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Original Article

Agreement of Major Diagnosis and Comorbidity between Self-reported Questionnaire and Medical Record Review in Patients with Rheumatic Disease

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Objective. Self-report questionnaires are frequently used to obtain information in epidemiological research. However, information reported by patients are sometimes inconsistent with medical records. This study compared self-reported major rheumatologic diagnoses and co-morbid conditions with those from a medical record review. **Methods.** A cross-sectional survey was conducted at two tertiary academic hospitals. All patients who visited the rheumatology department from September 2, 2009 to September 13, 2009 were enrolled in this survey. Structured patient questionnaires and medical record reviews were performed in each hospital. We evaluated agreement with kappa statistics (κ) between these two data sources for major rheumatologic diagnosis and Charlson Comorbidity Index (CCI) score. Multiple logistic regression models were used to investigate factors associated with disagreement. **Results.** A total of 369 patients were interviewed at clinic exit. Of them, 302 patients (81.8%) were female, and the average age was 52.1 years. The agreement for major rheumatologic diagnosis between the questionnaire and patient chart was good (κ =0.763). The agreement rate for all rheumatic diseases was 81.8%; rheumatoid arthritis with 94.9%, systemic lupus erythematosus with 96.3%, and ankylosing spondylopathy with 100%. Higher educational level and longer attendance at our clinic were associated with agreement between major rheumatologic diagnoses. The agreement rate for CCI score between the data sources was 76.1%. **Conclusion.** In patients with rheumatologic diseases, the agreement for major diagnoses between self-reports and the medical record review was good, although it varied with the specific disease and patient characteristics. Comparing major rheumatologic diagnoses, the agreement rate for CCI was low. **(J Rheum Dis 2016;23:348- 355)**

Key Words. Self report, Medical records, Diagnosis, Rheumatic diseases, Comorbidity

INTRODUCTION

Self-report questionnaires are frequently used to obtain information about rheumatologic diseases in epidemiological research [1,2]. They are considered a valuable, complete, and cost-efficient method to assess the prevalence and incidence of rheumatologic diseases in the absence of specific population registers for these diseases. However, information about their validity is varied. Many disease-specific registries also rely on patient self-reporting for much of their data [3-5]. Although several groups have suggested that self-reports are an excellent source of information for pain and function [6,7], others have noted the poor accuracy of self- reported diagnosis [8]. The accuracy of patient reported medication use is even less clear [9,10]. It can be difficult to diagnose rheumatic diseases because some symptoms and signs are common to many different diseases. Unfortunately, not all patients faithfully adhere to accepted diagnostic and classification criteria, making the data interpretation somewhat difficult. Furthermore, rheumatic diseases are sometimes difficult to accurately diagnose at the onset, and changes

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in diagnosis over time must be taken into account. Several diseases can be combined, and major diagnoses can change over time. This can cause disagreement in major diagnosis between physicians and patients.

Among various information related to patients with rheumatologic diseases, the evaluation of co-morbidity data is essential because such data can help to predict health outcomes. It can also increase understanding of morbidity, mortality, and long-term treatment complications [11]. Evaluation of co-morbidity can also contribute to care quality assessment, aid in treatment selection, and adjust in estimating the comparative survival and treatment rates [12]. The Charlson Comorbidity Index (CCI), a popular tool for estimating comorbidity, is often constructed from medical record abstracts or administrative data. Limitations in both sources have fueled interest in using patient self-reports as an alternative. However, little data exists on whether self-reported CCI can be replaced with medical records.

This study aimed to examine the agreement of self-reported rheumatologic diagnosis and CCI compared with medical records and to evaluate the factors associated with disagreements between two data sources.

MATERIALS AND METHODS

Data source and study participants

The study population consisted of patients with rheumatologic diseases who visited the rheumatology outpatient clinic at two tertiary academic hospitals from September 2, 2009 to September 13, 2009. All patients older than 18 years were requested to participate, and only patients who agreed to participate were enrolled in this survey after providing written informed consent. Interviews were performed by well-trained health workers in each hospital using pre-tested, structured questionnaires, and medical record reviews. All patients provided informed consent under an Institutional Review Board-approved protocol (HYUH 2016-09-13).

Data collection

1) Medical record based major diagnosis and comorbidities

All medical record data were collected by a group of study nurses who had been oriented to the chart auditing manual and had experience with clinical research using the medical records of patients in each hospital. To identify the major rheumatologic diagnosis of each patient, physician notes were used as the primary source of information when they specifically mentioned the major rheumatologic diagnosis for each patient. For patients with multiple diagnoses, diagnostic codes, medication lists, and physician notes were reviewed by enrollment date. Patients who had unclear major diagnoses were excluded from this study. All medical record data were collected independently of the patients' self-report.

