Differences in the Misreporting of Chronic Conditions, by Level of Education: The Effect on Inequalities in Prevalence Rates

ABSTRACT

Objectives. Many studies of socioeconomic inequalities in the prevalence of chronic conditions rely on self-reports. For chronic nonspecific lung disease, heart disease, and diabetes mellitus, we studied the effects of misreporting on variations in prevalence rates by respondents' level of education.

Methods. In 1991, a health interview survey was conducted in the southeastern Netherlands with 2867 respondents. Respondents' answers were compared with validated diagnostic questionnaires in the same survey and the diagnoses given by the respondents' general practitioners.

Results. Misreporting of chronic lung disease, heart disease, and diabetes may be extensive. Depending on the condition and the reference data used, the confirmation fractions ranged between .61 and .96 and the detection fractions between .13 and .93. Misreporting varied by level of education, and although various patterns were observed, the dominant pattern was that of more underreporting among less educated persons. The effects on prevalence rates were to underestimate differences by level of education to a sometimes considerable degree.

Conclusions. Misreporting of chronic conditions differs by respondents' level of education. Health interview survey data underestimate socioeconomic inequalities in the prevalence of chronic conditions. (Am J Public Health. 1996;86:706–711)

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Introduction

Many studies of socioeconomic inequalities in health rely on health interview survey data. These data are comprehensive in the sense of covering a wide variety of health problems, and they also permit an easy linkage between information on the presence or absence of health problems and socioeconomic characteristics of the same individuals.¹⁻⁴

A limited number of studies reported on the validity of health interview survey data, mainly on the validity of self-reports of respondents to a checklist of chronic conditions compared with either clinical examinations or medical records. 5.6 In general, the results are disappointing at the individual level, but it has remained unclear to what extent estimates of socioeconomic variation in the prevalence of chronic conditions are biased by the misreporting demonstrated by these validation studies.

We tried to assess the effects of differential misreporting on socioeconomic variation in the prevalence of three self-reported chronic conditions: chronic nonspecific lung disease, heart disease, and diabetes mellitus.

Materials and Methods

Data were collected within the framework of the GLOBE study. GLOBE is the Dutch acronym for Health and Living Conditions of the Population of Eindhoven and surroundings. For this study, a postal survey was conducted in 1991 among 27 070 noninstitutionalized inhabitants (aged 15–74 years) of Eindhoven and a number of surrounding municipalities, all in the southeastern part of the Netherlands. The sample was randomly drawn from the municipal population

registries, and the response rate was 70.1%, which resulted in a study population of 18 973 respondents (hereafter referred to as the original study population). The response rates were not substantially different by age, sex, marital status, urban or rural status, or socioeconomic status.⁷

After this postal survey was conducted, a subsample of 3970 respondents was approached for an oral interview. The postal questionnaire contained a checklist of chronic conditions, and all individuals with self-reported chronic nonspecific lung disease, heart disease, diabetes mellitus, and severe back complaints were selected for the subsample. In addition, a 10% random sample of persons who did not report one of these four conditions was taken. The response rate to the oral interview was 72.2%, which resulted in a study sample of 2867 respondents. No selective nonresponse was found by sociodemographic variables or by health status.8

The oral interview contained a number of questions on health status. First, the checklist of chronic conditions was administered again. The question was, "Will you check for each chronic condition separately whether you currently have this condition or whether you are under treatment or control for this condition? Yes/No." Items included "chronic bronchitis, asthma, emphysema ("overstretched" lung), or chronic nonspecific

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lung disease"; "serious heart disease or myocardial infarction"; and "diabetes mellitus." The respondents' answers to this checklist were taken as the starting points for the analyses to be reported here. These answers were compared with two other sources of information on the respondents' health status: extensive diagnostic questionnaires and general practitioners' diagnoses. No attempt was made to validate respondents' self-reported back complaints.

All respondents to the oral interview, regardless of their checklist answers, had to provide answers to a number of diagnostic questionnaires:

- For chronic nonspecific lung disease, the Dutch translation of the British MRC questionnaire was used. 9,10 Criteria used to establish a diagnosis were any or all of the following: period of coughing lasting at least 3 months a year, period of productive cough lasting at least 3 weeks a year, attacks of shortness of breath and/or wheezing, and shortness of breath at rest or during exertion.
- For heart disease, two questionnaires were used: the Dutch translation of the Rose questionnaire on angina pectoris^{11,12} and a Dutch questionnaire on heart failure. 12 Criteria used to establish angina pectoris were heavy feeling in the chest, chest pain, or chest discomfort, or attack of pain in the jaw, throat, fingers, or shoulders; these feelings occurred during moderate or heavy exertion and disappeared at rest or responded to medication. Criteria used to establish heart failure were at least two of three typical symptoms (swollen legs, nocturia, orthopnea) or shortness of breath in the absence of chronic nonspecific lung disease. Respondents were classified as having heart disease if they had signs of angina pectoris or signs of heart failure, or both.
- For diabetes mellitus, a Dutch questionnaire was used. 13 Criteria used to establish a diagnosis were reported treatment with insulin or oral antidiabetic drugs or both, and/or a sugar-free diet.

