MEASURING QUALITY OF LIFE IN INJECTION DRUG USERS

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Background

In the health and medical fields, most quality of life (QoL) measures focus on health-related quality of life (HRQOL) or the functional effects of respondents' perceived mental and physical health [1]. However, as Gill and Feinstein [1] note, QoL is a reflection of respondents' perceptions and reactions to not only their mental and physical health, but also to non-health related aspects of their lives (e.g., family, friends, work). A recently developed QoL measure, the Injection Drug User Quality of Life (IDUQOL) scale, was designed to capture the health and non-health related aspects of injection drug users' (IDUs) lives that comprise important components of their QoL, particularly given their individual circumstances and environment [2, 3]. IDUs live in a distinct environment characterized by a high prevalence of infectious disease, crime, violence, and lack of stable housing. Many IDUs cannot depend on basic necessities and experience considerable instability in many aspects of their lives.

When selecting and using an instrument, it is important that there be validity evidence that the instrument is meaningful, useful, and appropriate for a given population in a given context [4-6]. Previous research on the IDUQOL has examined content validity via subject matter experts (SMEs) [7] as well as factor structure, internal consistency, test-retest reliability of its scores, and criterion-related, convergent, and discriminant validity evidence [3].

Evidence of content validity is critical for both test development and validation [8-10]. It is important to determine the degree to which elements of one's instrument are representative of the intended construct and appropriate for the target population [11]. Although content validity studies typically make use of SMEs, some experts have strongly advocated the use of several approaches to content validation, including conducting interviews or focus groups with members of the target population [12, 13].

Overall Purpose

The overall purpose of the two studies presented here was to examine content validity evidence for the IDUQOL by (a) conducting focus groups with IDUs to explore qualitatively the life areas that they identify as important to them and obtain feedback about the descriptions and graphical representations of the life areas in the IDUQOL (Study 1), and (b) examine the percentage of participants who identify each of the IDUQOL life areas as important (Study 2).

Study 1

Sample

The sample consisted of 48 IDUs (68.8% men) who ranged in age from 22 to 60 (M = 40.0, SD = 9.87). Education ranged from 5 to 18 years (M = 10.3, SD = 2.83). Participants' ethnic backgrounds were predominantly either European (45.8%) or Aboriginal (44.8%). Most described themselves as 'never married' (54.2%) and just over half of the sample (52.1%) had children, although only 20.8% of this group had any of their children currently living with them. Of the 38 participants who responded to the employment question, most (79.2%) were unemployed.

Materials

The IDUQOL consists of 21 life areas that emerged from a combination of a literature review and focus groups conducted with IDUs [2]. Thus, several life areas (e.g., Drugs, Drug Treatment, Harm Reduction and Neighbourhood Safety) reflect the social and physical reality of IDUs as suggested by these focus groups. Each IDUQOL life area is represented on a 4" by 4" card, with the name of the area printed on the front along with a simple image to make the instrument more accessible to individuals with low literacy or English language skills.

Procedure

Participants took part in one of eight focus groups consisting of 4-8 participants each. They were told that we were interested in QoL and those important factors that, if improved, would really make a difference in their lives. In the first part of the session, participants were asked to record all the different areas of their life that were important to them. These were shared in a group discussion, after which they could make changes to their individual lists. They were also asked to number the five areas most important to them. Next, participants were shown the life area cards of the IDUQOL and asked whether any important life areas were missing, what they thought of the name used for each life area, and whether the images used to illustrate each of the life areas were clear and appropriate. All focus group sessions were audiotaped and transcribed. Participants received $10 CDN.

Results

- Table 1 lists the 21 most frequently mentioned life areas across the focus group participants.
  - Housing, Health, Family, Money, and Friends were the five most frequently mentioned life areas.

- Focus group participants were satisfied with most of the IDUQOL life areas, names, and images.

- IDUQOL life area images that participants felt needed improvement included Harm Reduction, Drug Treatment, and Health. For example,
  - the image on the Harm Reduction card was viewed as "harm enhancing" because two needles were excessive and a garbage can was noted to be an unsafe means of disposal for needles (see Figure 1), and
  - the image on the Health card looked like a "butterfly man" or "angel" and better images might include a person flexing his/her muscles, a heart monitor showing healthy EKG lines, or a more recognizable medical symbol (see Figure 2).

- Other useful suggestions by participants included broadening the Neighbourhood Safety life area to encompass a broader understanding of safety for self and others and including police in the image as they are a constant presence in the lives of many IDUs (see Figure 3).