The CCI [13,14], which has been tested with large samples in numerous settings [15-18], was used to generate comorbidity data from medical records. This index records the presence or absence of 18 health problems, each weighted for severity according to pre-defined values. The following health problems receive a weight of 1 in the index: myocardial infarction, congestive heart failure, peripheral vascular disease, cerebrovascular disease without hemiplegia, dementia, chronic pulmonary disease, connective tissue disease, peptic ulcer disease, mild liver disease, and diabetes mellitus without end-organ damage. Because most patients had at least one rheumatologic disease, we did not question the presence of connective tissue disease in the CCI to exclude the impact of this item on total agreement. The following health problems receive a weight of 2: hemiplegia, moderate or severe renal disease, diabetes with end-organ damage, malignant neoplasms, leukemia, and lymphoma. Moderate or severe liver disease receives a score of 3. Metastatic solid tumors and acquired immunodeficiency syndrome receive a score of 6. The final score is provided by the sum of the weights of each patient's health problems.

2) Self-reported major rheumatologic diagnosis and comorbidity

Self-report data were obtained by interviewing all eligible patients about their major rheumatologic diagnosis and comorbidities using a structured questionnaire. The questionnaire to determine their major rheumatologic diagnosis was constructed as multiple choices among several rheumatic diseases, and the CCI was applied to determine their comorbidities. A trained research assistant helped patients answer questions on the baseline questionnaire. Patients were also asked about demographic features including age, sex, region of residence, education level, income, and follow-up duration for rheumatologic clinic through an interview. As an alternative to medical records, patients were asked about their major rheumatologic diagnoses and comorbidities in face-to-face interviews.

Statistical analysis

Population characteristics were first described using mean, standard deviation (SD), and number with proportion. The kappa statistic was then calculated to estimate agreement between self-report and medical records. The agreement rate for major rheumatologic diagnosis and comorbidity between the two data sources was also calculated. The kappa statistic cannot be accurately calculated when there are zero observations in a given table cell. In such cases, the percent agreement was also calculated by dividing the sum of the agreeing observations by total observations. Furthermore, prevalence-adjusted and bias-adjusted kappa (PABAK) was calculated to assess the effect of the imbalance in observations [19]. The conventional interpretation of kappa is as follows: 0∼0.20=poor agreement, 0.21∼0.40=fair agreement, 0.41∼0.60=moderate agreement, 0.61∼0.80=good agreement, and 0.81∼1.00=excellent agreement. Multiple logistic regression analysis was performed to evaluate factors associated with diagnosis disagreement. All analyses were performed using SAS software, version 9 (SAS Institute, Cary, NC, USA) and SPSS software (version 22.0; IBM Co., Armonk, NY, USA).

RESULTS

Demographic and clinical characteristics of participants

Of 393 patients who agreed to participate in this study, 369 patients were eligible for an agreement test for major rheumatologic diagnosis and comorbidity. The mean age was 52.1 years (SD=14.9 years), and the number of female patients was 302 (81.8%). The majority of patients (79.2%) were urban residents. In terms of educational level, 35.5% patients graduated university or college, 34.4% patients graduated high school, and 28.5% patients did not graduate high school (Table 1).

The prevalence of each rheumatic disease based on medical records is presented in Table 1. Rheumatoid arthritis (RA) was the most common diagnosis at 36.9%, followed by osteoarthritis (OA) at 22.8%, and systemic lupus erythematosus (SLE) at 14.6%.

Agreement of major rheumatologic diagnosis between self-report and medical record

The prevalence of 17 rheumatic diseases and the agreement rate between two data sources were analyzed, and the results are presented in Table 2. Agreements between self-report and medical records were moderate (κ =0.763). The agreement rate for all rheumatic diseases was 81.8%, and it ranged from 33.3% to 100% for each disease. In cases of RA, SLE, ankylosing spondylopathy (AS), myositis, adult-onset still's disease, psoriatic arthritis, and Raynaud syndrome, the diagnosis agreement rate was more than 90%. In cases of OA, fibromyalgia (FMS), Sjögren's syndrome, and mixed connective tissue disease (MCTD), the diagnosis agreement rate was less than

Table 1. Demographic and clinical characteristics of enrolled patients (n=369)

