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The use of focus groups in the development of the KIDSCREEN HRQL questionnaire

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Abstract

There is increasing interest in the public health sector in the health-related quality of life (HRQL) of healthy children. However, most HRQL instruments are developed for children with a chronic illness. In addition, existing questionnaires are mostly based on expert opinion about what constitutes HRQL and the opinions and views of healthy children are seldom included. In the European project KIDSCREEN, a generic questionnaire was developed for children between the ages of 8 and 18 on the basis of children's opinions about what constitutes HRQL. Focus group discussions were organised in six European countries to explore the HRQL as perceived by children. There were six groups in each country, stratified by gender and age. The age groups were 8–9 years, 12–13 years, and 16–17 years, with 4–8 children in each group. Experienced moderators guided the discussions. The full discussions were audiotaped, transcribed and content-analysed. The discussions went smoothly, with much lively debate. For the youngest group, the most important aspect of their HRQL was family functioning. For both younger and older adolescents, social functioning, including the relationship with peers, was most important. Children in all groups considered physical and cognitive functioning to be less important than social functioning. These key findings were taken into account when designing the KIDSCREEN HRQL questionnaire for healthy children and adolescents, with more emphasis being placed on drawing up valid scales for family and social functioning. In addition, items were constructed using the language and lay-out preferred by the youngsters themselves. We conclude that focus groups are a useful way of exploring children's views of HRQL, showing that an emphasis should be placed on constructing valid social and family scales.

Key words: Qualitative research, Focus groups, HRQL questionnaire development, Children, Adolescents

Introduction

Monitoring the health status of the population is one of the main activities of public health. In addition to traditional health indicators such as mortality and morbidity, there is increasing interest in the subjective representation of health and well-being, also known as health-related quality of life (HRQL). As a result, a lot of effort has gone into developing and testing self-report questionnaires designed to measure HRQL. While most questionnaires are developed for adults, a number of questionnaires have also been developed for children. However, most HRQL instruments target children with a chronic illness [1] and most existing questionnaires are based on expert opinions about what constitutes HRQL. The opinions and views of children themselves about HRQL are seldom included. In addition, there are no cross-cultural instruments [2]. So the European project KIDSCREEN developed a generic questionnaire for children aged between 8 and 18 in order to monitor, evaluate and plan health prevention on a routine basis [3, 4]. In order to minimize cultural bias, the questionnaire was developed simultaneously in seven European countries. A general overview of the course of development and the initial psychometric results of the KIDSCREEN questionnaire can be found elsewhere [4].

The main aim of this article is to describe an important step in the questionnaire development: the focus group discussions with children and adolescents. In addition, to make clear how the results of the focus groups were used to construct the pilot questionnaire, the steps followed after the focus groups, will be briefly described. The focus group approach involves group discussions and capitalizes on communications between participants to generate data, explicitly using group interaction as part of the method [5]. Experienced moderators guide the discussions. Participants are encouraged to talk to each other, to ask questions, exchange experiences, and comment on each other's points of view. The method is particularly useful for exploring issues of importance to the participants in their own vocabulary, allowing them to pursue their own priorities. This method can be very helpful in developing a HRQL questionnaire based on the opinions of the target group because it can: (1) highlight important gaps in the previous conceptualization of the HRQL construct; (2) identify HRQL constructs that have been omitted completely from the conceptual framework; (3) identify specific items that measure relevant HRQL constructs (including those determined previously); and (4) provide the researcher with direct access to the language participants use [6]. Although most focus group research has been conducted with adult populations, there is evidence to suggest that focus groups are a valuable way of eliciting children's views on health-related matters [7].

The focus group discussions were preceded by a literature review and a Delphi procedure with HRQL experts [4]. The aim of the Delphi study was to elicit expert opinions and determine the degree of expert consensus on aspects of the conceptualization and operationalization of HRQL. A total of 24 experts (psychologists, paediatricians, sociologists and health services researchers) agreed that the HRQL questionnaire should cover a multidimensional concept, reflecting the respondents' own view of their state of health. The specific dimensions of HRQL listed for inclusion (e.g. psychological well-being, self-esteem, body image, cognitive functioning, mobility, energy/vitality, social relations and family/home function) related to aspects of physical, mental and social health. Agreement was reached that the questionnaire should aim to measure HRQL as a generic construct in largely healthy children, so more emphasis was placed on the inclusion of psychosocial domains, and less on domains such as physical functioning or pain symptoms [8]. The results of the Delphi procedure were used as the starting point for the focus group discussions.

