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Using cross-national focus groups to identify health related quality of life (HRQoL) aspects in children and adolescents with asthma and their parents: the European DISABKIDS approach

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Submitted

The need to incorporate patients' values and preferences is what distinguishes quality of life from all other measures of health (T.M. Gill, 1994).

Abstract

Focus groups and interviews were conducted to support the bottom-up developmental process of the DISABKIDS health related quality of life (HRQoL) instrument for children and adolescents with a chronic medical condition and their parents. The HRQoL statements which were identified through focus groups and interviews were used to develop the European DISABKIDS HRQoL instrument. Participants included children and adolescents with a chronic medical condition, their parents and health care professionals across Europe. The asthma results are presented in more detail. The asthma focus groups and interviews were conducted in four European countries (Greece, Italy, the Netherlands and Sweden). A total of 43 children and adolescents with asthma, 33 family members and 7 health care professionals participated in the focus groups and interviews. Asthma symptoms and related medical aspects were discussed in all groups. Additional issues related to asthma included physical limitations in the youngest groups and social issues in the adolescent groups. Parents were worried about prevention, long-term effects, medication and school. The discussed topics were similar between countries. A total of 637 HRQoL statements were collected from the asthma focus groups and interviews for the development of the European DISABKIDS instrument. In addition to having to live with the medical implementations of asthma, children and adolescents are also effected in social and physical areas. The children and adolescents discussed the current limitations they experienced while parents concentrated on the long-term consequences. A greater understanding of the impact of asthma on the lives of children and adolescents was achieved. The focus group discussions were also a useful tool in generating statements from children and adolescents with a chronic condition like asthma for the development of the DISABKIDS HRQoL instrument.

Introduction

There are several aspects that need to be considered during the development of a paediatric health related quality of life (HRQoL) questionnaire. Ideally a HRQoL questionnaire should give an accurate representation of the aspects in life that are affected by an illness. Choosing which issues should be included in a questionnaire and how to generate these items are important decisions. There is no standard procedure for developing a HRQoL questionnaire for children or adolescents. Existing questionnaires have been constructed in several ways, they vary in their definition of HRQoL, they consist of different multidimensional constructs and differ in the content of the domains¹⁻⁷. Selected items are often derived from one or more sources including relevant literature, existing questionnaires, health care professionals' opinions, investigators' opinions and the views of the child, adolescent or the parent⁸⁻¹⁸.

To make sure that a paediatric HRQoL questionnaire accurately represents the child or adolescent's HRQoL, it is important that the items are appropriate to the representation of their illness. Numerous studies have shown that using the expert or parent opinions to construct a paediatric questionnaire can lead to bias and poor face and content validity as their opinions can differ from those of the child or adolescent¹⁹⁻²⁵. As HRQoL is an attribute of the patient emphasis should be on the child and adolescent's perception of HRQoL. To accomplish this, the child and adolescent should be directly involved in the development of any paediatric HRQoL questionnaire by defining and identifying the issues that are important to them²⁶⁻²⁸.

There are various ways of involving children and adolescents in the development of a new questionnaire. Their opinion can be collected through surveys, interviews or focus groups. A focus group is a qualitative research method, which allows the investigator to explore the opinions, attitudes, knowledge, concerns and experiences of a group²⁹⁻³¹. Within HRQoL research focus groups can be used to explore the health care perception of a particular population, to study research questions or to support the development of a questionnaire^{31,32}. Focus groups are also useful in generating questionnaire items as participants can determine the topics and identify HRQoL issues that are important to them^{30,33}. This in contrast to having health care professionals, investigators or family members judge the importance for children and adolescents^{26,34}.

There are several publications on how a focus group can be used as an appropriate method to explore HRQoL issues in children and adolescents with a chronic medical condition³⁴⁻³⁸. The European DISABKIDS project included seven chronic medical conditions in the development of the paediatric HRQoL instrument. The findings reported in this paper are part of the larger DISABKIDS focus group study. We will only elaborate on the asthma results generated from the focus groups and interviews with children and adolescents with asthma, their parents and health care professionals. First, a qualitative description of the cross-national asthma focus groups and interviews is given. Secondly, the collected HRQoL statements will be described in a quantitative manner.

