

QUALITY OF LIFE

Patients' Views on Asthma-Specific Quality of Life Questionnaires: Qualitative Interview Study in Germany

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Objective. It is unclear which of the commonly used asthma-specific quality of life (QoL) questionnaires best capture the lived experience of people with asthma. The objective of this study was to explore patients' views on three asthma-specific QoL questionnaires. **Methods.** Ten adult individuals with asthma were asked to complete three asthma-specific QoL questionnaires (Standardized Juniper Asthma Quality of Life Questionnaire (AQLQ-J-s), Sydney Asthma Quality of Life Questionnaire (AQLQ-S), and Fragebogen zur Lebensqualität bei Asthma (FLA)). Interviews were conducted to elicit patients' views on the questionnaires. Interviews were transcribed verbatim and thematic content analysis was performed. **Results.** Participants spoke about response format and options, missing and redundant/similar content as well as content that was perceived to be irrelevant. A lack of specificity was named for some items, and issues concerning layout were raised. Despite the diversity of views expressed, participants mostly agreed on the ranking of the questionnaires and, overall, favored the AQLQ-S. **Conclusions.** Patient involvement highlights shortcomings and strengths of various asthma-specific questionnaires in terms of both format and content. The AQLQ-S was the most positively perceived questionnaire. Future research will need to explore other settings and potentially involve a larger and more diverse sample.

Keywords content validity, disease-specific quality of life, patient involvement, quality of life measurement, thematic content analysis

INTRODUCTION

The measurement of health-related quality of life (QoL) has become very popular in all areas of health research. Numerous questionnaires have been developed (1), which claim to measure aspects of life that are salient from the patient's perspective. Very little work is however being dedicated to the methodological foundation of the current existing questionnaires (2).

Affecting around 300 million people globally, asthma is a common chronic condition characterized by variable airflow obstruction and symptoms of wheezing, breathlessness, chest tightness, and coughing (3). Since the early 1990s, a number of questionnaires have been developed for the measurement of health-related QoL in asthma (4–12). A recently published structured review concluded that these questionnaires differ in almost all criteria used to review them (conceptual and measurement model, reliability, validity, interpretability, burden, administration format, and number of linguistic validations/translations) (13). In particular, a lack of explicit conceptual models was noted. The underlying conceptual models can only be

inferred from the domains in which the items are grouped and are hence implicit rather than explicit. It can therefore not be assumed that the instruments which are currently in use to measure asthma-specific QoL measure the same construct. From this finding, the following question arises: Which set of items best reflect the lived experience of people with asthma? To date, no attempt has yet been made to explore this question from the patient's perspective. Qualitative research methods are suitable to identify such perspectives, allowing an in-depth exploration of patients' views and experiences, highlighting common themes and differences, to reach an understanding of how they perceive the relevance of the questionnaires in the context of living with asthma (14).

The aim of this study is to capture the views that people affected by asthma have with respect to the existing asthma-specific QoL questionnaires. The study used three asthma-specific QoL questionnaires that are suggested by the German national guideline for asthma monitoring (15). Internationally, these questionnaires are also among the most widely used measures of asthma-specific QoL.

METHODS

Questionnaires

Patients were asked to evaluate the following questionnaires:

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Sydney Asthma Quality of Life Questionnaire. The Sydney Asthma Quality of Life Questionnaire (AQLQ-S) has been developed in Australia as a 20-item self-administered questionnaire with a five-point Likert scale and a 4-week recall period to measure QoL in adults with asthma (8). The AQLQ-S consists of four subscales: breathlessness, mood disturbance, social disruption, and concerns for health. A linguistically equivalent German language version of the AQLQ-S has been produced in Switzerland following sequential backward and forward translation (16).

Fragebogen zur Lebensqualität bei Asthma. The Fragebogen zur Lebensqualität bei Asthma (FLA) (17) represents the German revision of the “Living with Asthma Questionnaire (LWAQ)” (18). It comprises 40 items in three domains that were categorized on the basis of theoretical considerations into “physical symptoms”, “psychological distress”, and “functional status”. Like the original LWAQ, the FLA has a three-point Likert scale and consists of both positive and negative items, thus compensating for acquiescence bias.

