

Bronchial asthma and the short-term quality of life: follow-up study of childhood bronchial asthma in Hungary

Szabó A, Cserhádi E. Bronchial asthma and the short-term quality of life: follow-up study of childhood bronchial asthma in Hungary. *Pediatr Allergy Immunol* 2004; 15: 539–544. © 2004 Blackwell Munksgaard

The aim of our study is to determine and describe the current short-term health-related quality of life of recent adult patients who had bronchial asthma in childhood. Our objective was to investigate if symptom control in bronchial asthma could be in conflict with general quality of life. We made a follow-up study of 152 patients (105 male, 47 female) over the age of 30 (31–55 yr) who were allergic asthmatics in childhood. The patients' current symptoms and short-term quality of life were evaluated by a questionnaire. The patients developed asthmatic symptoms by age 4.4 (0.5–13) years on the average. Now 60% (91 persons) have no symptoms. They became symptom-free between 3 and 41 yr of age (mean = 14.2 ± 8.2). Amongst the currently asthmatic patients (58 patients, 38%), 34 patients (22%) belong to the Global Initiative for Asthma (GINA) I, nine patients (6%) to the GINA II, five patients (3.3%) to the GINA III, and five patients (3.3%) to the GINA IV classification. Five patients (3.3%) did not specify their own symptoms. Three persons (2%) did not answer this question. Symptomatic patients reached 5.28 on the Juniper Asthma Quality of Life Questionnaire, while their asymptomatic peers scored statistically higher with 6.8 on the scale. Amongst the symptomatic patients, the most limited areas were: 'bothered by heavy breathing', 'had to avoid a situation or environment because of dust', 'experienced difficulty breathing out as a result of asthma', 'experienced asthma symptoms as a result of the weather or air pollution outside'. They were least 'concerned about medication', 'frustrated as a result of their asthma', they were least limited in 'going outside because of the weather or air pollution'. The most problematic areas for the symptom-free patients were 'had to avoid a situation or environment because of dust', 'had to avoid a situation or environment because of cigarette smoke', 'experiencing asthma symptoms as a result of being exposed to dust and the 'need to clear throat'. It seems that having no asthma symptoms is not equal to having a good quality of life for asthmatic patients. Moreover, symptom control in bronchial asthma is in conflict with quality of life, as many prophylactic measures to prevent exposure to allergens also restrict the patient's life.

**Alexandra Szabó^{1,2} and
Endre Cserhádi¹**

¹First Department of Paediatrics, Semmelweis University, Budapest, Hungary, ²Bethesda Children's Hospital of the Hungarian Reformed Church, Budapest, Hungary

Key words: childhood bronchial asthma; short-term quality of life; follow-up to adulthood

Alexandra Szabó, First Department of Paediatrics, Semmelweis University, Bókay János u. 53, Budapest H-1083, Hungary
Tel.: +36-1-3138212
Fax: +36-1-3138212
E-mail: sza.part@axelero.hu

Accepted 5 May 2004

Significant increases in survival rate have been reported for a wide range of chronic non-communicable childhood diseases. These undoubtedly impressive improvements have generally been achieved through the use of increasingly aggressive treatment protocols, prompting some to question the relationship between quan-

tity and quality of life. Current ability to treat children with chronic disease, coupled with the inability to offer absolute cure, raises the issue of the quality of life of these children. We also have to bear in mind, what kind of a life awaits those saved children, who need permanent medical care, how their quality of life will look like.

The situation of diabetic or asthmatic children is naturally much better than their peers' with malignancies, but recurrent symptoms, the need for lifelong medication truly has an impact on their quality of life as well (1).

Moreover, symptom control in bronchial asthma could also be in conflict with quality of life, as many prophylactic measures to prevent exposure to allergens also restrict the patient's life.

There is a growing number of questionnaires on paediatric health-related quality of life in the international literature, mostly to measure patients with chronic non-communicable diseases (2–10) (Table 1).

In our study, we aimed to determine and describe the short-term health-related quality of life of recent adult patients who had bronchial asthma in childhood. Our objective was to investigate if symptom control in bronchial asthma could be in conflict with general quality of life. Our patients were asked to complete the Juniper Asthma Quality of Life Questionnaire (AQLQ) on short-term quality of life (8), and questions were also asked about current symptoms, life-circumstances. The AQLQ is the only international questionnaire translated and validated in Hungarian. It satisfies the research criteria of being: reproducible (scores on evaluative quality of life instruments should not vary significantly between two-points in time when a patient is clinically stable), valid (the instrument really measures the asthma-related quality of life), and responsive to changes (ability to detect small but significant changes in outcomes over time) (11).