Each respondent was asked permission to approach his or her general practitioner for further information on the respondents' health status. Eighty-three percent of respondents agreed to this request. Because of some nonresponse among general practitioners, we finally obtained this information for 52% of respondents. Losses because of refusal or general practitioner nonresponse did not vary by socioeconomic variables or by chronic disease status. Each general prac-

TABLE 1—Two-by-Two Comparisons of Self-Reports of Three Chronic Conditions to the Results of Diagnostic Questionnaires

Diagnosed	Self-Reported, in Study Sample			Self-Reported, Reweighted to Original Study Population		
	Yes	No	Total	Yes	No	Total
		Chronic	nonspecifi	c lung dise	ase	
Yes	376	219	595	672	910	1 582
No	98	2 097	2 195	237	12 348	12 585
Total	474	2 316	2 790	909	13 258	14 167
			Heart disc	ease		
Yes	167	482	649	261	1 753	2 014
No	109	1 979	2 088	171	11 782	11 953
Total	276	2 461	2 737	432	13 535	13 967
			Diabetes m	ellitus		
Yes	227	16	243	447	45	492
No	13	2 556	2 569	29	13 780	13 809
Total	240	2 572	2 812	476	13 825	14 301

Note. Totals differ between tables because of missing values.

titioner received a short questionnaire asking whether the respondent had one or more of the above-mentioned conditions. In case of a positive response, more detailed data on diagnosis and treatment were ascertained.

The analysis of the data involved the following steps. First, two-by-two tables were constructed, giving the correspondence between self-reported diagnoses and diagnoses inferred from either the diagnostic questionnaires or the general practitioners' information. Because the study sample had an overrepresentation of the chronic diseases under study, the numbers in each cell were then reweighted to the original study population, with the reverse of the sampling fractions and response fractions as weights.

In the second step, summary indices for the correspondence between selfreported diagnoses and the two types of reference data were calculated. Because the focus of the analysis was on socioeconomic variation, this calculation was done for each of four levels of educational attainment of the respondents. Confirmation fractions (proportion of self-reports confirmed by the reference data, equivalent to positive predictive value) and detection fractions (proportion of true diagnoses detected by the self-reports, equivalent to sensitivity) were calculated. In addition, the prevalence of each condition by educational level was calculated, according both to self-reports and to each type of reference data. All calculations were done on the basis of a logistic regression analysis, and the results of this regression analysis were used to calculate P values (for the overall effect of education on the confirmation and detection fractions and on the prevalence rates) and 95% confidence intervals. All P values and 95% confidence intervals were based on numbers before reweighting to the original population. The differences in confirmation and detection fractions and in prevalence rates by educational level were summarized as odds ratios (for primary school vs postsecondary education).

Results

Self-Reports vs Results of Diagnostic Questionnaires

Of 474 individuals reporting chronic nonspecific lung disease, only 376 (79%) had a positive score on the diagnostic questionnaire (Table 1). Conversely, of 595 individuals with a positive score on the diagnostic questionnaire for chronic nonspecific lung disease, only 376 (63%) reported that they had this disease. Although these figures represent the confirmation and detection fractions in our study sample, they cannot be taken as estimates of the confirmation and detection fractions in the entire population, due to the overrepresentation of individuals with chronic disease in our sample. After reweighting, the confirmation and

TABLE 2—Summary Indices Comparing Self-Reports of Three Chronic Conditions to the Results of Diagnostic Questionnaires (after Reweighting to the Original Study Population), by Respondents' Level of Education

