Expression of gastrointestinal symptoms and their impact: similarities and differences across countries

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IBS – The Global Perspective
An international symposium organized jointly by the
Rome Foundation and World Gastroenterology Organization

Milwaukee, Wisconsin
16:15-17:30
6 April 2010
Objectives

To review linguistic and cultural differences in the expression of gastrointestinal symptoms and impacts

---linguistic differences: cannot find literal equivalent

---cultural differences: cannot find equivalent concept

Make suggestions for the path forward
IBS-QOL Symptoms*

Frequency 0= Never 1=Rarely 2=Sometimes 3=Often 4=Very Often 5
Bothersome 0=Not at all 1=Slightly 2=Somewhat 3= Moderately 4=Very Much 5= Extremely

- Abdominal discomfort, pain or cramps
- Hard or lumpy stools
- Loose or watery stools
- Straining during a bowel movement
- Urgency- having to rush to the toilet for a bowel movement
- Feeling of incomplete bowel movement
- Passing mucus (white material) during a bowel movement
- Abdominal fullness, bloating or swelling
- Passing gas
- Heartburn or chest pain
- Feeling full soon after starting a meal
- Passing urine more frequently
- Nausea

* Items grouped in summary scores of symptom frequency and symptom bothersomeness
IBS-QoL Impact

1= not at all  2 =slightly  3 =moderately  4 =quite a bit  5 =a great deal

Q1. Feel helpless.
Q2. Am embarrassed by the smell.
Q3. Am bothered by time on the toilet.
Q4. Feel vulnerable to other illnesses.
Q5. Feel fat.
Q6. Feel like I’m losing control of my life.
Q7. Feel my life less enjoyable.
Q8. Feel uncomfortable talking it.
Q9. Feel depressed.
Q10. Feel isolated.
Q11. Have to watch the amount I eat.
Q12. Sexual activity is difficult.
Q13. Feel angry.
Q14. Feel like I irritate others.
Q15. Worry that problems will get worse.
Q16. Feel Irritable.
Q17. Worry people think I exaggerate.
Q18. Feel I get less done.
Q19. Avoid stressful situations.
Q20. Reduces my sexual desire.
Q21. Limit to what I can wear.
Q22. Avoid strenuous activity.
Q23. Watch the food I eat.
Q24. Difficulty around people
Q25. Feel sluggish.
Q26. Feel unclean.
Q27. Long trips are difficult.
Q28. Frustrated cannot eat when I want.
Q29. Have to be near a toilet.
Q30. Life revolves around bowel problems
Q31. Worry about losing control.
Q32. Fear I won’t have bowel movement.
Q33. Affects my close relationships
Q34. Feel no one understands.
Domains of IBS-QoL*

- Altered mood: 1, 6, 7, 9, 10, 13, 16, and 30 items
- Interference with activity: 3, 18, 19, 22, 27, 29, and 31
- Body image: 5, 21, 25, and 26
- Health worry: 4, 15, and 32
- Food avoidance: 11, 23, and 28
- Social reaction: 2, 14, 17, and 34
- Sexual problems: 12 and 20
- Relationship problems: 8, 24, and 33

* Items scored into domains with overall score 0 (worse) to 100 (better)
Translations

IBS-QOL Impact: 24 languages – 4 linguistic families

IBSQOL Symptoms: 9 languages – 2 linguistic families

Indo-European
- Czech, French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish
- Spanish (US)

Afro-Asiatic
- Arabic (Egypt)

Indo-European
- Afrikaans, English (South Africa)

Uralic
- Finnish, Hungarian

Altaic
- Korean

Indo-European
- French, French, English (Canada)
- Spanish (Argentina, Chile, Colombia, Ecuador, Mexico, Peru), Portuguese (Brazil)
- English (New Zealand)

British
- English (UK, UK), German, Italian, Norwegian, Portuguese, Spanish, Swedish

French
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish

German
- English (New Zealand)

Italian
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish

Norwegian
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish

Portuguese
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish

Spanish
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish

Swedish
- French (Belgium, France, France), Dutch, Dutch, English (UK, UK), German, German, Italian, Norwegian, Portuguese, Spanish, Swedish
Methods

Reviewed of 9 translations of symptoms (S) and 24 translations of impact (I).

