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Self-Reports and General Practitioner Information on the Presence of Chronic Diseases in Community Dwelling Elderly

A STUDY ON THE ACCURACY OF PATIENTS' SELF-REPORTS AND ON DETERMINANTS OF INACCURACY

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ABSTRACT. ***Object.*** **The object of the study is to investigate the (in)accuracy of patients' self-reports, as compared with general practitioners' information, regarding the presence of specific chronic diseases, and the influence of patient characteristics.** ***Methods.*** **Questionnaire data of 2380 community-dwelling elderly patients, aged 55–85 years, on the presence of chronic non-specific lung disease, cardiac disease, peripheral atherosclerosis, stroke, diabetes, malignancies, and osteoarthritis/rheumatoid arthritis were compared with data from the general practitioners, using the kappa-statistic. Associations between the accuracy of self-reports and patient characteristics were studied by multiple logistic regression analyses.** ***Results.*** **Kappa's ranged from 0.30 to 0.40 for osteoarthritis/rheumatoid arthritis and atherosclerosis, to 0.85 for diabetes mellitus. In the multivariate analyses, educational level, level of urbanization, deviations in cognitive function, and depressive symptomatology had no influence on the level of accuracy. An influence of gender, age, mobility limitations, and recent contact with the general practitioner was shown for specific diseases. For chronic non-specific lung disease, both "underreporting" and "overreporting" are more prevalent in males, compared to females. Furthermore, males tend to overreport stroke and underreport malignancies and arthritis, whereas females tend to overreport malignancies and arthritis. Both overreporting and underreporting of cardiac disease are more prevalent as people are older. Also, older age is associated with overreporting of stroke, and with underreporting of arthritis. The self-reported presence of mobility limitations is associated with overreporting of all specific diseases studied, except for diabetes mellitus, and its absence is associated with underreporting, except for diabetes mellitus and atherosclerosis. Recent contact with the general practitioner is associated with overreporting of cardiac disease, atherosclerosis, malignancies and arthritis, and with less frequent underreporting of diabetes and arthritis.** ***Conclusions.*** **Results suggest that patients' self-reports on selected chronic diseases are fairly accurate, with the exceptions of atherosclerosis and arthritis. The associations found with certain patient characteristics may be explained by the tendency of patients to label symptoms, denial by the patient, or inaccuracy of medical records.** *Copyright © 1996 Elsevier Science Inc.* J CLIN EPIDEMIOL 49;12:1407–1417, 1996.

KEY WORDS. Measurements, reliability, chronic diseases, survey studies, medical records, self-reports

INTRODUCTION

Both epidemiologic studies and national health surveys commonly rely on data collected through face-to-face interviews or self-administered questionnaires [1,2]. An important reason for this is that self-report types of data collection generally involve substantially lower costs as opposed to clinical assessments [3]. Investigators, however, rarely provide information regarding the reliability and validity of the measurements that are used [4–6]. In spite of the limited evidence of reliability and validity of these measures, data considered to measure objective health status, such as the presence of chronic diseases, are still commonly derived from self-reports.

In several studies, self-report data were compared with medical records [7–12], disease registries [13], or the results of clinical and laboratory investigations [14]. Some authors evaluate the accuracy of self-reports for both people who respond positively and people who respond negatively to a specific question about a chronic disease, whereas others limit their investigation to the "positive responders" or to people who have the condition according to the medical records or clinical examination. In the latter two situations, either false negatives or false positives are not taken into account [1].

Results of previous studies indicate that for some chronic diseases, such as diabetes mellitus, the accuracy of patients' self-reports is generally high [11], whereas for other diseases, such as arthritis, accuracy is much lower [12]. Apart from factors associated with the specific chronic disease that is studied, such as the necessity of a physician-provided diagnosis or medical treatment, this might be due in part to certain patient characteristics that often are presumed to influence the accuracy of self-report data. In several studies, associations have been examined between gender [12–14], age [12,13,15,16], ed-

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ucational level [12,13], cognitive functioning [17], psychological distress [14,18], and functional limitations [14] on the one hand, and the accuracy of self-report data on health on the other hand. Results vary across disease categories and are often contradictory.

The organization of the Dutch health care systems facilitates the study of the accuracy of patients' self-reports compared with medical records. In the Netherlands, every community-dwelling person is registered on the patient-list of one general practice. Access to other health care facilities, including outpatient clinics, is only possible through referral by a general practitioner. When the general practitioner has referred a patient to any of these other health care facilities, he or she is informed about the results of any further clinical investigations, diagnosis, treatment, and so forth. Thus, in principle, a patient's general practitioner should have available a complete record of the patient's medical status.

The present study was specifically designed to compare self-report data of community-dwelling elderly people on the presence of a number of specific chronic diseases with data collected through general practitioners, providing the opportunity to take several limitations of previous studies into account. The accuracy of patients' self-reports, compared with general practitioners' information is studied in a large sample of community-dwelling older adults, and the simultaneous influence of patient characteristics that have been reported to be associated with the accuracy of self-reports for some diseases is examined for seven different chronic diseases that often afflict the elderly. As a result, it is possible to determine whether the accuracy of patients' self-reports, and the influence of certain patient characteristics on the level of accuracy, is different across specific chronic diseases.

The following questions will be addressed:

1. To what extent do patients' self-reports accurately reflect the presence or absence of specific chronic diseases as judged by general practitioners' information?
2. Do certain patient characteristics (age, gender, urbanization level of the area of living, educational level, deviations in cognitive functioning, depressive symptomatology, mobility limitations, contact with general practitioner) influence the accuracy of self-reports of specific chronic diseases, as compared to general practitioner information?

METHODS

The data were collected as part of the first data collection cycle of the Longitudinal Aging Study Amsterdam (LASA) [19], a 10-year longitudinal study on predictors and consequences of changes in physical, cognitive, emotional, and social functioning in older persons.

