ORIGINAL ARTICLE

Development of the Revised Final Version of the Quality of Life of Japanese School Aged Children with Asthma Questionnaire: The Characteristics of the Low QOL Scoring Group and Development of an Evaluation Form

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ABSTRACT

Background: A self-recorded instrument for children with asthma needed to be developed to measure their quality of life (QOL). Therefore, the JSCA-QOL questionnaire was revised into a briefer third version, consisting of 5 domains (25 questions) and a summative scale. The purpose was to examine the possibility of identifying children with poor QOL requiring medical or social support, and to devise a practical form of evaluating a nationwide investigation using this instrument.

Methods: Doctors at hospital and clinics throughout Japan distributed the JSCA-QOL to 5308 10- to 18-year-old children with asthma. The questionnaires were returned by mail, after having been filled out by the subjects, who authorized their participation in the investigation by signing the questionnaire.

Results: A total of 2097 children with asthma, who fully completed the questionnaire, were included in the study. As a result of analysis, it was clear that the characteristics of the low score group (under the 10th percentile of QOL scores) were noticeably different from those of the other groups, in the following ways: (i) many children had moderate to severe asthma, (ii) the answers showed different distributions from those of the other groups, (iii) the answers in most "feeling level" questions showed a significantly different distribution. A radar chart was developed for efficient evaluation of children's QOL profiles.

Conclusions: It was very useful to separate the low score group (LSG) with the 10th percentile of the QOL score to distinguish the children who needed special support. The evaluation of the QOL profile was simplified by using the radar chart concept.

KEY WORDS

adolescent, asthma, children, evaluation form, quality of life

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INTRODUCTION

There are many children who suffer from bronchial asthma during infancy, and the age of onset is lowe.[1]

The rate of children with asthma has been increasing and is now 0.5−1 children per elementary school classroom according to investigations conducted by the Japanese Ministry of Education, Culture, Sports,

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Table 1 Characteristics of subjects

Sex	Boy			Girl			Unknown		
	1322			766			9		
Grade	Elementary school			Junior high school			High school		
	4th	5th	6th	7th	8th	9th	10th	11th	12th
	384	421	363	271	196	179	134	94	55
Severity (%)	Remission		Mild		Moderate		Severe		Unknown
	285 (13.5)		1224 (58.4)		440 (21.0)		41 (2.0)		107 (5.1)

Severity was followed the classify asthma severity of Japanese Pediatric Guideline for the Treatment and Management of Asthma 2000.

Science and Technology. Although advances have been made in the treatment of bronchial asthma in recent years, we believe that the quality of life (QOL) of children with asthma may still remain poor. Not only the symptoms of asthma need to be improved, but also it is important that children are aware of and involved in the management of their own condition.

In many countries, the questionnaires developed by Juniper et al.[2] and Christie et al.[3] are used to measure the QOL of children with asthma. In Japan, following the standards of Guyatt et al. concerning the development and evaluation of QOL questionnaires,[4] Torii et al. developed a parent-rated QOL questionnaire for children with asthma and their parents or caregivers and verified its reliability and validity.[5] This instrument consists of 31 questions covering five domains (Physical, Social, Family, Emotional and Individual Growth). Kondo et al. developed a revised briefer version of this questionnaire consisting of 21 questions, and verified its reliability and validity.[6] However, these Japanese instruments were designed to be answered by parents or caregivers only. Because parents' global ratings did not correlate with the children's QOL,[7] a self-recorded instrument for children with asthma needed to be developed.

The WHOQOL group developed the WHOQOL-BREF constituting four domains: Physical Health, Psychological, Social Relationships and Environment.[8] We started to develop the QOL of Japanese School-aged Children with Asthma (JSCA-QOL) questionnaire in 1998 based on the WHOQOL-BREF and Torii's questionnaire. The resulting first version of the JSCA-QOL was composed of 40 questions covering four domains (Physical, Social, Familial, and Emotional), and its reliability and validity were examined.[9] As a result, five domains were indicated: Asthma Attack Triggers (Domain A), Change in Daily Life (Domain B), Family Support (Domain C), Satisfaction with Daily Life (Domain D), and Restriction of Daily Activities (Domain E). A second version composed of 30 questions covering these domains was developed and further examined.[10] Finally, a briefer third version of the JSCA-QOL composed of 25 items and a summative scale was developed.

The purpose of this paper is to examine the possibility of identifying children with poor QOL who require medical or social support, and to devise a practical form for evaluating a nationwide investigation using the third version of the JSCA-QOL.

METHODS

QUESTIONNAIRE
The JSCA-QOL v.3 was used for this investigation. This questionnaire consisted of 25 items covering five domains (Asthma Attack Triggers (Domain A), Change in Daily Life (Domain B), Family Support (Domain C), Satisfaction with Daily Life (Domain D), Restriction of Daily Activities (Domain E)) and a summative scale. All questions had response choices on a five-point Likert Scale. The domain score and the QOL score were calculated on the basis of the scores of the 25 items, which ranged from 1 to 5 points representing poor to good QOL. The summative scale consisted of the question 'How has your life been the last few days?'