Level of Education	Confirmation Fraction (95% CI)	Detection Fraction (95% CI)	Prevalence: Self-Report (95% CI)	Prevalence: Diagnosed (95% CI)
	Chronic	nonspecific lung dise	ase	
Primary school	.78 (.71, .84)	.48 (.41, .56)	.100 (.086, .117)	.163 (.142, .187)
Secondary school, lower level	.72 (.64, .78)	.39 (.33, .46)	.055 (.047, .064)	.100 (.087, .114)
Secondary school, higher level	.77 (.64, .87)	.45 (.35, .55)	.057 (.045, .071)	.098 (.080, .118)
Postsecondary	.60 (.46, .73)	.36 (.26, .48)	.047 (.036, .060)	.077 (.061, .097)
Total	.74 (.69, .78)	.43 (.39, .47)	.064 (.058, .070)	.110 (.101, .119)
P (education)	<.10	NS	<.001	<.001
OR (primary vs postsecondary)	2.39 (1.19, 4.79)	1.64 (.93, 2.89)	2.28 (1.65, 3.14)	2.32 (1.72, 3.14)
		Heart disease		
Primary school	.67 (.57, .76)	.14 (.10, .18)	.043 (.034, .053)	.208 (.183, .236)
Secondary school, lower level	.61 (.50, .70)	.12 (.10, .16)	.026 (.021, .032)	.127 (.112, .144)
Secondary school, higher level	.60 (.47, .72)	.13 (.09, .19)	.029 (.022, .038)	.133 (.110, .160)
Postsecondary	.46 (.30, .63)	.12 (.07, .20)	.030 (.021, .042)	.112 (.088, .142)
Total	.61 (.55, .67)	.13 (.11, .15)	.031 (.028, .035)	.146 (.135, .157)
P (education)	NS	NS	<.05	<.001
OR (primary vs postsecondary)	2.36 (1.06, 5.27)	1.13 (.59, 2.18)	1.44 (.95, 2.19)	2.09 (1.52, 2.86)
	C	Diabetes mellitus		
Primary school	.96 (.90, .98)	.96 (.90, .98)	.059 (.047, .073)	.059 (.047, .073)
Secondary school, lower level	.97 (.92, .99)	.84 (.72, .92)	.033 (.027, .040)	.037 (.031, .046)
Secondary school, higher level	.74 (.47, .90)	.94 (.80, .99)	.021 (.015, .029)	.016 (.012, .023)
Postsecondary	1.00 (.92, 1.00)	.96 (.75, .99)	.013 (.008, .020)	.013 (.009, .020)
Total	.96 (.93, .97)	.93 (.89, .96)	.030 (.026, .034)	.030 (.026, .034)
P (education)	<.05	NS	<.001	<.001
OR (primary vs postsecondary)	a	.98 (.11, 8.62)	4.80 (2.94, 7.85)	4.59 (2.83, 7.44)

Note. CI = confidence interval; NS = not significant; OR = odds ratio.

TABLE 3—Two-by-Two Comparisons of Self-Reports of Three Chronic Conditions to General Practitioners' Diagnoses

Diagnosed	Self-Reported, in Study Sample			Self-Reported, Reweighted to Original Study Population		
	Yes	No	Total	Yes	No	Total
		Chronic	nonspecifi	c lung disea	se	
Yes	173	51	224	339	196	535
No	70	1137	1207	130	6439	6569
Total	243	1188	1431	469	6635	7104
			Heart dis	ease		
Yes	132	127	259	202	415	617
No	17	1177	1194	23	6504	6527
Total	149	1304	1453	225	6919	7144
			Diabetes m	ellitus		
Yes	119	17	136	231	69	300
No	10	1285	1295	25	6732	6757
Total	129	1302	1431	256	6801	7057

Note. Totals differ between tables because of missing values.

detection fractions for chronic nonspecific lung disease were 74% and 43%, respectively.

For heart disease the confirmation and detection fractions (after reweighting) were 61% and 13%, respectively. The latter figure was due to the large number of cases of heart disease identified by the diagnostic questionnaire but not reported by the respondents themselves.

For diabetes mellitus the situation was much better: the two-by-two table shows very small numbers of false-negative and false-positive reports, and after reweighting the confirmation and detection fractions were 96% and 93%, respectively.

Misreporting was not the same in all educational groups (Table 2). For chronic nonspecific lung disease, confirmation fractions were lower in the higher educational groups. Although this does imply a larger extent of overreporting, the difference was not primarily a matter of different test behavior, but rather reflected the lower prevalence of chronic

^{*}Odds ratio cannot be calculated because the confirmation odds for postsecondary education are infinite. When the observed value of 0 false-positive cases in the postsecondary education group is replaced by an arbitrary value of ½, the OR (primary vs postsecondary) becomes .37 (.02, 6.87).