Patients

A sample of people aged 55 to 85 years, stratified according to age, gender, and expected attrition due to mortality at mid-term of LASA (after 5 years) in each age group, was drawn from the population registries of 11 municipalities in three culturally distinct geographical areas in the west, east, and south of the Netherlands. Each area consists of one middle- to large-size city and two or more rural municipalities that border on the city. The cohort was recruited in 1991 for the NESTOR-LSN study "Living arrangements and social networks of older adults" (response rate 62.3%) [20]. Although there was a decline in response with increasing age ($p < 0.05$), the stratified sampling frame has ensured representativity on age, gender, and level of urbanization of the sample [20].

After 11 months, the participants in NESTOR-LSN were approached for the first LASA cycle. From the initial sample of 3805 persons who participated in NESTOR-LSN, a total of 3107 participated in the main interview of LASA (81.7%). Data were collected in the period from September 1992 through October 1993. Details of the procedures and results of the field work are described elsewhere [21]. Of the persons who did not participate, 260 (6.8% of initial sample) proved to be ineligible (deceased or not able due to severe physical and/or cognitive disturbances). Of the other 438 nonparticipants, 394 (10.4% of initial sample) refused and 44 (1.2% of initial sample) could not be contacted. The corrected response percentage, excluding those who were ineligible after all, was 87.6%. Older age was significantly associated with refusal to participate ($p < 0.001$) and ineligibility because of severe physical or cognitive disturbances ($p < 0.0001$).

The present study is limited to participants who were, at the time of the LASA interview, living independently in the community ($n = 2982$), because primary medical care in residential and nursing homes in The Netherlands is not comparable to standard general practice care. Medical care in nursing homes is delivered by specialized nursing home physicians and the structure and organization of nursing home care are more comparable to hospital care than to general practice care. The organization of primary medical care in residential homes varies widely, and therefore also is not easily comparable to general practice. Participants had to give permission to collect additional information from their general practitioners ($n = 2840$; 95.2% of those living independently).

As a result, the study population is a relatively healthy selection of the original sample, although the stratified sampling frame guaranteed that sufficient numbers of subjects in the highest age group, as well as subjects with physical and mental health problems, were included.

General Practitioners

All 447 general practitioners of whom the patients had given their written informed consent were approached. The questionnaires were mailed in two waves. For each wave, reminders were sent 2 and 4 months after the questionnaires were mailed. The general practitioners were offered a financial incentive of Hfl. 7.50 ($5.00) for every completed questionnaire they returned.

A total of 371 general practitioners (83.0%) returned completed questionnaires on 2380 community-dwelling patients (83.8% of those who gave informed consent). The response was 85.7% after it was corrected for patients who were unknown to the general practitioner ($n = 46$), or of whom no records were available after they deceased ($n = 17$). There was no difference between the response percentages of general practitioners over the three regions (western, eastern, and southern parts of the Netherlands). The average number of returned questionnaires per general practitioner was 6.5, with a range from 1 to 99.

Measurements

PATIENT QUESTIONNAIRE. The questionnaires were administered by trained interviewers during a face-to-face interview in the patient's home. The patient questionnaire included questions on the presence, or absence of specific chronic diseases: chronic non-spe-

cific lung disease (asthma, bronchitis and pulmonary emphysema), cardiac diseases, atherosclerotic disease of the abdominal aorta or the arteries of the lower limb, cerebrovascular disease (stroke, excluding transient ischemic attacks), diabetes mellitus, malignant neoplasms, osteoarthritis, and rheumatoid arthritis. Answers were coded "yes" or "no." For each disease reported present, the patient was asked whether medication was used ("yes" or "no"), and whether he or she was regularly checked by a doctor for that disease ("yes, either by the general practitioner or by a specialist" or "no").

Potential determinants of the accuracy of patients' self-reports compared with general practitioner information included age, gender, urbanization level of the area of living, educational level, presence of depressive symptomatology or deviances in cognitive function, self-reported presence of mobility limitations, and self-reported contact with the general practitioner during the previous six months. Gender and age of the patients were derived from the municipal registries. Urbanization level was defined as the number of addresses within one square kilometer of the patient's home [22]. Categories range from "not urbanized" (<500 addresses/km^2) through "very highly urbanized" (>2500 addresses/km^2). The patients were asked which was their highest educational level attained, and this was coded as "low" (lower vocational education or less), "middle" (general intermediate through general secondary education), or "high" (higher vocational through university education).

The presence of depressive symptoms was assessed by means of the Dutch version [23] of the Center for Epidemiologic Studies Depression Scale (CES-D) [24], which proved to have satisfactory psychometric properties (Cronbach's $\alpha = 0.87$) [23]. A clinically relevant level of depressive symptomatology was considered present when the total score, which ranges from 0 to 60, on the CES-D was ≥16, which is the generally accepted cut-off score. In the present sample, the CES-D scores ranged from 0 to 48 (mean 7.5; SD 7.4). The presence of a deviation in cognitive functioning was determined by using the Mini Mental State Examination (MMSE) [25]. A total score, range 0–30, was computed by summing the individual item scores (taking the highest score of the "serial 7" item and the "reversed spelling" item). A score ≤23 was considered to indicate the presence of a clinically relevant deviation in cognitive function, whereas a score ≥24 was considered normal [26,27]. The MMSE score in our sample ranged from 5 to 30 (mean 27.1; SD 2.7). Mobility limitations were assessed using three self-report items pertaining to mobility activities in daily life: ability to walk up and down a 15-step staircase without stopping, ability to use private or public transportation, and ability to cut one's own toenails. Based on the results of pilot studies [28], these items were shown to constitute the best scale out of a set of nine items. The reliability of this scale was adequate (Cronbach's $\alpha = 0.72$), and all items loaded on one factor (all factor-loadings >0.75). In the present study, limitations were defined as present when the patient reported experiencing difficulty in performing at least one of the three activities.

