Challenges in the development of new instruments for non-mainstream populations: Some examples from the QoLHHI Impact Survey

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Abstract

The development of the Quality of Life in Homeless and Hard-to-House Individuals (QoLHHI) Impact Survey provides several illuminating examples of the challenges involved in creating new measures, particularly for non-mainstream populations. These challenges included ensuring the relevance of both item content and item language to homeless and vulnerably housed (HVH) individuals, developing a response format that acknowledges that some things (e.g., medication) might simultaneously have both positive and negative impacts, and ensuring that the QoLHHI Impact Survey assesses impact in a way that captures each person's own situation (e.g., currently in pain, no longer in pain, never in pain). To meet these challenges, we based items on information provided by HVH individuals, developed a new dual-scale response format, and tried to incorporate a range of experiences. Revision and pilot testing of the QoLHHI Impact Survey continues, but we have already learned some valuable lessons about key issues that arise when developing new measures for non-mainstream populations such as HVH individuals.

INTRODUCTION

There are numerous considerations involved in the development of new measures. When the target population differs from the mainstream population, it is necessary to consider its members' unique characteristics and context.

Homeless and vulnerably-housed individuals (HVH individuals):

- Experience high rates of mental illness and drug and alcohol use, which can affect their cognitive ability to respond to survey items
- Experience lower levels of educational attainment compared to the general population

- Live within a physical and social environment that is in many ways quite different from that experienced by most members of the general public

A measure must reflect these factors if it is to truly capture the experience of HVH individuals.

The **Quality of Life in Homeless and Hard-to-House Individuals (QoLHHI) Impact Survey** assesses subjective quality of life (QoL) by measuring the impact of various life areas (e.g., Health, Living Conditions, Financial Situation) on HVH individuals. For the Health section, respondents rate the impact of a range of health-related conditions and behaviours. Ratings range from “large negative impact” to “large positive impact”.

The **Health Section** of the **QoLHHI Impact Survey** was pilot tested in 2007 and 2008. One hundred and twenty-seven HVH individuals (Mean age = 43.44 years, SD = 11.53 years, range 22-74 years, 71.1% male) took part in two studies. Most participants were White (51.2%), single (59.1%), and reported having been homeless at some point in their lives (72.4%). Approximately one third (29.9%) had some high school education, 25.9% had completed high school, and 29.9% had some post-secondary education.

CHALLENGES

The challenges faced throughout the development of the QoLHHI Impact Survey can be categorized as follows:

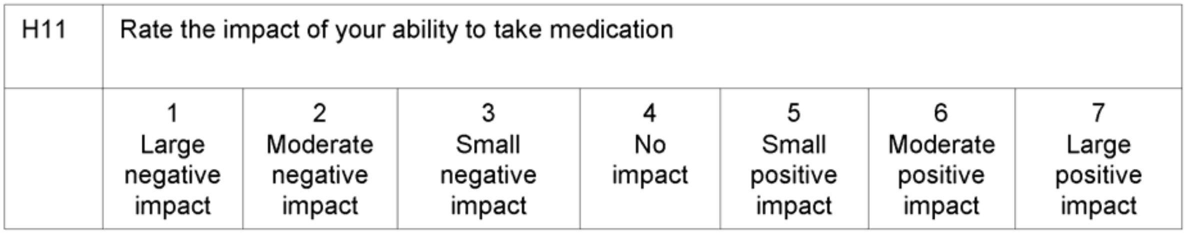
- Reducing the cognitive demands of item responding
- Ensuring the relevance of item content and language
- Reflecting the diverse meanings of “No”
- Providing a visual response scale
- Addressing multiple impacts