Characteristic	Data
Age (yr)	52.1±14.9
Female	302 (81.8)
Follow-up duration (mo)	54.5±65.0
Residence area	
Urban	292 (79.2)
Rural	75 (20.3)
Not replied	2 (0.5)
Education level	
Less than high school	105 (28.5)
High school	127 (34.4)
University	131 (35.5)
Not replied	6 (1.6)
Income (US dollar/mo)	
≤2,000	132 (35.8)
2,001∼4,000	116 (31.4)
>4,000	104 (28.2)
Not replied	17 (4.6)
Major diagnosis based on medical records	
Osteoarthritis	84 (22.8)
Rheumatoid arthritis	136 (36.9)
Systemic lupus erythematosus	54 (14.6)
Ankylosing spondylitis	12 (3.3)
Gout	13 (3.5)
Behçet's disease	15 (4.1)
Myositis	3 (0.8)
Adult-onset still's disease	2 (0.5)
Scleroderma	7 (1.9)
Fibromyalgia	12 (3.3)
Osteoporosis	1 (0.3)
Sjögren's syndrome	2 (0.5)
Vasculitis	4 (1.1)
Psoriatic arthritis	2 (0.5)
Raynaud disease	1 (0.3)
Mixed connective tissue disease	3 (0.8)
Others	18 (4.9)
Charlson comorbidity index	0.35±0.81 (0∼6)

Values are presented as mean±standard deviation (range) or number (%).

Table 2. Agreement of major rheumatologic diagnosis between self-reports and medical records

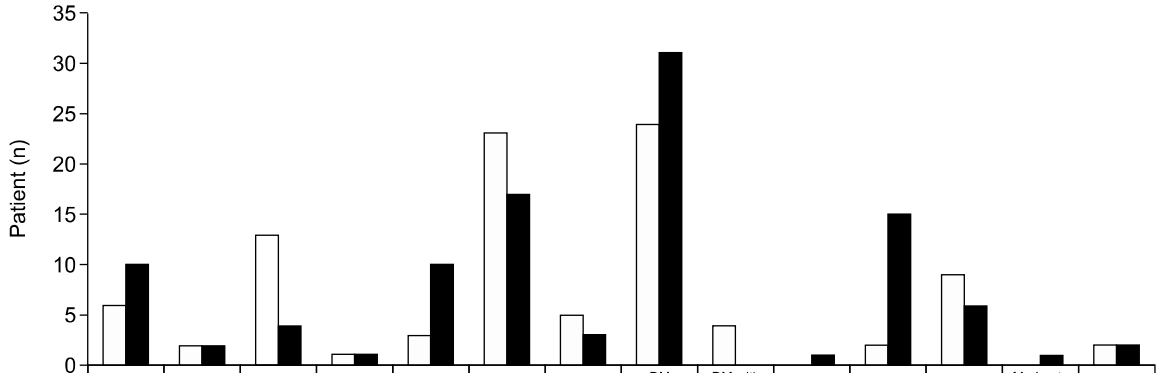
Diagnosis	Major diagnosis based on medical record																	
	OA	RA	SLE	AS	Gout	Behçet's disease	Myo-sitis	AOSD	Systemic sclerosis	FMS	Osteo-porosis	Sjögren's syndrome	Vas-culitis	PsA	Raynaud syndrome	MCTD	Others	Total
Major diagnosis based on self-report																		
OA	58	4	0	0	0	1	0	0	0	5	1	0	0	0	0	0	4	73
RA	23	129	1	0	2	1	0	0	1	2	0	1	0	0	0	0	4	164
SLE	0	0	52	0	0	0	0	0	1	0	0	0	1	0	0	1	1	56
AS	0	0	0	12	0	0	0	0	0	0	0	0	0	0	0	0	1	13
Gout	0	1	0	0	11	1	0	0	0	0	0	0	0	0	0	0	0	13
Behçet's disease	0	0	0	0	0	12	0	0	0	0	0	0	0	0	0	0	0	12
Myositis	2	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	1	6
AOSD	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0	0	2
Systemic sclerosis	0	0	1	0	0	0	0	0	5	0	0	0	0	0	0	0	0	6
FMS	0	1	0	0	0	0	0	0	0	4	0	0	0	0	0	0	0	5
Osteoporosis	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	2
Sjögren's syndrome	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
Vasculitis	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	1	4
PsA	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	2
Raynaud syndrome	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	2
MCTD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1
Others	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	6	7
Total	84	136	54	12	13	15	3	2	7	12	1	2	4	2	1	3	18	369
Concordance rate (%)	69.0	94.9	96.3	100	84.6	80.0	100	100	71.4	33.3	0	50.0	75.0	100	100	33.3	50.0	81.8

Values are presented as number. OA: osteoarthritis, RA: rheumatoid arthritis, SLE: systemic lupus erythematosus, AS: ankylosing spondylitis, AOSD: adult-onset still's disease, FMS: fibromyalgia, PsA: psoriatic arthritis, MCTD: mixed connective tissue disorder.