Reliability and validity were examined with factor analysis and Cronbach's alpha, and the test-retest reliability was examined using the same subjects. The JSCA-QOL had high reliability with a reliability coefficient of 0.86, and Cronbach's alpha for each domain was higher than 0.70. Furthermore, the test-retest examination showed high stability with Spearman's rho 0.6.

SUBJECTS
Children aged 10−18 were selected from children with asthma who were receiving medical treatment at hospitals or clinics in various places in Japan. The age range was set to be the same as that in the investigation of the previous version of the JSCA-QOL. At each participating institution, the selection of the children to administer the questionnaire to was left to the physician's discretion.

PROCEDURE OF INVESTIGATION
Letters were sent to doctors at hospitals and clinics throughout Japan whose patients included children with asthma, requesting their cooperation in distrib-
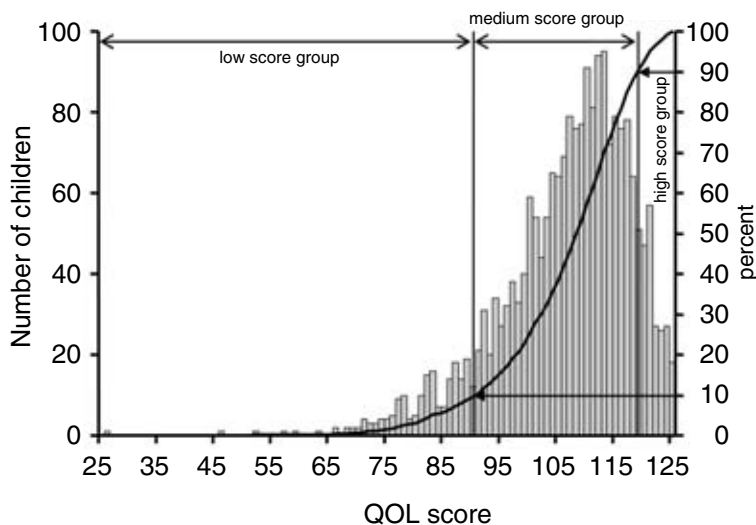
Fig. 1 The distribution of QOL scores and subjects were divided into three groups according to cumulative percentages. All subjects were divided in the level of the 10th percentile and 90th percentile. The low score group (LSG) is under the 10th percentile. The medium score group (MSG) is in the 10th percentile or more, and the 90th percentile or less. The high score group (HSG) is over the 90th percentile. The LSG, MSG and HSG consisted of 196, 1690 and 202 subjects, respectively. The black bold line (—) plotted on the graph indicates the cumulative percentages. The white arrow indicates the 10th percentile level, and the black arrow the 90th percentile level.

uting the questionnaire. As a result, a total of 5308 questionnaires were distributed to the subjects. These questionnaires were returned by mail, after having been filled out by the children at home. This investigation was conducted from January to June 2003.

ETHICAL CONSIDERATIONS

The cover letter accompanying the questionnaire clearly specified the purpose of the investigation and included a request for participation. Freedom of participation and protection from disadvantage provisions were also included. Additionally, the cooperation of guardians was requested in writing. The questionnaires were then distributed. Language which children could easily understand was used, and kana-characters were used to explain the kanji-characters. The subject's agreement of participation was certified by their signatures. The questionnaires and data files were kept confidential.

DATA ANALYSIS

Questionnaires without the child's agreement were excluded from the analysis. Incomplete questionnaires were also excluded from the analysis of the 26 questions. The SPSS 12.0J software package (SPSS Japan Inc., Tokyo, Japan) was used for descriptive

statistics, correlation and chi-square test.

The item 'unpleasant feeling to be told about asthma' was transferred from Satisfaction with Daily Life (Domain D) to Change in Daily Life (Domain B) as a result of the factor analysis, and all data were analyzed statistically.

RESULTS

SUBJECTS' CHARACTERISTICS

From the 5308 children who received questionnaires, 2425 questionnaires were returned (45.7%), and a total of 2097 children with asthma with fully completed questionnaires were included in the study (Table 1). The gender ratio was 1.7 (1322 boys and 766 girls), and the average age was 12.5 (SD 2.2) years. The majority of children (55.7%) were elementary school students, and the number of students in junior high school and high school were 646 (30.8%) and 283 (13.5%), respectively. The asthma severities (severe, moderate, mild, remission) were 41 (2.0%), 440 (21.0%), 1224 (58.4%) and 285 (13.5%), respectively.