These focus group discussions took place in six European countries[1] (Germany, United Kingdom, France, the Netherlands, Spain and Switzerland) to explore the concept, construct and content of HRQL as perceived by children and adolescents. The specific aims of the focus group discussions in the KIDSCREEN project were (a) to identify dimensions and items for establishing the item pool by exploring the meaning of quality of life for the participants and the impact of health problems, and (b) to evaluate the lay-out and answer categories in other generic quality of life questionnaires by presenting the groups with short individual paper-and-pencil questionnaires including specimen items (e.g. parts of existing questionnaires).

In addition to the focus group discussions, questionnaires were sent to parents to determine their perceptions of HRQL in children and adolescents. It was considered important to determine their perceptions as well because children (and particularly the younger children) may lack the cognitive abilities to consider all aspects and they may lack a long-term perspective. In addition, the aim was to also develop a parent version of the questionnaire. Parents' views were seen as complementary to the information of the children.

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[1] Austria also participated in the development of the KIDSCREEN questionnaire. However, for logistical reasons, there were no focus groups in Austria.

Methods

Participants

The plan was for six focus groups in each country, with four to eight participants in each group. To optimize group discussion, the composition of the groups had to be as homogeneous as possible. The research teams were therefore assigned to separate gender and age groups. Groups were planned with girls aged 8–9, boys aged 8–9, female adolescents aged 12–13, male adolescents aged 12–13, female adolescents aged 16–17 and male adolescents aged 16–17. These age groups were chosen to include children in different developmental stages. It was considered preferable if the children in the groups did not know each other and were from different socio-economic backgrounds. The participants were therefore recruited via a large number of schoolteachers in different regions in each country. The regions were selected on the basis of postal codes associated with different levels of wealth as categorized by the different national institutes for statistics. Thus, the regions were used as a proxy measure for SES and there was no formal assessment of SES. Children who were willing to participate received a letter at home. Written informed consent was obtained from all parents and from children aged 12 years and older. The parents of children who participated were also asked to complete a short questionnaire about sociodemographics and about the health status of their child (indicating whether the child suffered from a chronic condition or not).

Procedure

The focus group procedures of Morgan, Krueger and King [5] were used to prepare and conduct the sessions. The following definition was used: a focus group is a discussion group with 4–8 children or adolescents talking about different aspects of their perceived quality of life. A carefully constructed protocol was followed in each country. This protocol included information about the methodology (e.g. inclusion criteria as described earlier), about the organisation and logistics (e.g. setting, this had to be a quiet and cosy room, where children would feel comfortable, and there had to be a break during the discussion with refreshments available), about the content to be discussed and about the documentation for the discussions. The content to be discussed proceeded from open questions (“When do you feel good?”) to increasingly closed questions (“What activities do you like to do in your free time?”). A list was provided with 26 topics stemming from literature review and Delphi procedure that were addressed in the focus group discussions.

In addition, seven response scales were selected from four existing questionnaires (VSP-^{A} [9], KINDL^{R} [10], CHQ [11], TACQOL [12]). Specimen questions were presented to the children and they were asked to answer on the different response scales. Two smiley pictograms were presented alongside the verbal response categories. A discussion was then initiated, in which the children were asked to decide which answer scale they found more or less difficult and which one they would prefer.

Conducting the discussions

Two experienced moderators ran the sessions. One of the moderators led the discussion (encouraging the children to discuss topics, putting new questions and keeping the discussion on the topic), while the other took notes and made observations. Each discussion was limited to two hours, with a break in between.

All the discussions began with the moderator describing the aim of the project. This was followed by some “get-acquainted activities” and an explanation of the ground rules, like respecting the opinions of others, avoiding put-downs and giving everybody a chance to talk. After the introduction, the key content section began, starting with global questions like: “What is important for you to feel good?” followed by more specific questions like “What kinds of activities do you like?” or “When do you feel ill?”. The children were then asked to discuss and rate the importance of existing dimensions. Finally, the children were asked to comment on the format and answering scales of existing questionnaires.