70%. Among patients with OA (n=84), 27.4% (n=23) reported RA as their major diagnosis.

CCI agreement between self-report and medical record

The CCI agreement rate between self-reports and the medical record was 76.1%. To assess agreements for 14 comorbidities between medical records and self-reports, kappa statistics and PABAK were used. To calculate the kappa value, none of the cell frequencies should be zero, although this was observed in seven comorbidities of our study. Hence, the kappa value was calculated based on seven comorbidities. PABAK ranged from 0.80 to 1.00 for each disease, and peptic ulcer disease had the lowest



	Myocardial infarction	Congestive heart failure	Cerebrovas-cular disease	Dementia	Chronic pulmonary disease	Peptic ulcer disease	Mild liver disease	DM without complicati-ons	DM with chronic complicati-ons	Hemiplegia or paraplegia	Renal disease	Solid tumor non-metastatic	Moderate to severe liver disease	Metastatic solid tumor
Medical record	6	2	13	1	3	23	5	24	4	0	2	9	0	2
Patient report	10	2	4	1	10	17	3	31	0	1	15	6	1	2
PABAK	0.95	0.98	0.93	0.99	0.94	0.80	0.97	0.94	0.98	0.99	0.93	0.93	0.99	1.00

Figure 1. Comparison of frequency of comorbid conditions between self-reports and medical records. DM: diabetes mellitus, PABAK: prevalence-adjusted and bias-adjusted kappa.

Table 3. Factors influencing disagreement of major rheumatologic diagnosis or CCI

Variable	Adjusted OR (95% CI)	
	Disagreement of major rheumatologic diagnosis	Disagreement of CCI
Age	1.00 (0.98～1.02)	1.01 (0.99～1.03)
Female	0.66 (0.33～1.34)	2.39 (0.96～5.94)
Income (million won/mo)		
＞400	1	1
201～400	1.21 (0.59～2.51)	0.60 (0.25～1.43)
≤200	0.63 (0.30～1.34)	1.36 (0.64～2.86)
Education		
Graduated university/college	1	1
Graduated high school	2.72 (1.14～6.50)	0.87 (0.34～2.22)
Did not graduate high school	3.68 (1.78～7.64)	1.38 (0.66～2.87)
Follow-up duration	0.89 (0.83～0.96)	1.02 (0.97～1.08)
Residence area		
Urban	1	1
Rural	0.71 (0.40～1.26)	1.18 (0.64～2.17)
Patient reported number of comorbidities		
0	1	1
1	0.83 (0.37～1.85)	11.77 (5.77～23.99)
≥2	2.99 (1.01～8.89)	60.64 (12.62～291.48)

CCI: Charlson Comorbidity Index, OR: odds ratio, CI: confidence interval.

PABAK (0.80). Kappa analysis revealed that the kappa value of five diseases, myocardial infarction, cerebrovascular disease, mild liver disease, renal disease, and non-metastatic solid tumor, illustrated fair agreement. Chronic pulmonary disease and peptic ulcer diseases showed poor agreement. The kappa value of diabetes without complications was good, and that of metastatic solid tumors was excellent. Figure 1 compares the presence of comorbid conditions between self-reports and medical records.

Factors influencing disagreement of major rheumatologic diagnosis or CCI score

Factors associated with disagreement of major rheumatologic diagnosis were low education level (less than high school: odds ratio [OR] 3.68, 95% confidence interval [CI] 1.78～7.64 and high school: OR 2.72, 95% CI 1.14～6.50) and the number of comorbidities based on self-report (more than 2 comorbidity: OR 2.99, 95% CI 1.01～8.89). Longer follow-up duration showed decreased disagreement (OR 0.89, 95% CI 0.83～0.96). A higher number of comorbidities based on self-report was associated with CCI disagreement (one comorbidity: OR 11.73, 95% CI 5.77～23.99; more than two comorbidity: OR 60.64, 95% CI 12.62～291.48). Female showed low risk for disagreement of major rheumatologic diagnosis (OR 0.66, 95% CI 0.33～1.34) and high risk for disagreement of CCI (OR 2.39, 95% CI 0.96～5.94), but there was not statistical significance (Table 3).