The low score group (n = 197), the medium score group (n = 1614) and the high score group (n = 202) were divided into the 10th percentile and the 90th percentile levels of the distribution of the QOL scores (Fig. 1, Table 2). In the adjusted standardized residuals, the low score group (LSG) had a significantly

Table 2 Characteristics of three groups' subjects with QOL score

		LSG	MSG	HSG	Significance
Sex	Boy	120	1070	132	n.s.
	Girl	76	620	70	
Type of school	Elementary school	90†	940	138‡	$\chi^2 = 22.6$ $p < .0001$
	Junior high school	79‡	521	46†	
	High school	28	237	18†	
Severity	Remission	14†	240	31	$\chi^2 = 39.7$ $p < .0001$
	Mild	97†	1003	124	
	Moderate	59‡	343	38	
	Severe	12‡	28†	1	

Severity was followed the classify asthma severity of the Japanese Pediatric Guideline for Treatment and Management of Asthma 2000.
LSG: low score group, MSG: medium score group, HSG: high score group
‡: large of the adjusted standardized residuals significantly ($p < .05$)
†: small of the adjusted standardized residuals significantly ($p < .05$)

small number of elementary school students ($p < 0.01$), and a significantly large number of junior high school students ($p < 0.01$). In contrast, the high score group (HSG) had a significantly large number of elementary school students ($p < 0.01$) and a significantly small number of junior high school students ($p < 0.01$) and high school students ($p < 0.05$). The medium score group (MSG) had no significant tendency. The numbers in the three groups were significantly different ($p < 0.001$) when children were classified using the severity classification of the Japanese Society of Pediatric Allergy and Clinical Immunology. [11] The LSG had a significantly smaller number of children with remission and mild asthma ($p < 0.05$), and a larger number of children with moderate to severe asthma ($p < 0.01$) than other groups in the adjusted standardized residuals. The MSG had a significantly small number of children with severe asthma ($p < 0.05$).

QUESTION SCORES IN EACH OF THE THREE GROUPS

The QOL of the LSG was significantly poorer than that of the other two groups for all questions (Fig. 2). The average scores of all items in Domain D and 'being praised for making efforts toward asthma treatment' in Domain C, were particulary low. The average score of 'coughing because of cigarette smoke' was low in Domain A, and the average scores of 'restriction in participating in sports' and 'difficulty in playing cheerfully with friends' were lower than those of physical education and school events in Domain E. Five of the 6 items in Domain B showed small differences between the LSG and the other groups.

ANSWER PATTERNS OF THE LOW SCORE GROUP (LSG)

Compared with the MSG and the HSG, the LSG showed a peculiar pattern of distribution of answers.

When the LSG was examined for all questions, the answer distributions could be classified into five patterns (Fig. 3). The first pattern (Fig. 3-a) included the frequency of experience, and tended towards good QOL answers, similar to the MSG and the HSG patterns. However, the LSG had more poor QOL answers than the other two groups. The items 'coughing in a crowd', 'coughing because of a sudden change in temperature', 'being absent from school', 'disturbance of sleep', 'emergency visit', 'leaving school earlier', 'restriction in participating in physical education class', and 'restriction in participating in school events' in Domain A, Domain B and Domain E showed this tendency.

The second pattern (Fig. 3-b) included questions concerning the degree of feeling. This pattern showed a distinctive peaking only in the LSG. This tendency included 'family's careful consideration to prevent asthma attacks', 'family support in daily life', 'being as healthy as friends', 'enjoying daily life', 'enjoying at play', 'enjoying school life', 'enjoying what I want to do', 'spending daily life with satisfaction', and 'spending daily life as well as friends do' in Domain C and Domain D.

The third pattern (Fig. 3-c) included questions related to frequency of experience and degree of feeling. The distribution in the LSG was quite even from good to poor QOL answers, or good QOL answers were lower than poor QOL answers. This tendency was evident in all domain items, *i.e.* 'coughing because of cigarette smoke', 'family support when having an asthma attack', 'giving family trouble', 'having dreams or hopes for the future', 'restriction in participation in sports', and 'difficulty in playing cheerfully with friends'.

