

Agreement between parental and self-completed questionnaires about asthma in teenagers

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In studies of asthma in children, a common method is for the parents to complete questionnaires about their child's asthma symptoms. With longitudinal studies of asthma, children reach an age when they can complete the questionnaire themselves. The aim of this paper was to compare the prevalence of asthma symptoms as well as the agreement between responses to an asthma questionnaire completed by teenagers and their parents. As a part of the Obstructive Lung Disease in Northern Sweden Study (OLIN) pediatric study, where 3345, 13–14-yr-old children completed an asthma questionnaire, 294 (84%) randomly selected parents also completed the questionnaire, which included the International Study of Asthma and Allergies in Childhood (ISAAC) questionnaire. There were no significant differences in the prevalence of wheeze in the last 12 months, ever asthma, or physician diagnosed asthma as reported by the parents compared with the teenagers.

However, the teenagers reported a significantly higher prevalence of wheeze during or after exercise. The absolute agreement was generally very high while the level of agreement (kappa-value) was slightly lower. The highest results in both absolute agreement and kappa-value, were reached by the questions on diagnosis of asthma (98.9% and 0.93), use of asthma medicines (95.5% and 0.78), and whether the child ever had had asthma (97.2% and 0.86), respectively. In conclusion, the agreement between the parents' and the teenagers' responses to the asthma questionnaire was good. The change in methodology from parental to self-completion of the questionnaire did not affect the results in the study.

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For international comparisons of asthma prevalence and severity (1–4), standardized methods are required (5–8). In epidemiological studies of asthma in adults, self-completed questionnaires are commonly and traditionally used (9). Questionnaire studies of asthma in children, however, are usually based on parental reports (10). The International Study of Asthma and Allergies in Childhood (ISAAC) questionnaire was designed to measure the prevalence of asthma in children and allow for objective comparisons within and between countries (10). With longitudinal studies of childhood asthma, children reach an age when they can complete the questionnaire themselves.

Changes in the methodology of a study, including questionnaire studies, may influence the outcome. However, the nature of a longitudinal study of asthma in children necessitates a change, as children at a young age cannot respond reliably about symptoms, while older children are a better source of information on their own symptoms than their parents. There are several studies of asthma in children where a cohort was followed throughout childhood (11–15). Although many prevalence studies of asthma among children and teenagers have been performed, only a few studies have compared parental reports with self-reported symptoms (16–18). The agreement between

parental and self-reported symptoms was generally good when asthma was compared with other illnesses, and it was suggested that this was because asthma is a common, visible and a longstanding condition (16). Comparative studies of parents' and children's responses to questions exclusively about asthma symptoms, have shown that the prevalence of asthma was higher when the children completed the questionnaire themselves, and further that the level of agreement was moderate (17, 18).

The Obstructive Lung Disease in Northern Sweden Study (OLIN) pediatric study used the ISAAC questionnaire with additional questions in a longitudinal study of the prevalence and incidence of asthma and allergic sensitization and the associated risk factors among school children (13, 19–22). Earlier, when their children were 7–8 yr old, parents completed questionnaires annually for 5 yr. Beginning in the sixth year of the study, questionnaires were completed by the children themselves.

We have examined the prevalence of asthma symptoms among the study participants at 13–14 yr of age, as reported both by the parents and the teenagers themselves and assessed the agreement between the two methods.

Materials and method

Cohort background

In 1996, a longitudinal study of asthma, rhinitis, eczema, and type-1 allergy among school children in Northern Sweden started. The aims and methods of the study has been described previously (13). In short, all 3525 children enrolled in the first and second class in three towns, Luleå, Piteå, and Kiruna, were invited to participate in the OLIN pediatric study. The school teachers distributed a questionnaire to the parents and the response rate was 97% (3431 participated). In the following years, the questionnaire was annually completed by the parents in the same manner (19, 21–22). The response rates were 95–97%.

Current study cohort

From year 2001 the teenagers completed the questionnaires themselves instead of the parents. The questionnaire was distributed in the school by the participants' teachers who explained the meanings of terms used in the questionnaire. The teenagers in the study completed the questionnaire at school.