Standardized Juniper Asthma Quality of Life Questionnaire. The Standardized Juniper Asthma Quality of Life Questionnaire (AQLQ-J-s) (19) is a standardized version of the original AQLQ-J which had an idiographic component, that is, patients could choose the five items most important to them from a list of activities (7). In the standardized version, the five individualized activities were replaced with five generic activities (strenuous, moderate, social, work-related, and sleeping). The AQLQ-J-s comprises 32 items in four domains (activity limitation, symptoms, emotional functioning, and exposure to environmental stimuli). It uses a seven-point Likert scale and a 2-week recall period. The AQLQ-J-s is available in a linguistically equivalent German version.

Patient Recruitment

A convenience sampling strategy was used between mid-September and mid-November 2010 to identify potential participants living in the cities of Mannheim or Heidelberg or in surrounding communities in Germany. Individuals with asthma were recruited through posters in waiting rooms of general practitioners and pulmonologists, through the pneumology unit of the University Hospital Mannheim, through advertisement in a regional newspaper, and at an information event for patients organized by the local branch of the German Allergy and Asthma Association (DAAB, website: www.daab.de).

Patients were eligible for the study if

- (1) They reported that they were diagnosed with asthma by a physician and
- (2) They were between 18 and 45 years of age.

The upper age limit was set to minimize the likelihood of including individuals with respiratory disease other than asthma, in particular chronic obstructive pulmonary disease (COPD). Individuals were excluded from the study if any of the following criteria was met:

- (1) Comorbidity other than atopic disease,
- (2) Previous completion of QoL questionnaires, and
- (3) Profound language difficulties.

Ten individuals with asthma participated in this study: two patients contacted the study center in response to the posters in their GP's or specialist's practice, four patients were recruited at the University Hospital Mannheim, one patient participated in response to the newspaper advertisement, and three individuals with asthma were recruited at the information event. Written informed consent was sought from each study participant.

Data Collection

An information package was sent to potential participants upon their request (in response to posters at GP offices or the newspaper advertisement) or was handed over to them at the pneumology unit or the information event. The package contained information about the study, the consent form, and a basic demographic questionnaire. Participants were asked to take the completed questionnaire along at the occasion of the interview. The questionnaire covered age, gender, nationality, marital status, whether the participant lived with a partner, educational level, year of asthma diagnosis, and the currently prescribed, regular medication.

Data were collected through in-depth interviews to gain insight into people's subjective narratives of how the content of the questionnaires used related to their experience of living with asthma. All interviews were carried out by M.W. at a place chosen by the patients. Four patients were interviewed in their homes, three at the Mannheim Institute of Public Health, and the remaining three at the University Hospital Mannheim, the patient's office or a public place, respectively.

Data collection consisted of two steps for each participant interviewed. Prior to the interviews, participants were asked to complete the three different asthma-specific QoL questionnaires as a prompt for the subsequent interviewing. Table 1 illustrates that not the original names of the questionnaires, but common German names were used as a reference to the questionnaires. The questionnaires were given to participants in one of six different sequences

TABLE 1.—Ordering of questionnaires given to the 10 interviewees.

Participant	Koch (AQLQ-J-s)	Müller (AQLQ-S)	Weber (FLA)
P1	1	2	3
P2	3	2	1
P3	2	1	3
P4	3	1	2
P5	1	3	2
P6	2	3	1
P7	1	2	3
P8	3	2	1
P9	2	1	3
P10	3	1	2

Note: AQLQ-J-s, Standardized Juniper Asthma Quality of Life Questionnaire; AQLQ-S, Sydney Asthma Quality of Life Questionnaire; FLA, Fragebogen zur Lebensqualität bei Asthma.

TABLE 2.—Topics covered in the interview topic guide.