The fourth pattern (Fig. 3-d) showed that the distribution of the LSG (mostly poor QOL answers) and the HSG (mostly good QOL answers) were completely opposite. This pattern had only one question
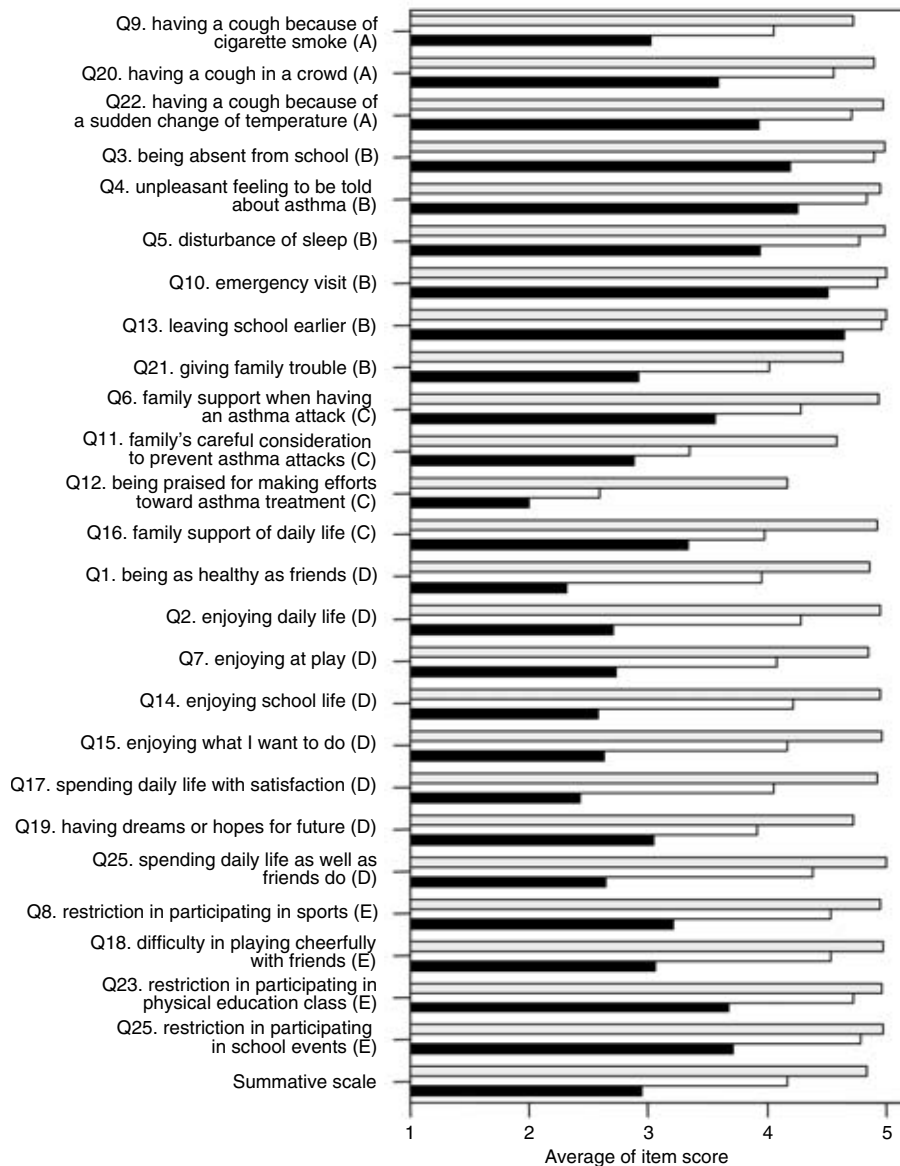
Fig. 2 Average scores of all answers in the LSG, MSG and HSG. Question numbers are shown on the left and the five domains of the JSCA-QOL are indicated on the right (A, B, C, D, E). The black bar shows the average of the LSG, the white bar that of the MSG, and the gray bar that of the HSG. The averages of the LSG were lower than those of the other two groups.
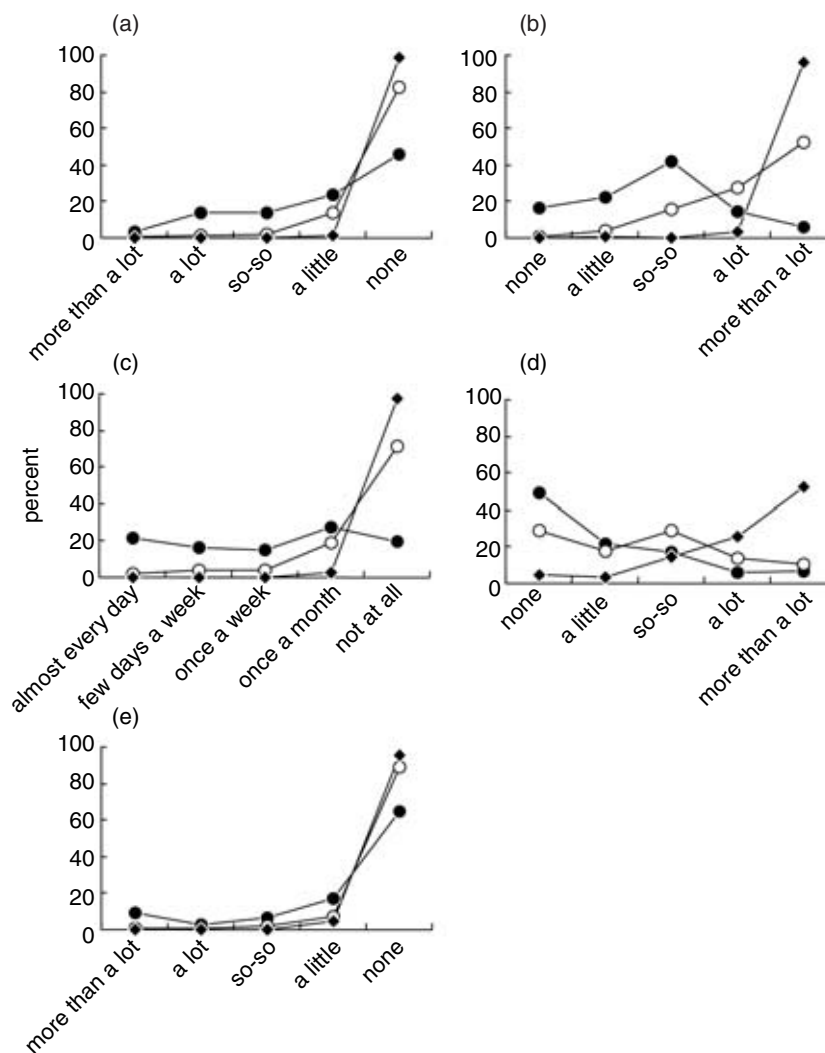
from Domain C 'being praised for making efforts toward asthma treatment'. Though the children attained asthma treatment, few LSG children felt family praise.