GENERAL PRACTITIONER QUESTIONNAIRE. The general practitioners received a written questionnaire about each patient who had given informed consent. Questions concerned the presence or absence of the same chronic diseases that were included in the patient questionnaire, and, when applicable, the date of diagnosis. Because the interval between the interview with the patient and the completion of the questionnaires by the general practitioners ranged from 6 to 22 months, all diseases diagnosed after the date of the interview with the patient were considered absent.

Representativity of the Study Population

The stepwise approach of the study sample, in which participants of LASA were recruited from the participants in the NESTOR-LSN study, could have resulted in a selection bias with possible consequences for the generalizability of the results of the present study. Of the community-dwelling participants in the NESTOR-LSN study ($n = 3634$; 95.5% of all participants) who also participated in LASA, 29 (1.0% of LASA participants) were institutionalized between the NESTOR-LSN and the LASA interview, and thus excluded for the present study. Of the community-dwelling NESTOR-LSN participants who did not participate in LASA, 101 (2.8%) were deceased, 83 (2.3%) were ineligible because of severe physical health problems, 25 (0.7%) were ineligible because of severe cognitive problems, and 43 (1.2%) could not be contacted after 10 attempts were made. Both nonparticipation in the LASA interview because of these reasons and exclusion because of institutionalization were associated with higher age, physical limitations, cognitive problems, and worse subjective health status at the time of the NESTOR-LSN interview. Patients' permission to collect additional information from their general practitioners was not associated with age, gender, educational level attained, urbanization, or physical health (physical limitations, presence of chronic diseases, and subjective health status). However, subjects with an MMSE score ≤23 (indicating clinically relevant deviation in cognitive function) gave permission to collect general practitioner information somewhat less often than those with an MMSE score ≥24 (92.8% versus 96.1%; $p < 0.05$). This was also the case for subjects with a CES-D score ≥16 (indicating a clinically relevant level of depressive symptomatology) compared with those with a CES-D score <16 (93.7% versus 96.3%; $p < 0.05$). Within the group of LASA participants who gave permission to collect information from their general practitioners, comparison of subjects whose general practitioner provided the information with those subjects whose general practitioner did not, no differences were found with regard to age, gender, educational level attained, the presence of chronic diseases, the presence of deviation in cognitive function, or subjective health status. General practitioners in highly or very highly urbanized regions (primarily Amsterdam) provided information less often than those from less urbanized regions ($p < 0.001$). Also, information was less often provided for patients who had a CES-D score ≥16 compared with those with a CES-D score <16 (78.4% versus 84.8%; $p < 0.01$), or who reported mobility limitations compared with those who did not (81.9% versus 85.3%; $p < 0.05$). The possible consequences of the differences between the study population and the original sample for the interpretation of our results will be enlarged upon in the discussion section.

Analysis

The accuracy of the patients' self-reports as compared with the general practitioner data was measured by means of overall percentages of concordance and discordance, and by using Cohen's kappa [29]. The decision to use the kappa statistic as a measure of the quality of the patients' self-reports, instead of sensitivity and specificity, which are also commonly advocated [30] and employed [12], was based on the fact that the present study is not a true validity study: there may be doubt as to the completeness of chronic disease registration in general practice [31,32], and complaints attributed to a specific disease by the patient may not have been presented to the

TABLE 1. Basic model for data analysis and measurements used

	According to general practitioner		
According to patient	**Disease present**	**Disease not present**	**Total**
Disease present	a	b	a + b
Disease not present	c	d	c + d
Total	a + c	b + d	n
Kappa		$(2(ad - bc))/((a + b)(b + d) + (c + d)(a + c))$	
Overall concordance		$((a + d)/n) \cdot 100$	
Proportion of underreporters		$(c/(a + c)) \cdot 100 = 1 -$ sensitivity	
Proportion of overreporters		$(b/(b + d)) \cdot 100 = 1 -$ specificity	
Proportion with disease according to patients		$((a + b)/n) \cdot 100$	
Proportion with disease according to GP		$((a + c)/n) \cdot 100$	

general practitioner. Thus, the general practitioners' information can not be considered a true gold standard to be used as an external criterion against which the validity of patients' self-reports can be determined. However, diagnoses of chronic diseases registered in Dutch general practices generally appear to be valid, as compared to standard diagnostic criteria [33], with low numbers of false positive cases [34]. General practitioners' information can, therefore, be used as an "alloyed gold" standard, particularly as far as the presence of chronic diseases is concerned. For that reason, the general practitioners' information will be considered the reference against which the patients' self-reports are compared. As a result, the kappa's may be interpreted as "iota's" [35]; the level of agreement between two data-sources, of which one is presumed to be more valid than the other, adjusted for agreement by chance. The category "patient positive, general practitioner negative" will be referred to as "overreporters," and the category "patient negative, general practitioner positive" as "underreporters" (see Table 1).

According to the terminology developed by Marquis [36], a complete design is employed, meaning that both positive and negative interview responses on the questions about the presence of chronic diseases are verified against the general practitioner information. To evaluate the level of accuracy measured with the kappa statistic, the classification system suggested by Landis and Koch [37] was used: kappa <0.40 represents poor to fair accuracy, 0.40–0.60 represents moderate accuracy, 0.60–0.80 represents substantial accuracy, and 0.80–1.00 represents almost perfect accuracy. The level of accuracy of the patients' self-reports compared with the general practitioners' information was assessed using two approaches. First, the answers on the interview questions concerning presence or absence of the specific diseases were compared with the general practitioner data. Second, separate analyses were carried out in which a specific disease was considered present only when the patient also reported using medication or was regularly checked by a physician for that disease. Moreover, because differences in this respect have been reported for malignant neoplasms [13], separate analyses were performed including, respectively excluding non-melanoma skin cancer. Differences in the level of accuracy were determined by calculation of the 95% confidence intervals for the kappa statistics of the first and second approach.

