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Agreement between Questionnaire Data and Medical Records of Chronic Diseases in Middle-aged and Elderly Finnish Men and Women

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The agreement between self-reported diseases in a questionnaire survey and data from medical records was assessed in a representative sample of Finnish men and women (n = 596) aged 45–73 years. The accumulated medical record information was abstracted from the records in the health centers and the central hospital in the study region. The agreement between the two information sources was substantial (kappa 0.73–0.80) for cardiovascular diseases as a group, hypertension, angina pectoris, myocardial infarction, and diabetes. The lowest agreement (kappa < 0.55) was found for lower back disorder, hip and knee arthrosis, and claudication. These results showed that the agreement between questionnaire data and medical records was good for well-known chronic diseases that have clear diagnostic criteria and are easily communicated to the patient. Conversely, the agreement was poor for diseases with nonestablished diagnostic criteria and a fluctuating course. *Am J Epidemiol* 1997;145:762–9.

medical records; questionnaires

Epidemiologic studies frequently use self-administered questionnaires to obtain individual data to study subjects' health status (1, 2). Self-reported questionnaire information can, however, be distorted for numerous reasons. The subjects may misunderstand the diagnosis reported by the physician, they may forget the diagnosis, or they may be unwilling to report it (2–5). For determination of the validity of such study results, the consistency between subjective self-reported diseases and medical sources of respective disease information can be compared (6).

Cardiovascular diseases and diabetes have been of greatest interest in studies of the agreement between self-reports and medical record information or the validity of self-reports (1–4, 7–9). Despite increasing evidence of the agreement and validity of results about chronic and acute diseases obtained from different sources, there is a paucity of information on the subject (10), and the accuracy or validity of self-reports for many medical conditions, especially in the elderly, is still uncertain (2, 11–14).

The purpose of this study was to assess the agreement and validity of self-administered questionnaire information on selected chronic diseases, namely cardiovascular diseases, diabetes, hip and knee arthrosis, and lower back disorders, with the information documented in the medical records of middle-aged and elderly Finnish men and women.

MATERIALS AND METHODS

A prospective follow-up study with a systematic representative sample of residents aged 19–63 years was initiated in 1980. Self-administered follow-up questionnaires were sent to the subjects in 1985 and 1990 (figure 1). Our study was targeted at those subjects who were aged 35–63 years in 1980 and who, regardless of their disease history, lived in the study region and answered the follow-up questionnaire in 1990. From these subjects, a random sample of 300 men and 300 women was selected for the analysis.

Self-reported information on various medical conditions was obtained in 1990 using the following structured question: "Do you have or have you had any of the following diseases?" The disease conditions of interest in this study were hypertension or high blood pressure, myocardial infarction, angina pectoris or other coronary heart disease, cerebral stroke or transient ischemic attack, claudication, diabetes or high blood glucose level, hip or knee arthrosis, and lower back disorder or chronic lower back symptoms. The response in each case was yes or no.

The accumulated medical record information was gathered from the local municipal health centers and

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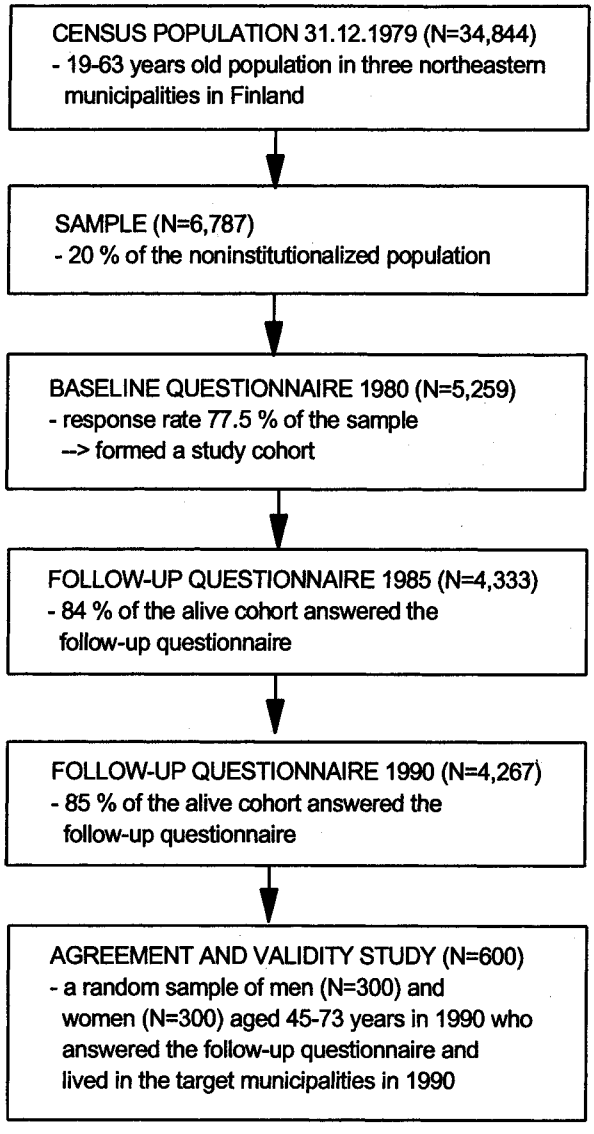

