Paediatric health related quality of life : a European perspective : instrument development, validation, and use in clinical practice

Baars, R.M.

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Item selection after focus group research: the European DISABKIDS approach

R.M. Baars, S. Schmidt, M. Bullinger, A.H. Zwinderman, J.M.Wit, H.M. Koopman and the DISABKIDS group.

> Good answers come from good questions, not from esoteric analysis (H.M. Schoolman, 1968).

Abstract

A description is given of how items were selected for the DISABKIDS pilot instrument from a pool of health related quality of life (HRQoL) statements. To insure a bottom-up procedure the collected statements were generated from simultaneous cross-national focus groups and interviews with children and adolescents with a chronic medical condition, their parents and health care professionals. The DISABKIDS approach included a sequence of reduction methods. Steps included a redundancy scoring to delete the double, unclear and irrelevant statements. Secondly, experts rated the statements for importance. The statements were then rewritten into an appropriate questionnaire format. A final card sorting method was applied to select domains and dimensions. Last refinements were made to remove any further unethical, unclear or similar items. Three hundred and twenty-two participants contributed to the focus groups and interviews. A total of 3515 HRQoL statements were identified from the literal transcripts. These included generic quality of life statements (n=488) not related to any medical condition, chronic generic statements (n=1647) related to any chronic medical condition and condition-specific statements (n=66 to 340) that related to one of the seven included chronic medical conditions. After the applied redundancy steps a 100 chronic generic items and 26 to 44 condition-specific items were retained for testing in the DISABKIDS pilot study. Several sequential reduction steps were necessary to cut down the vast amount of collected statements from the DISABKIDS focus groups and interviews to develop our pilot instrument. These steps determine the final construct of a questionnaire. In our case it was found that the card sorting method was the most comprehensive and straightforward method to reduce the statements and divide the items into domain groups.

Introduction

A fundamental process in the development of health related quality of life (HRQoL) questionnaires is the selection of items. Qualitative patient-derived research methods, as the focus group and interview, have increasingly been used to collect items for new HRQoL questionnaires [1-6]. Organisational aspects related to running focus groups and the resulting qualitative data (i.e. discussed themes) have also been regularly described [7-13]. However, we found that existing literature gives no standard criteria or clear description on how to select questionnaire items from the collected qualitative data [14-16]. Processing raw qualitative data to form an item pool seems to be a variable and possibly subjective process. Steps for selecting the item pool should be objectively described, as failure to explain this process results in a difficulty to understand how selection choices were or can be made [17]. Applied development and selection methods can also influence the outcome of the final questionnaire [18]. A clear description of the development and processing of qualitative data is thus required to improve the quality of qualitative research [16,19,20].

Investigators have used patient-derived methods, as the focus group and interview, to generate items for new questionnaires but have not described or are unclear about the item selection process from their raw qualitative data [1,3,5,21-25]. If item reduction methods were described these concerned limited item pools or the selection of items after the pilot or field testing of a questionnaire. Described methods include clinicians or investigators selecting items, principal components analysis, criterion keying or asking patients to score items on importance, frequency or severity [1-3,23,26,27]. The clinimetric technique or "clinical impact" method is commonly used and provides an item rank order based on item importance, frequency or severity ratings provided by patients [28]. Scores of the individual patient or the means of the patient group are either multiplied or added to establish an item rank order (Box 1). The applied clinimetric technique does not seem to affect the general result of the item reduction [28]. The top ranking items are rated as the most important as they represent the highest experienced burden or impact.

*Multiplication or addition of the individual's importance score (I) on an item with the individual's severity (S) score of that item. The resulting product is an individual item importance-severity (M) or importance-plus-severity (P) score, which can be averaged over the group.
Formula: $I \times S = M$ **or** $I + S = P$

*The mean importance score of the group (I^m) can be multiplied with or added to the mean severity value for the entire group (S^m). The resulting overall group importance-severity score (M) or importance-plus-severity score (P) can be used to rank the items.
Formula: $I^m \times S^m = M$ **or** $I^m + S^m = P$

*Multiplication or addition of the individual's importance score (I) on an item with the individual's frequency (F) score of that item. The resulting product is an individual item importance-frequency (M) score or importance-plus-frequency score (P), which can be averaged over the group.
Formula: $I \times F = M$ **or** $I + F = P$