Analysed differences between original and translations

- Linguistic differences: coded as lexical (use of synonyms, paraphrases, addition, deletion of words), or grammatical
- Cultural differences: coded as beliefs, social norms, or values

Items categorized in three groups:

- Minor differences: when differences are shown in 1 to 3 languages (S) or 1 to 7 languages (I) (color code: green);
- Medium differences: when differences are shown in 4 to 6 languages (S) or 8 to 16 languages (I) (color code: orange);
- Major differences: when differences are shown in 7 to 9 languages (S) or 17 to 24 languages (I) (color code: red).

Minor syntactic (mainly grammatical) differences indicated but not counted.

Differences which did not impact the item concept (e.g., changes in the order of the sentence) counted but not in the final group categorization.
Results
IBS-QOL Symptoms

- Difficulties all of linguistic nature (not cultural).
  - symptoms like: "nausea", "chest pain" have literal equivalent.
  - symptoms like: "abdominal discomfort, pain or cramps", "abdominal fullness, bloating or swelling" have literal equivalent except in some countries where the adjective abdominal had to be changed by a paraphrase "in the abdomen";
  - signs like: "hard or lumpy stools", "loose or watery stools" have literal equivalent except in some countries where synonyms had to be found for lumpy (pebble-like) or loose (soft, thin).

- "Bowel movement" has no literal equivalents (idiomatic), and therefore all items including this expression translated with synonyms or paraphrases: defecation, evacuation of stools, or stools.

- "Passing urine” has no literal equivalents.

- Items implying an action with the use of the gerund or describing an action (to rush to), or describing a feeling are the most problematic.
Symptom Example

- **Feeling of incomplete bowel movement**
  - **French:** Sensation d'évacuation incomplète des selles
    (Feeling of incomplete evacuation of stools)
  - **Italian:** Sensazione di defecazione incompleta
    (Feeling of incomplete defecation)
  - **Spanish:** La sensación de una evacuación incompleta
    (The feeling of an incomplete evacuation)
  - **German:** Gefühl einer unvollständigen Entleerung
    (Feeling of an incomplete evacuation)
Results
IBS-QOL impact

- All differences of linguistic nature
- The items raising most difficulty:
  
  "I have to avoid strenuous activity"
  "I feel unclean"
  "It is important to be near a toilet"
  "I worry about losing control of my bowels"
  "I fear I won’t be able to have a bowel movement"

- Most of the time: use of synonyms or paraphrases.
- “I feel unclean because of my bowel problems” needed to be clarified using brackets in 14 countries.
- Dysphoria, social reaction, relationships domains are less problematic.
- On the contrary, almost half the items of the Interference with activity domain have major differences items
Impact Example

- *I feel unclean because of my bowel problems.*
  - **Afrikaans:** I feel “not clean” as a result of my bowel problems.
  - **Swedish:** I feel like I am not completely fresh because of my bowel problems.
  - **Czech:** I have the feeling that I am not “clean” because of my bowel problems.
  - **Hungarian:** I feel that I am not “clean” because of my bowel problems.
  - **Korean:** I feel myself unclean because of the bowel problem.
  - **Arabic:** I have a "feeling of uncleanness" because of my bowel problems.
Recommendations

• Prepare concept sheet with concept being measured, intention of item, and patient quotes


• Use translatability assessment: Conway K, Patrick DL, Gauchon T, Acquadro C: Enhancing Cross-Cultural Appropriateness for Newly Developed Patient-Reported Outcome (PRO) Instruments: the Use of Translatability Assessment. REF?

• Use observable signs as well as feelings

• Limitations of our assessment: no African languages or Asiatic languages included in this analysis (problems describing discomfort in a similar study)