Health-related quality of life in Swiss adolescents with asthma

Validation of the AAQOL-D and comparison with Australian adolescents

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Asthma is the most common chronic disease in children and adolescents [1]. Countless empirical studies underline that a chronic disease such as asthma not only involves physical symptoms but may also cause difficulties in the social, emotional and school spheres [2]. Although physiological measures have greatly contributed to a better understanding of the pathophysiology of asthma and will continue to be important diagnostically and in evaluating the response to treatment, they fail to evaluate how patients feel and how far they can cope with everyday demands [3]. Despite the availability of a range of highly effective asthma medication, no significant reduction in morbidity and mortality has been achieved [4, 5].

Health-related quality of life (HRQOL) may be defined as “the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient” [6]. Understanding the patient’s subjective perception of the impact of asthma on his daily life may help to change asthma management with a potentially better outcome.

Assessment of asthma-specific HRQOL in children and adolescents is a relatively new field. A number of asthma-specific HRQOL questionnaires are available for children and adolescents in English [3, 7, 8]. The Adolescent Asthma Quality of Life Questionnaire (AAQOL) is the only instrument specifically for use in adolescents [9]. It was developed in response to conceptual and/or
methodological deficiencies of other available questionnaires for use in adolescents, such as lack of multidimensionality, absence of age-appropriate psychosocial items, insufficient asthma-specificity, and parent-completion instead of self-completion [10]. The AAQOL is a multidimensional questionnaire for adolescents aged 12–17 years consisting of the 6 domains symptoms, medication, physical activities, emotions, social interaction and positive effects of asthma (e.g. asthma-related social support) on the adolescent’s daily life. The AAQOL showed high internal stability and good construct validity with Australian adolescents suffering from asthma.

With regard to the use of the questionnaires in other languages, Guyatt et al. [11] recommend not only translation but also cross-cultural adaptation, including a new item reduction and validation in order to define and take into account both linguistic and transcultural differences in the subjective response to the effects of illness and consequent treatment. The aim of this study was (1) translation and re-validation of the AAQOL in German (AAQOL-D) and assessment of measurement characteristics while maintaining the properties of the original instrument; and (2) comparison of HRQOL in Swiss and Australian adolescents.

### Methods

#### Subjects

**Inclusion criteria.** As with the development and validation of the English version, eligible adolescents were 12–17 years old. A total of 60 in- and outpatients and former patients of the Alpine Children’s Hospital Davos, with asthma diagnosed by a paediatric respiratory physician, were enrolled. The patients suffered from frequent episodic or persistent asthma [12] and experienced asthma symptoms at least once a week or took asthma medication daily during the two weeks prior to enrolment. Participants were excluded if they had other chronic diseases (with the exception of atopic diseases such as eczema, hay fever, food allergies) and if their knowledge of German was poor. Demographic data are given in Table 1. Ethical approval was obtained from the Ethics Committee of the University Children’s Hospital Zurich. To be included in the study, participants and one of their caregivers were required to give written consent.

**Sample A.** One focus group interview was held with 3 and individual interviews were held with 8 German-speaking Swiss adolescents (7 males and 4 females; mean age 14.7 ± 1.65 yrs; duration of asthma 10.36 ± 4.9 yrs) as part of the item selection (see below).

**Sample B.** Item reduction and validation of the final version of the AAQOL-D was performed in a single study with 56 adolescents (26 males and 30 females; mean age 14.6 ± 1.8 yrs; duration of asthma 9.25 ± 3.8 yrs). For the purpose of comparing the results, the mean age of the Australian sample when developing and validating the AAQOL was 15.5 ± 1.9 yrs with 45.5% males and 54.5% female adolescents. With regard to asthma severity, the same inclusion criteria were applied for both the Australian and the Swiss adolescents (see above).

#### Study design

A standardised multi-step method was used to develop the questionnaire [13].

**Translation.** The existing English version of the AAQOL was translated into German and retranslated by an independent objective translator to omit any possible source of translation-derived errors. This preliminary questionnaire was presented to three independent German-speaking adolescents to identify any confusing wording, and any such was omitted.

**Item selection.** A semi-structured focus group interview with 3 adolescents and 8 individual interviews were held with participants of Sample A to scrutinise the existing questions of the translated AAQOL and to select further questions of potential importance to the adolescents, allowing for transcultural differences. Item generation was discontinued when no new items were identified in two subsequent interviews. The selected items were combined with the items of the original AAQOL to form the preliminary questionnaire.