*The mean importance score of the group (I^m) can be multiplied with the frequency ($F^{\%}$) of which an item occurs in a group. The resulting overall group importance-frequency score (P) can be used to rank the items.
Formula: $I^m \times F^{\%} = P$

I =importance, can be scored on a Likert scale (not important to very important)
S =severity of the complaint, can be scored on a visual analogue or ordinal scale
F = frequency, can be scored on a Likert scale (never, sometimes, often etc.)
$F^{\%}$ *= proportion of patients that report the item as troublesome (max = 100%)*
I^m *= mean importance score given to an item by a group of patients who find this troublesome*

Box 1. Examples of clinimetric techniques.

Above selection processes all assume that there is a limited list of items. The process of selecting items from a large statement pool generated from qualitative patient-derived data as in the DISABKIDS project has rarely been described [14,16]. The aim of this paper is to describe the stepwise item reduction process that was performed to develop the European DISABKIDS HRQoL instrument for children and adolescents with a chronic medical condition and their parents. Item selection, reduction steps and encountered problems are discussed.

Method

The DISABKIDS project

The DISABKIDS project is a collaboration of eight research institutions in seven European countries (Austria, France, Germany, Greece, the Netherlands, Sweden and the United Kingdom). The project's aim is to develop a European HRQoL instrument for children and adolescents with a chronic medical condition and their parents [29]. The project followed a cross-national approach, which combined a bottom-up and top-down strategy and where items were produced simultaneously in different countries. Only a few HRQoL questionnaires have been developed through such a strategy [30-32].

The final DISABKIDS instrument aims to include aspects that are of importance to the patients and is multidimensional, multilingual and cross-nationally applicable in several countries. Unique is that the DISABKIDS project developed a core chronic generic module, which is applicable to all children or adolescents with a chronic medical condition, supplemented by a condition-specific module, which is specific to a certain medical condition. These two modules make comparative clinical studies possible (i.e. comparison between illness samples) and also provide additional information on a specific disease [33]. Chronic conditions included in the project are asthma, juvenile idiopathic arthritis (JIA), atopic dermatitis, cerebral palsy (CP), cystic fibrosis (CF), diabetes and epilepsy. Existing questionnaires and literature were reviewed to support the framework of the instrument. In order to focus on the child's perspective, statements for the DISABKIDS instrument were collected through a bottom-up procedure based on cross-national patient-derived methods, including focus groups and interviews. These procedures made it possible to reflect on aspects that are important to the patient group and adapt item phrasing to the child's level. The development of the DISABKIDS instrument followed consecutive work packages alternating inductive and deductive steps (Table 1) [31]. Patients and investigators were alternately seen as the appropriate experts during the instrument's construction phases. The DISABKIDS project is closely linked to the KIDSCREEN sister project. This project has developed a generic quality of life (QoL) questionnaire for children of the general population through similar methodology [34,35].

Work package		Scientific source	Process*
1	Literature review	Investigator	Top-down
2	Focus groups	Patient	Bottom-up
3	Item selection	Investigator	Top-down
4	Translations	Investigator	-
5	Pilot testing	Patient	Bottom-up
6	Analysis pilot study	Investigator	Top-down
7	Field study	Patient	Bottom-up
8	Analysis field study	Investigator	Top-down
9	Implementation plan	Investigator	-
10	Implementation study	Patient	Bottom-up
11	Final analysis	Investigator	Top-down

Table 1. Work packages (WP) within the DISABKIDS project.
*Inductive versus deductive processes are named as bottom-up and top-down approaches, respectively.

Collecting patient-derived data

Collected statements from the focus group and interview transcripts functioned as the main item source. Children and adolescents between 4 and 16 years old with one of the seven chronic conditions, their parents and health care professionals participated in the focus groups and interviews. Separate focus groups were organised for children and adolescents with each of the included chronic conditions and their parents. Each group was divided by age and consisted of a mixture of severity and gender. Health care professionals also gave their opinion on relevant HRQoL aspects through focus groups or interviews. Each of the eight DISABKIDS centres planned focus groups: Edinburgh (UK), Hamburg (DE), Leiden (NL), Lübeck (DE), Lund (SW), Marseille (FR), Thessalonica (GR) and Vienna (AU). Verona (IT) participated in the DISABKIDS focus group work package as an affiliated centre. Some participants were unable to attend the planned focus group and participated in individual interviews. To assure that a similar method was used in all centres a manual was developed which included the outline of the focus groups, the structured questions and general guidelines. The responsible Ethics Committees approved the study and all participants signed a consent form.