Patients and method

A letter was sent to every recent adult patient over 30 yr old who has been diagnosed and treated with bronchial asthma in childhood at the Semmelweis University First Department of Paediatrics. Retrospective data was obtained from patient documentation, with discharge diagnosis of bronchial asthma. A total of 501 patients were identified.

The patients were asked to answer questions about their current symptoms of asthma/Appendix 1 and asthma-related short-term quality of life. These questionnaires were mailed to them and further help was not permitted for the patients. We consecutively numbered and coded the incoming answers. The person performing the statistical analysis was blinded of the coding. We conducted the statistical analysis using Windows Excel, and considered 95% confidence interval (CI) as statistically significant.

The AQLQ consists of 32-items, based on four domains: symptoms, activity limitation, emotional function and environmental stimuli. Every item concentrates on the previous 2 wk' problems and symptoms, so it measures the asthmatics' current state. The patients rate their experienced limitation, using the 7-point Likert scale according to Table 2, where 1 means worst and 7 is best. At certain answers there is only scale-unit 1, 3, 5 and 7 specified.

We divided the patients into symptomatic and asymptomatic subgroups. We determined the mean and CI of all the answers of the symptomatic and asymptomatic subgroup. After this, we determined the mean of each question item, and

Table 1. Important health-related quality of life questionnaires in the international literature

	Type of scale	Name of scale	Components	Respondents	Age range
Children	Cancer-specific	Quality of well-being (2)	Mobility, physical function, social activity, symptoms	Parents	4–18
		Perceived illness experience (PIE) (3)	Appearance, activity, disclosure, school, peer rejection, parental behaviour, manipulation, preoccupation with illness (treatment)	Child, parents	11–16
	Diabetes-specific	Quality of life (4)	Satisfaction, impact, worry diabetes, worry social/vocational emotional difficulty, attitude	Young adult	15–28
	Asthma-specific	Psychosocial adaption (5)	Emotional difficulty, attitude	Child, parents	10–17
		Child asthma (6)	Severity, enjoyment of passive distress, enjoyment of active pastimes	Child	4–7, 8–12, 13–16
Adults		Paediatric asthma quality of life (7)	Activity limitation, symptoms, emotional functioning	Child	7–17
		Asthma quality of life questionnaire (8)	Activity limitations, symptoms, limitations caused by exposure to environmental stimuli and emotional function	Adults	
		St George's respiratory questionnaire (9)	Symptoms activity, effect of disease	Adults	
		Living with asthma questionnaire (10)	Social factors and leisure, sports, holidays, sleep, work and other activities, colds, mobility effects on others, medication use, sex, and dysphoric states and attitudes	Adults	

analysed their diversion from the mean. In the article, we are only discussing the statistically significantly diverting items.

Results

Of the 501 patients identified, 253 patients moved away and we were unable to trace. Eighty-one patients did not respond. Twelve patients phoned in: seven said that they had no symptoms but were not returning the questionnaire, five said that they do not remember having asthma. Three patients died in accidents (Fig. 1). Response rate is 65% (162 of 258). We received 152 answers from 105 (69%) male and 47 (31%) female patients with the average age of 38.4 yr (31–55). The patients developed asthmatic symptoms by age 4.4 (0.5–13) years on the average.

To evaluate the quality of life results, we had to know the patients' current symptoms as well.

Ninety-one patients (60%) were symptom-free, 58 (38%) had current symptoms, three patients (2%) did not answer this question. Our patients became symptom-free between 3 and 41 yr of age (mean = 14.2 ± 8.2).

According to the WHO Global Initiative for Asthma (GINA) guidelines, modern management of bronchial asthma is based on sorting the patients' symptoms in four classes (GINA I intermittent, GINA II mild persistent, GINA III moderate persistent, GINA IV severe persistent) according to severity, and the treatment is also based on this classification (12). In the study out of the currently symptomatic patients, 34 (22%) patients belong to the GINA I intermittent, nine patients (6%) to the GINA II mild persistent, five patients (3.3%) to GINA III moderate persistent, five patients (3.3%) to GINA IV severe persistent classification. Five persons (3.3%) did not specify their own symptoms. Three patients (2%) did not answer this question (Fig. 2).

Fig. 3 represents the averages resulted on the AQLQ questionnaire. It is well demonstrated that only few persons were severely limited by their disease. With the average increasing, which means better state, the number of patients is exponentially increasing.