FIGURE 1. Study design of the prospective follow-up study and the selection criteria for the current analysis among men and women aged 45–73 years, northeastern Finland, 1990.

the central hospital in the study region. Apart from the inpatient wards of the health centers, which provide mainly long-term care, the central hospital was the only hospital in the study region, and most specialist physician services were provided there. The medical records of 96 percent in the sample of 600 subjects were available from the local health center, and the records for 89 percent were available from the central hospital. The subjects with medical records from either the health center or central hospital (n = 596) were included in the final analysis.

The diagnostic criteria defined before the medical record review are given in table 1. All medical records obtained from the health centers and the central hospital were reviewed. To ensure unbiased comparisons between the questionnaire data and medical records, the information from each subject's self-reported questionnaire was not referred to during collection of the medical record data.

The medical record diagnosis for each condition (yes or no) was cross-tabulated with that of the self-reported answer (yes or no) obtained from the questionnaire. The analysis of the agreement between the two methods was based first on definite diagnoses and subsequently on both possible and definite diagnoses in the medical records with the exception of hip and knee arthrosis, for which it was not possible to assess whether the diagnosis was possible or definite.

Kappa coefficients were calculated to determine the agreement between self-reported questionnaire data and medical records. A kappa value of less than 0.40 was considered poor-to-fair agreement, 0.41–0.60 was considered moderate agreement, 0.61–0.80 was considered substantial agreement, and 0.81–1.00 was considered almost perfect agreement, as suggested by Landis and Koch (15). The validity of the self-reported questionnaire data compared with the medical records was expressed in terms of sensitivity (true positives correctly identified/all true positives), specificity (true negatives correctly identified/all true negatives), positive predictive value (true positives correctly identified/all positives identified by the questionnaire data), and negative predictive value (true negatives correctly identified/all negatives identified by the questionnaire data) (16, 17).

Owing to the possibility that certain respondent-related characteristics affected the findings, the differences in the occurrence of true positive and true negative reports of any cardiovascular disease and lower back disorder and in the overall agreement between the different subgroups in the study population were analyzed with a logistic regression model. The results were expressed in terms of adjusted odds ratios for the sensitivity, specificity, and overall agreement between the self-administered questionnaire and the medical record information. Cases of cardiovascular diseases and lower back disorder obtained from the medical records were included in the analysis of the sensitivity. Similarly, the analysis of specificity included subjects with no evidence of cardiovascular diseases and lower back disorder in their medical records.

RESULTS

The main findings are summarized in table 2. For most conditions, the prevalence of the disease based on questionnaire responses was lower than that reflected in the medical records, when the prevalence was based on both possible and definite diagnoses in the medical records. When only definite diagnoses

TABLE 1. Classification criteria for different medical conditions obtained from medical records among men and women aged 45–73 years, northeastern Finland, 1990

Disease and classification	Criteria stated in the accumulated record data
Hypertension	Antihypertensive medication use
High blood pressure	Follow-up of high blood pressure Physician's or a public health nurse's notation about the follow-up Several measurements of systolic pressure >140 mmHg and/or diastolic pressure >90 mmHg
Myocardial infarction	
Definite	Diagnosis based on hospital examinations (ECG*, enzymes, symptoms) Physician's notes at the health center about simultaneous chest pain and ischemic changes in ECG
Possible	Later diagnosis at the health center or the criteria for the diagnosis not available from the medical record
Other coronary heart disease or angina pectoris	
Definite	Diagnosis based on hospital examination or on exercise ECG
Possible	Health center diagnosis without further examination or criteria for the diagnosis not available from the medical record
Claudication	
Definite	Hospital examination or diagnosis by a specialist physician
Possible	Health center diagnosis without further examination or criteria for the diagnosis not available from the medical record
Cerebral stroke or TIA*	
Definite	Hospital examination or diagnosis by a specialist physician
Possible	Health center diagnosis or the diagnosis not available from the medical record
Diabetes	Physician's note of the diagnosis or fasting plasma glucose >7 mmol/ liter and/or 2-hour sample >11 mmol/liter in glucose tolrance test
High blood glucose level	Fasting plasma glucose ≥5.6 mmol/liter or ≥8 mmol/liter in glucose tolerance test in 2-hour sample
Lower back disorder or symptoms	
Definite	Recurrent visits due to lower back disorder or symptoms or otherwise clear diagnosis (symptoms consistent with findings from x-ray examinations)
Possible	One-time visit for lower back symptoms or no subsequent examinations
Hip and knee arthrosis	Physician's notation of a possible or definite diagnosis