DISCUSSION

We determined that there is substantial agreement of major rheumatologic diagnosis between self-reports and medical records. However, the agreement varies with the specific disease; agreement rates of SLE, RA, and OA were 96.3%, 94.9%, and 69.0%, respectively. Previous studies have reported the validity of self-reported rheumatic disease diagnoses to be between 7%～96% in RA and 21%～84% in SLE [8,20-23]. Our study showed slightly higher agreement rates in RA and SLE. However, the agreement rate of OA in our study was slightly lower than the 73.6% of a previous study [8]. This may be caused by differences in study design, protocol, or population. For example, our study population is well aware of their rheumatic disease because this study was conducted in the rheumatology department of a university hospital. However, a high level of disagreement between OA and chronic back pain has also been presented in a previous study [24]. Rheumatologic diseases that are diagnosed with clinical signs and diagnostic tests distinctly can be explained clearly by physicians for instance RA, SLE, and AS. Those diseases showed high agreement rate between self-reports and medical record. However, the diseases diagnosed with insufficient diagnostics test; gout, OA, or the disease hard to be understood by patients despite meeting the classification criteria; MCTD, FMS showed low agreement rate between self-reports and medical record.

Self-report questionnaires are a valuable, complete, and cost-efficient method to gather data for clinical research. Although medical records are limited by the restricted availability of recent documentation and underreporting of pre-admission conditions [25,26], they are still valuable because they contain elements of both patient self-report and earlier provider documentation, offering a hybrid source of original data [25-27]. Self-reports and medical record reviews are still the most common methods of assessment due to their availability, efficiency, and relatively low cost [28]. Several research groups have suggested that the parallel use of comorbidity data collection methods from both sources may be necessary to analyze or predict some types of health outcomes [25,26,29,30]. However, information obtained from self-reports and medical records have been shown to be inconsistent. A number of studies have compared the two data sources for assessing medical history, medication use, body size measures, and other risk factors [9,11,19,28]. The results of these studies varied from high to low agreement, depending on variables compared and the characteristics of a study population.

Some studies have shown that patients can accurately self-report their current and past medical conditions, including comorbidities [31-33]. Our study demonstrated comorbidity agreement between self-reports and medical records. Diabetes without complications and metastatic solid tumors have higher levels of agreement, while myocardial infarction, cerebrovascular disease, mild liver disease, renal disease, non-metastatic solid tumors, chronic pulmonary disease, and peptic ulcer diseases were less concordant. This result is consistent with a previous report; diabetes and cancer had higher levels of agreement, while heart failure and pulmonary conditions were less concordant [25]. A recent report using the Self-Administered Comorbidity Questionnaire (SCQ) in the USA has been shown to have high agreement for liver

disease (99%), kidney disease (98%), and diabetes (97%), whereas those reported for heart disease (78%) and lung disease (88%) have been lower [34].

Our study also demonstrated factors associated with disagreement between self-report and medical records. High educational level and longer follow-up duration influenced agreement of main rheumatic disease, but did not influence CCI agreement. The number of comorbidities based on self-report was associated with both disagreement of major rheumatologic disease and CCI; its impact was much higher on CCI than major rheumatologic disease. This result is reasonable because more comorbidities increase the possibility of more errors. Previous studies have found that younger age, female sex, and more education significantly increased agreement levels [30,35], while one study showed that socio-demographic characteristics such as increased age, marital status, or completed education levels exert significant influences on agreement levels between reporting methods [24].

Our study may have been affected by several limitations. First, our medical record was limited to one university hospital for each patient. Patients may visit several hospitals for various conditions, so there is a possibility of under-recorded comorbidities. Second, the CCI was used to evaluate comorbid conditions. Although the CCI is a representative index about comorbidities used in epidemiologic study, it has possibility not to reflect actual comorbid conditions. In clinical practice, patients suffer from various acute and chronic conditions that are not included in the CCI.

The agreement between main diagnosis and CCI in patients with rheumatic diseases was substantial between self-report and medical record review. Therefore, both data sources are valuable for clinical research. However, the gold standard measurement regarding comorbidities remains an issue for clinical research. In addition, it was not confirmed to use the individual comorbid conditions of CCI from both data sources. Further research about which information is the most appropriate for research is needed.

CONCLUSION

Agreement between major diagnosis in self-report and medical record reviews is substantial in patients with rheumatologic diseases. However, it varies with the specific disease. Comparing major rheumatologic diagnoses, the agreement rate for CCI was low. Researchers should be aware of the underreporting of comorbidities in clinical research based on medical records.

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CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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