General impression of the questionnaires
Length of the questionnaires
Comprehensibility
Visual clarity
Redundancy of questions
Need for specification of question wordings
Sufficiency of response options
Adequacy/validity of questionnaires in relation to situation of living with asthma:
Do important aspects of living with asthma lack in the questionnaires?
If questionnaires should be judged as insufficient: which questionnaire is still the most adequate?
Suggestions for improvement

(Table 1) to avoid the potential for the order of questionnaire presentation to influence patient's perceptions.

The interviews were conducted using a topic guide as an aide memoir (see Table 2). Interviews were audio-recorded and transcribed verbatim by M.W.

Data Analysis

The focus of the data analysis was on illuminating patient views with respect to the asthma-specific QoL questionnaires described above. Thematic content analysis was performed by coding the data material and then grouping the codes into categories (20). Data were coded using ATLAS.ti 6.2 (ATLAS.ti GmbH, Berlin, Germany) (21) by M.W. and C.A. and the codes were then grouped into higher level categories using ATLAS.ti's network view manager. Credibility of the findings (how well categories actually represent data) was established by seeking agreement among coresearchers (M.W., C.A., and A.L.) (22).

When codes and categories had been agreed on, they were cross-translated into English by C.A. together with illustrative quotes from the participants. The actual names of the questionnaires (AQLQ-S, FLA, and AQLQ-J-s) were used in the translated quotes, replacing the German names used in the interviews.

Ethics

The study was reviewed and approved by the ethics board (EK-II) of the Medical Faculty Mannheim, Heidelberg University.

RESULTS

A total of 10 patients (4 women and 6 men) with asthma participated in this study. Their mean age was 29 years, ranging from 18 to 46 years. Two participants were married, one was divorced, and seven were single. Two participants had 9 years, 3 had 10 years, and 5 had 13 years of school education. The mean time since asthma diagnosis was 11 years, ranging from 2 to 21 years. Table 3 shows the types of asthma medications, the participants reported to be on.

Patients spoke about a wide range of diverse aspects pertaining to the questionnaires, which can be grouped into

TABLE 3.—Asthma medication reported by participants.

Participant	Medication
P1	Antihistamine plus ICS as needed
P2	SABA as needed plus ICS plus LABA
P3	—
P4	SABA as needed
P5	ICS plus LABA plus SABA
P6	Anticholinergic
P7	ICS plus SABA as needed plus leucotrien receptor antagonist
P8	ICS plus LABA plus SABA as needed
P9	ICS plus LABA plus leucotrien receptor antagonist plus SABA as needed
P10	Budesonid plus SABA

Note: ICS, inhaled corticosteroid; LABA, long-acting beta-agonist; SABA, short-acting beta-agonist.

the following main categories: response format/response options, missing items, redundant or similar content, irrelevant content, layout, and diverse issues. These categories are presented as broad headings with subthemes grouped under them. Table 4 gives a summary of categories, codes, and illustrative quotes.

Response Format/Response Options

Not Applicable Option. Patients often found the “not applicable” (N/A) option (which is solely a feature of the FLA) confusing. However, one patient had a distinctly different view and appreciated having a “not applicable” option.

Number of Response Options. Patients' views differed with respect to the optimal number of response options. Patients expressed that three or five response options were sufficient, and in a number of interviews, seven options were judged as too many; however, one patient also expressed a preference for seven response options because this allowed more choice.

Specification of Response Options. A desire for more specification of the meaning of the various options was expressed. For instance, one interviewee was unclear what “a little of the time”, “some of the time”, and “most of the time” actually meant.

Recall Period. Patients considered recall periods of 2 and 4 weeks as in the AQLQ-J-s and the AQLQ-S difficult and more appropriate for chronic rather than acute or fluctuating asthma.

Missing Items

Coughing from Cold or Coughing from Asthma. Interviewees found it problematic that there was no question to distinguish whether the patient currently suffered from a cold besides asthma.

Environmental Trigger Factors. Patients very often found that the questionnaires lacked coverage of environmental trigger factors or causes of their asthma. Pets, allergies, weather/climate, and odors were specifically mentioned.

TABLE 4.—Themes, codes, and illustrative quotes.