Reducing the cognitive demands of item responding

The Challenge

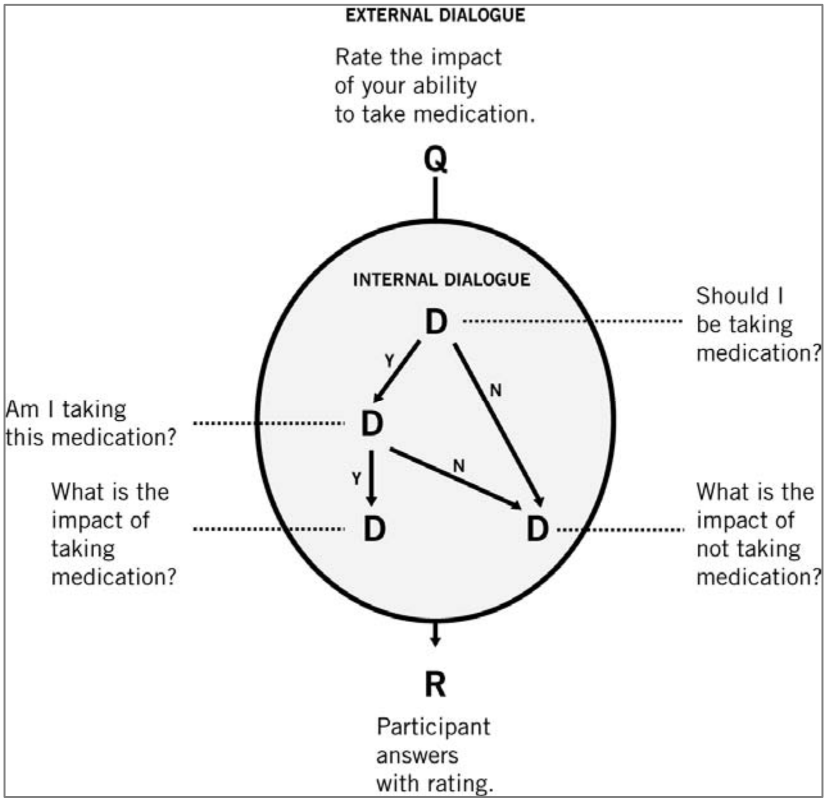
- There is a wide range of cognitive abilities and literacy levels among HVH individuals so it was important to reduce the cognitive burden on respondents when wording items.

<u>*Example*</u>*:* Original medication item



H11	Rate the impact of your ability to take medication						
	1 Large negative impact	2 Moderate negative impact	3 Small negative impact	4 No impact	5 Small positive impact	6 Moderate positive impact	7 Large positive impact

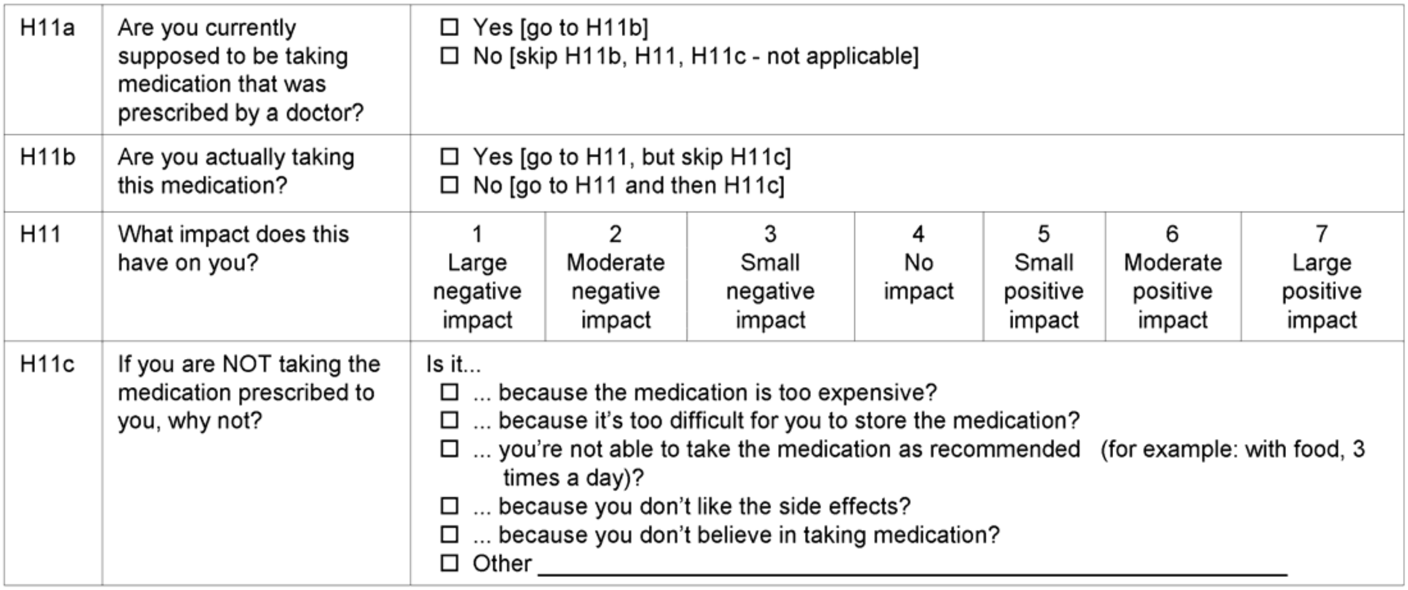
- This item was potentially problematic because it would require respondents to go through several stages of cognitive processing before it could be answered.



