scale and estimate

Response Options: Perfect

- Scale: very poor to perfect
- “No one is perfect”
- Refusal to use “perfect” even when adherence was 100%



Response Options: Feeling

- “ Overall, how do you feel about the way you took {MEDICINE NAME} in the last 7 days?”
 - Response options: Delighted to Terrible
- Confusion about how they felt physically and how they took the medications
- Delighted was not a term many associated with medicine taking



Response Options: Words vs. Numbers

- Respondents more comfortable and confident with words (adjectives or adverbs) than numbers
- For those with less than perfect adherence, respondents in general estimate rather than enumerate
- Words seem to match the cognitive process of estimation better than numbers



Best Items (1)

In the last 30 days, on how many days did you miss at least one dose of any of _____ your HIV medicines?

Write in number of days: _____ (0 – 30)



Best Items (2)

In the last 30 days, how good a job did you do at taking your HIV medicines in the way you were supposed to?

- Very poor
- Poor
- Fair
- Good
- Very good
- Excellent



Best Items (3)

In the last 30 days, how often did you take your HIV medicines in the way you were supposed to?

- Never
- Rarely
- Sometimes
- Usually
- Almost always
- Always



Limitations

- It was not feasible to test all previously used self-report items
- Cognitive testing done in 2 hospital settings in 2 Northeastern states in the US



Next Steps

- Psychometric testing is currently being done using pencil and paper surveys in 2 hospital HIV care settings and in web based surveys using online HIV communities
- Validity testing using electronic drug monitoring as a criterion variable



Conclusions

- Rigorous cognitive testing revealed several principles that should improve the performance of self-report items in HIV care
- Self-reports of medication adherence involve estimation more than enumeration, and patients are most comfortable and confident using adjectival and adverbial scales in this context

