

AGE-SPECIFIC ORIGINALS: USING THE PEDIATRIC QUALITY OF LIFE INVENTORY™ (PEDSQL™) DIABETES MODULE TO STUDY SIMILARITIES AND DIFFERENCES ACROSS LANGUAGES

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Background

The Pediatric Quality Of Life Inventory™ (PedsQL™) 3.2 Diabetes Module

- Is a 32/33-item paediatric outcome measurement consisting of age appropriate versions (Young Child self-report - ages 5-7, Child self-report - ages 8-12, Teen self-report - ages 13-18, Adult self-report - ages 18-45, Parent proxy-report for toddler - ages 2-4, Parent proxy-report for young children - ages 5-7, Parent proxy-report for children - ages 8-12, Parent proxy-report for teens - ages 13-18) which are parallel forms for child and parent to assess the effect of diabetes on children's, adolescents' and adult's health-related quality of life (HRQOL).
- Was developed in the United States by Prof. James Varni from Texas A&M University.
- With a recall period of the past 7 days (acute), and the past one month.

The Child, Teen and Adult forms were selected for this investigation as they provide a good basis for comparison between the different age-categories. **Three items are formulated differently across the Child, Teen and Adult forms** so that the items are appropriately adapted for each age-category, with the aim of making them easily understandable for the target population (see Table 1).

Table 1. Items formulated differently in the Child, Teen and Adult forms of the PedsQL™ 3.2 Diabetes Module

Child form	Teen form	Adult form
I have tummy aches	I have stomach aches	I have stomach aches
My parents and I argue about my diabetes care	My parents and I argue about my diabetes care	My spouse, significant other, and/or other family members and I argue about my diabetes care
It is hard for me to play or to do sports	It is hard for me to exercise	It is hard for me to exercise
	I worry about long-term complications from diabetes	I worry about long-term complications from diabetes

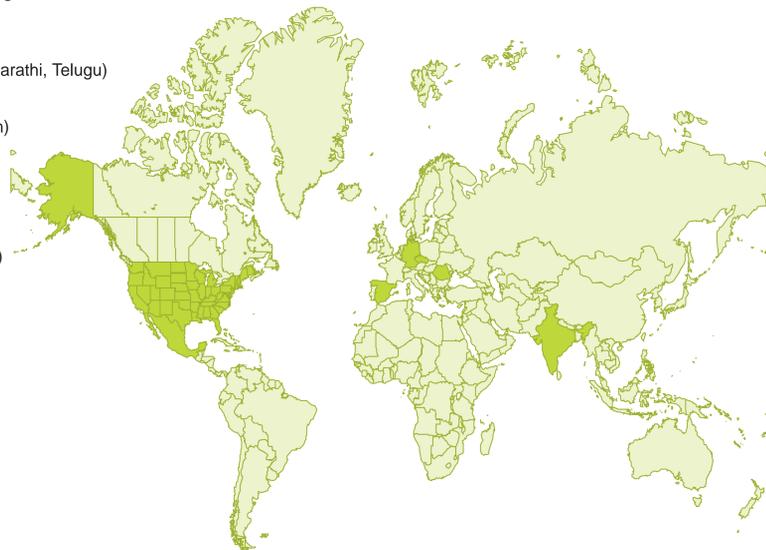
In addition, 1 item ("I worry about long-term complications from diabetes") is present in both the Teen and Adult form but not in the Child form. This item was not considered to be a developmentally salient concern for children between the ages of 8-12. Therefore, this item was not considered as an item that was common within the 3 forms.

Linguistic Validation

The linguistic validation of the PedsQL™ 3.2 Diabetes Module Child self-report, Teen self-report, Adult self-report, Parent proxy-report for children, and Parent proxy-report for teens was conducted in 10 languages by the Mapi Institute.

Table 2. List of Languages

- Asia**
- India** (Gujarati, Hindi, Marathi, Telugu)
- Europe**
- Czech Republic** (Czech)
- Germany** (German)
- Romania** (Romanian)
- Spain** (Spanish)
- North America**
- United States** (Spanish)
- South America**
- Mexico** (Spanish)



The linguistic validation process was conducted to develop reliable, valid and responsive instruments in language versions that:

- Facilitate the assessment of the impact of diabetes and treatment on the health-related quality of life of children, teens and adults with diabetes.
- Are conceptually equivalent to the original questionnaires and culturally relevant for each target country, as well as clear and easy to understand by all age-categories.
- Are adapted for and understood the same way (for items that are identical throughout the age-specific and proxy-report versions) by all age categories.
- Allow for data pooling across countries when used in international studies involving the assessment of the impact of diabetes and treatment on HRQOL of children, teens, and adults with diabetes.