Figs 4 and 5 represents the connection between each item's average, and the mean average of all the items, divided into two subgroups of symp-

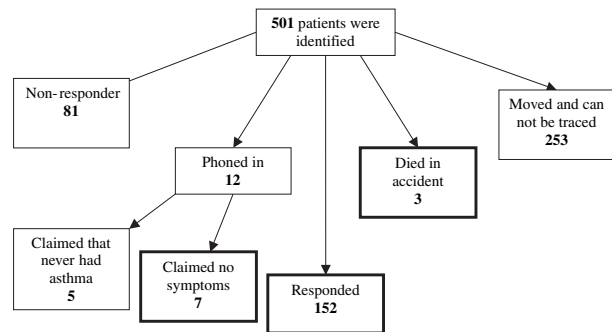


Fig. 1. Diagram of the response rate.

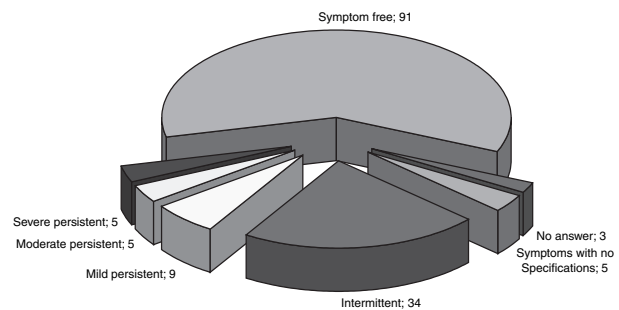


Fig. 2. Severity of asthmatic symptoms in 152 patients according to the WHO classification.

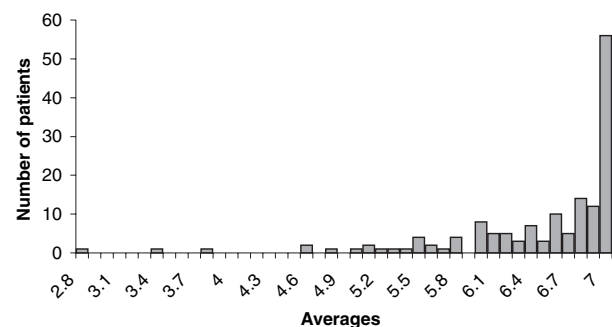


Fig. 3. Results of the Juniper Asthma Quality of Life Questionnaire (AQLQ) health-related quality of life questionnaire, reached averages taken as a function of the number of patients.

Table 2. Likert scale

1	2	3	4	5	6	7
Totally limited A very great deal All of the time Most not done	Extremely limited A great deal Most of the time	Very limited A good deal A good bit of the time Several not done	Moderate limitation Moderate amount Some of the time	Some limitation Some A little of the time Very few not done	A little limitation Very little Hardly any of the time	Not at all limited None None of the time No limitation

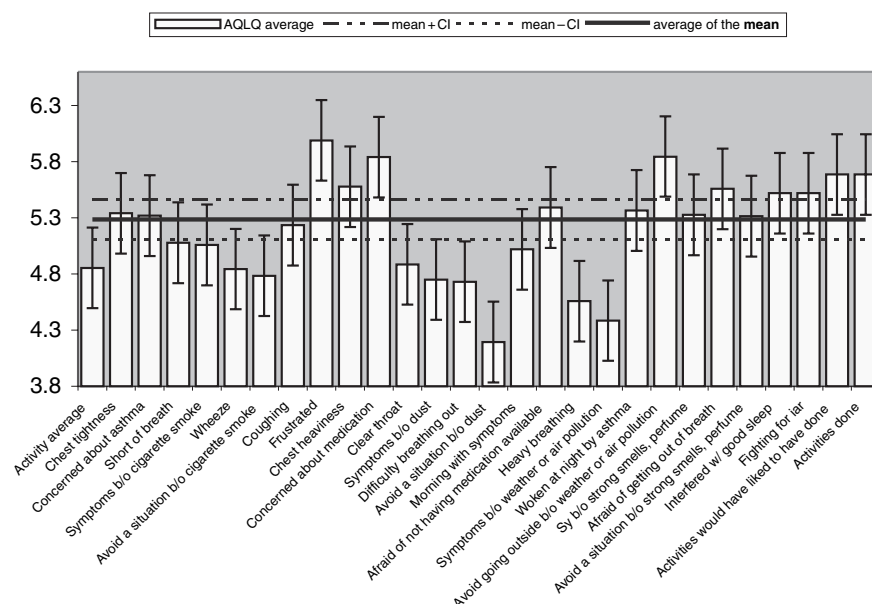


Fig. 4. Mean of each item, and the mean of all items of the Juniper Asthma Quality of Life Questionnaire (AQLQ) health-related quality of life questionnaire in symptomatic patients.