* ECG, electrocardiogram; TIA, transient ischemic attack.

were included as positives, the questionnaire responses indicated a higher prevalence of disease compared with the information in the medical records.

According to the medical records, about 50 percent of the subjects suffered or had suffered from some cardiovascular condition and lower back disorder. The agreement between the self-administered questionnaire information and medical record data was substantial (kappa 0.73–0.80) for cardiovascular diseases as a group as well as for the specific cardiovascular diseases for hypertension, angina pectoris, and myocardial infarction. Poor agreement was found for claudication. With only a few exceptions, the sensitivity and specificity of self-reported information on cardiovascular diseases compared with data from the medical records was also good.

The results also showed substantial agreement (kappa > 0.70) between the two reporting methods on the occurrence of diabetes. In contrast, the agreement was poor for musculoskeletal diseases. The consistency for hip and knee arthrosis was moderate (kappa = 0.48). Similarly, the agreement for lower back disorder was

TABLE 2. The estimates of percentage proportion of positive responses according to definite diagnosis and definite and possible diagnosis (the latter named as possible diagnosis), kappa coefficients, sensitivity, specificity, and positive predictive and negative predictive values of the self-administered questionnaire information compared with the medical record among men and women aged 45–73 years, northeastern Finland, 1990

Disease	Percentage proportion			Kappa		Se*		Sp*		PV+*		PV-*	
	Questionnaire	Medical record											
		Definite diagnosis	Possible diagnosis	Definite diagnosis	Possible diagnosis	Definite diagnosis	Possible diagnosis	Definite diagnosis	Possible diagnosis	Definite diagnosis	Possible diagnosis	Definite diagnosis	Possible diagnosis
Hypertension or high blood pressure ($n = 586$)	31.6	29.2	36.0	0.77	0.78	87	80	91	96	81	91	95	90
Myocardial infarction ($n = 586$)	6.7	5.6	6.8	0.79	0.77	88	78	98	99	74	80	99	98
Angina pectoris ($n = 586$)	16.2	14.8	23.2	0.74	0.73	82	68	95	99	75	93	97	91
CHD* ($n = 586$)	17.4	15.5	22.5	0.80	0.78	88	73	96	99	78	94	98	93
Claudication ($n = 586$)	5.1	0.9	1.4	0.28	0.30	100	75	96	96	17	20	100	99.6
Cerebral stroke or TIA* ($n = 585$)	5.1	5.0	7.2	0.66	0.62	69	55	98	99	67	77	98	97
Any CVD* ($n = 587$)	47.5	41.6	53.0	0.74	0.74	92	83	84	92	80	92	94	83
Diabetes or high blood glucose level ($n = 587$)	8.0	7.5	10.7	0.75	0.78	80	70	98	99	75	94	98	97
Hip or knee arthrosis ($n = 587$)	22.3		19.9		0.48		62		88		56		90
Lower back disorder ($n = 587$)	40.9	36.3	57.1	0.54	0.42	77	60	79	84	68	83	86	61

* Se, sensitivity; Sp, specificity, PV+, positive predictive value; PV–, negative predictive value; CHD, coronary heart disease (including myocardial infarction and angina pectoris); TIA, transient ischemic attack; CVD, cardiovascular disease (including hypertension or high blood pressure, angina pectoris, cardiac insufficiency, myocardial infarction, claudication, cerebral stroke or transient ischemic disease, arrhythmia, and valvular disorder and cardiomyopathia, in addition to the above-mentioned cardiovascular diseases).

poor (kappa 0.42–0.54), regardless of the classification method of the medical records used. Both the sensitivity and specificity of lower back disorder were among the poorest of all the diagnoses.

Age and number of health service contacts during 1980–1990 were statistically significantly associated with the occurrence of true negative responses, indicating increased misclassification of self-reported cardiovascular diseases among elderly subjects and those with many visits to a doctor (table 3). For lower back disorder, age, length of occupational training, and employment status were statistically significantly associated with the occurrence of true positive responses, indicating increased sensitivity of self-report of lower back disorder among elderly, poorly educated, and nonworking persons (table 4).