Objective

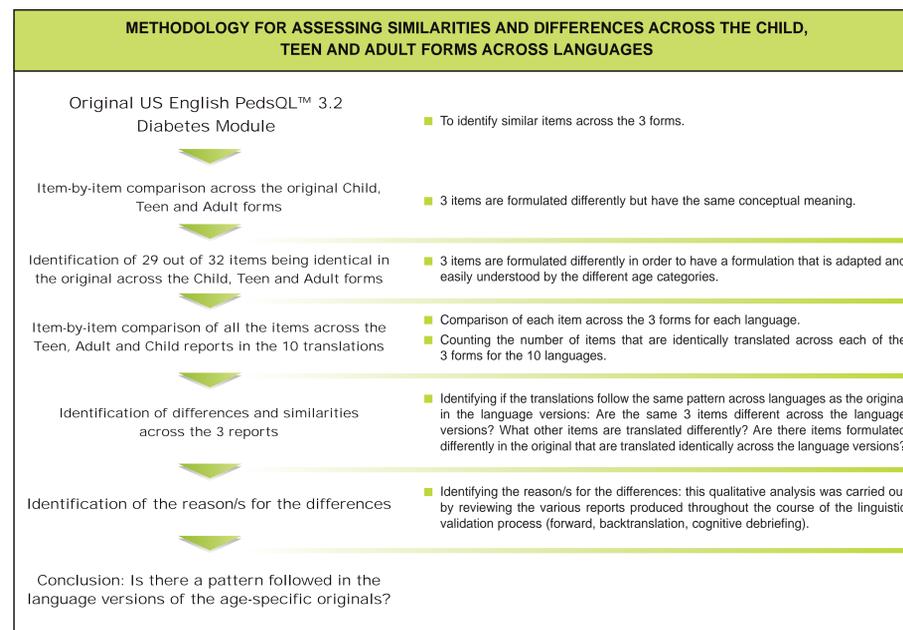
29 out of 32 items being identical in the original across the Child, Teen and Adult form, the aim of our study was:

- To investigate whether the same differences exist in the language versions, the extent to which the similarities and differences for identical items vary from the original,
- To determine a potential pattern should there be differences according to languages, and
- To make recommendations on the basis of the results.

Methods

This investigation was carried out as follows: (1) comparison of the 29 identical items across the Teen, Adult and Child reports in the 10 translations; (2) identification of differences across the 3 reports and (3) determination of a pattern in the differences. See Table 3.

Table 3. Methods



Results

Differences and Similarities across each form for 10 languages

- None of the 10 languages followed exactly the same pattern as the original, even though the 10 language versions are relatively similar across the 3 reports with few differences. The number of items identical across the 3 forms in these 10 languages is between 25 to 30. In particular, there seems to be more differences between the Adult and Child forms and there is the highest number of similarities between the Adult and Teen forms.
- Differences across the 3 forms seem to be based on 3 main factors.
 - Firstly**, same words from **everyday use** are not used in the same way by different age-categories to express the same notion. These items relate to general symptoms linked to diabetes.
 - Secondly**, wordings linked to **activities or situational context** are adapted for the different age groups.
 - Thirdly**, the PedsQL Diabetes Module contains some **technical terms**. Children, adolescents and adults do not have the same understanding of these words. In contrast however, it also seems that some technical words are harmonised across the 3 forms.
- None of the formulations differ for grammatical reasons as all the items are addressed in the first person "I" (unlike the "Directions" part of the forms which is addressed to the patient in second person "You").

1. Translation of words of everyday usage/general symptoms

Examples: 1."I feel weak" (all 3 forms), 2."I get cranky or grumpy" (all 3 forms), 3."I feel dizzy" (all 3 forms), 4."I have stomach aches" (Teen and Adult forms)/"I have tummy aches" (Child form)

1."I feel weak"

A direct translation of "I feel weak" in German, whilst proven to be easily understood by adults and teens during the cognitive debriefing step, was not clearly understood by the children interviewed. The interviewer probed further and the translation of "I lacked power/strength" was implemented in the Child form.