Theme	Code	Illustrative quote
Response format/response options	Not applicable (N/A) option	“And this ‘not applicable’; it’s not clear what this is supposed to mean.” (P6) “What I liked was that there is ‘not applicable.’” (P3) “I’d actually like to have one to five, that is four or five choices plus ‘not applicable.’” (P1) “[...] well there’s a range of five options here. I think that is enough.” (P3) “[...] seven distinctive features: that’s just too much.” (P8) “Regarding the choices in the FLA, I would definitely say ‘grade E’. AQLQ-J on the other hand, grade A. You have more choices that could apply, which [you don’t have with FLA].” (P5)
	Number of response options	“A definition of the frequency is lacking in all of them a little bit.” (P3) “Practically if one defines what ‘a little of the time’, ‘some of the time’, ‘most of the time’ means.” (P3) “In general, I found the AQLQ-J very difficult, because it really just pertains to the last two weeks and this actually doesn’t make sense for chronic asthmatics who have asthma regularly or else always during a certain peak phase.” (P1)
Missing items	Specification of response options	“And that something like this isn’t asked—whether you have a cold at the same time—this isn’t very realistic.” (P6) “Well they ask a lot about activities, but never [about] the environment.” (P4) “And animals—if I remember correctly—were somehow not mentioned anywhere, and I find that important because animal hair plays a role again and again for almost any asthmatic.” (P2)
	Recall period	“That you are asked, do you have allergies or do you not? I didn’t see that in any [questionnaire]” (P9) “There are some foods, for example, [which] asthmatics cannot eat, for instance again related to the allergies. This is also very limiting.” (P9)
	Coughing from cold or coughing from asthma Environmental trigger factors, for example Pets	“Well it’s really not always about sports or work. It also has something to do with weather or food.” (P9) “What I realized is that in the FLA and AQLQ-S questionnaires odors are not even addressed, one can be exposed to when short of breath. And me for instance I am a person who reacts very strongly to odors.” (P8) “What about when I haven’t got my asthma spray with me and I am out somewhere. Well I think this issue is not covered very well.” (P1)
	Allergies	“The most important question for me would be whether the patient has already had asthma education, yes or no. Because one often makes mistakes applying the inhalers wrongly” (P5) “How often do I need the medications or how often do I need my emergency inhaler? I didn’t read anything about this so far, when it comes to medications.” (P9)
	Weather/climate Odors	“I find they are strongly repetitive. Well in general I think this could be reduced to—[...] six, seven questions. And the remainder are variations of those questions. That was my feeling somehow [...].” (P10) “Well I find it starts here already [points to AQLQ-S questionnaire] whether I am impaired when doing housework, in my hobbies, whether I am generally impaired [...].” (P1)
Redundant or similar content	General	“[...] this AQLQ-J asked about perfume and other odors twice: once because of asthma itself and once whether I feel rather limited by those [perfume/odors] [...]. And I find it unnecessary to ask about this twice. And else [...] AQLQ-J does this quite often in general: it always asks about asthma-complaints and then again separately whether I feel impaired there, or had avoided it, to go there.” (P2)
	AQLQ-S	“Well in the FLA I find very many redundancies. Here I have ‘I have a sound sleep’ and ‘I sleep poorly because of my asthma.’; so precisely the direct opposite question. Or here another one ‘I can climb up the stairs without stopping’ and then again ‘I can only climb the stairs if I have one or several breaks.’ Well here I really noted it, that often the same is asked for.” (P1)
	AQLQ-J	
	FLA	

TABLE 4.—(Continued).