To determine whether patient characteristics influence the accuracy of patients' self-reports, logistic regression analyses were performed for the specific chronic diseases. Logistic regression analyses were performed separately for overreporters and underreporters. For overreporters (patient positive, general practitioner negative), the cases in which the general practitioner and patient both reported a specific chronic disease to be absent (patient negative, general practitioner negative) was used as the reference category. For underreporters (patient negative, general practitioner positive), the reference category included all cases in which both reported a specific disease to be present (patient positive, general practitioner positive). All patient characteristics described in the measurements section were entered in the logistic regression models simultaneously.

RESULTS

The distribution of patient characteristics included as potential determinants of the accuracy of self-reports is presented in Table 2. For peripheral atherosclerotic disease and osteoarthritis/rheumatoid arthritis, the accuracy of the patients' self-reports, as compared with the general practitioners' information, is poor (see Table 3). Moderate accuracy of self-reports is found for chronic non-specific lung

TABLE 2. Characteristics of the study population

Variable		*n*[a]	%
Sex	Male	1,172	49.2
	Female	1,208	50.8
Age	55–64	748	31.4
	65–74	761	32.0
	≥75	871	36.6
Urbanization level (addresses/km²)	<500	586	25.2
	500 to 1000	440	18.9
	1,000 to 1,500	527	22.7
	1,500 to 2,500	351	15.1
	≥2,500	420	18.1
Educational level	Low	1,511	63.6
	Middle	605	25.5
	High	260	10.9
CES-D score	<16	2,060	87.1
	≥16	306	12.9
MMSE score	≥24	2,156	91.1
	≤23	210	8.9
Mobility limitations	No	1,452	61.6
	Yes	907	38.4

[a]Differences in the total number of subjects per variable are due to missing information.

TABLE 3. Proportions of concordance and discordance between patient and general practitioner regarding the presence or absence of specific diseases and kappa-values (K), including 95% confidence intervals (95% CI)

Disease	GP− P−[a]	GP+ P+[b]	GP− P+[c]	GP+ P−[d]	K	95% CI
Chronic non-specific lung disease	85.4	6.8	4.5	3.3	0.59	0.53–0.65
including medication/check doctor	87.7	6.0	2.2	4.1	0.63	0.57–0.69
Cardiac disease	74.3	15.6	3.7	6.3	0.69	0.65–0.73
including medication/check doctor	75.3	14.4	2.9	7.3	0.68	0.64–0.72
Peripheral atherosclerotic disease	89.3	2.8	6.4	1.4	0.38	0.30–0.46
including medication/check doctor	91.6	2.4	4.3	1.8	0.41	0.33–0.49
Cerebrovascular disease	92.9	2.9	2.1	2.1	0.56	0.48–0.64
including medication/check doctor	93.7	2.3	1.4	2.7	0.50	0.42–0.58
Diabetes mellitus	91.3	6.6	0.6	1.4	0.85	0.81–0.89
including medication/check doctor	91.5	6.5	0.5	1.6	0.85	0.81–0.89
Malignant neoplasms						
including non-melanoma skin cancer	87.5	6.3	2.4	3.7	0.64	0.58–0.70
including medication/check doctor	89.1	4.9	0.9	5.1	0.59	0.53–0.65
excluding non-melanoma skin cancer	89.8	5.3	2.1	2.8	0.66	0.60–0.72
including medication/check doctor	92.0	4.3	0.8	2.8	0.68	0.62–0.74
Osteoarthritis and/or rheumatoid arthritis	59.5	12.5	21.8	6.1	0.31	0.27–0.35
including medication/check doctor	74.4	7.6	7.1	10.9	0.35	0.31–0.39

[a]General practitioner negative and patient negative.
[b]General practitioner positive and patient positive.
[c]General practitioner negative and patient positive.
[d]General practitioner positive and patient negative.

disease and cerebrovascular disease, whereas substantial accuracy is present for cardiac disease and malignant neoplasms. Almost perfect accuracy of patients' self-reports is present for diabetes mellitus. Inclusion of the use of medication or being regularly checked by a doctor in the definition of the presence of a specific disease according to the patient does not significantly alter the levels of accuracy, although the distribution over the different categories of concordance and discordance is affected to some extent (see Table 3). Obviously, the use of these additional parameters to obtain a more restricted measure of disease presence results in somewhat higher percentages of underreporters and lower percentages of overreporters. In the remaining analyses, only the variables concerning presence or absence of the specific diseases are used. Also, exclusion of non-melanoma skin cancer does not significantly increase the accuracy of patients' self-reports regarding the presence or absence of malignancies (see Table 3). No further distinction is made in the remaining analyses, therefore, between malignancies including, respectively, excluding non-melanoma skin cancers.

Overall percentages of concordance regarding the presence or absence of specific chronic diseases between patient and general practitioner information are high (see Table 4), with the exception of osteoarthritis/rheumatoid arthritis, in which the percentage is considerably lower, compared with the other chronic diseases. Both underreporting and overreporting occur in a substantial percentage of patients of whom the general practitioners report a specific chronic disease to be present, respectively, absent. Percentages of underreporters range from 19.9% for diabetes mellitus through 41.5% for cerebrovascular disease. For overreporters, percentages range from 0.6% for diabetes mellitus to 26.8% for osteoarthritis/rheumatoid arthritis.