Item selection

The focus group discussions and interviews were literally transcribed. From these transcripts each country selected statements related to HRQoL. These statements were then translated into English and pooled into an ACCESS database grouped per condition. The ACCESS database was used to reproduce the taken steps, protect the input data with a password and give a clear overview. The statements per chronic medical condition were subdivided into three groups and a general domain name was designated to each statement by the investigator. One group consisted of generic statements, which could be applicable to all children, healthy or with a chronic medical condition. The generic statements from each condition were merged and transferred to the KIDSCREEN project. Merging those statements that were applicable to children with any chronic medical condition formed the second group; the DISABKIDS chronic generic module. The third division of statements formed the seven DISABKIDS condition-specific modules. The statements in each condition-specific module originated from the transcripts of a specific chronic medical conditions and reflected specific aspects related to that medical condition. These three groups were the basis of the modular build-up of the DISABKIDS and KIDSCREEN instrument.

The reduction of the statements was done per module and combined different methods in four steps (Figure 1). All steps have been documented and the final items can be retraced to the original source.

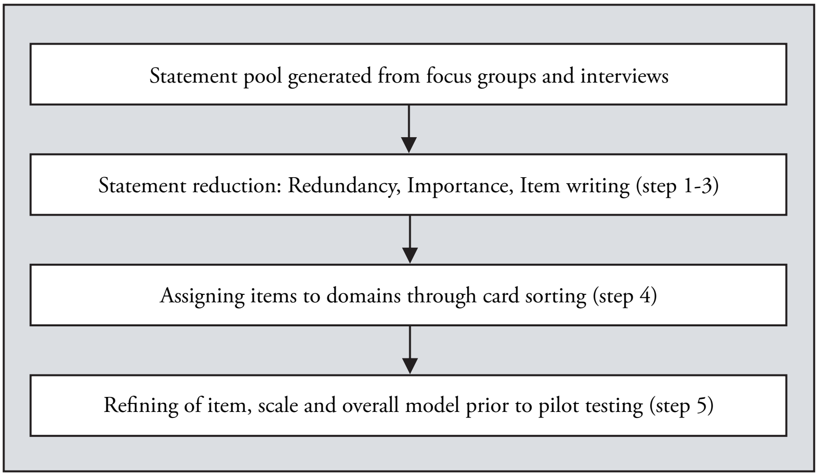

Figure 1. Item reduction progress.

Step 1: Redundancy scoring

The first step was aimed at limiting the excessive amount of statements. A DISABKIDS member from Scotland, Germany and the Netherlands each scored the collected statements derived from the focus groups and interviews on forms in a protected ACCESS database. The reduction of statements was based on criteria presented in the European Health Interview Survey (EUROHIS) study protocol [36]. Three independent raters marked the statements when they were redundant, semantically equivalent or unclear. Statements that did not meet the criteria of the project, like aspects related to health care needs, health care satisfaction or insurance problems, were also marked as failing the criteria. A statement was removed when two or more raters had marked it under one of the exclusion criteria.

Step 2: Importance scoring

The next step was to ask experts to rate the remaining statements in terms of importance. Each chronic generic statement was scored by all centres on importance to the

DISABKIDS HRQoL instrument, relevance to the child's age group (4-7, 8-12 and 13-16) and relevance for a parent questionnaire. Two to three experts from different DISABKIDS centres also scored the condition-specific statements on importance according to the same procedure. An importance scoring of 0-5 was given, with 5 being extremely important.

Step 3: Item writing
Each statement was rewritten into appropriate questionnaire items. Writing instructions were based on a general questionnaire format as presented in the World Health Organization Quality of Life (WHOQOL) study and the EUROHIS study protocol [32,36]. According to these guidelines, items should use simple language, avoid ambiguity in terms of either wording or phraseology, use short sentences, avoid double negatives, be convertible to a rating scale, ask about a single issue only, be applicable to individuals with a range of health status and should be stylistically comparable. At the same time the experts again checked statements for double, unclear or non-HRQoL statements. Each country wrote items for the condition-specific statements collected in their own centre. All chronic generic statements were rewritten and further reduced by the Dutch investigators.