**Item reduction.** As with the development of the original version, the most relevant items were again identified by applying the “clinical impact” method described by Guyatt and Juniper and colleagues [13, 14]. This method is consistent with the HRQOL definition mentioned above. 56 adolescents (sample B) were questioned via the preliminary questionnaire to ascertain how frequently the event occurred and how bothered they were or how important the event was to them. “Clinical impact” was calculated as the product of the frequency and importance.
rating of each item. The rankings of the original questionnaire and the AAQOL-D were compared.

Allocation of items to domains. As with the original version of the AAQOL, each item of the AAQOL-D was allocated to one of the predefined domains according to the original version of the AAQOL, provided that the item correlated higher with the total score of the predefined domain than any other domain.

Response scales. As with the AAQOL, a seven-point Likert scale was used for the preliminary as well as the final version of the AAQOL-D. The seven-point response scale facilitates interpretation of data, since it has been shown that the minimal clinically important difference from this scale is 0.5 [15]. Scores for each domain, and a total score, were calculated. The total score excluded the “positive effects” domain, since the response scores of this domain cannot be meaningfully added to scores of the other domains.

Construct validity. Construct validity was assessed by correlating the scores of the final version with the scores of two health outcome measurements and with several clinical parameters of asthma severity and lung function. These were (1) the German version of the Paediatric Asthma Quality of Life Questionnaire (PAQLQ), an asthma-specific 23-item quality of life instrument [3, 16] for children and adolescents (major focus on symptoms and emotions, as discussed elsewhere [10]); (2) a health status thermometer (HST), a visual analogue scale from 0–100 with 0 the worst imaginable health status and 100 equal to perfect health; (3) clinical parameters of asthma severity such as the adolescent’s subjective perception of severity, number of hospitalisations in the last 12 months, number of medications, self-completed recording of cough/wheeze/sleeping disorders in the last 7 days. All questionnaires were completed by 56 adolescents (sample B). Of these, 27 also completed a peak-flow chart over three days to obtain more detailed information on clinical parameters of asthma severity. Whether a peak-flow chart was completed or not depended on (a) whether the individual had a peak-flow meter available (not all adolescents completed peak-flow charts on a regular basis), and (b) the individual’s disposition (it was decided that overall compliance would be improved if this matter were treated in a voluntary manner).

Based on the literature [3, 10] and the validation of the original version of the AAQOL, it was hypothesised that there would be (1) a high correlation with the PAQLQ; (2) a moderate correlation with the HST; (3) a weak correlation with clinical parameters of asthma severity; (4) a weak or no correlation with peak flow measurements.

Table 2

<table>
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<tr>
<th>Items</th>
<th>AAQOL</th>
<th>AAQOL-D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortness of breath</td>
<td>23.1</td>
<td>29.7</td>
</tr>
<tr>
<td>Wheezing</td>
<td>25.8</td>
<td>31.3</td>
</tr>
<tr>
<td>Tightness of chest</td>
<td>25.9</td>
<td>27.6</td>
</tr>
<tr>
<td>Coughing</td>
<td>28.3</td>
<td>22.1</td>
</tr>
<tr>
<td>Asthma due to change in weather/air pollution</td>
<td>28.6</td>
<td>28.9</td>
</tr>
<tr>
<td>Difficulty taking a deep breath</td>
<td>30.4</td>
<td>24.6</td>
</tr>
<tr>
<td>Feeling tired due to asthma*</td>
<td>32.9</td>
<td>33.4</td>
</tr>
<tr>
<td>Waking up at night due to asthma*</td>
<td>33</td>
<td>37.4</td>
</tr>
</tbody>
</table>

* Item omitted in both AAQOL and AAQOL-D due to low ranking.

Results

Translation

The presentation of the translated questionnaire to independent German-speaking adolescents led to the identification of 2 misleading or confusing types of wording; these were omitted and the phrasing was optimised in the light of the adolescents’ comments.

Item selection

The initial Australian item pool comprised 44 items. Of these, 4 items, which had been eliminated from the original item pool during development of the AAQOL, were selected as important in the focus interviews and included in the preliminary questionnaire of the AAQOL-D. These items included questions regarding tiredness and nightly waking due to asthma, as well as feeling different or left out due to asthma and fear of asthma attacks. In addition, two new items were identified, one asking about the influence of asthma on school performance and one concerning the influence on the adolescent’s mood. Any newly identified items were allocated to the end of each domain in the preliminary questionnaire, so as to interfere as little as possible with the patients’ reactions to the original questions.