In 2002, the questionnaires were distributed to all 3512 children, now 13–14 yr old, and enrolled

in seventh and eighth grades. Among the invited teenagers, 3345 (95.2%) participated in the study. Of the responders, 350 (10%) teenagers were randomly selected for the current study, and questionnaires were also sent to the parents of those teenagers. The response rate was 84% and the present comparison study is based on the results of the responses to these 294 questionnaires (Table 1). The response rates were similar in all areas. Of the questionnaires completed by the parents, 253 (86%) were answered by the mothers, 29 (10%) by fathers, and 10 (4%) by other guardian, while it was unclear in two questionnaires who completed it.

The study was approved by the Ethical Committee at the University of Umeå and the University Hospital of Northern Sweden in Umeå.

Definitions

The definitions used in this paper are based on following questions.

Wheeze ever: Have you (Has your child) ever had wheezing or whistling in the chest at any time in the past? (10)

Wheeze in the last 12 months: Have you (Has your child) had wheezing or whistling in the chest in the last 12 months? (10)

Number of attacks of wheeze: '1–3 attacks, 4–12 attacks, or more than 12 attacks' on the question: How many attacks of wheezing have you (has your child) had in the last 12 months? (10)

Wheeze disturbing sleep: 'less than one night per week, or one or more nights per week' on the question: In the last 12 months, how often, on average, has your (your child's) sleep been disturbed due to wheezing? (10)

Wheeze limiting speech: In the last 12 months, has wheezing ever been severe enough to limit your (your child's) speech to only one or two words at a time between breaths? (10)

Wheeze during or after exercise: In the last 12 months, has your (your child's) chest sounded wheezy during or after exercise? (10)

Table 1. Number of teenagers and parents who were invited and participated in the OLIN pediatric questionnaire study 2002

	Boys	Girls	Total
Total study			
Invited (n)	1788	1724	3512
Participated, n (%)	1696 (95)	1649 (96)	3345 (95)
Comparison study			
Invited (n)	178	172	350
Participated, n (%)	153 (86)	141 (82)	294 (84)

Nocturnal dry cough: In the last 12 months, have you (has your child) had a dry cough at night, apart from a cough associated with a cold or a chest infection? (10)

Wheezing without cold: Have you (Has your child), in the last 12 months, had wheezing or whistling in the chest without having a cold? (10)

Asthma ever: Have you (Has your child) ever had asthma? (10)

Physician diagnosed asthma: Have you (Has your child) been diagnosed by a physician as having asthma? (13)

Use of asthma medicines: 'sometimes, often/periodically, or every day' to the question: During the last 12 months, how often have you (has your child) taken medicines for asthma? (13)

Treatment of data and statistical analysis

Analyses were made using the data programs Statistical Package for Social Sciences (SPSS 10.0, SPSS Inc, Chicago, IL, USA) and EPI-info 6.0 (Atlanta, GA, USA). Prevalence of asthma, asthma symptoms, and use of asthma medicines were calculated for the parents' responses and the teenagers' responses in the comparison study ($n = 294$), as well as in the total questionnaire study ($n = 3345$). Differences in prevalence between the groups were assessed by chi-squared tests. Missing values in individual questions (0–4%) has been considered as negative responses when calculating prevalence. Missing values has not been included in calculations of agreement.

Absolute agreement and kappa-coefficient were used to consider the level of agreement between

the responses of the teenagers and their parents to the same questions. Absolute agreement is the number of positive responses from both parents and teenagers, added with the number of negative responses from both parents and teenagers, and divided with the total number of responses. The absolute agreement measures the proportion of pairs of parents and teenagers who have given the same answer, kappa takes all combinations of answers in account. The kappa-coefficient compares the level of agreement between different groups of data (23). Calculations of 95% confidence intervals for the kappa-value were also made. To be able to interpret the kappa-value, the following definitions has been used: < 0.2 , slight or poor agreement; $0.21–0.4$, fair agreement; $0.41–0.6$, moderate agreement; $0.61–0.8$ substantial agreement; and > 0.81 , indicate an almost perfect agreement (23). In the analysis of agreement, the questions 'number of attacks of wheeze', 'wheeze disturbing sleep', and 'use of asthma medicines', the alternatives 'none', or 'never' were considered as no, and the others as yes.

Results

Prevalence

There were no significant differences in prevalence of asthma symptoms, asthma diagnosis or use of asthma medicines between the parental and the self-completed questionnaires, except for the question about 'wheeze during or after exercise', 7.5% and 13.6%, respectively, $p < 0.05$ (Table 2).