Step 4: Card sorting
The next step consisted of a card sorting process in a DISABKIDS workshop to categorize the items into domains and dimensions [6,37]. This process was performed on the remaining item pool were each item was printed onto a card. The cards from each module (chronic generic and condition-specific) were sorted into three domains: the psychological, social and physical domain, each of which was perceived to be multidimensional. The process started with the chronic generic item pool, which needed to be reduced to roughly 100 items. Three to four DISABKIDS members worked with each of the domains. The cards in each domain were checked for correct placement and grouped according to similarity into several dimensions within this domain. This procedure was continued until all the cards in a domain had been placed in a dimension. If necessary, cards were replaced into another more appropriate domain for sorting. The same process was then applied to the item pool of the seven condition-specific modules with as aim to minimise the item pool to approximately 30 items. Formed expert groups identified the domains and dimensions. All sub-standard or double items were rejected and if the wording was unclear items were corrected.

Step 5: Refinement
In the final step the remaining chronic generic and condition-specific items were read out loud in a DISABKIDS workshop. All attending DISABKIDS members had the opportunity to comment on each statement. Some items were removed or rewritten in instances that they were unethical, had double meaning, and were still redundant or not applicable to all countries.

Results

A total of 154 children and adolescents, 142 family members and 26 health care professionals participated in either focus groups or interviews. A total of 3515 statements were identified from the DISABKIDS focus group and interview transcripts. The 488 generic statements, which were not related to having a disease were sent to the parallel KIDSCREEN project [35]. Of the remaining statements 1647 were applicable to any of the chronic medical conditions (chronic generic) while between 66 and 340 statements were specific to one of the seven chronic conditions (condition-specific). These two groups were the start of the two modules in the development of the DISABKIDS HRQoL instrument.

One DISABKIDS member in Scotland, Germany and the Netherlands scored all of the items in the first redundancy procedure (Step 1), each voted to remove 1404, 1614 and 2239 statements respectively, with between 50 and 68% being scored as semantically equivalent or redundant. Eventually 1802 of the 3027 items were marked under one of the rules by 2 or more raters (Box 2). This left us with 1225 statements, a reduction of 60%.

Fails criteria:
You have got to be well informed, either search the internet or read books.
She had had epilepsy for a long time but it was only noticed when she had a big seizure.
One feels so small at the hospital, you can't find a parking place, it's impersonal, stressed.
We didn't get any compensation for having a child with epilepsy and it costs money.

Semantically equivalent:
Do your teachers know that you have asthma?
The teachers didn't know that he had asthma.
We told them about asthma before the school started.

Box 2. Examples of removed statements in the first reduction phase.

After the redundancy scoring (Step 1) the general domain distribution, as given by each investigator after selecting statements from the literal transcripts, remained the same (Table 2). The health care needs domain was minimised, which was consistent with our aim, as this topic did not meet the criteria for our HRQoL instrument. These items were processed in a separate questionnaire development study [38].

Top 10 domains	Original statements	Remaining statements
Social	428 (14,1 %)	214 (17,5 %)
Coping	396 (13,1 %)	138 (11,3 %)
Health care needs	336 (11,1 %)	46 (3,8 %)
Psychological	262 (8,7 %)	143 (11,7 %)
Physical	253 (8,4 %)	112 (9,1 %)
Emotion	180 (5,9 %)	91 (7,4 %)
Medical	126 (4,2 %)	35 (2,9 %)
Treatment	123 (4,1 %)	52 (4,2 %)
School	95 (3,1 %)	39 (3,2 %)
Family	70 (2,3 %)	17 (1,4 %)

Table 2. General distribution of the top 10 original domains (as provided by each investigator after selection from the literal transcripts) for the combined 3027 chronic generic and condition-specific statements before reduction and the remaining 1225 statements after step 1 (%).