Method

The DISABKIDS project

The DISABKIDS project is a collaboration of eight research centres in seven European countries. The aim of the project was to develop a new HRQoL instrument for children and adolescents with a chronic medical condition and their parents³⁹. Seven chronic conditions were included in the project: asthma, juvenile idiopathic arthritis (JIA), atopic dermatitis, cerebral palsy (CP), cystic fibrosis (CF), diabetes and epilepsy. The instrument aims to consist of aspects that are important to the patient, be multidimensional, cross-nationally applicable, valid, reliable and sensitive⁴⁰. The developmental process followed predefined steps (Box 1). The final HRQoL instrument consists of two modules: a chronic generic module that is applicable to all children or adolescents with a chronic

medical condition and condition-specific modules for each of the seven included chronic conditions. Central to the DISABKIDS methodology was the ‘bottom-up’ construction or patient-derived method. Relevant HRQoL aspects were identified from the perspective of the child, the adolescent, their parents and health care professionals. Unique to this project is that focus groups were run cross-nationally. Subsequently the collected HRQoL statements are formulated into items and incorporated into the chronic generic or a condition-specific module ⁴¹.

- 1: Literature review
- 2: Focus groups
- 3: Item selection
- 4: Translations
- 5: Pilot testing
- 6: Analysis pilot study
- 7: Field study
- 8: Analysis field study
- 9: Implementation

Box 1. Developmental steps within the DISABKIDS project.

Participants

Children (aged 4-7 and 8-12) and adolescents (aged 13 -16) with a chronic medical condition and their parents were invited to participate in the focus groups. Families were identified through patient associations or their hospital clinicians. They received an invitation by mail and were phoned to ask whether they would participate. Patients with additional chronic conditions or who did not verbally master the national language were excluded. The focus groups were divided by chronic condition and stratified by age (4-7, 8-12 and 13-16 years). Each focus group consisted of a mixture of disease severity and gender. If participants were unable to attend a planned focus group they could take part in a personal interview. Parents were invited to participate in separate focus groups (grouped according to the chronic condition and age of their child). Health care professionals were contacted directly and where often affiliated to the research centres. The responsible local Ethics Committees approved the study and all participants signed a consent form.

Focus groups

To insure that a similar method was used in all participating countries a manual was written which included the outline of the focus group process and the question structure. A moderator led the focus groups and asked the questions, while an assistant observed, wrote minutes and operated a tape recorder. At the start of the focus groups the aim, duration and confidentiality was explained. Permission was also obtained for audio-taping. The moderator started with the semi-structured questions, given in the manual, and allowed the participants to direct the discussion. During the session the questions were directed towards more illness related topics. The moderator made sure to create a safe environment, encouraged involvement and probed for comments. As a closing exercise children and adolescents were asked to write their own questions of what would give a

clinician a good impression of their HRQoL. Approximately 90 minutes was planned for each session. At the end, all participating children and adolescents received a gift. The focus groups and interviews were transcribed verbatim. This raw data was used for two purposes. Firstly, the transcripts were used to illustrate the discussed themes and the perceptions of the participants. Secondly, statements related to HRQoL were identified from the national transcripts by investigators in each country. These statements were entered into a database and used for the development of the DISABKIDS items ⁴¹.

Results

Population

Asthma focus groups and interviews were conducted in Greece, Italy, the Netherlands and Sweden from June to August 2001. A total of 9 child/adolescent focus groups and 8 parent groups were conducted, with an average of two of each in every country. In total, 43 children and adolescents with asthma (6, 23 and 14 in the age group 4-7, 8-12 and 13-16, respectively) and 33 family members participated in the focus groups and interviews. Generally the focus groups consisted of 3-6 participants. The Dutch centre also included two focus groups with experts (4 asthma nurses and 3 paediatricians), in order to collect their opinions and to enable comparison with the child or parent's view.