The Solution

- Potentially problematic items were broken down into several items to make the reasoning process more explicit.

- For example, the impact of medication use is now addressed through up to 4 items.



H11a	Are you currently supposed to be taking medication that was prescribed by a doctor?	☐ Yes [go to H11b] ☐ No [skip H11b, H11, H11c - not applicable]						
H11b	Are you actually taking this medication?	☐ Yes [go to H11, but skip H11c] ☐ No [go to H11 and then H11c]						
H11	What impact does this have on you?	1 Large negative impact	2 Moderate negative impact	3 Small negative impact	4 No impact	5 Small positive impact	6 Moderate positive impact	7 Large positive impact
H11c	If you are NOT taking the medication prescribed to you, why not?	Is it... ☐ ... because the medication is too expensive? ☐ ... because it's too difficult for you to store the medication? ☐ ... you're not able to take the medication as recommended (for example: with food, 3 times a day)? ☐ ... because you don't like the side effects? ☐ ... because you don't believe in taking medication? ☐ Other ____________________						

The Outcome (from pilot studies)

- Breaking down some items (medication, diet, experiencing pain, and drug and alcohol use) into a series of items appeared to be effective. Participants were, for the most part, able to follow the required reasoning sequence.

Ensuring the relevance of item content and language

The Challenge

- HVH individuals have numerous experiences and perspectives that are outside of our own range of experiences.

- There is a wide range of literacy levels in the target population. Overly complex or academic language might affect comprehension for some respondents.

- HVH individuals might be suspicious of research and researchers. Overly academic language could alienate respondents and cause unfavourable responses to the instrument.

The Solution

- Relevance of item content was ensured by basing the items on information provided by HVH individuals themselves:

  140 HVH individuals (69% men, mean age = 31.5 years, SD = 14.8 years, range = 15 to 73 years) took part in focus groups (reported in Russell, Hubley, & Palepu, 2005). Participants were recruited from shelters, hospices, supported housing, and other services for HVH individuals in 4 Canadian cities (Montreal, Ottawa, Toronto, and Vancouver), and asked to discuss what was important to their QoL.

- Health-related issues raised by focus group participants:
  - Chronic illness
  - Drug and alcohol use
  - Access to prescribed medication
  - Ability to store and take prescribed medication
  - Poor quality of sleep due to sleeping outside or in shelters
  - Difficulties in trying to follow specific dietary recommendations due to limited food options at meal programs or lack of cooking facilities
  - Exercise and fitness
  - General mental and physical health

- As a result of the emphasis placed on these aspects of health, we included items in the Health section of the QoLHHI Impact Survey that address each of these.

- In creating the items, we paid close attention to the language used by the focus group participants to ensure that this was reflected in the final items.

The Outcome (from pilot studies)

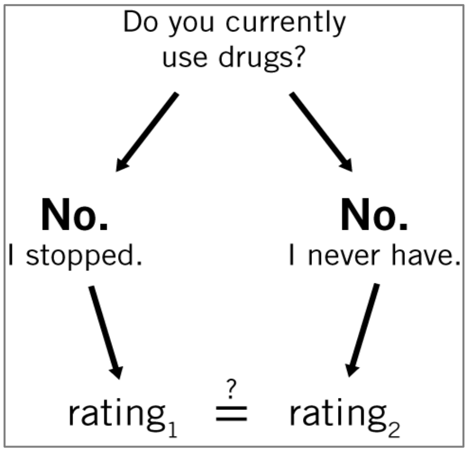
- Most HVH individuals related to the item content and language.

Reflecting the diverse meanings of “No”

The Challenge

- The *absence* of some aspects of health might have different impacts on a person depending on whether or not that absence represents a change in the respondent’s life.

- For example, for someone who has stopped using drugs, the impact of *not* using may be quite different than for someone who has never used drugs or used them only casually.



- Also, it might be difficult for someone who has *never* used drugs to rate the impact of not using.