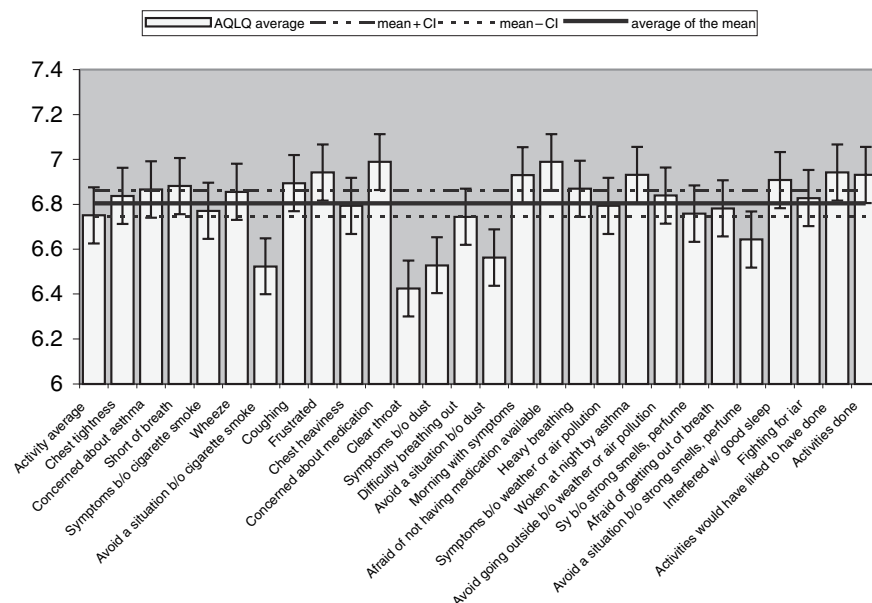


Fig. 5. Mean of each item, and the mean of all items of the Juniper Asthma Quality of Life Questionnaire (AQLQ) health-related quality of life questionnaire in asymptomatic patients.

tomatic and asymptomatic patients. A column represents each question, showing the mean values. The continuous line shows the mean of all the questions, with the CI. Because the first five questions are about every day activities listed by the patients themselves, we represented them in the first contracted column: 'activities'.

Symptomatic patients reached 5.28 (CI: 5.1–5.45) on the AQLQ questionnaire, while their asymptomatic peers scored statistically higher with 6.8 (CI: 6.74–6.86).

In the short-term AQLQ (events of the last 2 wk), amongst the patients still having symptoms, the most limited areas were: 'bothered

by heavy breathing' (4.55; CI: 4.2–4.9), 'had to avoid a situation or environment because of dust' (4.19; CI: 3.84–4.54), 'experienced difficulty breathing out as a result of asthma' (4.73; CI: 4.38–5.08), 'experienced asthma symptoms as a result of the weather or air pollution outside' (4.38; CI: 4.03–4.73). They were least 'concerned about medication' (5.84; CI: 5.49–6.19), 'frustrated as a result of their asthma' (5.99; CI: 5.64–6.34), they were least limited in 'going outside because of the weather or air pollution' (5.84; CI: 5.49–6.19).

The most problematic areas for the symptom-free patients were: 'had to avoid a situation or

environment because of dust' (6.52; CI: 6.47–6.57), 'had to avoid a situation or environment because of cigarette smoke' (6.56; CI: 6.51–6.61), 'experiencing asthma symptoms as a result of being exposed to dust' (6.52; CI: 6.47–6.57) and 'need to clear throat' (6.42; CI: 6.37–6.47).

Discussion

The loss of 253 patients to follow-up because of moving away seems to be high. However, we believe that this does not function as a bias, as people move away more or less regardless of asthmatic symptoms. According to Fig. 1, we counted the three accidental deaths, the 152 responders and the seven persons who claimed no symptoms into the 'responder group', the 81 non-responders and the five who claimed they never had asthma into the 'non-responder group'. Therefore, we calculated our response rate as 162 of 258 (65%). In Hungary, women are changing their names after getting married, this can elevate the over-representation of men amongst our respondents, which possibly causes distortion in our data. (Normally the male/female ratio in childhood asthma varies between 1.5–2:1.)

