

A Cognitive Test

Of How Adolescents Conceptualize Health-Related Quality of Life Constructs in Survey Questions:

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The Issue

- A widely used HRQoL battery of 9 questions had been cognitively tested for use with adults (Beatty 2004)
- The battery had been used with other populations including teenagers, and speakers of other languages, without the same rigorous testing.

Questions to Answer

- CDC wished to learn if there were indications that adolescents, either in English or Spanish, have patterns of interpretation or response for these questions that vary from those of adults, warranting further research.

- Questions to answer in the study included:
 - Do these items act as comparable stimuli for teenagers and adults?
 - Are they comparable or equivalent items in translation?
 - How do adolescents interpret the concept of HRQOL?
 - Do the questions tap into that concept for this population?

Respondents

- ❑ 24 interviews conducted in Chicago
- ❑ Spanish-speaking respondents were primarily monolingual immigrants from Mexico
- ❑ English-speaking respondents were monolingual English speakers of varied race/ethnicity
- ❑ Ages 12 – 17
- ❑ 12 male and 12 female
- ❑ Recruited through schools, after school programs, churches, and word-of-mouth

Battery of 9 Questions

1. Would you say that in general your health is excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, school, or recreation?

Battery of 9 Questions (cont.)

5. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?
6. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?
7. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?
8. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?
9. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?

Approach

- The question was asked as the first in the battery of 9 questions.
- Retrospective probing was done after each 2 to 4 related questions.
- Typical probes included:
 - You said in general your health is xxxx. What made you say that?
 - What would someone with (INSERT RESPONSE CATEGORY) health be like?
 - Why did you answer xxxx and not (ADJACENT AND BETTER HEALTH STATUS)?

Q1

- Would you say that in general your health is...
 - excellent,
 - very good,
 - good,
 - fair,
 - or poor?

- ¿Dirías que en general tu salud es...
 - excelente,
 - muy buena,
 - buena,
 - regular
 - o mala?

Q1 Quotes

(Eng., age 12, female)

- I: And how did you come up with 'very good'? R: Because I don't get tired, I don't feel like I eat a lot all the time, I play sports, I like to play outside, I like to run, I feel active."

(Eng., age 12, male)

- I: How come it's good? Tell me about what that means. R: Because I play sports, and I tend to eat fruits and vegetables.

(Eng., age 13, female)

R: very good I: So can you tell me what were you thinking, and how you came up with that answer? R: I was thinking like what I usually do like that involves exercise, and like how many times I like feel lazy and stuff. So I came up with that, because like some days, I just feel like sitting on the couch, but others, I'm like really active.

Findings for Q1

- ❑ In prior study with 68 Latino adults (English and Spanish speakers) we found that 10% of Rs based their answer on whether they engage or not in healthy behaviors (diet, exercise)
- ❑ Among the 12-14 year olds in this study, regardless of language, 90% of Rs did this
- ❑ Among the 15-17 year olds a few other factors were considered, including feeling well or not, injuries and illness. Nutrition and exercise were present in about half of the narratives

Q2

- Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
- Ahora piensa acerca de tu salud física, la cual incluye enfermedades físicas y accidentes: ¿Durante cuántos de los pasados treinta días no gozaste de buena salud física?

Findings for Q2 (Spanish)

- Translation of 'your physical health was not good' was done using a common idiomatic phrase: 'no gozaste de buena salud física' [you did not enjoy good health]. This is commonly used but is formal.
- While this is an expression that is well known to adult native speakers, we found that adolescents were not always familiar with it and interpreted as literally asking about 'enjoyment'.

Q3

- Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
- Ahora piensa acerca de tu salud mental, la cual incluye tensión, depresión y problemas emocionales: ¿Durante cuántos de los pasados treinta días no gozaste de buena salud mental?

Q3 Findings

- Over two thirds of the Rs answered thinking of a much longer period than last 30 days, many of them thinking back through the whole school year to date.