Analysis

All the sessions were audiotaped, transcribed without paraverbal expressions, repetitions, deviation from the subject and the like, and content-analysed [6]. Several steps were considered: (1) going through the transcripts and identifying sections that were relevant to the research questions; (2) marking different topics with different symbols in the text based on a classification system. Coded materials may be phrases, sentences or longer exchanges. The only requirement was that the material must be relevant to the particular category; (3) allocating sampled statements to categories. The amount of material coded for each topic together with the notes of the observer reflected the importance granted to that topic. We did not derive statistical results from content analysis. The transcriptions of the focus group discussions, supplemented by the parents' questionnaires, were used as the basic material for content analysis. Predefined dimensions, based on an earlier literature review and the Delphi procedure [1, 5] were used as starting categories but redefined and completed in the process of analysis. Within the categories, all the different aspects/items were written up as statements. Relevant statements that did not fit into the predefined categories were assigned to new categories. The content analysis was conducted separately in each country by two independent raters. See Figure 1 for the content analysis procedure.

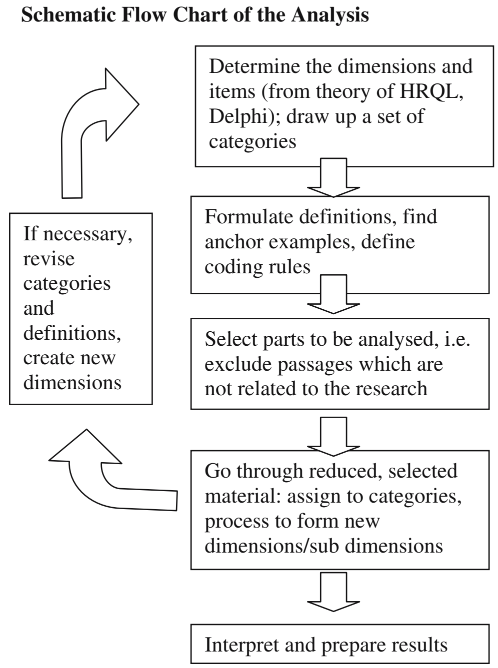

Figure 1. Schematic flow chart of the analysis.

Results

Sample and process

There were six focus groups in each country. Table 1 provides an overview of the characteristics of the children who participated. A total of 214 children participated, 12% of whom had a chronic condition. Ten percent were from ethnic minorities.

In most groups, the children did not know each other. All the countries managed to recruit children from different neighbourhoods that were associated with different levels of wealth, indicating different levels of SES. In general, the discussions went off smoothly, with much lively debate. An example of the discussion is as follows: “What is important for you to feel good”? (silence) ..... “Nice weather”, “Doing nice things”, “What do you mean by nice things”? (all respond) ...“Going out with my friends” “Going to a movie”, “Having a good time with my friends”... “When do you have a good time with your friends”? ...“Always when we are together” ... “When we are talking”.

Content

In general, all the age and gender groups mentioned more or less the same aspects and

Table 1. Characteristics of participating children

Gender	
Male	109 (51%)
Female	105 (49%)
Age groups	
8–9	66 (31%)
12–13	75 (35%)
16–17	73 (34%)
Health status	
Healthy	188 (88%)
Chronic illness	26 (12%)
Nationality	
Etnic majority	193 (90%)
Ethnic minorities	21 (10%)