- Life areas that participants raised that were either not included in the IDUQOL or had been subsumed under another IDUQOL life area but seemed quite distinct to the present sample included Food & Nutrition, Services & Support, Relationships with Others, Emotional State, and Exercise.

- The IDUQOL life areas that participants did not highlight in their top 21 categories included Community Resources, Feeling Good About Yourself, Independence & Free Choice, Sex, Transportation, and How Others Treat You.

Discussion

In this study, there was considerable overlap between the list of the 21 most frequently mentioned life areas provided by IDU focus group participants and the life areas included in the IDUQOL, indicating that the measure successfully captures many important aspects of the QoL of participants. Moreover, IDU participants were satisfied with most of the IDUQOL life areas, descriptions, and images. However, participants did make suggestions for how life area descriptions and images could be modified to better reflect their experiences. In addition, a few important aspects of participants' lives were not captured by the IDUQOL. Adding these areas to the IDUQOL might increase its relevance to IDUs. Finally, consideration should be given to whether IDUQOL life areas not raised at all in the focus groups should be removed from the instrument (although it is noteworthy that participants did not question the relevance or importance of these areas when they reviewed the IDUQOL materials).

Study 2

The data for this study were taken from research that evaluated the validity of inferences from the IDUQOL and the utility of subjective importance weighting that was formerly part of the IDUQOL [3, 14].

Sample

The sample consisted of 241 injection drug users (62.7% men) who ranged in age from 19 to 61 years (M = 39.4, SD = 9.46). The majority of participants had completed high school (84.6%). Just over one third of the sample self-identified as Aboriginal.

Procedure

Participants took part in a one-on-one session of approximately 25-30 minutes and received $10 CDN for their participation. The interviewer first showed the participant the 21 IDUQOL life area cards and discussed the written description provided on the back of each card. The participant selected the life areas that he/she thought were important to his/her QoL and the remaining cards were set aside. The cards representing important life areas were laid out and the participant was given 3 small plastic chips for each of the selected cards (i.e., the total number of chips provided could range from 0 (no life areas are important) to 63 (all 21 life areas are important)). The participant redistributed the chips across the cards to indicate the level of importance of each life area, with more chips indicating greater importance. Each card

selected as important had to be marked with at least one chip but, otherwise, the chips could be distributed freely. In the original study [3, 14], the participants next provided satisfaction ratings for each of the life areas; however, as these ratings are not relevant to the present study, they will not be discussed further.

Results

- Table 2 shows the percentage of participants that identified each life area on the 21-item IDUQOL as important.
  - Most of the life areas were important to at least 60% of the participants
  - The only exceptions were Sex (43%), Transportation (54%), Partners (56%), and Education (59%)
  - The areas selected by as important by the largest percentage of participants were Health (92%), Health Care (88%), Housing and Feeling Good About Yourself (both 87%), Independence (85%), and Money (81%)

Discussion

The fact that all IDUQOL life areas but one were selected as important by over half the participants in this study suggests that these areas are relevant to the QoL of IDUs. Even the life area that received the least endorsement as an important life area (i.e., Sex) was still viewed as important by 43% of participants.

General Discussion

Results from both of these studies provide content-related validity evidence supporting the meaningfulness and appropriateness of the IDUQOL for the target population of IDUs. All of the IDUQOL life areas received support as being relevant to the QoL of participants. Whether the task was to spontaneously list important life areas (as in Study 1) or select these areas from among a pre-determined list (as in Study 2), Health, Housing, and Money were among the 5 most frequently chosen areas. Friends was the 5th most frequently cited life area in Study 1 and ranked 6th in terms of the percentage of IDUs selecting it in Study 2. Health Care was listed by focus group participants (albeit less frequently than others) in Study 1, but it was the 2nd most frequently retained life area in Study 2. It is also worth noting that when the focus group participants in Study 1 discussed Money as an area, one aspect of its importance that they mentioned was being self-sufficient; this overlaps somewhat with the IDUQOL life area of Independence & Free Choice, which was one of the 5 life areas most frequently retained as important in Study 2. Among the less important life areas were Sex and Transportation, which were not mentioned in Study 1 and were also the two least-endorsed areas in Study 2.