Qualitative focus group results

Child and adolescent

Children and adolescents indicated that it was bothersome to take medication on a daily basis. They often forgot to take the medication and some felt that they didn't need medication when they had no complaints. It was noted that those who discussed non-compliance to the medical regimen were also uncertain about how the medication worked or how it affected them (Box 2). Some found that they were insufficiently informed about side effects, worried about taking prednisolon or had an aversion to frequently changing their medication. The younger children complained about the taste of the medication. Most said that they did not mind taking medication in front of others but they tended to avoid this as much as possible. When discussing their relationship with the clinician some indicated that they would prefer the clinician to talk to them on a more personal level. Others were happy with the ways things were and felt understood. Especially the younger children disliked specific procedures such as getting injections, blowing peak flow or lung function tests. Hospital admittance generally had a negative impact on the child and adolescent.

The children and adolescents experienced several physical symptoms related to having asthma. They complained about their cough, feeling short of breath or feeling like they are breathing through a straw. Symptoms were influenced by cigarette smoke, dust, sports, weather seasons or emotions. They indicated that they got tired easily, had less energy than their peers and experienced limitations during physical activities. Sport is a recurring topic in the focus groups. The majority had experienced the need to stop during sport because

they were out of breath or didn't have enough energy to keep up with the rest of the group. This is troublesome because they feel left out of the group. Children and adolescents with allergies to pollen, dust or animals experienced even more limitations. These irritants are influential in classrooms, at a friend's place and on school trips. Having to avoid certain places and activities has an impact on everyday life in terms of encountered limitations. The younger children often spoke about not being allowed to play with pets or missing their cuddly toys. The adolescents knew that they needed to avoid cigarette smoke but found it hard, as going to a friend's place or going out sometimes makes this unavoidable.

Non-compliance:

- The teacher said that medication is bad
- I shake because of the side effects so I don't take my medication on the days I have a school-test
- I don't take medicationto forget that I have asthma

Medical care:

- I am bothered by having to visit the hospital when I have an asthma attack
- I don't like going to the doctor to do injections for the allergy
- Lying in the hospital, that is most bothersome
- Family doctor never lets you finish talking

Limitations:

- Having asthma is not so nice, because you can't join in so many games
- I dislike the fact that I have to have a rest when I run
- Cannot go to parties at homes with pets

Social:

- The kids at school don't know that I have asthma
- Others go and tease you with it
- School parties are unpleasant because of the smoking
- They don't understand that you're short of breath
- I don't talk with my friends about my problem
- X understands that he is different from the other children and is worried about it

Box 2. Statement examples from the focus groups and interviews.

Children and adolescents don't want to feel any different from their peers. They find it important to belong to a group and to go out with friends. However, especially in the adolescent groups we found that due to the asthma they often felt different and left out of school activities. Experienced physical limitations made it harder to keep up with peers. Being ill, missing school or being behind in schoolwork sometimes prevented them from participating in social activities.

Some become angry when they are restricted in what they want to do. Others worry about getting teased because they cannot keep up with sports or need to take medication at school. For this reason some avoid mentioning that they have asthma. Most have come across not being understood by others, not only with peers but also with teachers or adults. School was not mentioned much by the younger group. Adolescents found it frustrating to miss school or school tests due to asthma complaints, hospital check-ups or admissions. This made it harder to keep up with the school's learning schedule. They indicated that it is important that the teachers understand the implications of having asthma.

Parents

The main issues discussed by the parents' concerned medication and emotional effects of asthma. Most parents indicated that there were frequent arguments because of their child not wanting or forgetting to take their medication. Parents worry about possible side effects from the asthma medication, especially about any long-term effects and whether their children can lead a healthy life in the future. Parents frequently discussed health care and the treatment they receive from clinicians. They want more information about health care facilities and medication. Having a doctor who listens and explains this is very important to them.

Parents know that their children are not able to participate in all activities. They acknowledged that their children get tired easily, cannot compete as well in some sports and avoid extreme activities. They also mentioned that their child misses out on certain activities as playing at a friend's house or having sleepovers. They believe that this makes it harder for them to make friends and may make them feel different from their peers. Parents also acknowledged that some children try to hide their asthma from friends. Some worry about their children being ashamed of having asthma. They find it hard to find out how their child really feels and how they cope with their asthma.