TABLE 4. Overall concordance between patients and general practitioners, and numbers and proportions of underreporters and overreporters using general practitioner information as a reference[a]

Disease	Concordance		Underreporters		Overreporters	
	n	%	*n*	%[b]	*n*	%[c]
Chronic non-specific lung disease	2,175	92.2	78	32.8	107	5.0
Cardiac disease	2,137	89.9	150	28.8	89	4.8
Peripheral atherosclerotic disease	2,188	92.1	34	33.7	152	6.7
Cerebrovascular disease	2,258	95.8	49	41.5	50	2.2
Diabetes mellitus	2,305	97.8	39	19.9	15	0.6
Malignant neoplasms	2,233	93.8	89	37.2	58	2.7
Osteoarthritis and/or rheumatoid arthritis	1,706	72.0	144	32.7	517	26.8

[a]Numbers of overreporters and underreporters may be different in this table, compared with Appendix 3, due to missing information on patient characteristics.
[b]In Table 1: (c/(a + c))100; c = number in which GP+ and P−; (a + c) = total number in which GP+.
[c]In Table 1: (b/(b + d))100; b = number in which GP− and P+; (b + d) = total number in which GP−.

TABLE 5. Influence of patient characteristics on the accuracy of self-reports compared with general practitioner information: odds ratios (ORs) and 95% confidence intervals (95% CI) of patient characteristics associated* with overreporting or underreporting

Patient characteristic	Disease	Overreporting		Underreporting	
		OR	95% CI	OR	95% CI
Sex (female versus male)	Chronic non-specific lung disease	0.56	0.37–0.86	0.45	0.23–0.89
	Stroke	0.30	0.16–0.59	—	—
	Malignancies	2.60	1.39–4.86	0.26	0.14–0.48
	Arthritis	2.08	1.66–2.60	0.39	0.24–0.64
Age (for every year older)	Cardiac disease	1.04	1.01–1.07	1.06	1.02–1.09
	Stroke	1.07	1.03–1.12	—	—
	Arthritis	—	—	1.04	1.01–1.08
Educational level (middle versus low)	Arthritis	—	—	0.50	0.28–0.89
Mobility limitations (yes versus no)	Chronic non-specific lung disease	2.82	1.79–4.46	0.38	0.19–0.76
	Cardiac disease	1.80	1.10–2.96	0.44	0.27–0.70
	Atherosclerosis	2.19	1.48–3.24	—	—
	Stroke	2.43	1.20–4.88	0.09	0.03–0.26
	Malignancies	1.93	1.05–3.53	0.47	0.23–0.94
	Arthritis	2.68	2.10–3.44	0.20	0.12–0.35
Recent contact with GP (yes versus no)	Cardiac disease	2.20	1.14–4.24	—	—
	Atherosclerosis	2.83	1.60–5.00	—	—
	Diabetes mellitus	—	—	0.12	0.04–0.40
	Malignancies	2.33	1.03–5.27	—	—
	Arthritis	1.41	1.09–1.84	0.40	0.22–0.72

*$p < 0.05$.

Multiple logistic regression analyses were performed for the specific chronic diseases. For every disease, separate models were built for the two different levels of inaccuracy, that is for overreporters and underreporters. Reference categories are those cases in which both patient and general practitioner report a specific chronic disease to be absent for overreporters, and those cases in which they both report a specific disease to be present for underreporters. Gender, age, urbanization level of the living area, highest educational level attained, the presence of clinically relevant depressive symptomatology, the presence of clinically relevant deviation in cognitive function, mobility limitations, and recent contact with the general practitioner were simultaneously entered as determinants. In Table 5, a summary of the results is presented, in which only those patient characteristics are included that have a statistically significant association ($p < 0.05$) with overreporting or underreporting of a specific chronic disease by the patient, as compared with general practitioners'information.

The results (Table 5) show that, adjusted for the other potential determinants, neither urbanization level of the living area, educational level (with only one exception), depressive symptomatology, nor deviation in cognitive function are associated with underreporting or overreporting for any of the specific chronic diseases. The influence of the other determinants (gender, age, the presence of mobility limitations, and recent contact with the general practitioner) is different for the specific chronic diseases.

For chronic non-specific lung disease, overreporting occurs significantly more often in males, compared with females, and in people who report mobility limitations, compared with those who do not. Underreporting for chronic non-specific lung disease is also more common among males, compared with females, and underreporting is less common in people who have mobility limitations, compared with those who have no such limitations. In cardiac disease, both underreporting and overreporting are related to higher age. Compared with people without mobility limitations, overreporting is more common in people with mobility limitations, and underreporting is less common. Overreporting of cardiac disease is more common among those who report to have contacted their general practitioner during the previous six months, compared with those who have not. Overreporting of peripheral atherosclerotic disease is associated with the presence of mobility limitations and recent contact with the general practitioner. With regard to cerebrovascular disease (stroke), overreporting is more common in males, as compared with females. Overreporting of stroke is positively associated with older age. Overreporting is also more common in people reporting mobility limitations, whereas underreporting is more common in people not reporting such limitations. In diabetes mellitus, underreporting is less common in people who have contacted their general practitioner recently, compared with those who have not. Malignant neoplasms are more often overreported and less often underreported by females, as compared with males. Also, overreporting of malignancies is associated with the presence of mobility limitations and recent contact with the general practitioner. Underreporting of malignancies is more common in people without mobility limitations, compared with those with such limitations. Overreporting of osteoarthritis/rheumatoid arthritis is associated with female gender and the presence of mobility limitations, and is also more common in people who have had recent contact with their general practitioner. Underreporting is less common in females, compared with males. Higher age is positively associated with underreporting of osteoarthritis/rheumatoid arthritis. Finally, underreporting is less

common in people reporting mobility limitations and recent contact with their general practitioner.

DISCUSSION

The accuracy of patients' self-reports, as compared to general practitioners' information, regarding the presence or absence of specific chronic diseases is generally satisfactory, with the exceptions of peripheral atherosclerotic disease and arthritis. Some authors state that the accuracy of patients' self-reports can be improved by restricting the definition of a positive self-report to those cases in which medical consumption is also reported present [9,38]. Our data do not provide evidence supporting this statement. The kappa's found in the present study for the specific diseases are comparable to those from other studies [1,6,9,38].