Theme	Code	Illustrative quote
Irrelevant content		“Well in the FLA I really had to think twice about the question about what asthma has to do with sexual frustration. Well, this would be one of those questions I would consider unnecessary.” (P2) “[...] [participant pointing to questions in the FLA and AQLQ-S] Sad or depressed because of asthma? Why should I be sad? I have got it, I have to live with it, ok. I accept it, but depressed or sad?” (P5) “And the first question in the AQLQ-S is relatively unnecessary because that one is short of breath when having asthma is logical.” (P7) “Well whether asthma has any influence on where to go for one's holiday vacation or influence on travelling possibilities. Well I thought this was ridiculous.” (P10)
Layout		“Well I found the layout of the FLA weird because I didn't have any clue where to make the mark, it was the same with the AQLQ-J. And this one [AQLQ-S] I found rather well done; here you are supposed to mark such a circle and that was relatively clear.” (P6) “And the AQLQ-J questionnaire, this one's (layout) needs to be totally redone, this one is really absolutely confusing.” (P8)
Diverse issues	Inadequacy of scales to assess quality of life	“Because quality of life is not necessarily captured with words and sentences that are just checked off. I rather find that certain questions should be better adapted to every respondent [...].” (P5) “Because you cannot say [with] a scale of one to seven or of one to ten ‘I am doing so and so’, I think.” (P9) “Well maybe there should be an open-text field in the questionnaires themselves where you can reveal things that are important, which are not covered in them [...]. But a [questionnaire] certainly doesn't cover everything that could occur or everything that you would want to say, [...].” (P2)
	QoL questionnaires as a means of psychological testing	“[...] it appears to me that the whole thing [is] kind of a psycho test. That's my impression. Because there are questions in it [which] actually, in my opinion, [have] nothing to do with asthma at all.” (P5)
	Desire for better specification/better examples	“[...] there were items [in the FLA] like ‘for example decorating’. Well I cannot imagine that someone gets asthma problems particularly while decorating. I think when you are doing housework, when you're drilling a hole, and thereby create a lot of dust. Such things! They are more likely to impair, I think. And decorating I don't think is impaired when you have asthma!” (P7) “Well I don't have any limitations when it comes to swimming. Because this is not a problem at all for a person with allergies, while a 1000-meter run is a sport where there are limitations. Erm, or also indoor sports are always do-able, or at least more do-able compared to something outdoors. So, there is a difference here and a little more specification would definitely yield more precise results here.” (P1)

Medication/Medication Needs. Patients felt that the questionnaires did not cover medication and the limitations arising from ongoing dependence on medication. In connection with medication, patients also spoke about previous asthma education as a lacking content area in the questionnaires.

Redundant or Similar Content

Patients often spoke about questions being similar or even redundant. This was a general impression, but was specifically noted for items in each questionnaire. The different questions about impairment in the AQLQ-S were mentioned. In the AQLQ-J-s, the questions about having to avoid situations due to an exposure (such as strong odors/perfumes or cigarette smoke) and then having asthma symptoms because of these were noted as redundant. The use of positive and negative items in the FLA was also perceived as generating redundancies.

Irrelevant Content

Beyond issues of redundancy or similarity, patients also found particular items in the questionnaires irrelevant. This pertained to questions about being short of breath (AQLQ-S), being sexually frustrated (FLA), and being sad or depressed (AQLQ-S and FLA).

Layout

Participants judged the layout of the AQLQ-S in a positive way, and contrasted it with the layout of the FLA and the AQLQ-J-s. Participants often emphasized that the varying writing in small and capital letters in the AQLQ-J-s was confusing to them.

Diverse Issues

Some participants perceived scales as inadequate means to assess QoL in the first place. A desire for having space for free text was expressed.

One interviewee contextualized space for free text within asthma control (P3).

[. . .] because asthmatics are often relatively well controlled and surely always tick off 'never' in the questionnaire; there are however things or situations which are not captured then, which nonetheless impair quality of life. (P3)

There was also a perception that the questionnaires were more a means of psychological testing.

Furthermore, interviewees mentioned that some of the items needed a clearer specification. One interviewee (P7) contrasted the environmental exposure stemming from a particular activity with the activity itself (dust from decorating vs. decorating). With regard to sports, one interviewee (P1) said that swimming or indoor sports were not a problem, but running was. One participant expressed a preference for statements (as in the FLA or AQLQ-S) as opposed to questions.

TABLE 5.—Patients ratings of quality of life questionnaire (from 1 = best to 3 = worst).