dimensions of HRQL, but they varied in terms of the wording and the importance given to each aspect. Important aspects of HRQL for younger children were family functioning, including the relationship and interactions with parents and the atmosphere at home, and social functioning, including positive and negative encounters (playing, bullying) with peers. These issues were earlier raised in the discussions and many different aspects were mentioned. (examples of positive statements were: I like playing with my friends, I like going to the movie with my mother; examples of negative statements were: I feel sad when we quarrel at home, I feel sad when there is nobody to play with, I feel sad when other children tease me). In both adolescent groups, HRQL included social functioning, in particular the relationship with peers (receiving social support from peers), family functioning and emotional well-being. Again, these issues were the first issues brought up in these groups, ideas were shared by most participants and many different aspects were mentioned. (examples of positive statements were: I like going out with my friends, sitting with my friends, talking with my friends, examples of negative statements were: I feel sad when parents/teachers stress me too much, I feel sad when I don't have money to do the same things as my friends, I feel sad when others think I am different, I feel sad when I am excluded from activities). In all groups, the children mentioned fewer issues relating to physical and cognitive functioning than issues relating to social functioning. The perceived impact of health problems was rated both positively and negatively. Positive aspects mentioned were: "Everybody is nice to you", "You receive extra attention" and "You don't have to go to school". Negative aspects mentioned were: "Your friends are doing things without you", "You are really on your own", "You can't go out" and "You feel miserable". The groups in the different countries gave very similar ratings to the importance and content of dimensions. Only a few differences were seen in the frequency with which topics were discussed within dimensions. For example, in Germany and Switzerland, more items relating to cognitive functioning were mentioned than in the other countries.

Response scale options

The focus groups discussed different response scale options (e.g. boxes with verbal descriptors, smileys, visual analogue scales) and time frames originating from other HRQL questionnaires. All the children agreed that tick boxes with a Likert scale were the most convenient response format. Overall, they preferred them to other response formats (e.g. yes/no, a line). There were differences with respect to the number of tick boxes: while 8–9 year old children in general preferred three choices, adolescents preferred five or more choices. Differences between countries were seen in younger children. For example, younger Spanish children preferred three response options, but younger German children preferred four to five options.

In general, frequency scales were thought to be easier than intensity scales.

Results for time frames show that younger children preferred answer scales in the "last week" range and that a time interval of the "last 4 weeks" was too difficult for them. Adolescents chose the "last week", "in general" or "recently" options.

The results of the focus group discussions concerning the content of HRQL and the response categories were used as a starting point in the item development.

Item development

A total of 2,505 statements, 1,642 of which came from the focus groups, with the remaining 863 coming from the parent questionnaires, were allocated to 26 dimensions. Of these 26 dimensions, eight were predefined on the basis of the literature and the Delphi procedure and 18 were established on the basis of the discussions. These 2,505 statements formed the basis for item development. The first step was to reformulate all the statements as items and translate them into English. The following step was item clearance. A multidisciplinary group consisting of HRQL experts, child psychologists and educational specialists from three countries was formed. They rated all items for clarity using the EUROHIS criteria (redundancy, HRQL concept, substandard) [13]. This resulted in 1,070 items in 24 dimensions. See table 2.

This step was followed by a card sorting procedure in which all countries participated. This

Table 2. Different statements within (predefined) dimensions after item clearance

Dimension	No. of statements
1 Social relations	206
2 Family/home functioning	190
3 Self-esteem	132
4 Psychological well-being	119
5 Cognitive/school	96
6 Energy	61
7 Leisure	49
8 Environment	38
9 Mobility	34
10 Physical functioning	24
11 Autonomy	23
12 Future	16
13 Physical complaints	11
14 Body image	10
15 Special activities	10
16 Physical well-being	9
17 Health concerns	7
18 Finances and material circumstances	6
19 Spiritual	5
20 Unidentified	4
21 Social activities	3
22 Creativity	3
23 Sedentary activities	2
24 Life perspective	2
25 Limitations	0
26 Free time and fun	0

technique is employed in cognitive psychology [14] and it reduced the number of items while taking into account the dimensions of HRQL that the children and parents deemed to be important as an underlying theoretical model. In each dimension, the cards were divided into a number of categories on the basis of certain common features. In each category, the items were ranked by the research team according to how well they represented the dimension. In addition, chosen items had to be representative for all countries because the aim was to develop a cross-cultural questionnaire suitable for children of 8 years of age and older. As a result of the card sorting procedure the number of items was reduced to 185 items. These 185 items were translated into the languages of the participating countries in accordance with international guidelines [15] and the translated questions were tested in interviews using cognitive debriefing. In each country, eight children were asked to read each question aloud and to comment on the difficulties, the comprehensibility and importance of that question. A total of 49 children participated (23 aged 8–11 and 26 aged 12–18). In general, the pilot questionnaire was not too difficult to fill in, the questions were mostly comprehensible and the children thought they were important for them. The younger children found a number of questions difficult to answer. The next step was to reach agreement on final item selection and formulation at a meeting attended by all research teams. During this meeting it was decided to conduct pilot tests of two versions, one for the younger children (8–11) with 177 items and one for the adolescents (12–18) with the same 177 and 8 additional items.