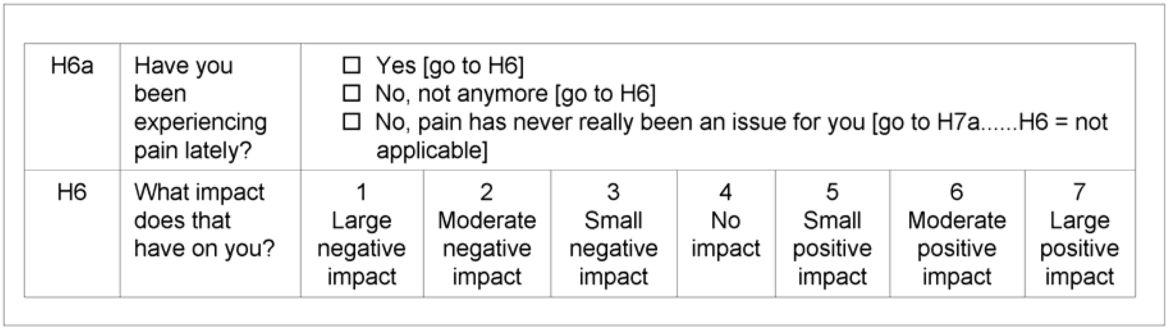
The Solution

- We created two “No” options for some items.

- The first option reflects a change (e.g., no longer using drugs).

- The second option is used when something has never been a significant issue for the respondent.

- If the respondent chooses the latter option, the impact rating item is skipped.



<table>
<tr><td>H6a</td><td>Have you been experiencing pain lately?</td><td colspan="7">☐ Yes [go to H6]
☐ No, not anymore [go to H6]
☐ No, pain has never really been an issue for you [go to H7a......H6 = not applicable]</td></tr>
<tr><td>H6</td><td>What impact does that have on you?</td><td>1
Large negative impact</td><td>2
Moderate negative impact</td><td>3
Small negative impact</td><td>4
No impact</td><td>5
Small positive impact</td><td>6
Moderate positive impact</td><td>7
Large positive impact</td></tr>
</table>

The Outcome (from pilot studies)

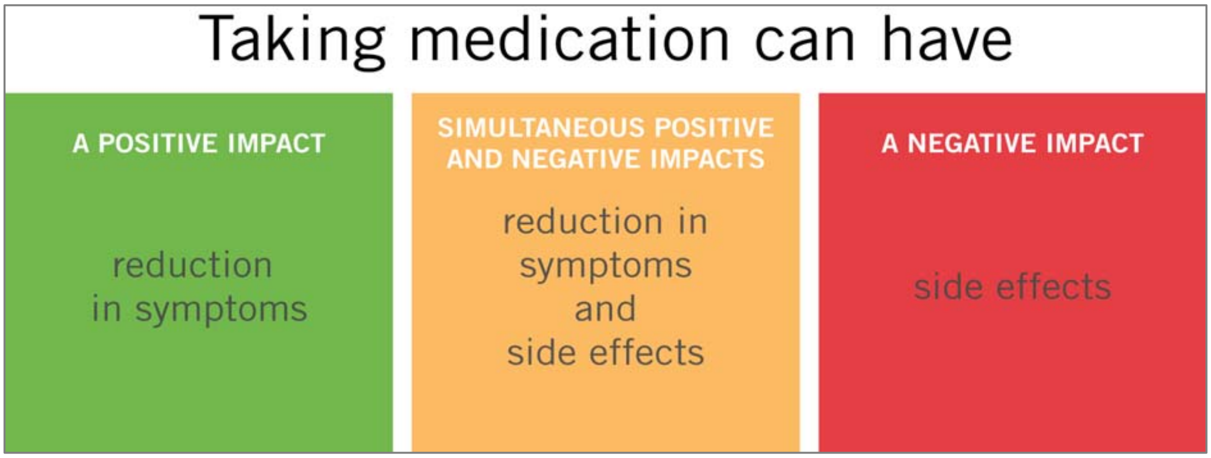
- Participants were, for the most part, able to follow the required reasoning sequence to respond to these items.

Addressing Multiple Impacts

The Challenge

- The original response format for the QoLHHI Impact Survey was a 7-point Likert-type scale ranging from “large negative impact” to “large positive impact”, with a midpoint of “no impact”.

- There are, however, multiple ways in which something can have an impact on a respondent.