Participant	Weber	Müller	Koch
	(AQLQ-S)	(FLA)	(AQLQ-J-s)
P1	1	2	3
P2	1	2	3
P3	2	1	3
P4	1	2	3
P5	3	2	1
P6	1	2	3
P7	1	2	3
P8	1	2	3
P9	1	3	2
P10	Missing	Missing	Missing
Mean rank (SD)	1.33 (0.71)	2.00 (0.50)	2.67 (0.71)

Note: AQLQ-J-s, Standardized Juniper Asthma Quality of Life Questionnaire; AQLQ-S, Sydney Asthma Quality of Life Questionnaire; FLA, Fragebogen zur Lebensqualität bei Asthma, SD, standard deviation.

Comparative Aspects

Seven out of nine participants rated the AQLQ-S first, 7/9 participants rated the FLA second, and 7/9 participants rated the AQLQ-J-s last. The rating of each individual patient is detailed in Table 5. Participants compared the questionnaires in many ways, and emphasized the clarity of the AQLQ-S and that it was a very compact questionnaire.

Personally I would consider the AQLQ-S best. Simply because it covers a relatively broad spectrum with not too many questions and still follows a logical structure. (P1)

The AQLQ-J-s was criticized for its lack of clarity and that there was a perceived overlap of the questions.

and I found the AQLQ-J worst, firstly because it is so poorly structured, there were quite a few overlaps in the questions [. . .] and because it was a lot about resilience. (P3)

However, preferences were not uniform, and despite the majority favoring the AQLQ-S, contrasting views were also expressed.

[. . .] well in my view the options to answer the questions I think are best here [AQLQ-J] with the options from one to seven. [. . .] There are a number of questions—32—this is OK. Well I would judge the AQLQ-J best of all. (P5)

Well best in terms of the question and most adequate, where I could make the greatest number of statements, was in fact the FLA. (P3)

DISCUSSION

The qualitative interview study presented here is novel in two respects. First, we are not aware of a study with an in-depth approach involving patients to provide views on asthma-specific questionnaires in terms of format and

content. Second, the study is unique in that it uses several questionnaires, adding a comparative component.

Summary of Findings

The study demonstrates a range of diverse views with respect to format and content of three commonly used asthma-specific QoL questionnaires. Participants spoke about the different response formats, missing and redundant, or similar content as well as content that was perceived to be irrelevant. A lack of specificity was noted for some items, and issues concerning layout were also raised. Despite the diversity of views expressed, participants mostly agreed on the ranking of the questionnaires and, overall, favored the AQLQ-S.

Ideas for Improving the Three Questionnaires

The findings from this qualitative interview study suggest potential avenues for improving the questionnaires. This pertains for instance to the recall period that was often judged to be inadequate. Based on these interviews, one might also consider omitting a "not applicable" option, although it is meant as a means of improving questionnaires. Furthermore, three or five response options compared to seven seemed to be preferred by patients in our study. Seven options require a very fine graded patient response.

The questions in the AQLQ-S which ask about being limited in housework, hobbies, and so on because of asthma or shortness of breath were mentioned as redundancies and could perhaps be collapsed, but it is important to bear in mind that their content is indeed different. Being limited in housework is different from being limited in one's hobbies and being limited in light housework is also different from being limited in hard housework.

Lost Items

When patients spoke about missing items, accounts were mostly centered around factors that trigger asthma such as cough, allergies, or odors. Patients also felt that the impairment arising from asthma control by medication was missing. With regard to the latter, one may argue that asthma control is a different construct measured by different patient-reported outcome measures such as the Asthma Control Questionnaire (ACQ) (23), the Asthma Therapy Assessment Questionnaire (ATAQ) (24), or the Asthma Control Test (ACT) (25). These measures assess the degree to which asthma is controlled. The patients' views, however, suggest that items assessing restrictions experienced in connection with having to use regular medication should be part of an asthma-specific QoL measure. This notion is different from an asthma control measure.

The initial process in questionnaire development normally involves patients (usually through interviews or focus groups) to generate an item pool, that is, a large number of areas of concern or bother which are brought up. This is because there are a large number of different subjective experiences in individuals with the same disease.