For peripheral atherosclerotic disease, one of the diseases for which patients' self-reports were insufficiently accurate compared with general practitioners' information, no comparable studies are available. In this particular disease, a likely explanation for the observed discrepancy between patients' self-reports and general practitioner information is a problem specific to the Dutch language. Although confusion between diseases (or atherosclerosis) of the arteries and varicose veins would seem to be far-fetched for an English-speaking audience, in Dutch, arteries are called "slagaderen" whereas veins are "aderen." Probably, patients in our study often reported their varicose veins (in Dutch, "spataderen") as a disease of the arteries, explaining the lack of accuracy, compared with most other diseases.

In arthritis, the other disease in which poor accuracy was present according to the kappa-value, other studies report comparable figures for underreporters and overreporters [12,14]. These conditions are generally characterized by symptoms and complaints that are not perceived to be life-threatening. Therefore, although the patients themselves may attribute pain and stiffness in the joints to "rheumatism" or "arthritis" and give a positive answer to questions pertaining to specific conditions, it is very well possible that they have not brought their joint complaints to the attention of their general practitioner, resulting in a proportionally high frequency of overreporting. As was the case in the study of Kehoe *et al.* [12], overreporting of arthritis was more common in females, compared with males. Underreporting was associated with higher age, which has also been reported previously [14].

With regard to diabetes mellitus, the only disease which, according to the kappa-value, is reported by patients with excellent accuracy, the results are also comparable to, or better than, that of previous studies [1,6,7,11,12,39]. In conformity with the results of Kehoe *et al.* [12], who did not find any association between patient characteristics (except for the frequency of physician visits) and the accuracy of patients' self-reports, the only patient characteristic influencing the accuracy of the patients' self-report of diabetes was whether there had been recent contact with the general practitioner; underreporting of diabetes was less common in those who contacted the general practitioner during the previous six months.

For chronic non-specific lung disease, comparison of our data with the literature is hampered by the fact that, in our questionnaire, asthma, chronic bronchitis, and pulmonary emphysema were asked in one question. Our results are comparable to those found in earlier studies in the Netherlands [9,10].

The results of the present study regarding self-reported cardiac disease are comparable to those reported previously for myocardial infarction [7], coronary heart disease, and other cardiovascular diseases [12]. In cardiac disease, older age has been reported to be associated with underreporting, and frequent physician visits has been associated with overreporting [12], whereas in the present study, older age was associated both with overreporting and with underreporting, and recent contact with the general practitioner with overreporting.

For cerebrovascular disease, the percentage of positive self-reports confirmed by medical records was not very different compared to previous studies [7,40]. It is possible that the inaccurate self-reports of stroke are partly due to labeling of symptoms, such as dizziness or fainting, as a cerebrovascular problem.

The results of recent studies on the accuracy of patients' self-reports on cancer compared with general practitioner records [12], respectively, a population-based cancer-registry [13], which is a far better gold standard than general practitioner information, were comparable to those found in the present study. In conformity with Schrijvers *et al.* [13], who report an underestimation of cancer prevalence by survey, as compared with registry data, for men, overreporting in our study was more frequent in women, and underreporting was more frequent in men. In the present study, no association was found between age and the accuracy of a self-report of malignancies. Overreporting may partly reflect the inaccuracy of general practitioner records regarding disease events in the past; patients may have been treated for cancer and cured many years before entering the practice of their current general practitioner. Differences in survival rates of malignancies with the highest incidence in men (lung cancer) and women (breast cancer), respectively, can thus be responsible for the observed association between gender and overreporting.

With few exceptions, educational level, urbanization, the presence of deviation in cognitive function, and depressive symptomatology had no effect on the accuracy of patients' self-reports regarding the presence or absence of specific chronic diseases. The influence of gender and age appears to be different in specific chronic diseases, whereas the influence of mobility limitations and recent contact with the general practitioner appears to be rather consistent for the different diseases.

Male gender is associated with overreporting of chronic non-specific lung disease and stroke, and with underreporting of chronic non-specific lung disease, malignancies, and osteoarthritis/rheumatoid arthritis. Compared with males, females more frequently overreport malignancies and osteoarthritis/rheumatoid arthritis. Overall, males tend to underreport, whereas females tend to overreport some of the specific chronic diseases studied. This tendency to underreport may well be due to denial of a serious chronic disease by men. In general, women more easily admit the presence of symptoms and complaints [41]. Given the high prevalence of arthritis in women, they may attribute pain or stiffness in the joints more easily to arthritis or rheumatism than men, explaining the association between female gender and overreporting of osteoarthritis/rheumatoid arthritis.

Older age is, independently of the other characteristics studied, associated with less accurate self-reports of some diseases, both with regard to overreporting and with regard to underreporting. Although it has been stated that less accurate self-reports in elderly people might be due to cognitive decline [3], this appears not to be the case in the present study, since we controlled for the presence of clinically relevant deviations in cognitive functioning in the analyses. Elderly people may be reluctant to admit that they have life-threatening chronic diseases, or they may not perceive their symp-

toms as severe enough to warrant labeling them as belonging to a disease, which will result in underreporting. On the other hand, they may be more likely than younger people to label symptoms as belonging to diseases that are generally associated with higher age, resulting in overreporting.

People experiencing mobility limitations tend to overreport chronic non-specific lung disease, cardiac disease, peripheral atherosclerotic disease, stroke, malignancies, and osteoarthritis/rheumatoid arthritis, whereas those without such limitations more often underreport chronic non-specific lung disease, cardiac disease, stroke, malignancies, and osteoarthritis/rheumatoid arthritis. The most likely explanation for the consistent associations between mobility limitations and the accuracy of self-reports is that people who experience difficulty in their daily functioning may be more inclined to attribute their problems to a medical condition, compared with those without such difficulties.