In summary, the results of the focus groups formed the basis for developing items to be included in the questionnaire. This was followed by including the comments from parents, the card sorting process, and the cognitive interviews with children and adolescents. These steps together led to the KIDSCREEN HRQL pilot questionnaire with 177 items for children and 185 items for adolescents. The items covered 26 specific dimensions, which were combined on the basis of common themes and the theory underlying the procedure into ten broader domains (see Annex 1).

Discussion

This study demonstrated the development of an HRQL questionnaire using focus groups with children and adolescents and indicated that this approach was beneficial and successful. Although HRQL is an abstract and rather broad concept, vivid discussions between children took place and valuable information was obtained about the content of HRQL for children. Children, even those as young as eight years of age, and adolescents were able to describe and prioritize aspects of HRQL. Nevertheless, during the discussion the youngest children were easily distracted and were very associative. Overall, their answers were linked more to their everyday experiences; adolescents were able to answer the questions in both concrete and abstract ways. In addition, the oldest girls appeared to be more inclined to conform with group ideas. The rating of the importance and the content of the dimensions was very similar between the participating countries. Nevertheless, some differences were seen in the frequency with which items were mentioned within dimensions. In Germany and Switzerland, more items referring to cognitive functioning were mentioned than in the other countries. This may be a result of cultural differences.

The results showed that social functioning and social relations are the most important aspects of HRQL for both children and adolescents. Limitations in social functioning were also mentioned most in response to questions about the consequences of illness. The emphasis on social relations is not unexpected, given that these children constituted a largely healthy group and that this is a very important dimension for children, whereas the physical dimension becomes more important when there are limitations on activity or when handicaps are present. These results were taken into account during the design of the KIDSCREEN HRQL questionnaire. In particular, more attention was paid to establishing scales for family and social functioning and more items focus on these aspects than is usual in an HRQL questionnaire. In most HRQL questionnaires, these scales are less valid and reliable [1]. In addition, the wide range of material generated by the focus group discussions made it possible, in the scale construction phase, to establish a scale that asks children and adolescents if they are bullied. So the KIDSCREEN instrument contains a scale measuring social rejection; this is an important topic to assess in a general HRQL questionnaire. In addition to these content-related issues, the focus group discussions showed that questions about the response scale options and the time frame are important. In general, children and adolescents favour tick boxes combined with verbal descriptors to other response formats used in HRQL questionnaires. Furthermore, both children and adolescents prefer a time frame in the "last week" range. These findings are important for the development of an understandable and easily answerable questionnaire for children and adolescents.

Population samples consist of largely healthy children, but chronically ill children are also included in population samples. The questionnaire is primarily intended for use in open population samples but it is expected to be useful as a generic questionnaire for children with a chronic illness if the focus is on their general health related quality of life rather than on specific illness related aspects. Given that 12% of the participating children in the focus groups had a chronic disease we expect that their perspective of HRQL is included, bit this needs further testing. The pilot study has already shown that the KIDSCREEN dimensions of psychological well-being, moods and emotions, and self-perception are moderately to highly correlated with the Psychosomatic Complaint Index: children and adolescents with more psychosomatic complaints reported lower levels of psychological well-being, more depressive moods, emotions and stressful feelings, and their perception of their own body appearance was more negative than in individuals with fewer psychosomatic complaints [4]. This means that the KIDSCREEN instrument may be sensitive to such psychosomatic complaints. However, sensitivity to physical discomfort, pain and or prevalent chronic conditions needs to be investigated in future studies.

In conclusion, focus groups proved useful for exploring children's views of HRQL and resulted in issues that are relevant for the development of a HRQL instrument for children and adolescents. The focus group approach allowed the social dimension to be explored in greater depth, thereby increasing the validity of the measure for children and adolescents.