Q4

- During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, school, or recreation?
- ¿Durante cuántos de los pasados treinta días, el mal estado de salud mental o física le impidieron realizar sus actividades, tales como cuidado personal, trabajo o recreación?

Q4 Findings

- Spanish language Rs., in particular the younger ones, were often not familiar with 'cuidado personal' to refer to self-care, and interpreted the words literally, as taking care of yourself ("watching out from danger", "staying away from drugs and alcohol")

Q6

- During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?

- Durante los últimos 30 días, ¿aproximadamente cuántos días te has sentido TRISTE, MELANCÓLICO o DEPRIMIDO?

Findings for Q6 (English)

- 'Blue' was a term familiar to English-speaking adolescents in context.
- All were able to explain how they interpreted the question, and to give examples in their narrative that addressed interpretation of the three terms: sad, blue, or depressed.

Q6 Quotes

(Eng, female, age 12)

R: Sad is when you are upset and you don't feel very good about something. And blue is when just can get out of being sad an gloomy and you are kind of upset for maybe a longer time. I: And what about depressed? R: That's when it's actually, it may be more severe that just sad and it could be maybe like an illness too.

(Eng, male, age 17)

R: Well, when I think of depression I think of the color blue. Like a deep and washed out blue. I can like picture kind of feeling that way. Sadness, is more like a serious kind of a depression and blue is like I feel like it's almost in the same category as sad. I usually associate them together. I think depression is an actual diagnosed kind of thing.

Findings for Q6 (Spanish)

- ❑ Translated terms for 'sad' (triste) and 'depressed' (deprimido) were interpreted as in English.
- ❑ Translated term for 'blue' (melancólico) was not a term some of the Rs were familiar with, particularly some of the younger. One guessed it was related to 'alcohólico'.

Q7

- During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?
- Durante los últimos 30 días, ¿aproximadamente cuántos días te has sentido PREOCUPADO, TENSO, o ANSIOSO?

Q7 Findings

In English, 10 respondents interpreted “anxious” as anticipation and sometimes excitement for things to come, either good or bad; things such as getting test scores, an upcoming fieldtrip, or a school dance.

- “When I am anxious, I am usually anxious to see what I got on a test or I am anxious to go to a friend's house.”
- “You're kind of jittery, and you're waiting for something, and you're feeling excited or you really want it to happen, or you're still waiting for something.”

In Spanish this sense of ‘ansioso’ was not elicited. However, not all Rs were familiar with the term.

Q8

- During the past 30 days, for about how many days have you felt you did NOT get enough rest or sleep?
- Durante los últimos 30 días, ¿aproximadamente cuántos días has sentido que NO descansaste o dormiste lo suficiente?

Q8 Findings

- English-language Rs. did not have difficulty with this question or concept. They provided appropriate examples of sleep variation, such as during sleepovers or weeknight and weekend sleep patterns.
- In Spanish, however, the younger Rs. focused just on the number of hours of sleep rather than on the quality of the sleep.

Q9

- During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?
- Durante los últimos 30 días, ¿aproximadamente cuántos días te has sentido MUY SANO Y LLENO DE ENERGÍA?

Q9 Findings

- In English, all respondents associated “feeling healthy and full of energy” with feeling happy, energized, not sick, not sleepy, not tired, alert, in a good mood, healthy physically and emotionally, and excited about different things that happen during the day.
- In Spanish, however, only one of the six respondents in the younger group associated the question to being happy while all six respondents in the older group considered it this way.

Conclusions

- ❑ Adolescents conceptualize some aspects of health differently from adults (e.g. many more teens considering nutrition and exercise when self-rating health)
- ❑ Older teens are closer to adults in interpretation of questions
- ❑ Keeping reference periods in mind appears affected by school cycles
- ❑ Terminology of Spanish translation, while common for adult immigrant populations, not always clear to teenagers.