TABLE 4—Summary Indices Comparing Self-Reports of Three Chronic Conditions to General Practitioners' Diagnoses (after Reweighting to the Original Study Population), by Respondents' Level of Education

Level of Education	Confirmation Fraction (95% CI)	Detection Fraction (95% CI)	Prevalence: Self-Report (95% CI)	Prevalence: Diagnosed (95% CI)
	Chronic	nonspecific lung dise	ase	
Primary school	.79 (.70, .86)	.75 (.62, .84)	.128 (.104, .158)	.136 (.110, .168)
Secondary school, lower level	.58 (.47, .68)	.46 (.35, .57)	.053 (.043, .066)	.067 (.054, .083)
Secondary school, higher level	.80 (.66, .90)	.61 (.40, .79)	.045 (.032, .062)	.059 (.042, .082)
Postsecondary	.80 (.63, .91)	.90 (.74, .97)	.044 (.030, .065)	.039 (.026, .059)
Total	.73 (.67, .78)	.65 (.58, .72)	.064 (.056, .073)	.075 (.065, .085)
P (education)	<.01	< .001	<.001	<.001
OR (primary vs postsecondary)	.94 (.35, 2.53)	.31 (.08, 1.19)	3.21 (2.00, 5.15)	3.89 (2.36, 6.43)
		Heart disease		
Primary school	.86 (.74, .93)	.30 (.22, .39)	.049 (.038, .064)	.141 (.115, .173)
Secondary school, lower level	.89 (.76, .95)	.23 (.16, .31)	.021 (.016, .028)	.082 (.067, .101)
Secondary school, higher level	.94 (.79, .99)	.55 (.40, .69)	.035 (.023, .051)	.059 (.043, .081)
Postsecondary	.92 (.74, .98)	.53 (.35, .70)	.032 (.020, .050)	.055 (.038, .079)
Total	.90 (.84, .93)	.33 (.28, .39)	.032 (.027, .037)	.085 (.075, .097)
P (education)	NS	< .001	<.001	<.001
OR (primary vs postsecondary)	.50 (.10, 2.60)	.37 (.16, .87)	1.59 (.90, 2.78)	2.84 (1.79, 4.50)
	ı	Diabetes mellitus		
Primary school	.95 (.86, .98)	.70 (.52, .83)	.053 (.040, .072)	.073 (.055, .096)
Secondary school, lower level	.87 (.68, .96)	.77 (.59, .89)	.043 (.032, .057)	.048 (.037, .063)
Secondary school, higher level	.79 (.55, .92)	.88 (.63, .97)	.019 (.012, .030)	.017 (.011, .028)
Postsecondary	1.00 (.33, 1.00)	.91 (.56, .99)	.012 (.006, .023)	.013 (.007, .024)
Total	.91 (.84, .95)	.79 (.69, .86)	.033 (.027, .039)	.037 (.031, .044)
P (education)	NS	NS	<.001	<.001
OR (primary vs postsecondary)	a	.23 (.03, 2.07)	4.58 (2.25, 9.31)	5.77 (2.93, 11.39)

Note. CI = confidence interval; NS = not significant; OR = odds ratio.

aOdds ratio cannot be calculated because the confirmation odds for postsecondary education are infinite. When the observed value of 0 false-positive cases in the postsecondary education group is replaced by an arbitrary value of ½, the OR (primary vs postsecondary) becomes .74 (.03, 16.06).

nonspecific lung disease in the higher educational groups. At the same time, detection fractions showed a tendency to be lower in the higher educational groups, implying a larger extent of underreporting. These two phenomena kept each other more or less in balance, so that the differences in prevalence based on self-reports (odds ratio for the lowest ν s the highest educational group = 2.28) gave a surprisingly accurate picture of the differences in prevalence based on the results of diagnostic questionnaires (odds ratio = 2.32).

For heart disease, there also was a tendency for the confirmation fraction to be lower in the higher educational groups, but detection fractions were the same regardless of educational level, so that the net effect was that self-reported data (odds ratio = 1.44) underestimated the differences in prevalence as measured by the diagnostic questionnaires (odds ratio = 2.09). In a second series of analyses for heart disease (results not shown), we checked whether this conclusion was

affected by changing the criteria for determining heart disease with the diagnostic questionnaires. For example, when a diagnosis of angina pectoris was made based on chest pain and related symptoms during light exertion (instead of moderate or heavy exertion), the detection fractions increased and the diagnosed prevalences decreased, but the pattern of underestimation of socioeconomic inequalities in prevalence remained the same.

For diabetes mellitus, no clear patterns emerged, and there was no difference between prevalence estimates by educational group based on self-reports and those based on diagnostic questionnaire.

Self-Reports vs General Practitioner Diagnoses

The data obtained through the respondents' general practitioners confirmed that self-reports of chronic conditions often were inaccurate. Table 3 shows that the extent of misreporting again was smallest for diabetes mellitus.

The large number of false-negative self-reports of heart disease again is striking.