An importance score (Step 2) was given to each of the remaining statements by members of the DISABKIDS group. The interrater agreement between the expert importance ratings varied strongly and the interrater correlations were relatively low (overall ICC = 0.37, ranging from 0.05 to 0.69). Statements from the JIA and CF groups scored high on importance for a HRQoL questionnaire (3.44 (SD 0.59) and 3.48 (SD 0.48) resp.), while the asthma and epilepsy statements scored low on importance (2.77 (SD 0.74) and 2.76 (SD 0.78) resp.). After analysing the results the decision was made to omit this step. It was decided to go directly to the next phase (Step 3): a standard methodology of writing items on the basis of statements. Statements in the database were sent around for item writing, which was based on existing criteria [32,36]. The 1225 statements were divided into groups and rewritten by the DISABKIDS members into items appropriate for our instrument (Table 3). At the same time additional redundant or equivalent items and items not related to HRQoL were identified and removed. This further reduced the data file to 796 items.

Original statement	Rewritten statement
Leading a normal life and being together with others is important.	I can lead a normal life.
I'm glad that I've had arthritis for so long, so I don't know many things I can't do and therefore I didn't have to give anything up.	I accept that there are things I cannot do because of my condition.
It helps when others understand what you have, that they don't tease you.	Others understand what I have.
They want to do everything like the other children... but that is not possible…. afterwards she stays two days in bed, to recover.	I get exhausted easily.
I took her to psychosomatic counselling because she was so depressed (because of the illness) it was really bad.	I was depressed because of my condition.

Table 3. Examples of rewritten statements.

An iterative card sorting procedure (Step 4) was employed to assign items to (a) modules (chronic generic vs. condition-specific), (b) domains within modules and (c) dimensions within domains. At the same time remaining redundant or equivalent items were removed. This resulted in 148 items for the chronic generic module and between 25 to 54 items in each of the condition-specific modules. The rereading of the items in a DISABKIDS workshop again gave a slight reduction (Step 5). The final chronic generic pilot module consisted of 100 items and the condition-specific pilot modules consisted of between 26 and 44 items per condition (Table 4).

Module	Collected statements	After redundancy (step 1)	After item writing (step 3) *	After card sorting (step 4)	Refinement (step 5)
Generic					
Generic	488	-	-	-	-
Chronic generic					
Chronic generic	1647	583	307	148	100
Condition-specific					
Asthma	304	105	85	50	32
JIA	340	142	128	47	44
Atopic dermatitis	66	49	48	43	36
CP	183	121	34	25	26†
CF	167	86	73	54	38
Diabetes	141	62	61	31	28
Epilepsy	179	77	60	31	27
Total	3515	1225	796	429	331

Table 4. Results of the stepwise statement reduction process. Listed are the amounts of remaining statements after each reduction step.
*Step 2 was omitted in the statement reduction procedure.
†An item on independence was re-added.

Discussion

The current opinion in HRQoL research is that patient-derived approaches are required for valid questionnaire development in which a common methodology is the focus group approach [10,16,39,40]. The DISABKIDS project collected qualitative patient-derived data from seven chronic conditions. Unique is that the DISABKIDS project not only collected the items cross-nationally but that the selection steps were also carried out multi-centred, as experts from different countries participated in each step.

We have discussed a combination of steps to reduce the vast amount of collected statements from focus groups and interviews to develop the DISABKIDS pilot instrument. This stepwise process was done in an effort to make the item selection transparent and replicable. It is important to have a database showing all the taken steps so that one can refer to where each statement came from. It is conceivable that such an extensive process has not been presented before, as it is a complex system to describe in detail, often combining objective and intuitive judgements. The bottleneck was that investigators needed to make decisions about data that were supplied by children, adolescents and parents, causing the top-down procedure (investigators) to conflict with the bottom-up procedure (patients).

Before the pilot version items were selected, the DISABKIDS group had several moments of decision making. This started with which questions to ask in the focus groups, which HRQoL statements to select from the literal transcripts, how to translate these statements to one language, how to reduce the amount of statements, how to rewrite statements to items, which domains to utilize and whether all HRQoL aspects were selected. This process was complicated by the large amount of statements (3515 in total), the inclusion of seven chronic conditions and working in a multi-national group.

