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Prevalence estimates of asthma or COPD from a health interview survey and from general practitioner registration: what's the difference?

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Background: The aim of this study was to compare prevalence estimates of asthma or chronic obstructive pulmonary disease (COPD) derived from self-report in a health interview survey and from general practitioners' (GPs') medical records, and to explain any differences. **Methods:** the presence of asthma or COPD was measured by self-report in a random sample of 104 general practices in the Netherlands ($n = 19\ 685$) participating in the second Dutch National Survey of General Practice (DNSGP-2). This was compared with the presence of GP-diagnosed asthma or COPD in the same population as recorded using the International Classification of Primary Care by their GPs during a 12-month period. Gender, age, health insurance, ethnic background, educational level, tobacco exposure, and other symptoms and conditions were evaluated as explanatory variables using logistic models. **Results:** The prevalence of self-reported asthma or COPD (9.7%) was almost twice as high as the prevalence based on GP information (5.2%). The medical records of patients who reported having asthma or COPD, without having a diagnosis in their medical records, usually included other respiratory conditions. Patients reporting no asthma or COPD but whose medical records carried a diagnosis of asthma or COPD, were relatively older ($P < 0.01$) and tended to be exposed to smoking in their home ($P < 0.05$). **Conclusions:** Two methods for estimating prevalence of asthma or COPD yielded different results: compared with GP medical records, self-reported prevalence shows an overestimation in people who suffer from other respiratory conditions and an underestimation in elderly persons living in a smoky environment.

The most commonly used method to obtain data in epidemiological studies is through personal interviews or self-administered questionnaires.¹⁻⁸ Whether or not the data obtained by these methods are more accurate than physician-reported data is questionable.⁹⁻¹⁵ Several studies have reported that conditions such as asthma, sinusitis and chronic bronchitis are all more likely to be reported by the patient, but not diagnosed by their general practitioner (GP).¹⁶ A comparison of self-reports of chronic conditions with medical history data in patients aged 55-85 years revealed that the accuracy of

self-reporting was associated with the chronic condition; chronic non-specific lung disease, for example, was reported with moderate accuracy.¹⁷ However, various studies on asthma or chronic obstructive pulmonary disease (COPD) in the Netherlands reported that prevalence estimates in the general population were approximately four times higher than that observed in studies in general practices.¹⁸⁻²⁰ The prevalences depended largely on whether asthma or COPD was defined as a GP diagnosis or whether it was defined as the presence of respiratory symptoms.

It is difficult to compare the results of these studies, since there are considerable differences in the methods used and the study populations included. The aim of the present study was therefore to assess the similarities and differences between prevalence estimates from a structured health interview and estimates from a computerized longitudinal contact-based GP registration at the individual level, in order to develop a better understanding of the differences between these prevalence estimation methods. We also sought to gain insight into which groups of patients demonstrated agreement between the self-reported data and their medical records, which groups did not, and the underlying characteristics of both. Groups without agreement are especially relevant target groups for prevention and health education.²¹⁻²³ For example, patients who have asthma or COPD but who do not consult a GP should do so to prevent chronic and troublesome symptoms; those who do not report asthma or COPD are apparently not aware of it and should be involved in primary care.

The research questions were: (i) to what extent do patients' self-reports on asthma or COPD differ from the data reported by their GPs; and (ii) to what extent can the observed differences be explained by general patient characteristics (gender, age, health insurance, ethnic origin and educational level) and by health characteristics (self-reported smoking status and self-reported health status)?