A few parents think that their children are more grown up, tougher, have more drive to prove themselves because of the asthma. Others parents worry about the amount of responsibility a child can have. They are constantly checking on their kids, what they can and can't do. Parents are concerned about their child's vulnerability and try to protect them from exhaustion and irritants (i.e. limiting activities, keeping their home clean, getting rid of pets or cuddly toys). Their main aim is to prevent their child from getting asthma symptoms. The downside is that this sometimes restricts their child, for instance in developing social contacts. School performance was also a frequently discussed topic. Parents worry about the effect asthma had on the child's schoolwork due to getting tired easily, missing school or redoing tests. They try to inform the school on the impact of asthma and the importance of avoiding irritants. However, not all teachers understand the implications of asthma.

Country specific issues

In general similar topics were discussed in all four countries. There were some country specific aspects like riding a bike in the Netherlands, going to the beach in Greece and into the mountains in Italy. Greece was the only country where allergies, pets and difficulty to visit friends were not discussed in the focus groups.

Age differences

Children in the age group 4-7 did not spontaneously speak about their illness. They discussed basic things like what games they liked. Some discussed getting tired when running or playing. They often spoke about wanting pets. Children aged 8-12 talked about

the more practical aspects as needing to use medication, not being able to do as well as other kids in sports or physical activities, about their symptoms bothering them and about not wanting to take medication. Some also discussed wanting a pet but not being allowed to have one. Next to the practical implication of using medication the teenaged group (aged 13-16) discussed more topics related to social activities. They discussed being less able to join in sports and physical activities or that some social activities were a problem (school parties, going out, disco, staying at a friends place, family gatherings). Most issues related to trying not to be any different from others and fitting into the peer group.

Health care professionals

The Dutch paediatricians and specialised asthma nurses that participated in the focus groups reported that it is difficult to understand the child's perspective. Current emphasis is on the presentation of symptoms and objective measurements of the disease. They try to specifically ask the child for their views as they realise that there might be a discrepancy between what parents tell them and what the children and adolescents experience. The problem as they see it is asking the right questions. They generally ask questions about sports and use of medication, but know that the answers may not reflect the actual problem the child is experiencing. Adolescents rarely talk about problems spontaneously. The clinicians and nurses acknowledge this as a problem as they know that they might miss valuable information about aspects in the adolescents' life, such as associated problems at school or in their social life. However, especially the clinicians feel limited by the time they have available when running a busy outpatient clinic.

Quantitative asthma focus group results

Item pool description

A total of 637 statements related to HRQoL were identified from the asthma focus group and interview transcripts and pooled in an asthma data bank. Three hundred and four statements were recognized as being specifically asthma related (condition-specific). These statements were used to develop the asthma specific module of the DISABKIDS instrument. Three hundred and thirty three statements could be appropriate to a child or adolescent with any chronic medical condition (chronic generic) and were not specific to having asthma. These chronic generic statements, collected from the asthma transcripts, were merged with the chronic generic statements collected from the focus groups and interviews of the other chronic medical conditions.

The statements collected from the asthma focus groups and interviews were given domain names by two investigators (RMB and JEC). Their interrater reliability was 0.52 (Cohen's kappa). When the given domain differed a third investigator (HMK) assigned the final domain name (Table 3). Most collected statements entered into the database were related to symptoms, treatment or medical care (35%). Statements related to limitations and restrictions mostly originated from the younger children and their parents. The children and adolescents generated most of the social statements. The adolescent's parents generated the majority of the statements related to school.

Domain	All 637 statements (%)	Percentile distribution of statements per group*			
		Child (8-12 yr)	Parent (8-12 yr)	Adolescent (13-16 yr)	Parent (13-16 yr)
Medical/hospital/doctor	20	20	19	18	18
Symptoms/complaints	15	21	12	15	11
Psychological / emotion	14	11	19	16	14
Limitations / restrictions	13	13	16	7	9
Social (friends/peers)	8	10	4	14	6
Physical / sport	7	8	5	6	7
School	7	4	7	8	13
Coping	7	5	11	6	11
Family / home	6	7	3	5	5
Health care	3	1	4	5	6

Table 3. Domain distribution of the collected statements, from children, adolescents and their parents in the asthma focus groups and interviews (%).