Recent contact with the general practitioner was associated with overreporting of cardiac disease, atherosclerosis, malignancies, and osteoarthritis/rheumatoid arthritis, and with underreporting of cardiac disease and stroke. Some possible explanations are incorrect labeling or denial by patients themselves and inaccuracies in the general practitioner records, which were already discussed.

The selectivity of the study population as compared with the original sample may have affected our results, and therefore it may have affected the generalizability to some extent. As was presented in the methods section, the final study population was a relatively healthy, both physically and mentally, selection of the original sample. The overrepresentation of elderly subjects with relatively good physical health is unlikely to have resulted in an overestimation of the accuracy of patients' self-reports as compared with general practitioners' information. On the contrary, subjects with more severe disease can be presumed to be more aware of the presence of this disease, and the same holds true for their general practitioners. Therefore, the selection of the study population towards better physical health may have resulted in an underestimation of the accuracy of self-reports, rather than an overestimation. Whether the overrepresentation of subjects with relatively good mental health, both with regard to cognitive function and with regard to the presence of depressive symptomatology, has resulted in relevant bias of the results is uncertain. Impairments in cognitive function may be associated with less accurate self-reports, but this may be both underreporting as well as overreporting. However, although deviation in cognitive functioning was associated with response, in the Netherlands 80% of cognitively impaired or demented elderly people live in the community [42] and general practitioner information was available for a large majority of community-dwelling elderly with cognitive problems in our study population. A high level of depressive symptomatology may be associated with a general negative attitude towards one's physical health status, which would probably result in a higher level of overreporting of physical diseases. The problems associated with the selectivity of the study population are, to a certain extent, covered by the fact that the parameters of physical and mental health were included in the analyses on determinants of overreporting and underreporting for the specific chronic diseases.

Our results have consequences for future studies on determinants and consequences of specific chronic diseases in population surveys that use self-reported data. For potential determinants related to overreporting of a specific disease, for example, the presence of mobility limitations, the association with specific diseases will be overestimated.

Summarizing, the accuracy of patients' self-reports compared with general practitioners' information on the presence or absence of specific chronic diseases is adequate in the present study. Only for peripheral atherosclerotic disease and osteoarthritis/rheumatoid arthritis the accuracy of self-reports is low, for which explanations were outlined. Cognitive or emotional disturbances do not appear to be of particular influence on the accuracy of patients' self-reports, but age, gender, physical mobility, and recent contact with the general practitioner are.

The results of this study do not allow a conclusion regarding the preferable source of information (patient or general practitioner) for all chronic diseases from a validity point-of-view. Although general practitioners' information may be valid as far as medically diagnosed cases are concerned [34], it remains uncertain whether these diagnosed cases reflect the actual prevalence of a specific disease in the community. For some chronic diseases, which require a physician-made diagnosis and continuous medical treatment, such as diabetes mellitus, both general practitioner and patient will provide sufficiently valid information. For other diseases, patients' self-reports may be more valid, although the disease may not be diagnosed or recorded by a physician. Examples are malignancies, which have been treated and cured in the past, and are not included in the medical record anymore. Also, patients may have complaints due to a chronic disease, such as osteoarthritis, for which they have not consulted their general practitioner yet. As a result, there will be no diagnosis in the medical record, although the disease may be present.

Depending on the specific purpose of a study, the use of patients' self-reports may have several important advantages for survey studies, compared to medical record information. Self-report types of data collection generally involve substantially lower costs [3] and less organizational demands as opposed to clinical assessments or medical record extraction. An important issue for longitudinal studies is that long-term stability of patients' self-reports on major illnesses, such as the chronic diseases studied, was shown to be much better compared to that of physician-asked questions or physical examinations [43]. Moreover, the use of self-reports enhances the possibilities of international comparison of the results of survey studies; because there are substantial differences between the health care structures across different countries, medical record information is often not easily comparable. To further enhance the accuracy of patients' self-reports, questionnaires should be carefully worded. The way lay people define diseases and symptoms, which may be different across cultures, should be taken into account.

In view of the advantages of patients' self-reports for survey studies and their, though for several chronic diseases satisfactory, limited accuracy, it is important to consider whether the validity of self-report survey measures of chronic diseases can be improved, for instance by including additional disease-specific information reflecting the severity of disease.

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APPENDIX. Results of multiple logistic regression analyses on the influence of patient characteristics on the accuracy of self-reports compared with general practitioner information: odds ratios (ORs) and 95% confidence intervals (95% CI)*