METHODS

Design

The present study made use of data collected within the framework of the second Dutch National Survey of General Practice (DNSGP-2), which was carried out in 104 general practices in the Netherlands in 2001, and comprised 195 GPs (in total 165 GP full-time equivalents), representative of all Dutch GPs.²⁴ The DNSGP-2 provides nationally representative data on both patients' self-reported and GP-diagnosed asthma or COPD.²⁴ DNSGP-2 encompasses a population of 400 912 registered patients, who are a good representation of the Dutch population in terms of the characteristics age, gender and type of health insurance.²⁴ Over a period of 12 months, all consultations with participating patients were recorded in the practice computer by the participating GPs. GP diagnoses were made according to the current evidence-based guidelines of Dutch general practitioners.^{25, 26} Diagnoses of all consultations were coded according to the International Classification of Primary Care (ICPC) and were clustered into episodes for the same disease.²⁷⁻³⁰ From a random sample of the practice population ($n = 19\ 685$), on average 80 Dutch-speaking patients per full-time participating GP, supplementary information was collected by means of a health interview survey ($n = 12\ 699$; response rate 64.5%). Questionnaires were administered by trained interviewers during a face-to-face interview. To avoid seasonal patterns in morbidity, all interviews were carried out within the space of 1 year (2001) and distributed equally across all four seasons. Children aged 0-11 years were interviewed by means of a proxy interview with a parent, and those aged 12-17 years, with one parent present.

Patient self-reports and GP information on asthma or COPD

The health interview included questions on the presence of 19 chronic conditions. The prevalence of self-reported asthma or COPD was based on the answers to the following question from the interview: 'Have you experienced frequent spells of asthma, chronic bronchitis, lung emphysema or chronic nonspecific lung disease during the past 12 months?' Answers were coded as 'yes' or 'no'. Prevalence of GP-diagnosed asthma or COPD was estimated from GP registration. Asthma or COPD was defined as being present if the patient had experienced one or more episodes coded as ICPC R96 (asthma), R91 (chronic bronchitis) or R95 (pulmonary emphysema/COPD) in the course of a single year.

Patient characteristics

Information on patient characteristics was obtained from the health interview. It included information on gender, age, health insurance (private or public health insurance), ethnicity (native or non-native;

on the basis of country of birth of the patient and both parents) and educational level [low (none, elementary), middle (high school) or high (college or university)]. Smoking status was defined by current smoking (yes or no) and by whether smoking occurred in the patient's home (yes or no). The health interview also included questions on the presence of acute symptoms during the past 14 days. Health characteristics were defined in three ways: (i) as the presence of self-reported acute respiratory symptoms (coughing or dyspnoea; yes or no); (ii) as the presence of self-reported non-respiratory acute symptoms (none or one versus more than one); and (iii) as the presence of self-reported chronic diseases other than asthma or COPD (none or one versus more than one).

Definitions

The presence of asthma or COPD according to both GP and patient was referred to as 'concordance'. The presence of asthma or COPD according to the GP only was referred to as 'underreporting'. If asthma or COPD was present according to the patient, but not their GP, this was referred to as 'overreporting'.

Statistical analysis

Patients with missing values on the question about asthma or COPD were excluded from the present analysis ($n = 28$). Because of incomplete GP registration on morbidity items, we also excluded all patients from nine general practices ($n = 708$). Consequently, the analyses were performed in the remaining study population of 11 963 patients. We stratified the study population according to whether or not the GP had been consulted, regardless of the reason for consultation. Baseline characteristics for the study population were calculated and expressed as a proportion. Differences in proportions of a particular characteristic were tested using the χ^2 -test. Agreement between GP and patient on the prevalence of asthma or COPD was investigated by cross-tabulation and was expressed as Cohen's kappa.³¹

The independent contribution of general patient characteristics and health characteristics to the presence or absence of concordance was subsequently investigated by multivariate logistic regression analyses. We computed two models. In the first, the outcome variable overreporting was defined as the proportion of self-reported asthma or COPD that was not diagnosed by the GP. In the second, the outcome variable underreporting was defined as the proportion of GP-diagnosed asthma or COPD that was not reported by the patient. The reference category in both models was the proportion of all patients in which both patient and GP reported asthma or COPD to be present (concordance). If both patient and GP reported asthma or COPD to be absent, they were not included in the logistic model.