Annex 1

Dimension 1: Physical well-being

This dimension explores the level of a child's/adolescent's physical activity, energy and fitness. The level of physical activity is examined with reference to the child's/adolescent's ability to get around the home and school and to play or do physically demanding activities such as sports, since a child's/adolescent's impairment does also affect physical activity. The dimension also looks at a child's/adolescent's capacity for lively or energetic play. In addition, the extent to which a child or adolescent feels unwell and complains of poor health is examined.

Dimension 2: Psychological well-being

This dimension examines the psychological well-being of the child/adolescent, including positive emotions and satisfaction with life. It specifically reveals the positive perceptions and emotions experienced by the individual. The questions look at how much a child/adolescent experiences positive feelings such as happiness, joy, and cheerfulness. They also reflect the person's view of their satisfaction with life so far.

Dimension 3: Moods and emotions

This dimension deals with the extent to which the child/adolescent experiences depressive moods and emotions and stressful feelings. It specifically reveals feelings such as loneliness, sadness, sufficiency/insufficiency and resignation. Furthermore, this dimension takes into account how distressing these feelings are perceived to be. This dimension shows a high score for quality of life if these negative feelings are rare.

Dimension 4: Self-perception

This dimension explores the child's/adolescent's perception of self. It includes whether the appearance of the body is viewed positively or negatively. Body image is explored by questions about satisfaction with looks as well as with clothes and other personal accessories. The dimension examines how secure and satisfied child/adolescents feel about themselves as well as their appearance. They are meant to reflect the value somebody assigns to him/herself and the perception of how positively others value him/herself.

Dimension 5: Autonomy

This dimension looks at the opportunity given to a child or adolescent to determine what they do with his/her own social and leisure time. It examines the child's/adolescent's level of autonomy, which is seen as an important developmental issue for creating an individual identity. Autonomy refers to the child's/adolescent's freedom of choice, self-sufficiency and independence. In particular, the extent to which the child/adolescent feels able to shape his/her own life as well as being able to make decisions about day-to-day activities will be considered. The dimension also looks at whether the child/adolescent feels sufficiently provided with opportunities to participate in social activities, particularly in leisure activities and pastimes.

Dimension 6: Parental relations and home life

This dimension examines the relationship with the parents and the atmosphere in the home of the child/adolescent. It explores the quality of the interaction between the child/adolescent and parent or carer, and the child's/adolescent's feelings towards parents/carers. Particular importance is attached to whether the child/adolescent feels loved and supported by the family, whether the atmosphere at home is comfortable or not and also whether children/adolescents feel they are treated fairly.

Dimension 7: Social support and peers

This dimension examines the nature of the child's/adolescent's relationships with other children/adolescents. Social relationships with friends and peers are considered. The dimension explores the quality of the interaction between the child/adolescent and peers as well as their perceived support. The questions examine the extent to which the child/adolescent feels accepted and supported by friends and the child's/adolescent's ability to form and maintain friendships. In particular, aspects concerning communication with others are considered. It also explores the extent to which the person experiences positive group feelings and how much he/she feels part of a group and respected by peers and friends.

Dimension 8: School environment

This dimension explores a child's/adolescent's perception of his/her cognitive capacity, learning and concentration and feelings about school. It includes the child's/adolescent's satisfaction with his/her ability and performance at school. General feelings about school, such as whether school is an enjoyable place to be, are also considered. In addition, the dimension explores a child's view of the relationship with his/her teachers. For example, questions include whether a child/adolescent gets along well with his/her teachers and whether the teachers are perceived as being interested in the student as a person.

Dimension 9: Social acceptance

This dimension covers the aspect of feeling rejected by peers in school. It explores both the feeling of being rejected by others as well as the feeling of anxiety towards peers.

Dimension 10: Financial resources

The perceived quality of the financial resources of the child/adolescent is assessed. The dimension explores whether a child/adolescent feels that he/she has enough financial resources to allow him/her to engage in a lifestyle comparable to other children/adolescents and provides the opportunity to do things together with peers.

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