DISCUSSION

Our findings showed substantial agreement between self-reported and documented medical conditions such as diabetes, hypertension, coronary heart disease, and cardiovascular diseases as a general group. With some exceptions, the sensitivity and specificity of the questionnaire data on cardiovascular diseases were high as well. The agreement was further indicated by the finding that the prevalence of a disease based on the questionnaire responses was higher than that indicated by definite diagnoses in the medical records, but lower than that indicated by both possible and definite diagnoses, again in the medical records.

Our findings showed poor agreement between self-administered questionnaire data and medical records in the identification of lower back disorder and hip or knee arthrosis. Similarly, the validity of the self-reported information on musculoskeletal diseases was poor compared with agreement for cardiovascular diseases and diabetes. It is apparent that people with mild symptoms may report lower back disorder in the self-administered questionnaire even if they have not sought medical help for their condition. On the other hand, the study subjects may have suffered from lower back pain several years before and failed to report it in the questionnaire.

Several studies are in agreement with our findings that the consistency is good for cardiovascular diseases (1–3, 7, 18) and diabetes (2, 3, 7–9). Similarly, the few studies concerning the agreement between the self-report and medical record information for musculoskeletal diseases (3, 19) are in agreement with our results.

In agreement with some earlier studies (3), some respondent-related characteristics affected the sensitivity and specificity of the two information sources. We found that the importance of the respondent-related characteristics was higher for a disease with low agreement, such as lower back disorder, compared with a disease with high agreement, such as cardiovascular diseases. This difference is partly due to the higher agreement for cardiovascular diseases, whereby there are few cases with low agreement, and thus little variation remained to be explained by respondent-related characteristics. The respondent-related differences may also be due to the nature of the diseases. Cardiovascular diseases are often chronic, while the symptoms associated with lower back disorders often remain unspecified and may follow a fluctuating course with asymptomatic and symptomatic periods, especially in younger age groups, and thereby may be forgotten. The differences associated with education may be due to the different conception of lower back disorder symptoms in different jobs. Subjects with low education often engage in jobs with heavy lifting and may suffer from lower back symptoms more than well-educated subjects, who usually work in physically undemanding jobs.

Some authors have criticized the validity of medical records on the grounds that the coverage and validity of ordinary health care records can be low (3, 20–23). Given the differences that certainly exist between the medical reporting practices and health care organizations in various countries, the system in Finland provides a relatively reliable and uniform source of medical information because physicians are obliged to record the reason, the main findings, and the therapy provided for every patient contact. Similarly, the records are systematically stored in Finnish health care organizations. In addition, the coverage of the medical records was improved for this study by collecting and combining the medical information from both the local municipal health centers and the central hospital. The high proportion of study subjects who had used the health care services is in agreement with general statistics in Finland showing that municipal health centers and hospitals provide the vast majority of the physician services to the population (24). Our data from 1980 support this, with 58 and 18 percent of all annual visits to physicians accounted for by local health centers and the central hospital, respectively (25).

In summary, the results for this regionally representative sample of Finnish men and women aged 45–73 years indicate wide variation in agreement between questionnaire data and medical records, depending on the specific diagnosis. The agreement was substantial for coronary heart disease and for all cardiovascular diseases as a group and for some specific conditions such as hypertension and diabetes. There was low agreement for some general medical conditions, in-

TABLE 3. The association of gender, age, length of occupational training, and employment status with any cardiovascular disease reported on the questionnaire in relation to possible and definite cardiovascular disease obtained from the medical record among men and women aged 45–73 years, northeastern Finland, 1990