Item reduction techniques (such as factor analysis or reduction by importance scores) are then used to produce

questionnaires with an acceptable number of items that can be administered and are easy to use. Hence items are necessarily lost, and it is therefore not surprising that patients talk about missing content when probed in the type of interviews that was conducted for this study.

Thus, to a certain degree, the findings from this study reflect the tension between measurement and subjective experience. A questionnaire development process will always yield a questionnaire with items that are judged as most important by patients or which contain items that form an internally consistent dimensional structure.

In the original development of the AQLQ-J-s, the importance method was used. The original item pool was later reanalyzed using factor analysis, and it emerged that the two methods of analysis led to differential selection of items when applied to the same list of potentially troublesome items (26). The emotional and environmental items with the highest impact were actually discarded when factor analysis was used. In summary, however, both methods discard items from a pool of potentially relevant items.

Strengths and Weaknesses of this Research and the Similarity to Other Published Work

Patients are usually involved in the development of a questionnaire, but in-depth patient involvement ceases as the questionnaire development process progresses. In a "rush to measurement" (27) detailed in-depth research often seems to be sacrificed.

In our structured review (13), we have commented on sources used for item generation for the questionnaires among which qualitative methods are mentioned (patient interviews for the AQLQ-J, focus groups for the AQLQ-S, and the LWAQ). We acknowledge that the development of all the questionnaires involved qualitative work with patients. However, the question: "What questionnaire is most valid from the patients' perspective?" can only be answered by eliciting patients' views on the final questionnaires. Taking this stance represents the novelty of this study. We aimed to elicit patients' views on the end-product-questionnaires to understand issues patients might have with design and content of commonly used asthma-specific questionnaires.

Although the number of patients in our study is limited, we were able to include patients with a range of socio-demographic and clinical characteristics using four different recruitment channels (hospital-based and population-based, i.e., care-seeking and non-care seeking patients). However, findings cannot be generalized, and particular caution needs to be exercised with regard to generalizing findings to other cultural settings. Generalizability as conceptualized in empirical quantitative research is not usually sought in qualitative research that seeks theoretical but not empirical generalizability (22).

The study at hand generated evidence for the much needed guidance with respect to choice of instrument. It can also be considered a starting point for the potential de novo development of an asthma-specific QoL questionnaire that might be more valid from the patient perspective compared with the existing ones.

In a qualitative assessment of the most widely used health status questionnaire, the Short-Form (SF)—36 Health Status Questionnaire, some important problems were revealed (28). The study explored how older people with chronic health problems interpret the questions used in the SF-36. Like in the study presented here, participants considered some of the questions as vague, for instance, “Can you walk half a mile?” or “How about lifting or carrying groceries?” It was unclear to the participants how far half a mile would actually be, and the question about groceries does not make clear how heavy these are (by for instance saying “a bag of groceries”). In this study, questions about activities such as swimming or decorating were likewise described as vague.

Implications

Our findings highlight the need to involve patients iteratively in questionnaire development and to listen to them until the very end of that process. However, the patient’s view needs to be balanced with a research perspective. For instance, clinical trials often have limited timeframes and are expected to demonstrate effects over the period of the trial. Hence, the choice of recall period often depends on the purpose of the research, even though participants in this study perceived short recall periods as inadequate. One participant thought that asking about being depressed or sad was irrelevant but on average depression has been found to affect both asthma control and QoL (29). This means that while single patient perceptions provide valuable insights their views may not represent those of the majority of patients.

Based on this study, the AQLQ-S seems to be the questionnaire with the best rating from the patients’ perspective and seems most appealing in terms of format and response options at the same time. Interestingly, the above mentioned structured review including a quantitative assessment of the questionnaires also suggested the AQLQ-S to be the most promising questionnaire (13) and hence should be recommended for clinical practice and research. However, there may be reasons for use of the AQLQ-J in multinational studies as it exists in many different languages. The FLA might be considered if there is a particular interest in the psychological aspects of suffering from asthma. Future research will need to explore patient responses in other cultural or language settings and will benefit from involving a larger and more diverse sample.

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DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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