All patient characteristics described above were included in the logistic models. Each characteristic was first studied in bivariate models. Subsequently, multivariate models were constructed using a manual enter selection method, deleting those variables with the highest P -values, until all remaining variables had a P -value of 0.05 or less. All analyses were performed using the Statistical Package for the Social Sciences (SPSS), version 10.0.

RESULTS

The study population (mean age 39 ± 23 years, 46% were men and 64% had public health insurance) differed only slightly from the practice population (mean age 38 ± 22 years, 50% were men and 67% had public health insurance). Patients who consulted their GP during the registration year (as compared with those who did not) were more likely to be women, to be older, to have more self-reported acute symptoms (respiratory and nonrespiratory) and to have chronic diseases other than asthma and COPD (table 1). All other characteristics did not differ significantly between patients with and without GP consults.

Of the patients with self-reported asthma or COPD ($n = 1008$), 914 had consulted their GP (91%) while 94 had not (9%). Patients with self-reported asthma or COPD who had not consulted their GP, compared with those who had, were more likely to be men (58 versus 45%; $P < 0.05$), to be < 20 years of age (58 versus 27%; $P < 0.001$), and to have less acute respiratory symptoms (46 versus 61%; $P < 0.05$) and other chronic diseases (43 versus 61%; $P < 0.05$), (data not shown).

Of the patients who had consulted their GP ($n = 9411$), 914 reported having asthma or COPD (9.7%), while 486 had asthma or COPD according to the GP (5.2%). Concordance was observed in 35% (321/914) of patients with self-reported asthma or COPD and in 66% (321/486) of those with GP-

diagnosed asthma or COPD (table 2). From all patients with self-reported asthma or COPD, 65% had no such diagnosis in their medical records ($n = 593$; overreporting). Of the patients carrying a diagnosis of asthma or COPD according to the GP, 34% failed to report having asthma or COPD ($n = 165$; underreporting).

Table 3 shows the distribution of patient characteristics among groups of patients who demonstrated concordance and those who did not. Older patients, aged 60 years and above, were more often in the underreporting group (39 versus 31%; $P < 0.05$) and less often in the overreporting group (23 versus 31%; $P < 0.05$). Patients who were exposed to smoke in their home were more often in the underreporting group (47 versus 38%; $P < 0.05$). Those who had a lower educational level were more often in the overreporting group (23 versus 31%; $P < 0.05$). A higher prevalence of acute respiratory symptoms (72%), which often accompany asthma or COPD, was observed in the concordance group compared with the overreporting (54%) and underreporting (33%) groups. Finally, the underreporting group generally had a better self-reported health status, reporting fewer acute symptoms and chronic diseases ($P < 0.001$).

The results of multivariate analyses (table 4) show that the observed agreement between patients and GPs was more profound if accompanying respiratory symptoms were taken into account: for overreporting [adjusted odds ratio (OR) 0.45; 95% confidence interval (CI) 0.34–0.61] and for underreporting (adjusted OR 0.17; 95% CI 0.11–0.27). Underreporting was also associated with higher age (adjusted OR 3.10; 95% CI 1.70–5.63), smoking in the patient's house (adjusted OR 1.75; 95% CI 1.12–2.74) and with less chronic conditions (adjusted OR 0.31; 95% CI 0.19–0.49).

DISCUSSION

This is one of the first studies to evaluate the difference between the prevalence of self-reported and GP-diagnosed asthma or COPD at the level of the individual patient in a large population study. The prevalence of self-reported asthma or COPD (9.7%) was almost twice as high as the prevalence estimated from GP computer records (5.2%). The observed difference in prevalence was higher in previous studies in the Netherlands.^{18–20} In those studies the prevalences were not compared at the individual level and different populations were included. The observed agreement was high (92%), while the kappa statistic was low (0.4). The kappa has the disadvantage that it is affected by the prevalence (table 2) and emerges in low values. This phenomenon of 'high agreement but low kappa' has been described in previous studies.^{32, 33}

A limitation of our study is that we could not distinguish between asthma and COPD. Several studies have reported that asthma is often underdiagnosed and undertreated due to underrepresentation.^{34–36} Since asthma is episodic in nature, some patients might have been free of symptoms during the registration year, which explains why they had not visited their GP. Children who had asthma during first years of life often have periods free of symptoms and therefore do not need to consult their GP. On the other hand, underreporting is associated with older age, implying that this group most probably consists of patients with COPD.