There were some differences between the two studies, with a few areas that were not raised in Study 1 receiving fairly high endorsement in Study 2 (e.g., Feeling Good About Yourself, Independence & Free Choice). Similarly, some areas that were raised relatively frequently in Study 1 were among the lowest in terms of endorsement in Study 2. For example, Family was the 3rd most frequently cited area in Study 1, but in the bottom 50% of areas selected as important in Study 2. One reason for this may have been that the description of Family on the IDUQOL life area card was not as broad as focus group participants' conceptualization of family (which may have included friends), thereby limiting the perceived importance of this area in Study 2. Differences between the findings of the two studies may also reflect the different task involved in each – that is, spontaneously listing important areas (in Study 1) versus selecting from among a list of life areas (in Study 2).

Despite the fact that some of the IDUQOL life areas were not raised in Study 1, the endorsement of all of these areas in Study 2 suggests that none of the current areas should be removed. The results from Study 1 do suggest some useful revisions that would further enhance the IDUQOL. Of the life areas that could be added, some are quite new and were not raised at all in the literature and original focus groups upon which the IDUQOL was based. The addition of a life area for Food & Nutrition would be one example. Other potential new life areas appear to be areas that were previously explicitly or implicitly subsumed under other life areas. For example, Exercise was originally thought of as implicit to Health but focus group participants saw it as a separate area. Finally, changes to some of the life area card images suggested by IDUs in the focus groups would also serve to improve the IDUQOL.

The data from these two studies provide evidence that the content of the IDUQOL is meaningful and relevant to the QoL of IDUs. Changes based on the findings of these studies will serve to further enhance the validity of inferences made from this instrument.

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Table 1

Most Frequently Listed Life Areas by Focus Group Participants (N=48)

Life Area	Overall Frequency[a]	Frequency in Top 5[b]
1. Housing (e.g., place to stay, personal space, home, shelter)	31	28
2. Health	23	21
3. Family	20	16
4. Money (e.g., finances, stay out of debt, be self-sufficient)	20	14
5. Friends	16	12
6. Drugs & Alcohol (e.g., addiction)	15	10
7. Be Productive (e.g., employment, work, help out)	14	9
8. Food & Nutrition	12	9
9. Services & Support (e.g., support groups re: mental or physical health issues, sexual abuse, or addiction)	12	9
10. Partner (e.g., spouse, lover, life partner)	11	10
11. Health Care (e.g., proximity to clinics or doctors, treatment options, better medicine)	11	6
12. Children*	10	8
13. Leisure Activities (e.g., music, reading, entertainment, fun, hobbies)	10	4
14. Religion & Spirituality (e.g., God, Jesus, faith, spirituality)	9	5
15. Relationship with Others (e.g., patience, forgiveness, sharing, fighting, communicating, take care of others)	9	2
16. Emotional State (e.g., anger, stress, depression, well being)	7	4
17. Learning (e.g., education, learning, trades)	7	3
18. Drug Treatment & Harm Reduction (e.g., drug rehabilitation, safe injection sites, free needles)	6	5
19. Exercise (e.g., recreation, sports, exercise)	6	3
20. Safety (e.g., for self and others)	5	3
21. Police and Legal Matters (e.g., treatment, knowledge)	5	2

[a] Number of participants who listed this life area as important to their quality of life
[b] Number of participants who included this life area among their top 5 areas
* Children may have been included in “family” for some participants but this was not clear from the written data provided by participants.

Table 2

Percentage of Participants for Whom Each Life Area was Important (N=241)

Life Area	%	Life Area	%
Health	91.7	Family	71.0
Health Care	87.6	Community Resources	70.1
Feeling Good About Yourself	86.7	Leisure	66.0
Housing	86.7	Spirituality	65.2
Independence	84.7	Drug Treatment	62.2
Money	80.9	Drugs	60.6
Friends	75.9	Education	58.9
Being Useful	74.2	Partners	56.4
Harm Reduction	73.9	Transportation	53.5
Neighbourhood Safety	73.4	Sex	42.7
How Others Treat You	73.4		

Figure 1

Original and Revised Cards – Harm Reduction

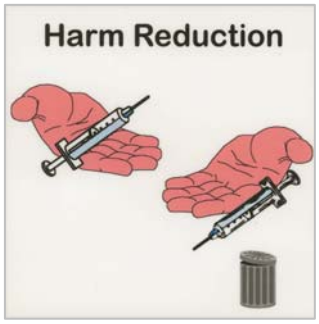
Original Card	Revised Card
	

Figure 2

Original and Revised Cards – Health

Original Card	Revised Card
	

Figure 3

Original and Revised Cards – Neighbourhood Safety

Original Card	Revised Card