Table 2. Prevalence of asthma, asthma symptoms and use of asthma medicines. Comparison of prevalence between parents' and teenagers' responses, and between teenagers in the comparison study and the total study, respectively

Question	Comparison study					Total question- naire study		Difference teenagers– all teenagers p-value
	Parents (n = 294)		Teenagers (n = 294)		Difference parents– teenagers p-value	All teenagers (n = 3345)		
	n	%	n	%		n	%	
Wheeze ever	56	19.0	44	15.0	0.18	656	19.6	0.052
Wheeze in the last 12 months	21	7.1	26	8.8	1.00	353	10.5	0.36
Number of attacks of wheeze								
1–3 attacks	14	4.8	17	5.8	0.93	228	6.8	0.50
>3 attacks	7	2.4	9	3.0	0.57	129	3.8	0.49
Wheeze disturbing sleep	5	1.7	5	1.7	1.00	62	1.8	0.85
Wheeze limiting speech	0	0	2	0.7	0.31	56	1.7	0.19
Wheeze during or after exercise	22	7.5	40	13.6	0.02	518	15.5	0.39
Nocturnal dry cough	18	6.1	27	9.2	0.27	284	8.5	0.68
Wheezing without cold	16	5.4	21	7.1	0.39	294	8.8	0.36
Asthma ever	31	10.5	34	11.6	1.00	449	13.4	0.37
Physician diagnosed asthma	24	8.2	26	8.8	0.88	326	9.7	0.62
Use of asthma medicines	33	11.3	31	10.5	0.59	351	10.5	0.97

The prevalence of 'wheeze in the last 12 months' was 8.8% according to the teenagers and 7.1% according to the parents. On the question about ever wheeze 19% of the parents and 15% of the teenagers reported the symptoms. However, these differences were not significant (Table 2).

Comparison between the teenagers' responses in the comparison study and the total questionnaire study, did not show any significant differences in prevalence. There were no significant differences in prevalence between responses given by mothers and other guardians either.

Level of agreement

The level of agreement between the parents' and the teenagers' responses was assessed by using absolute agreement and kappa-coefficient. Absolute agreement ranged from 86.2% (wheeze ever) to 98.9% (physician diagnosed asthma). The level of agreement ranged from kappa 0.27 (nocturnal dry cough) to kappa 0.93 (physician diagnosed asthma). The highest results in both absolute agreement and kappa-value, were reached by the questions on diagnosis of asthma (98.9% and 0.93), use of asthma medicines (95.5% and 0.78), and whether the child ever had had asthma (97.2% and 0.86), respectively.

Comparison between answers given by parents, and boys and girls, respectively, and between the teenagers and mothers and fathers/other guardian, respectively, were also made. No specific pattern was found and the agreement was generally similar in the different groups.

Discussion

In epidemiological longitudinal studies, standardized methods are essential to reach valid and reliable results. Changes in methods may have a crucial effect on the outcome of the study. In a study such as the OLIN pediatric study, the change in methods necessitates an evaluation of the reliability of the instruments used. From the present study we can conclude that a change from parental reporting to self-reporting did not effect the outcomes of this study.

The participating families in this study have completed the questionnaire repeatedly over years. The questions about asthma and asthma symptoms have been the same and the response rate has been between 95% and 97%. The parents and children in the study have annually in the last 6 yr been presented information about the study and answered questions. The issues in the questionnaire have probably been

discussed in the homes as well as in the schools. These facts may have resulted in a higher awareness about asthma, among both the parents and the teenagers of this study compared with an average 13–14-yr-old child. This is both an advantage and a disadvantage for this study. The advantage is that the parents and teenagers of the study have the same opinion and understand the questions they answer, however, they maybe not represent the average population's response to a questionnaire about asthma. However, also in other populations where parents' and their children's responses to questions about asthma were compared, the agreement was good (16).

The comparison study population was randomly selected from the total OLIN pediatric study group. There were no major differences in participation rates between the comparison study population and the total study population with regard to area and sex. Furthermore, there were no significant differences in prevalence between the study groups, and the response rate in the parental questionnaire was good (84%). Although there were no significant differences between the total group and the comparison study population, the prevalence rates of asthma and asthma symptoms in the total group were slightly higher (Table 2). However, the teenagers in the comparison study were representative and the small differences in prevalence did not bias the result, as only the responses between the parents and the teenagers within the group were compared.