Another limitation of our study is that the health interview was restricted to the Dutch-speaking practice population. The results of our study should therefore be applied with great care to the non-Dutch-speaking practice population. Our analyses were restricted to those patients who consulted their GP during the registration year. Therefore, the conclusions of our study are probably not valid for the healthiest people: those who did not consult their GP at all. Another possibility is that some misclassification may have occurred when the diagnosis was made by the GPs and in the coding of the diseases. For example, some GP may diagnose and code a patient with 'recurrent wheezing with coughing' as having 'asthma', while others register the same event as 'chronic wheezing'.

According to GP medical records, patients in the overreporting group (65% of patients with self-reported asthma or COPD) were more likely to be diagnosed with other respiratory conditions, including shortness of breath, wheezing and coughing. Asthma and COPD are clinically characterized by respiratory symptoms such as shortness of breath, wheezing and coughing. Patients may attribute their respiratory symptoms or even conditions like acute bronchitis or sinusitis to asthma or COPD.¹⁷ A patient who has dyspnoea may well receive a prescription and subsequently report this as asthma or COPD.

Patients in the underreporting group (34% of the GP-diagnosed patients) were more likely to be older and to live in an environment where they were exposed to smoking. With the exception of the elderly, this group had fewer acute respiratory symptoms and chronic diseases. Older patients may be unaware of their condition, and therefore fail to report this. Patients who smoke generally have respiratory symptoms, but do not always report them, because they are aware that smoking is associated with their symptoms. Some patients have symptom-free periods; others have made adjustments to their lives and did not report their condition during the health interview.

In conclusion, both methods were found to have their own advantages and disadvantages. The self-reported prevalence of asthma or COPD, when compared with GP registration, is associated with an overestimation in people who suffer from other respiratory conditions and with an underestimation in elderly persons living in a smoky environment who have fewer chronic diseases. These findings should certainly be taken into account when deciding on a method to measure prevalence rates. Overall, we strongly recommend that the underestimation found in the elderly be further studied. These patients are in all likelihood COPD patients. We also recommend future studies to include a capacity to distinguish between asthma and COPD.

KEY POINTS

- Explain differences between the prevalence of self-reported and GP-diagnosed asthma or COPD on the level of the individual patient.
- The prevalence of self-reported asthma or COPD (9.7%) was almost twice as high as the prevalence based on GP-information (5.2%).
- The self-reported prevalence of asthma or COPD is associated with an underestimation in elderly persons living in a smoky environment.
- The self-reported prevalence of asthma or COPD is associated with an overestimation in people who suffer from other respiratory conditions.
- The underestimation of asthma or COPD in the elderly should be further studied.

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TABLES

Table 1 General characteristics of the study population, stratified for having consulted their GP

	Study population (n = 11 963) (%)	With GP consultation (n = 9411) (%)	Without GP consultation (n = 2552) (%)
General characteristics			
Gender, male	46.1	43.1 ^a	57.1
Age (years)			
≤20	25.6	22.7	36.2
20–39	22.9	22.6	24.0
40–59	30.4	31.1	27.9
≥60	21.1	23.6 ^a	11.9
Health insurance, public	64.1	66.1	56.5
Ethnicity, non-native	10.1	10.5	8.7
Educational level			
Low	21.1	21.3	20.3
Middle	59.8	60.2	58.1
High	19.1	18.5	21.6
Health characteristics			
Current smoking, yes	29.4	29.0	30.8
Environmental smoking, yes	41.1	40.6	42.8
Acute respiratory symptoms, yes	22.5	24.2 ^a	16.4
Other acute symptoms, >1	72.2	75.7 ^a	59.6
Other chronic diseases, >1	30.5	35.4 ^b	12.5