There are some issues in the DISABKIDS item selection methodology that need to be discussed. First, although the statements were generated from patient-derived methods the final item selection was based on the investigators (top-down) judgement (Table 1). As there was such an extensive amount of statements the DISABKIDS group decided to have the experts (instead of the patients) do the statement redundancy scoring (Step 1) and the importance scoring (Step 2). The data pool was so large that even the experts found it difficult to get an overview of all the statements. This is illustrated in the first reduction step where there was a distinct difference in the amount of statements removed by each of the experts and several redundant or equivalent items were missed. In an effort to bring back the children and adolescent's opinion, we asked them to approve the selected items and judge them on comprehension and applicability in a cognitive interview during the pilot test [41].

Other issues concern the construction of the statement pool. First, there was no opportunity to monitor how each country had selected the HRQoL statements from their national focus group and interview transcripts. The use of a computer was not applicable as the data were in several languages [42,43]. Thus personal interpretations, interests and subjective factors may have influenced the statement selection process [44]. In addition, there is a risk that when statements are taken out of their context they loose their original meaning [45]. Secondly, the investigator was responsible for the translation of the selected statement into English. As there was no official forward-backward translation the quality of the supplied English translation may have altered the meaning of the original statement and influenced the chance of it being used as a final item. Using expert or panel translators in this phase may have improved the quality of the statements and made the literal wording in the questionnaire more likely [46].

The DISABKIDS members provided the expert importance scoring, which was aimed at selecting those items that were fundamental to the DISABKIDS HRQoL instrument. Such an expert importance scoring has been used in other cross-cultural studies, such as the WHOQOL group [32]. Potential limitations resulted from this chosen method. Asking only the experts for the importance of a statement may have linked the importance scoring to their experienced severity of the condition. The JIA and CF statements where generally scored higher than the asthma and epilepsy statements. This indicates that the severity of the condition was probably scored and not the importance of each statement for the HRQoL instrument. Furthermore the given results may not reflect the highest frequency or importance as perceived by the patients with low and high disease severity. The expert scoring came with a risk that certain items (important to the patients) would be rejected in the selection process. Therefore the expert importance scoring (Step 2) was discarded by the DISABKIDS group. In future we would reconsider an importance scoring but per chronic medical condition and for separate degrees of severity, to avoid an item bias in the retained statements. Due to time and organisational constraints it was not possible to redo the importance rating and the step was omitted.

As most statements were literal phrases given by children and adolescents, the statements needed to be rewritten into items appropriate for the instrument. There was a danger revealed in the rewriting of the statements, as some items were no longer related to the original statement. For example: "My teacher thinks that I can't do anything" was changed to "Do you find schoolwork easy?" or "I can get colds much easier than others and have them longer" was rewritten into "Do you worry more than your friends about staying healthy?". Even though these changes lead to a conflict with our bottom-up approach the opinion prevailed that these new items were of importance, and thus remained in the item pool. In future an international item-writing group would be preferred to guard for uniformity and quality.

During the DISABKIDS item development process the card sorting was found to be a comprehensive and straightforward method to apply. As the item cards were grouped in piles, comparison was straightforward and it was easy to divide the items into domains and dimensions, identify redundant or equivalent statements or determine whether items had to be placed into another domain. Theoretically all previous reduction steps could have been performed in the card sorting method. A preferred strategy would have been to apply the earlier reduction steps in a card sorting method and to identify themes instead of statements to avoid a large data pool (Box 3).

• Statement selection	Have two or more experts select the statements from the transcripts
• Card sorting	Look for reoccurring themes per chronic condition and combine these in piles
• Redundancy	Remove excessive and semantically equivalent statements from the card sorting piles
• Modules	Compare the statements between the conditions and merge the overlapping statements to a chronic generic module
• Item writing	Rewrite the remaining statements into items

Box 3. Suggested steps in reducing qualitative data based on expert decisions.

Conclusion

We have described the DISABKIDS reduction process in detail and have shown that a few thousand HRQoL statements can make the item selection process of a new instrument quite complex. The current study shows that expert decisions were necessary to form a pilot instrument. By combining several reduction steps in this selection phase we tried to create the conditions for adequate face and content validity. Describing statement reduction methods has added value for future research as there is currently no basic guide of how to process qualitative patient-derived data. The DISABKIDS pilot and field study will provide further data on internal consistency, stability, validity and reliability [41].

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