When other similarly conducted studies compared parental and self-completed questionnaires about asthma, the children reported significantly higher prevalence rates than their parents, especially in questions about symptoms in the last 12 months (17, 18). These results are confirmed in the present study where prevalence rates, although not significantly, are a few points higher in the children's responses to questions regarding the last 12 months (Table 2). The parents' responses to 'wheeze ever', a question that goes further back in time, was almost the only question where more parents than children reported positive responses. In questions regarding early childhood, the parental answers are probably more reliable as the child does not remember ever having had asthma symptoms, for instance wheezing. In a study where subjects were followed from birth to age 33, 29.1% recalled having asthma or wheezing at any age when subjects were asked at age 33. However, according to parents reports on successive follow-ups, 42.9% had had asthma or wheeze at any age (12).

Table 3. Level of agreement between the teenagers and their parents in responses to questions about asthma, asthma symptoms, and use of asthma medicines

Parent response*	Yes	Yes	No	No	Kappa (95% CI)	Absolute agreement (%)
Teenager response*	Yes	No	Yes	No		
Wheeze ever	29	26	14	220	0.51 (0.38–0.64)	86.2
Wheeze in the last 12 months	15	6	11	258	0.61 (0.44–0.78)	94.1
Number of attacks of wheeze (y/n)	14	7	12	257	0.56 (0.38–0.74)	93.4
Wheeze during or after exercise	15	7	24	241	0.44 (0.27–0.60)	89.2
Nocturnal dry cough	7	11	18	252	0.27 (0.08–0.46)	89.9
Wheezing without cold	10	6	11	263	0.51 (0.31–0.71)	94.1
Asthma ever	27	4	4	251	0.86 (0.76–0.95)	97.2
Physician diagnosed asthma	23	1	2	250	0.93 (0.86–1.00)	98.9
Use of asthma medicines (y/n)	25	8	4	232	0.78 (0.66–0.90)	95.5

*The figures in each cell are absolute numbers.

In this study there was only one significant difference between the parents' and the teenagers' responses; in the question about 'wheezing during or after exercise'. The results may be explained by the fact that the parents are not necessarily present at the child's exercise time, at school or in their spare time. Further, perhaps the children only report severe respiratory symptoms to their parents and not mild symptoms, such as wheeze on exercise.

The absolute agreement between the parents' and the teenagers' responses in the comparison study was high (86.2–98.9%), which is in line with the results of other similar studies (17, 18). The absolute agreement only measures the proportion of pairs of parents and teenagers that have given the same answer, either both answered yes or both answered no. However, kappa corrects for chance and takes all combinations of answers in account. The highest results in both absolute agreement and kappa, were reached by 'physician diagnosed asthma', 'asthma ever', and 'use of asthma medicines' (Table 3). The results indicate that both parents and teenagers are well aware of these conditions, based on information given by a pediatrician or the family physician. Consequently, the parent-teenager agreement was greater in common, visible or diagnosed conditions, which has been concluded in other studies (16, 18).

As expected, there were no major differences between parents and responses given by boys and girls, respectively. The agreement between the teenagers and their mothers and fathers/other guardians were also similar.

Studies to compare responses to the ISAAC written questionnaire and video questionnaire have been made and the results have varied (7–8,24). These studies have focused on 13–14-yr-old children, participating in the study on one occasion. Studies to compare the shift from parental to self-completed questionnaires in ISAAC are scarce (17, 18). Further, it is

important to perform such studies in populations with cultural differences. However, cultural differences should not result in poor agreement, but in differences in prevalence estimate. The ISAAC videotape is an attempt to make the asthma questionnaire less language and cultural dependent (10, 24). All in the interest to get internationally comparable data about asthma prevalence in children. To further ensure this objective, and to be able to make reliable longitudinal epidemiological studies, the level of agreement between parents and children's responses should be taken into account when 13–14-yr-old children start to complete the questionnaire themselves.

In conclusion, there were no significant differences in prevalence of asthma between the parents' and the teenagers' responses, and the level of agreement was good. Further, the study concluded that children at 13 and 14 yr of age were able to complete the questionnaire in an adequate way. The change from parental to self-completion of the questionnaire did not affect the outcome of this longitudinal study.

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