*The collected statements from children in the 4-7 age group, their parents and health care professionals are not shown due to the small numbers.

Discussion

This study describes the qualitative patient-derived research method applied in the DISABKIDS project to explore the patient's view on the influence of asthma on their daily life. As stated earlier there are several advantages to using cross-national focus groups for item generation. Collected statements come directly from the target population and provide access to the child and adolescent's own language. In addition the probability of cultural bias will be reduced as a result of the cross-national setup where uniformity of the items between countries was sought after.

We found that focus groups with children and adolescents were more difficult compared to adult groups. Especially the youngest children (aged 4-7) were not really capable of expressing their opinions or feelings in more than a few words. Overall, children often preferred to wait until someone else had answered a question or the question was directed to them personally. This in contrast to the groups with parents and health care professionals where the conversations went almost automatically. Even for the adolescents, 90 minutes turned out to be the maximum time they could focus on the topic. Like others we found that near the end the motivation declined, the responses were less extensive and more irrelevant topics were raised²⁷. In general the children and adolescents did feel acknowledged as being the experts and expressed that they would volunteer to participate again. The parents appreciated the chance to talk about their experiences and found it especially valuable to hear from others in a similar situation.

During the focus groups the children and adolescents admitted their non-compliance, they said that they forgot to take their medication, believed that it did not work, thought it was not necessary or wanted to avoid any side effects. Similar aspects related to non-

compliance have been found in previous studies ⁴²⁻⁴⁵. Social issues were found to be a dominant theme, especially for the adolescent, which was similar in other studies, even in other chronic conditions ^{34,35,46,47}. The impact of physical limitations and prevention measures on a child or adolescent's social life has also been illustrated before ⁴⁵. Adolescents indicated that they did not want to be seen or be treated as different and wished to be accepted by their peers. Younger children were more concerned with the actual physical limitations they experienced (running, riding a bike, sports). Parents were mostly troubled about medical aspects concerning insufficient confidence in medication, side effects, little knowledge of the medication or the treatment plan and fear of any long-term consequences. Similar outcomes have been discussed in other studies reporting that the children found the symptoms and limited physical activities most bothersome and that parents were worried about the medication, long-term effects of the illness and feeling helpless when a child has an asthma attack ^{11,46,48-50}. Not all topics were discussed in each country. For example allergy, pets and difficulty to visit friends were not discussed in Greece. This might be related to the fact that their living conditions are different from other countries and can be a reflection of selection bias as most of these children had exercise-induced asthma.

The focus groups with the health care professionals illustrated that parents and clinicians have different aims. While the parents and children often aim at limiting the use of medication as much possible, health care professionals accept a higher dose of medication to accomplish minimal physical limitations. This can cause a conflict in aims and influence non-compliance. Health care professionals indicated that they find it hard to recognise issues that are of importance to the patient, and that they mostly concentrated on the functional ability. The health care professionals do realise that if a child is not happy about using medication the chances increase that they will not use the medication properly. They also understand that they should explain their decisions more clearly to the child and parents to enhance compliance with medication. The risk of a child or adolescent becoming socially isolated or not being able to join in all activities was acknowledged. However, health care professionals suggest that this might also relate to a child's personality.

On the whole, asthma has a major impact on the child and adolescent's life. Keeping up with aspects important to the child or adolescent's HRQoL is important to facilitate and improve clinical practice. Recognition and knowledge of any problems can enable clinicians and nurses to help and support these families. Another aspect illustrated by the focus groups discussions was that children and adolescents concentrate on the 'here and now'. Their focus is on the present limitations they experience and how this influences them in daily life. The parent's centre of attention is on the future (schooling, future jobs) and they aim for the lowest possible medication doses for fear of long-term consequences. Clinicians concentrate on the physical function, reducing the current symptoms, aiming for the best possible lung function and optimising treatment compliance.