2."I get cranky or grumpy"

In German, this was translated as "I feel irritable" in the Adult and Teen forms. For the Child form however, it was translated as "I feel irritable and angry" as the meaning of "irritable" might not be clear to all children.

3."I feel dizzy"

A direct translation of "I feel dizzy" in Czech, whilst proven to be easily understood by adults and teen during the cognitive debriefing step, was not clear for the children interviewed. The interviewer probed further and the translation of "My head turns" was implemented for clarity for children, as it is an idiomatic formulation that children are familiar with and appropriate to describe the symptoms of having low blood sugar.

4."I have stomach aches"

In the US English original, "I have stomach aches" (Adult and Teen form) is formulated as "I have tummy ache" in the Child form. Another alternative, as validated by the developer of the instrument, is "I have belly ache". However in all languages, this was translated as "I have stomach ache" as there is no other variation of formulating this and children are also familiar with the direct translation of "stomach ache". Therefore all the 10 languages harmonised the same translation for this item in the 3 forms.

2. Translation of wordings linked to activities or situational context

Examples:

1."My parents and I argue about diabetes care" (Child and Teen forms)/"My spouse, significant other, and/or other family members and I argue about my diabetes care" (Adult form)

2."It is hard for me to exercise or do sports" (Teen form) /"It is hard for me to play or do sports (Child form)/It is hard for me to exercise" (Adult form)

"My parents and I argue about diabetes care" (Child and Teen forms)/"My spouse, significant other, and/or other family members and I argue about my diabetes care" (Adult form)

The difference in the items is due to children or teens in a family context would argue with their parents and adults being more likely to argue with their spouse or partner.

"It is hard for me to play or do sports (Child form)/"It is hard for me to exercise or do sports" (Teen form)/It is hard for me to exercise" (Adult form)

The difference in the items is linked to the different situations in which children, teens and adults are likely to do leisure physical activities. A child would do physical leisure activities through playing as well as sport activities, a teen is more likely to use the word exercise and do sports and for an adult the word exercise would cover all aspects of leisure physical activity.

Therefore, justifiably, for these items, all 10 language versions remain faithful to the diverging content of the original form and therefore follow the same difference across the 3 forms.

3. Translation of technical terms/words

a) Translations that change across the 3 forms

Examples: 1."I worry about going high", 2."I go low", 3."It is hard for me to snack when I go low"

For these items "go high" is translated "blood sugar going up/high", "I go low" is translated as "blood sugar going down/low" in Marathi, Telugu and US Spanish for the Child forms.

b) Translations that do not change across the 3 forms

Examples: 1."It is hard for me to carry a fast-acting carbohydrate" (all 3 forms), 2."It is hard for me to take insulin shots" (all 3 forms), 3."It is hard for me to take blood glucose test" (all 3 forms)

For these items containing the highlighted technical words, the translation is harmonised in contrast with the above examples because there is no simpler way to translate these words for children. Furthermore, children, teens and adults understood these words as being exposed to getting treatments and having had explanations on diabetes and on how to take care of themselves, they are familiar with these terms. In the Indian languages, these words have been transliterated, as there is no direct equivalent. These terms have been borrowed from English, and patients with diabetes, including children, are familiar with them, as proven during the cognitive debriefing test.

In both cases a) and b), as confirmed in the cognitive debriefing step, children are surprisingly receptive to technical words.

Conclusion

The similarities across the 3 age-specific forms for the 10 languages seem to indicate the universal and intergenerational acceptability of the original concepts and their formulations. Given the differences without identifiable pattern across age-categories in some languages however, it is essential to test the understanding of each item through cognitive debriefing on a sample of each age group despite the use of identical formulations in the original. This will ensure appropriate comprehension across age groups and translations, and facilitate international comparison and pooling of data.

General Recommendations

When refining or developing age-specific versions for international use:

- Beware of idiomatic expressions which may cause difficulties in finding suitable equivalents with cross-cultural and age-specific appropriateness.
- Have a list of concepts, validated by the developer of each instrument, with concepts explained clearly and alternatives for wordings and technical words in the framework of each age-category early in the process.
- Apply the cognitive debriefing step by testing each form with the corresponding sample of patients with the chronic health condition concerned to identify and solve culturally and age-specific sensitive items and formulations.