	No. of MR+* subjects		OR*	95% CI*	No. of MR–* subjects		OR	95% CI	Total no. of subjects		OR	95% CI
	All	SR+*			All	SR–*			All	MR+SR+ or MR–SR–		
Gender												
Men	165	141	1.00		130	118	1.00		295	259	1.00	
Women	146	116	0.66	0.36–1.19	146	136	1.38	0.58–3.32	292	252	0.88	0.54–1.42
			$p = 0.163$				$p = 0.466$				$p = 0.589$	
Age (years)†												
45–54	75	60	1.00		161	153	1.00		236	213	1.00	
55–64	132	110	1.22	0.59–2.53	88	79	0.46	0.17–1.23	220	189	0.65	0.37–1.16
65–73	104	87	1.33	0.62–2.89	27	22	0.23	0.07–0.76	131	109	0.54	0.29–1.01
			$p = 0.763$				$p = 0.050$				$p = 0.127$	
Length of occupational training (years)‡												
0	125	103	1.00		84	75	1.00		209	178	1.00	
2	139	114	0.96	0.51–1.82	129	122	1.81	0.63–5.23	268	236	1.21	0.71–2.07
>2	21	20	4.25	0.54–33.49	52	48	0.99	0.27–3.60	73	68	2.03	0.75–5.52
			$p = 0.217$				$p = 0.469$				$p = 0.326$	
Employment status‡												
Participant in working life	72	57	1.00		174	166	1.00		246	223	1.00	
Nonparticipant in working life	239	200	1.22	0.55–2.69	100	87	0.42	0.12–1.46	339	287	0.65	0.33–1.28
			$p = 0.623$				$p = 0.172$				$p = 0.207$	
Average no. of health service contacts per year during 1980–1990§												
<1	35	29	1.00		70	67	1.00		105	96	1.00	
1–3	96	77	0.86	0.27–2.69	105	100	0.74	0.13–4.11	201	177	0.65	0.26–1.60
>3	180	151	1.08	0.37–3.21	101	87	0.21	0.04–1.00	281	238	0.48	0.20–1.11
			$p = 0.810$				$p = 0.022$				$p = 0.161$	

* MR+, possible or definite cardiovascular disease obtained from the medical record; MR–, neither possible nor definite cardiovascular disease obtained from the medical record; SR+, some cardiovascular disease reported on the self-reported questionnaire; OR, odds ratio; CI, confidence interval; SR–, no cardiovascular disease reported on the self-reported questionnaire.

† Adjusted for gender.

‡ Adjusted for gender and age.

§ Adjusted for gender, age, and length of the occupational training.

TABLE 4. The association of gender, age, length of occupational training, and employment status with lower back disorder reported on the questionnaire in relation to possible and definite lower back disorder obtained from the medical record among men and women aged 45–73 years, northeastern Finland, 1990

	No. of MR+* subjects		OR*	95% CI*	No. of MR−* subjects		OR	95% CI	Total no. of subjects		OR	95% CI
	All	SR+*			All	SR−*			All	MR+SR+ or MR−SR−		
Gender												
Men	166	104	1.00		129	105	1.00		295	209	1.00	
Women	169	96	0.78	0.51–1.21	123	107	1.53	0.77–3.04	292	203	0.94	0.66–1.34
			$p = 0.275$				$p = 0.223$				$p = 0.725$	
Age (years)†												
45–54	120	58	1.00		116	101	1.00		236	159	1.00	
55–64	142	89	1.76	1.07–2.89	78	64	0.67	0.30–1.49	220	153	1.10	0.74–1.64
65–73	73	53	2.80	1.49–5.24	58	47	0.57	0.24–1.37	131	100	1.57	0.96–2.55
			$p = 0.003$				$p = 0.401$				$p = 0.176$	
Length of occupational training (years)‡												
0	131	90	1.00		78	62	1.00		209	152	1.00	
2	148	82	0.61	0.37–1.01	120	101	1.42	0.67–3.01	268	183	0.84	0.56–1.25
>2	29	11	0.34	0.15–0.81	44	40	2.51	0.77–8.22	73	51	0.92	0.51–1.68
			$p = 0.023$				$p = 0.261$				$p = 0.675$	
Employment status‡												
Participant in working life	118	53	1.00		128	111	1.00		246	164	1.00	
Nonparticipant in working life	216	147	2.05	1.14–3.69	123	100	0.87	0.33–2.28	339	247	1.18	0.74–1.90
			$p = 0.016$				$p = 0.782$				$p = 0.492$	
Average no. of health service contacts per year during 1980–1990§												
<1	35	18	1.00		70	59	1.00		105	77	1.00	
1–3	95	65	1.26	0.52–3.06	106	84	0.79	0.35–1.80	201	149	0.94	0.54–1.66
>3	205	117	1.01	0.45–2.27	76	69	2.03	0.72–5.70	281	186	0.71	0.42–1.21
			$p = 0.722$				$p = 0.119$				$p = 0.268$	

* MR+, possible or definite lower back disorder obtained from the medical record; MR−, neither possible nor definite lower back disorder obtained from the medical record; SR+, some lower back disorder reported on the self-reported questionnaire; OR, odds ratio; CI, confidence interval; SR−, no lower back disorder reported on the self-reported questionnaire.
† Adjusted for gender.
‡ Adjusted for gender and age.
§ Adjusted for gender, age, and length of the occupational training.

cluding lower back disorders and hip and knee arthrosis, in which a definite diagnosis is difficult to make and the course of the disease may fluctuate. For this reason, the agreement of the results is likely to be more a function of the medical phenomenon than of the method for recording data.

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