The preliminary questionnaire contained 38 items. The majority (33) of the items asked about the negative impact of asthma on HRQOL, and the remainder focused on positive issues in the experience of asthma.

Item reduction

Applying the clinical impact method, all the new items which had been selected in addition to those of the AAQOL were omitted, because little relevance was attached to them when compared with the items in the original version of the AAQOL. Therefore, applying the clinical impact method, the same items were identified as clinically relevant and were included in the AAQOL-D as in the AAQOL. Among those items that were confirmed as clinically important, there was a slightly different order in the item ranking. Within the symptom domain, for example, coughing and having trouble taking a deep breath were perceived to be more important by the Swiss adolescents than by the Australian sample (see Table 2). Within the “activities” domain the item “missing school due
to their family’s helpfulness over their asthma than Australian adolescents (AAQOL 5.5 and AAQOL-D 10.5). Overall, 72% of all items were ranked higher (i.e. higher clinical impact) by the Australian adolescents than their German-speaking peers.

Allocation of items
As in the original questionnaire, none of the items allocated to a particular domain showed a significantly higher correlation with the total score of another domain. The allocation of items to domains therefore remained the same as in the AAQOL.

Internal consistency for the six dimensions (symptoms, medication, physical activity, emotions, social interaction, positive effects) was high ($\alpha = 0.76–0.87$), as it was for the total score ($\alpha = 0.87$), as shown in Table 3. Comparison with the results for the AAQOL showed a similar distribution.

Construct validity
As had been hypothesised, high correlation existed between the AAQOL-D and the German version of the PAQLQ ($\rho = 0.86; p <0.0001$). Even excluding items common to both scales, the correlation remained high ($\rho = 0.85; p <0.0001$). Correlation with a health status thermometer was high for both the AAQOL-D (0.74; $p <0.0001$) and the PAQLQ (0.69; $p <0.0001$). Both the AAQOL and the PAQLQ showed a statistically significant correlation with patient-rated symptom severity (see Table 4). Correlation of severity of coughing, wheezing and shortness of breath was weak to moderate for both the AAQOL-D and the PAQLQ. No statistically significant correlation was found with the number of medications taken or the number of hospitalisations during the last 12 months, and neither the AAQOL-D nor the PAQLQ showed a statistically significant correlation with peak-flow rating.

Table 3

<table>
<thead>
<tr>
<th>Domain</th>
<th>AAQOL</th>
<th>AAQOL-D</th>
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<tbody>
<tr>
<td>Symptoms</td>
<td>0.82</td>
<td>0.85</td>
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<tr>
<td>Medication</td>
<td>0.82</td>
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<tr>
<td>Physical activities</td>
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<td>0.85</td>
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<tr>
<td>Emotion</td>
<td>0.87</td>
<td>0.90</td>
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<tr>
<td>Social interaction</td>
<td>0.76</td>
<td>0.76</td>
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<tr>
<td>Positive effects</td>
<td>0.80</td>
<td>0.70</td>
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<tr>
<td>Total score</td>
<td>0.87</td>
<td>0.93</td>
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Table 4

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<th>Measure</th>
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<tr>
<td>PAQLQ</td>
<td>0.85**</td>
<td></td>
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<tr>
<td>Health status thermometer</td>
<td>0.74**</td>
<td>0.69**</td>
</tr>
<tr>
<td>Patient-rated symptom severity</td>
<td>0.73**</td>
<td>0.76**</td>
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<tr>
<td>No. of hospitalisations in last 12 months</td>
<td>−0.22</td>
<td>−0.20</td>
</tr>
<tr>
<td>No. of medications per day</td>
<td>−0.22</td>
<td>−0.01</td>
</tr>
<tr>
<td>Coughing last 14 days</td>
<td>−0.59**</td>
<td>−0.44*</td>
</tr>
<tr>
<td>Wheezing last 14 days</td>
<td>−0.51**</td>
<td>−0.42*</td>
</tr>
<tr>
<td>Shortness of breath last 14 days</td>
<td>−0.71**</td>
<td>−0.50*</td>
</tr>
<tr>
<td>Sleeping last 14 days</td>
<td>−0.52**</td>
<td>−0.45*</td>
</tr>
<tr>
<td>FEV1</td>
<td>0.57*</td>
<td>0.41</td>
</tr>
</tbody>
</table>

*: p <0.005; **: p <0.0001.

Discussion
The aim of this study was to translate into German and revalidate the AAQOL, a multidimensional instrument for assessing the HRQOL of adolescents with asthma.