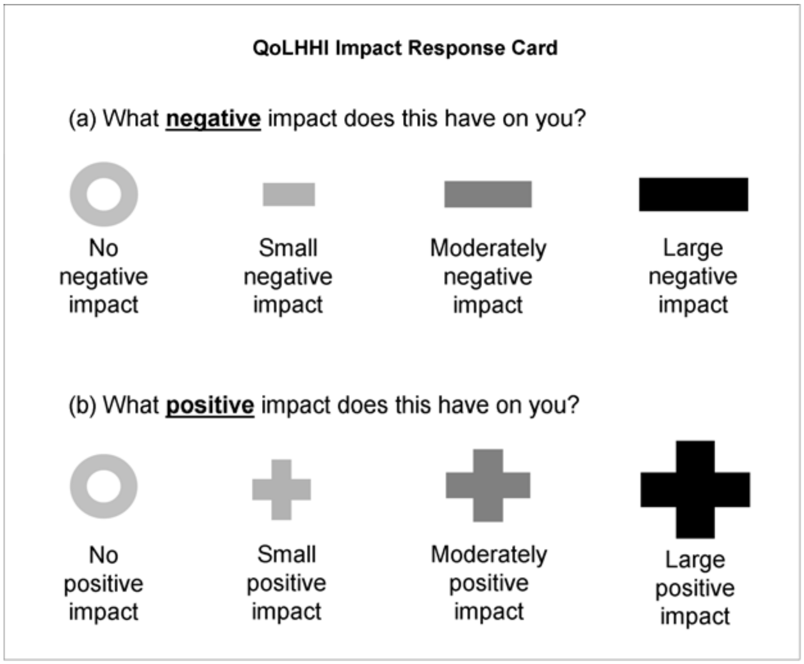


The Solution

- We split the response scale into two scales, one measuring positive impact and the other measuring negative impact.

- For each item, the respondent would provide a rating on both the negative scale and the positive scale.

- This would allow for a wide variety of responses, including positive impact only, negative impact only, no impact, and mixed impact.



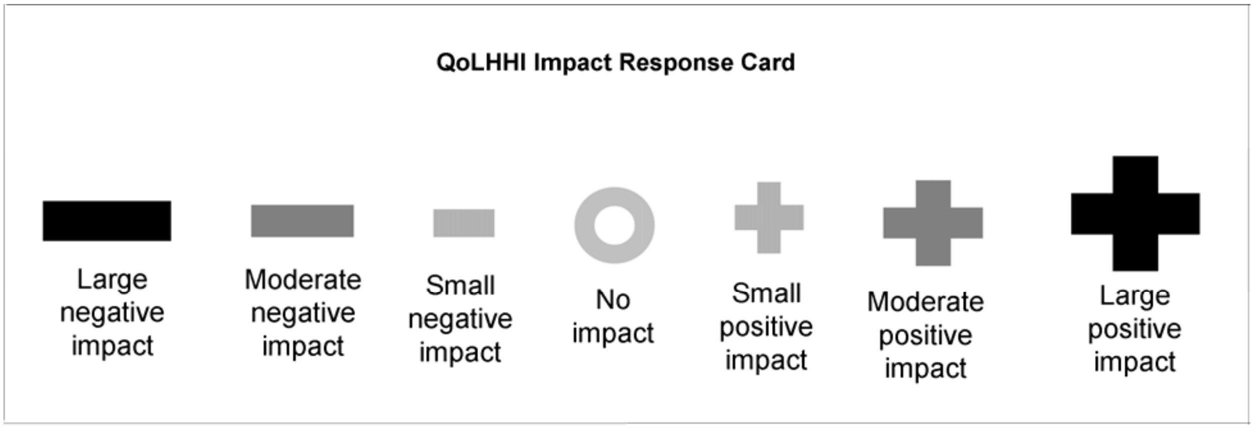
QoLHHI Impact Response Card

(a) What **negative** impact does this have on you?

(b) What **positive** impact does this have on you?

The Outcome (from pilot studies)

- Most participants could identify positive and negative sides to aspects of health, but many had difficulty translating this into negative and positive *impact* ratings.
- Some participants reported that they quite liked the two-scale format, noting that nothing is all good or all bad.
- Despite some positive feedback about the two-scale format, it was too complicated and unfamiliar for many HVH individuals, who reported that they did not like it.
- We reverted back to the original response format of a single scale anchored at “large negative impact” and “large positive impact”.



QoLHHI Impact Response Card

Providing a Visual Response Scale

The Challenge

- We realized that some HVH individuals would have low literacy skills, making it difficult for them to read response scale options.

The Solution

- We designed a response card for the QoLHHI Impact Survey that contains visual representations of the response options, supplemented by text labels (see Section on Addressing Multiple Impacts).

The Outcome (from pilot studies)

- Participants did not have difficulty understanding the response options.

- Several participants commented that they liked the visual aspect of the response card.

NEXT STEPS

Revision and pilot testing of the QoLHHI Impact Survey continues, but we have already learned some valuable lessons about issues that may arise when developing new measures for non-mainstream populations such as HVH individuals.

Section of the QoLHHI instrument will be available beginning in January 2009. For more information, please visit:

http://www.educ.ubc.ca/faculty/hubley/qolhhi.html