We found that despite that most of our symptomatic patients have few symptoms; they experience significantly poorer quality of life than their asymptomatic peers. Having only a few asthma attacks per year can still affect the quality of the patients' everyday lives.

However, it seems that having no current asthma symptoms is not equal to having the best achievable quality of life for asthmatic patients. Moreover, symptom control in bronchial asthma is in conflict with quality of life, as many prophylactic measures to prevent exposure to allergens also restrict the patient's life, limits his freedom. Patients with symptoms claim that they are limited more by the disease itself (heavy breathing, difficulty in breathing out), but asymptomatic patients seem to struggle more with the avoidance measures (avoiding events because of dust or smoke).

Clinicians treating asthmatic patients must be aware of this 'double-edged sword', which by trying to eliminate the most allergens from their patients' life, they should not cause bigger damage with the patients' restrictions in their quality of life.

We could not find any similar study investigating the adult quality of life of childhood asthmatics in the international literature, so we were unable to compare our results with other research.

Acknowledgments

Authors would like to express their gratitude to Prof. Elizabeth Juniper for sending and letting them use her validated Hungarian AQLQ questionnaire, and her precious advice during the study.

We would also like to thank Dr Adrienn Halász for lending her database; which made the work easier.

Our work was supported by the Hungarian Scientific Health Council (ETT-319/2000; ETT-539/2003).

Appendix 1. Symptoms questionnaire

Please read the following questions. Give your answers on the dotted line, or cross the appropriate box

How long have you been asthmatic?

Do you at the moment have asthmatic symptoms? Yes ☐ No ☐

Please tick the most appropriate from the following:

Intermittent symptoms, less than once a week, brief exacerbations (from a few hours to a few days), night-time asthma symptoms less than two times a month ☐

Symptoms more than once a week, but less than once daily, exacerbations affect activity and sleep, night-time symptoms more than twice a month ☐

Symptoms daily, exacerbations affect activity and sleep, daily use of short acting β_2 agonists ☐

Continuous symptoms, frequent exacerbations, frequent night-time symptoms, physical activities limited by asthma symptoms ☐

If you do not have symptoms at the moment, how long have you been symptom-free?

References

1. EISER C. Children's quality of life measures. *Arch Dis Child* 1997; 77: 350–4.
2. BRADLYN AS, HARRIS CV, WARNER JE, RITCHEY AK, ZABOY K. An investigation of the validity of well-being scale with pediatric oncology patients. *Health Psychol* 1993; 12: 246–50.
3. EISER C, HAVERMANS T, CRAFT A, KERNAHAN J. Development of a measure to assess the perceived illness experience after treatment for cancer. *Arch Dis Child* 1995; 72: 302–7.
4. WALLYMAHMED ME, BAKER GA, MACFARLANE IA. Quality of life assessment in diabetes: a preliminary study of young adults in Liverpool. *Pract Diabetes* 1992; 9: 193–5.
5. CHALLEN AH, DAVIES AS, WILLIAMS RJW, HASLUM MN, BAUM JD. Measuring psychological adaptation to diabetes in adolescence. *Diabet Med* 1998; 5: 739–46.
6. CHRISTIE MJ, FRENCH D, WEATHERSTONE L, WEST A. The patient's perceptions of chronic disease and its management: psychosomatics, holism and quality of life in contemporary management of asthma. *Psychother Psychosom* 1991; 56: 197–203.
7. JUNIPER EF, GUYATT GH, FEENY DH, FERRIE PJ, GRITH LE, OWNSEND M. Measuring quality of life in children with asthma. *Qual Life Res* 1996; 5: 35–46.
8. JUNIPER EF, GUYATT GH, FERRIE PJ, GRITH LE. Measuring quality of life in asthma. *Am Rev Respir Dis* 1993; 147: 832–8.
9. JONES PW, QUIRK FH, BAVEYSTOCK CM, LITTLEJOHNS P. A self-complete measure of chronic airflow limita-

- tion: the St George's respiratory questionnaire. *Am Rev Respir Dis* 1992; 145: 1321–7.
10. HYLAND ME. The living with asthma questionnaire. *Respir Med* 1991; 85: 13–6, 33–7.
 11. SHUVAYU SS, GUPCHUP GV, THOMAS J. Selecting among health-related quality-of-life instruments. *Am J Health Syst Pharm* 1999; 56: 1965–71.
 12. Global Initiative for Asthma (GINA). Global Strategy for Asthma Management and Prevention. NIH Publication No. 02-3659. Bethesda, MD: NHBLI 2002: 1971.