In the item reduction process the same 32 items, covering six domains of HRQOL as included in the AAQOL, were shown to be relevant for German-speaking adolescents. This provides strong evidence that those items most important to adolescents with asthma were identified and that both the AAQOL and the AAQOL-D are age-appropriate HRQOL instruments.

Validation of the AAQOL-D confirmed the good internal reliability of each domain and the total score. Furthermore, the AAQOL’s good construct-validity was confirmed, with a high correlation with the PAQLQ and a health status thermometer, and a moderate correlation with various clinical parameters of asthma severity. The high correlation of the AAQOL/AAQOL-D with the PAQLQ does not put the AAQOL/AAQOL-D’s use in question but may in fact favour it. The AAQOL not only addresses more age-specific issues for adolescents but, by focusing on a broader range of domains, also provides a more comprehensive HRQOL assessment than the PAQLQ.

Repeat investigation of test-retest reliability was not performed, since test-retest validity was high for all domains and for the total score of the AAQOL, with intraclass correlation coefficients ranging from 0.76 for the symptom domain to 0.85.
for the emotion domain and 0.90 for the AAQOL’s total score [9].

It can be argued that the sample size of this study was relatively small. However, as there is no uniquely accepted way of calculating minimally required sample sizes for HRQOL questionnaires such as the AAQOL-D, which were developed by applying the clinical impact method, it was decided that the sample size should be approximately the same as for the original development and validation of the AAQOL (sample size 66 for item reduction and validation) and the PAQLQ (sample size 52).

Like the AAQOL, the AAQOL-D does not allow comparison of data between children and adolescents. However, doubts have been raised recently about whether children under 12 are capable of differentiating between perceived limitations of daily functioning imposed by a particular disease such as asthma, and limitations not caused by the disease [10]. The minimum age required for self-reported HRQOL assessment using disease-specific instruments has not yet been investigated properly and still needs to be determined.

Like the AAQOL, the AAQOL-D is unique in including a domain which deals with positive impacts that asthma may have on the individual’s daily life. Although the assessment of construct validity for this domain presented a methodological difficulty, as described elsewhere [9], the items of the positive effects domain were again rated highly important by the adolescents, and this resulted in the inclusion of this domain in the AAQOL-D.

Intercultural differences were not found with regard to identification of the most relevant items to be included in the AAQOL-D. However, among these items there were some ranking differences between Swiss and Australian adolescents. Within the symptom domain, the different ranking of the items asking about coughing and having difficulty taking a deep breath may suggest that these two items represent bigger restrictions for the Swiss sample than for their Australian peers, who feel more restricted through wheezing and shortness of breath. A possible explanation for this is the difference in climate between the European and the Australian continents.

Differences were also found in the social domain. Missing school seemed to pose more of a problem for the Australian adolescents. The reasons for this difference are not clearly understood.

One could argue that school attendance is more important to the Australian adolescents, but equally it may be that Swiss adolescents feel under greater pressure to succeed at school and therefore miss school less frequently despite suffering from asthma symptoms. Equally, the role of the adolescents’ families appears to differ in the two cultures. Australian adolescents seem to be more bothered by their parents’ overprotectiveness and attach more importance to helpfulness on their families’ part in regard to their asthma than do their German-speaking peers. The Swiss respondents are evidently more bothered by cigarette smoke and having to avoid going to places where cigarettes are smoked. This correlates with the data on smoking rates in the two countries; whereas in Australia 29% of male adolescents and 31% of female adolescents aged 16–19 years regularly smoke cigarettes [18], the proportion of Swiss adolescents of the same age that smoke cigarettes is larger (42% of males and 38% of females) [19]. Another factor to be taken into consideration is the importance attached to non-smoking policies in Australia, with a high proportion of smoke-free environments which makes it easier for Australian adolescents with asthma not to be bothered by cigarette smoke.

In summary, this study has confirmed the AAQOL’s validity as a multidimensional asthma-specific and age-appropriate instrument for assessing the health-related quality of life of adolescents with asthma. With the AAQOL-D an equally valid instrument is available for HRQOL assessment in German, allowing comparison with data obtained by the original AAQOL due to its similar content of items.

With regard to the comparison of HRQOL in Swiss and Australian adolescents, the Swiss sample was more bothered by cigarette smoke and having to avoid places where cigarettes are smoked, and this provides strong evidence that non-smoking policies promoting a high proportion of smoke-free environments enhance HRQOL in adolescents with asthma.

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