For differences between patients with and without having consulted their GP: a: $P < 0.05$ and b: $P < 0.01$

Table 2 Patients with self-reported asthma or COPD compared with patients with GP-diagnosed asthma or COPD

	GP-diagnosed asthma or COPD		Total
	Present	Not present	
Self-reported asthma or COPD			
Present	321	593	914
Not present	165	8.332	8.497
Total	486	8.925	9.411

Self-reported asthma or COPD 914/9411 (9.7%);
 Overreporting 593/914 (64.8%);
 GP-diagnosed asthma or COPD 486/9411 (5.2%);
 Underreporting 165/486 (34.0%);
 Observed agreement (321 + 8.332)/9.411 (91.9%);
 Cohen's kappa 0.41

Table 3 Characteristics of groups of patients with and without agreement with their GP

	Overreporting (n = 593)	Concordance (n = 321)	Underreporting (n = 165)
General characteristics	(%)	(%)	(%)
Gender, male	42.7	47.7	55.8
Age (years)			
<5	8.1	5.6	8.5
5–19	19.1	23.1	18.2
20–39	20.4	15.3	12.1
40–59	29.3	25.2	21.8
≥60	23.1 ^a	30.8	39.4 ^a
Health insurance, public	69.4	66.7	72.6
Ethnicity, non-native	10.0	8.7	11.0
Educational level			
Low	22.7 ^a	31.1	35.6
Middle	61.6	54.6	51.5
High	15.8	14.3	12.9
Health characteristics			
Current smoking, yes	28.8	28.7	32.3
Environmental smoking, yes	39.6	38.3	47.3
Acute respiratory symptoms, yes	53.8 ^b	72.3	32.7 ^b
Other acute symptoms, >1	86.7	86.6	72.1 ^b
Other chronic diseases, >1	68.8	63.6	39.4 ^b

For difference between overreporting/underreporting and concordance: a: $P < 0.05$ and b: $P < 0.001$

Table 4 ORs and 95% CIs for overreporting and underreporting

	Overreporting (n = 593)		Underreporting (n = 165)	
	Bivariate	Multivariate	Bivariate	Multivariate
General characteristics				
Gender (male/female)	0.82 (0.62–1.07)		1.38 (0.95–2.02)	
Age (20–39/<20 years)	1.41 (0.93–2.15)		0.85 (0.45–1.61)	
Age (40–59/<20 years)	1.23 (0.85–1.77)		0.93 (0.55–1.58)	
Age (≥60/<20 years)	0.79 (0.55–1.14)		1.37 (0.85–2.21)	3.10 (1.70–5.63)
Health insurance (public/private)	1.14 (0.85–1.52)		1.32 (0.87–2.00)	
Ethnicity (non-native/native)	1.17 (0.71–1.93)		1.31 (0.67–2.53)	
Educational level (middle/low)	1.55 (1.08–2.20)		0.82 (0.52–1.31)	
Educational level (high/low)	1.51 (0.92–2.46)		0.78 (0.40–1.55)	
Health characteristics				
Current smoking (yes/no)	1.01 (0.72–1.41)		1.19 (0.75–1.87)	
Environmental smoking (yes/no)	1.06 (0.80–1.40)		1.44 (0.99–2.11)	1.75 (1.12–2.74)
Acute respiratory symptoms (yes/no)	0.45 (0.33–0.60)	0.45 (0.34–0.61)	0.19 (0.12–0.28)	0.17 (0.11–0.27)
Other acute symptoms (0–1/>1)	1.01 (0.68–1.50)		0.40 (0.25–0.64)	
Other chronic diseases (0–1/>1)	1.27 (0.95–1.68)		0.37 (0.25–0.55)	0.31 (0.19–0.49)