The fifth pattern (Fig. 3-e) was 'unpleasant feeling to be told about asthma', from Domain B, where all three groups showed a similar distribution.

CORRELATION OF FIVE CATEGORY SCORES AND QOL SCORE

The Spearman's rank-order correlations between the five domains, the QOL score and the severity of asthma showed differences between the group including all subjects and the LSG, MSG and HSG (Table 3). The correlations between the QOL score and the five domains were moderate to strong in the case of all subjects. However, in each of the three groups, the correlation coefficients between the QOL score and the five domains were smaller than that for all subjects. The correlation in the LSG, in particular, between the QOL score and Domain A was weak. Between the QOL score and Domain C of the LSG, and between the QOL score and Domain E of the HSG, there was also a weak correlation.

(a)

(b)

(c)

(d)

(e)

Fig. 3 Five patterns of the answer distributions of the low (●), medium (○) and high (◆) score groups. (**a**) disturbance of sleep, (**b**) enjoying daily life, (**c**) difficulty in playing cheerfully with friends, (**d**) being praised for making efforts toward asthma treatment, (**e**) unpleasant feeling to be told about asthma.

The correlation coefficient between the asthma severity and Domain B was −0.21, showing a weak negative correlation. However, in each of the three groups, the LSG showed a moderate negative correlation (Spearman's rho = −0.34), but the MSG showed a weaker correlation. The HSG showed no correlation.

Amongst the five domains, weak to moderate correlations were seen between Domains A-B, Domains A-E, Domains B-E, Domains C-D and Domains D-E in the group including all subjects. However the correlations were weaker in each of the three groups (Fig. 4). In contrast, for each subject of the LSG, between Domains A-D, Domains B-C, Domains B-D and Domains C-E there were weak to moderate negative correlations, as opposed to the very weak to weak correlations in the case of the group including all sub-

jects (Fig. 5)

DISCUSSION

From the JSCA-QOL it was clear that the characteristics of the LSG were obviously different from those of the other groups, in the following ways: (i) the LSG under the 10th percentile had many children with moderate to severe asthma who needed follow-up, (ii) the answers in the LSG showed different distributions from those of the MSG and the HSG, (iii) the LSG, in particular, showed very different distributions of the answers in most "feeling level" questions than the other two groups. Consequently, it seemed that the 10th percentile level of the LSG could quite validly be distinguished as children with important support needs.

Table 3 Correlations of between QOL score and severity of asthma and five domains

	QOL score	Severity	Domain A	Domain B	Domain C	Domain D	Domain E	
QOL score	1.00							
Severity	− 0.13**	1.00						LSG correlation
	− 0.07							MSG correlation
	− 0.09**							HSG correlation
	− 0.04							
Athma attack triggers (Domain A)	0.41**	− 0.11**	1.00					
	0.11	0.02						
	0.26**	− 0.09**						
	0.21**	− 0.03						
Change in daily life (Domain B)	0.43**	− 0.21**	0.30**	1.00				
	0.31**	− 0.34**	0.19*					
	0.29**	− 0.19**	0.21**					
	0.28**	0.00	− 0.07					
Family support (Domain C)	0.56**	0.04	0.03	− 0.05*	1.00			
	0.12	0.13	− 0.16*	− 0.41**				
	0.44**	0.08**	− 0.14**	− 0.21**				
	0.53**	0.00	− 0.12	− 0.21**				
Satisfaction with daily life (Domain D)	0.87**	− 0.09**	0.21**	0.26**	0.34**	1.00		
	0.52**	0.08	− 0.40**	− 0.24**	0.12			
	0.79**	− 0.04	0.01	0.08**	0.14**			
	0.41**	− 0.08	− 0.08	0.03	− 0.13			
Restriction of daily activities (Domain E)	0.58**	− 0.12**	0.27**	0.35**	0.06*	0.46**	1.00	
	0.51**	− 0.11	− 0.01	0.24**	− 0.28**	0.08		
	0.42**	− 0.08**	0.13**	0.23**	− 0.14**	0.26**		
	0.11	0.03	0.05	0.05	− 0.22**	0.13		

Spearman's rho, **$p < .01$, *$p < .05$
The numbers in a bracket indicates Spearman's rho with three groups.
LSG: low score group, MSG: medium score group, HSG: high score group