Some methodological issues need to be discussed. One issue concerns selection bias. Participants may not be representative for the population of interest as the more confident individuals can be more willing to participate. Those who did not join may have a different view on their illness and the effect it has on their lives. Another point is that the total group of children, adolescents and parents was also relatively small. On the other hand the discussed topics were widespread and showed similarities between countries. As a result the collected statements were acknowledged as important to our research population. While some investigators have conducted focus groups or interviews till no new issues were presented, this was not possible in the DISABKIDS project due to time constraints^{35,37,51}.

Despite the fact that dynamic group interaction can stimulate additional information, interaction can also be inhibited. One person's opinion can prevail in the group by silencing less confident participants or by constantly changing topics^{31,52}. Personal expectations of participants, group incompatibility or lack of respect may also cause problems, as can mixed gender groups^{32,53-55}. In our focus groups the moderator needed to deal with limited interaction between participants, the more dominant child, the quiet child and, sometimes different priorities between the girls and boys.

Collected focus group data can only be interpreted or reported in a qualitative manner, with selected phrases and quotes as outcome. The strength of a certain viewpoint cannot be measured by counting the number of collected statements or by the intensity in which it is expressed³¹. Firstly, the amount of collected statements within a group can depend on the number of conducted focus groups and interviews. Secondly, the discussed issues can be biased as a result of the questions asked by the moderators or the interaction within the group³¹. Additionally, the selection of HRQoL statements from the transcripts depends on the investigator. The distribution of the collected statements (Table 3) therefore functions solely as illustration. Nevertheless, the fact that major topics were discussed in all four countries and that obtained results were similar to earlier studies helps to strengthen the validity of the findings.

There was no objective method for extracting the HRQoL statements from the literal transcripts. One DISABKIDS member identified the appropriate statements in each country. The quality of individual content analysis has been questioned, as the agreement between raters can be low and individual raters may not extract all information⁵⁶. However, other investigators have suggested that individual judgement is valid and they find external or group ratings unnecessary as the context in which the data were conducted may be missed^{57,58}. A computer program can also be used to code and analyse the transcripts but has its limitations and was not applicable in the DISABKIDS project due to the different languages of the transcripts^{58,59}.

Appointing domains to the statements also included a subjective element, with the first two raters disagreeing on quite a number of the statements. However, this does not

indicate that one or the other is incorrect, as some statements can be applicable to several domains. The most frequently mentioned domains included the medical, symptoms, psychological and limitation domains, which is similar to the domains incorporated in most current paediatric questionnaires⁶⁰. This means that these topics are either important or we recognised these HRQoL statements because we are familiar with these topics from earlier research⁴⁰.

The need to assess HRQoL in different countries and cultures is increasingly being discussed⁶¹⁻⁶³. However, when a HRQoL questionnaire is developed in one country and is translated into another language this might cause cultural obstacles and true comparability may not be achieved⁶⁴⁻⁶⁶. Developing a HRQoL questionnaire cross-nationally can limit cultural and socio-economic influences. This brings us to the advantage of the cross-national method within the DISABKIDS project. The focus groups and interviews were an effective way to gather topics that were important and appropriate to children and adolescents in several countries. This benefited the international consensus that was achieved within the DISABKIDS group by selecting those items that reflected the universal concerns of our research population. Only a few HRQoL questionnaire have been developed in simultaneous collaboration with different countries^{16,62,64,67}. One well-known project is the World Health Organization Quality of Life (WHOQOL) project, which works in collaboration with several countries around the world. However, this concerns adult research⁶⁸.

Conclusion

Overall, the focus groups and interviews gave insight into a range of important issues and viewpoints, identified recurring themes between groups and generated items for the new DISABKIDS instrument. It provided an impression of the HRQoL of children and adolescents with a chronic medical condition like asthma and ensured that aspects found important to the patients were included. However, one must keep in mind that a substantial amount of time and effort does need to be put into the organisation of focus groups and that there are special demands in moderating, transcribing and analysing the data. The information we have gathered is not only of importance to the DISABKIDS project but also for those who work with young patients in clinical practice or research.

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