Although the patterns of misreporting with reference to general practitioner diagnoses were not always the same as those seen with reference to the results of the diagnostic questionnaires, they do confirm that misreporting differed according to educational level (Table 4). Self-reported data underestimated the prevalence differences by educational group for all three chronic conditions.

Discussion

As stated in the Introduction, there have been a number of studies on the validity of reporting chronic conditions in health interview surveys. Many of these studies were done in the 1950s and 1960s, 14-23 but recently there has been some renewed attention to this subject area, 24-30 perhaps because of the institutionalization of regular health interview surveys in many industrialized countries. 31

Reviews of the accumulated evidence concluded that both underreporting and overreporting occur on a large scale and that the net effect mostly tends toward underestimation of the prevalence of chronic conditions in the population.^{5,6} There are large differences between conditions in the degree of underand overreporting. For the three conditions included in the present study, the evidence from previous studies suggests that validity is highest for self-reports of diabetes mellitus, lowest for chronic respiratory disease, and in between for heart disease.^{5,6}

The findings in our study with a few exceptions clearly fit this pattern. Although we did not find evidence for selective nonresponse, the cumulative nonresponse rates were substantial and it is difficult to exclude the possibility that our results were affected by biased participation. Nevertheless the results clearly suggest that the extent of under- and overreporting of chronic conditions is extensive and that the net effect tends toward underestimating the prevalence of chronic nonspecific lung disease and heart disease in the population. The picture is much better for diabetes mellitus than for the other two conditions (Tables 2 and 4). The only discrepancy with the results of previous studies is that the validity of self-reports of chronic nonspecific lung disease on the whole was higher than that of self-reports of heart disease in our study. This is perhaps because chronic nonspecific lung disease was described rather specifically in the questionnaire ("chronic bronchitis, asthma, emphysema ['overstretched' lung], or chronic nonspecific lung disease").

Previous studies did not produce clear evidence of socioeconomic differences in under- and overreporting. The two reviews mentioned before concluded that socioeconomic differences are small,5,6 but thereby concealed the sometimesconflicting findings of different studies. Our study suggests that when compared with general practitioners' diagnoses, selfreports of more highly educated persons usually were better than those of less educated persons (Table 4). When selfreports were compared with the results of diagnostic questionnaires, there was a tendency for the reverse to be true (Table 2). Perhaps disease in less educated persons more often goes undetected by general practitioners, and in that case we should place more confidence in the comparison of self-reports with the results of diagnostic questionnaires. On the other hand, the validity of diagnostic questionnaires may also differ between educational groups, and it is actually impossible to decide between the two data sources.

Neither of the two data sources is a perfect gold-standard measurement. Diagnostic questionnaires are not completely insensitive to individuals' perceptions (many questions refer to perceived symptoms), and general practitioners do not always have an accurate idea of their patients' diagnoses, especially if these diseases are actually treated by specialists (or not at all). Combining these two data sources may partially alleviate these problems, however, especially if the conclusions based on each of the two sources point in the same direction.

Both comparisons suggest that health interview survey data underestimate prevalence differences by educational level. This was very true when general practitioners' diagnoses were used as the reference data, but it was also true when results of diagnostic questionnaires were used, especially in the case of heart disease. This underestimation of inequalities in morbidity was also found in a previous study that we did in the same population, in which we linked data on self-reported cancer from the postal survey to data from a cancer registry operating in the same area.30 Although we do not know with certainty whether the same conclusion applies to other chronic conditions, we consider it likely that this is the case, because the four conditions studied (chronic nonspecific lung disease, heart disease, diabetes mellitus, and cancer) cover a wide spectrum of conditions. We also consider it likely that a similar pattern will be found in other countries. As a result of the Dutch system of universal health care insurance, there is less inequality of access to health care in the Netherlands than in many other countries. Consequently, underreporting of chronic conditions by less educated persons and underestimation of differences in prevalence by educational level may well be even greater in other countries. The possibility of underestimation should therefore be considered seriously in the interpretation of data on educational differences in self-reported chronic conditions.

Of course, it is not at all surprising that a simple device such as a conventional checklist of chronic conditions leads to serious misreporting by respondents. It has repeatedly been shown that even minor variations in the phrasing of questions lead to gross differences in overall prevalence estimates of chronic conditions.³² It is likely that the cognitive processes involved in answering these questions (e.g., memory retrieval) can be supported better—for example, by extending and specifying the questions. It is to be welcomed that the US National Center for Health Statistics is conducting a research program on these cognitive aspects.^{5,33} We recommend that this research program take into account the educational differences in misreporting that we found in our study. □

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