The number of subjects decreased with age. This may be because the children outgrew asthma or because for older children only the mother consulted the doctor on the child's behalf. In the development process of the JSCA-QOL questionnaire, investigations were conducted three times. Children with severe asthma numbered 12% in the first investigation in 1999, but had decreased to 2% in the most recent study, and 35% of children with moderate asthma had decreased to 21%. During these 5 years, the remedies and use of controllers were examined.[12] Due to the change in criteria for the use of inhaled steroids and tulobuterol patches in childhood asthma, the treatment of children with asthma has changed greatly.[1] The number of children with moderate to severe asthma has decreased. Tanabe found that the internal control of junior high school students with chronic disease had declined.[13] In our investigation the response rate was 45.7%, possibly because the internal control of the junior high school students with moderate to severe asthma may also have declined, and the questionnaires distributed to the children might not have been returned. The item scores of Domain D of the LSG were very low in comparison with those of the other groups. This tendency was also observed in the emotional domain of the LSG of the JSCA-QOL in version 1.[14] Therefore, it seems that the child's feelings in daily life greatly influence the QOL. The feelings of the LSG were different, and they felt that they were never praised even when their parents did in fact encourage them.

The QOL score of the item 'coughing because of cigarette smoke' in Domain A was poor. The smoking rate of twenty year olds and over in Japan has been steadily decreasing, but the rate is still high (male: 48.3%, female: 13.6%) compared with that of other advanced countries.[15] There is a strong possibility that the QOL of children with asthma is poor because
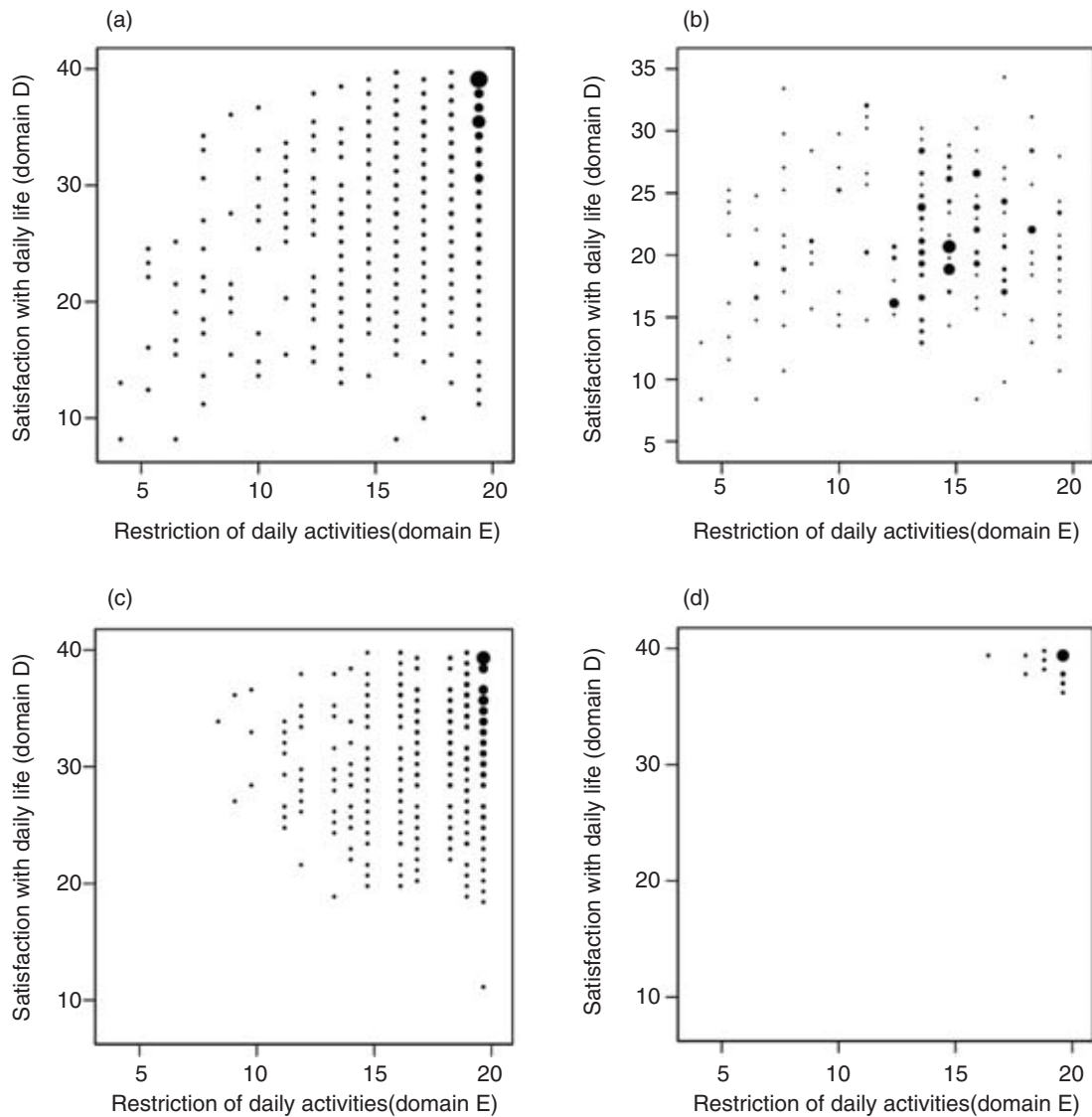
Fig. 4 Relationships between the five domains in each of the three groups and all subjects. Though there is a correlation between the domains in all subjects, the correlation between the domains is weak in each group. (**a**) relationship between two domains of the group including all subjects, (**b**) the LSG under the 10th percentile, (**c**) the MSG in the 10th percentile or more, and the 90th percentile or less, (**d**) the HSG over the 90th percentile. For example, the correlation coefficient between Domain E and Domain D is 0.46. However, in the LSG it is 0.08, in the MSG 0.26, and in the HSG 0.13.

there were many subjects whose family member(s) smoked, triggering asthma attacks.