	Disease			
	CNSLD			
	Overreporters (n = 101) vs. GP − P − (n = 1866)		Underreporters (n = 65) vs. GP + P + (n = 141)	
Determinants	**OR**	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	0.56	0.37–0.86	0.45	0.23–0.89
Age (for every year older)	1.00	0.98–1.03	1.04	0.99–1.08
Urbanization (for every level higher)	1.03	0.89–1.20	0.88	0.70–1.10
Educational level middle vs. low	1.02	0.63–1.65	1.67	0.78–3.59
high vs. low	0.72	0.35–1.50	1.46	0.50–4.21
MMSE score ≤ 23 (yes vs. no)	0.47	0.18–1.19	0.70	0.24–2.09
CES-D score ≥ 16 (yes vs. no)	1.31	0.74–2.31	0.79	0.35–1.76
Mobility limitations (yes vs. no)	2.82	1.79–4.46	0.38	0.19–0.76
Recent contact with GP (yes vs. no)	1.37	0.80–2.34	0.47	0.20–1.07
	Cardiac disease			
	Overreporters (n = 83) vs. GP − P − (n = 1628)		Underreporters (n = 134) vs. GP + P + (n = 343)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	0.73	0.86–2.17	1.51	0.97–2.36
Age (for every year older)	1.04	1.01–1.07	1.06	1.02–1.09
Urbanization (for every level higher)	0.92	0.78–1.08	0.98	0.85–1.14
Educational level middle vs. low	1.25	0.73–2.14	0.99	0.60–1.64
high vs. low	0.77	0.32–1.86	1.78	0.93–3.38
MMSE score ≤ 23 (yes vs. no)	1.67	0.85–3.29	0.67	0.32–1.44
CES-D score ≥ 16 (yes vs. no)	1.43	0.77–2.64	1.21	0.67–2.18
Mobility limitations (yes vs. no)	1.80	1.10–2.96	0.44	0.27–0.70
Recent contact with GP (yes vs. no)	2.20	1.14–4.24	1.35	0.72–2.52
	Atherosclerosis			
	Overreporters (n = 140) vs. GP − P − (n = 1956)		Underreporters (n = 31) vs. GP + P + (n = 59)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	1.04	0.72–1.49	0.99	0.30–3.22
Age (for every year older)	1.01	0.98–1.03	1.01	0.93–1.09
Urbanization (for every level higher)	0.97	0.86–1.10	1.25	0.86–1.83
Educational level middle vs. low	1.04	0.68–1.59	1.13	0.29–4.44
high vs. low	1.02	0.55–1.90	0.65	0.15–2.88
MMSE score ≤ 23 (yes vs. no)	1.27	0.71–2.26	1.65	0.38–7.16
CES-D score ≥ 16 (yes vs. no)	1.21	0.75–1.94	0.50	0.13–1.89
Mobility limitations (yes vs. no)	2.19	1.48–3.24	0.56	0.21–1.52
Recent contact with GP (yes vs. no)	2.83	1.60–5.00	0.39	0.08–2.00
	Stroke			
	Overreporters (n = 45) vs. GP − P − (n = 2026)		Underreporters (n = 43) vs. GP + P + (n = 56)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	0.30	0.16–0.59	2.29	0.72–7.22
Age (for every year older)	1.07	1.03–1.12	1.06	0.99–1.15
Urbanization (for every level higher)	0.96	0.78–1.19	0.86	0.59–1.24
Educational level middle vs. low	0.60	0.26–1.41	0.54	0.14–2.05
high vs. low	0.46	0.14–1.56	0.70	0.12–4.14
MMSE score ≤ 23 (yes vs. no)	1.32	0.56–3.14	0.33	0.07–1.46
CES-D score ≥ 16 (yes vs. no)	1.88	0.89–3.96	0.79	0.17–3.58
Mobility limitations (yes vs. no)	2.43	1.20–4.88	0.09	0.03–0.26
Recent contact with GP (yes vs. no)	1.63	0.67–3.96	0.45	0.07–2.81

appendix continued

APPENDIX. Continued.

	Diabetes mellitus			
	Overreporters (n = 15) vs. GP − P − (n = 1983)		Underreporters (n = 31) vs. GP + P + (n = 142)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	0.77	0.27–2.20	0.40	0.16–1.04
Age (for every year older)	1.03	0.96–1.10	1.00	0.94–1.06
Urbanization (for every level higher)	0.88	0.61–1.28	0.78	0.54–1.13
Educational level middle vs. low	1.83	0.57–5.87	0.69	0.21–2.30
high vs. low	1.57	0.32–7.78	0.88	0.16–4.88
MMSE score ≤ 23 (yes vs. no)	0.68	0.08–5.52	0.47	0.09–2.43
CES-D score ≥ 16 (yes vs. no)	2.42	0.71–8.29	0.61	0.10–3.72
Mobility limitations (yes vs. no)	2.35	0.73–7.62	0.58	0.22–1.51
Recent contact with GP (yes vs. no)	0.72	0.22–2.38	**0.12**	**0.04–0.40**
	Malignancies			
	Overreporters (n = 56) vs. GP − P − (n = 1916)		Underreporters (n = 84) vs. GP + P + (n = 136)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	**2.60**	**1.39–4.86**	**0.26**	**0.14–0.48**
Age (for every year older)	0.97	0.94–1.01	1.02	0.98–1.07
Urbanization (for every level higher)	1.05	0.87–1.27	1.10	0.88–1.36
Educational level middle vs. low	0.74	0.37–1.49	0.54	0.26–1.12
high vs. low	0.93	0.35–2.46	1.93	0.54–6.89
MMSE score ≤ 23 (yes vs. no)	1.08	0.41–2.85	1.72	0.56–5.31
CES-D score ≥ 16 (yes vs. no)	1.11	0.53–2.87	0.59	0.22–1.57
Mobility limitations (yes vs. no)	**1.93**	**1.05–3.53**	**0.47**	**0.23–0.94**
Recent contact with GP (yes vs. no)	**2.33**	**1.03–5.27**	0.63	0.29–1.36
	Arthritis			
	Overreporters (n = 490) vs. GP − P − (n = 1294)		Underreporters (n = 127) vs. GP + P + (n = 269)	
	OR	**95% CI**	**OR**	**95% CI**
Sex (female vs. male)	**2.08**	**1.66–2.60**	**0.39**	**0.24–0.64**
Age (for every year older)	0.99	0.98–1.01	**1.04**	**1.01–1.08**
Urbanization (for every level higher)	1.01	0.94–1.10	1.10	0.94–1.29
Educational level middle vs. low	1.11	0.85–1.45	**0.50**	**0.28–0.89**
high vs. low	1.05	0.72–1.51	0.63	0.24–1.66
MMSE score ≤ 23 (yes vs. no)	0.83	0.55–1.26	0.95	0.39–2.30
CES-D score ≥ 16 (yes vs. no)	1.36	0.99–1.87	0.87	0.42–1.79
Mobility limitations (yes vs. no)	**2.68**	**2.10–3.44**	**0.20**	**0.12–0.35**
Recent contact with GP (yes vs. no)	**1.41**	**1.09–1.84**	**0.40**	**0.22–0.72**

*Bold: $p < 0.05$.