The item scores in Domain B showed a small difference between the LSG and the other two groups. As most items in this domain concerned the frequency of experiences, and two-thirds of the subjects had only mild asthma or were in remission, the frequency of asthma attack experiences might be decreased.

Ireland explored children's perceptions of having asthma.[16] She found that 'establishing normality' was a core variable and specified four major categories including 'normal for me'. These findings influenced each child's appraisal and response to having asthma. Normality was very important for children with asthma, and was irrespective of the length of their asthma history or of medical judgments of asthma severity. Because the QOL of Domain A, Domain C and Domain E is poor, the children of the LSG whose QOL is low might experience difficulty in 'establishing normality'. If 'establishing normality' is difficult because of asthma attacks, the QOL can be thought
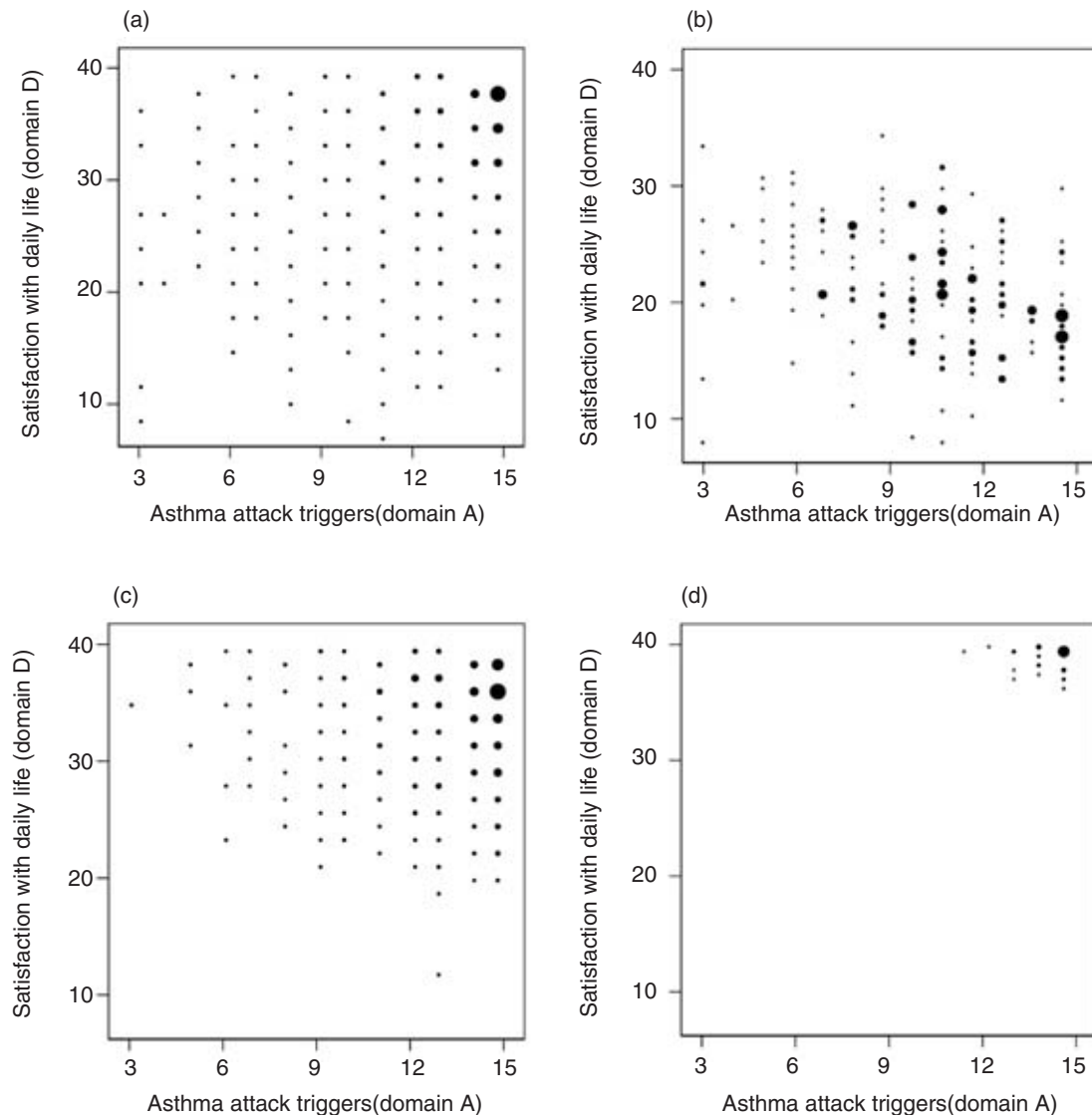
Fig. 5 Relationships between the five domains in each of the three groups and all subjects. Though there is weak correlation between the domains in all subjects, the correlation between the domains is moderate in the LSG. (**a**) relationship between two domains of the group including all subjects, (**b**) the LSG under the 10th percentile, (**c**) the MSG in the 10th percentile or more, and the 90th percentile or less, (**d**) the HSG over the 90th percentile. For example, the correlation coefficient between Domain A and Domain D is 0.21. However, in the LSG it is − 0.40, in the MSG 0.01, and in the HSG − 0.08.

to decline easily.

In this study, a specific domain may be low, similar to the LSG children, in subjects classified in the MSG. Therefore, not only the total QOL score but also each domain score must be taken into consideration. When a domain has a poor QOL, the physician should discuss the item with the child fully, and must confirm the reason why the QOL is poor. Cooperation between the doctor, nurse and the Certified Nurse Specialist (CNS) of child health nursing is important. In the future, the JSCA-QOL questionnaire will be used for longitudinal studies in the clinical

scene, and sensitivity to changes in children's QOL will have to be confirmed.

EVALUATION FORM OF THE QOL OF CHILDREN WITH ASTHMA

In evaluating the data of the JSCA-QOL questionnaire, we developed a radar chart so that a child's QOL profile might be efficiently evaluated and used for screening of children with asthma with problematic QOL (Fig. 6). Visual evaluation of each domain is made possible by this chart. The median and 10th percentile levels of all subjects were represented in
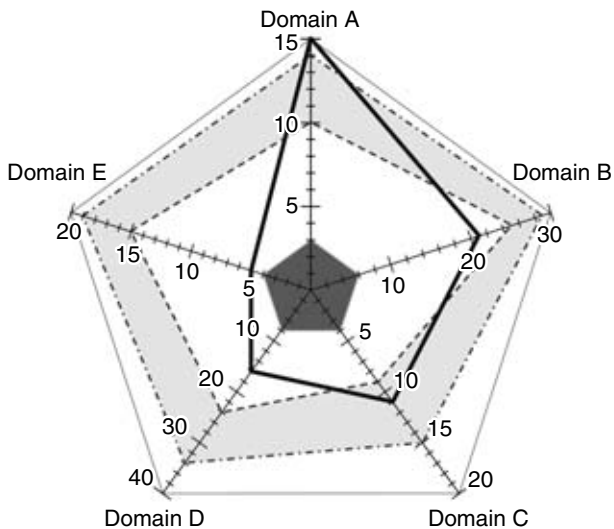
Fig. 6 The plotting form of the five domains for efficient evaluation of children's QOL profile and for screening of children with asthma with problematic QOL. The dark gray regular pentagon in the center indicates the minimum score of the five domains; and the gray zone the median to the 10th percentile value of all subjects. The black bold line (—) plotted on the radar chart indicates the answers of a 7th grade adolescent with severe asthma of the LSG. His domain scores were 15 points for Domain A, 21 points for Domain B, 11 points for Domain C, 16 points for Domain D, and 5 points for Domain E. Domain A: Asthma Attack Triggers, Domain B: Change in Daily Life, Domain C: Family Support, Domain D: Satisfaction with Daily Life, Domain E: Restriction of Daily Activities.

the chart as a standard of the evaluation. The gray zone where evaluation was difficult was defined between these two levels. When the QOL value of each domain is poorer than the 10th percentile or when the plot of each domain in the chart is skewed, the child must be interviewed. For example, a junior high school student in the LSG was chosen at random, and plotted on the form. This adolescent had a perfect score in Asthma Attack Triggers (Domain A), although he had severe asthma. However, the Family Support (Domain C) score did not exceed the level of the 50th percentile. Furthermore, Change in Daily Life (Domain B), Satisfaction with Daily Life (Domain D) and Restriction of Daily Activities (Domain E) scored lower than the level of the 10th percentile. His Domain E score of five was especially low. Therefore, firstly, based on his QOL profile, he must be interviewed more specifically about all items of this questionnaire. Then, if necessary, his family should be interviewed. Horiba reported that subjects with mild symptoms, such as a cough or a wheeze, occupied more than half of the group which feels no attacks.[17] His high score in Domain A indicates that he must be

interviewed or seek a doctor's opinion. Moreover, it is essential to talk with his family, class teacher and school nurse about whether he is enjoying school life, as his scores in Domain B and Domain E were low. Teachers and school nurses must be educated about coping strategies for dealing with children with asthma in the school situation and, as indicated by Matsuura's study, 90% of teachers want this information.[18]

As a result of our nationwide investigation using the JSCA-QOL, it was clear that the characteristics of the LSG were obviously different from those of the other groups. Therefore, it was very useful to divide the LSG with the 10th percentile of the QOL score to distinguish children who needed special support. The evaluation of the QOL profile was simplified by using the radar chart concept.

ACKNOWLEDGEMENTS

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