

Validity of self-reported endometriosis and endometriosis-related questions in a Swedish female twin cohort

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Objective: To examine the validity of self-reported endometriosis and to improve the reliability of questionnaires by including endometriosis-related questions.

Design: Analysis of survey questionnaire data.

Setting: Cross-sectional study.

Patient(s): Cohort of 26, 898 female twins aged 20–60 years at interview, who participated in either of two surveys (1998–2002 or 2005–2006).

Intervention(s): None.

Main Outcome Measure(s): Endometriosis diagnosis in the Swedish National Inpatient Registry (IPR).

Result(s): The self-reported endometriosis diagnoses and endometriosis-related questions from a nationwide population-based twin registry were linked with the IPR. Fairly good agreement was found between the self-reported and IPR data on endometriosis. The receiver operating characteristics (ROC) curves showed fairly good predictive ability of self-reported endometriosis to have a confirmed endometriosis diagnosis in the IPR with an area under the curve (AUC) 0.79 (95% confidence interval [CI], 0.77–0.81). Further, the predictive ability increased to AUC 0.89 (95% CI, 0.88–0.90) when there was additional information about infertility and age.

Conclusion(s): Our results indicate that self-reported data on endometriosis are moderately accurate and may be useful in studies when register data are not available. (Fertil Steril® 2016; ■: ■ – ■. ©2016 by American Society for Reproductive Medicine.)

Key Words: Endometriosis, in-patient register, questionnaire, self-report

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Epidemiologic studies are often performed either by using national registers with health-care-based diagnoses or by questionnaires that include self-reported diagnoses. Several investigators have reported excellent agreement between self-reported endometriosis and medical records (1–3). Dysmenorrhea, chronic pelvic pain (CPP), deep

dyspareunia, cyclical intestinal complaints, fatigue/weariness, and infertility continue to be the leading symptoms and signs of endometriosis (4–7). Dysmenorrhea was the chief complaint, reported by 62% of women with mainly peritoneal endometriosis in a Brazilian study (7). In the same study, the prevalence of CPP was 57%, deep dyspareunia 55%, cyclic

intestinal complaints 48%, and infertility 40%. One review by Guo and Wang (8) that included 27 publications based on estimation of prevalence of surgically confirmed endometriosis showed that the average prevalence of endometriosis in women with self-reported CPP was 28.7% (95% CI, 27.0, 30.4).

It was reported by Meisinger et al. (9) that the postal questionnaire method seems to be a useful method to identify incident nonfatal acute myocardial infarction cases treated in a hospital in an epidemiologic cohort study. One very recent Norwegian study reported good concordance between self-reported hypertension and/or proteinuria during previous pregnancies and actual clinical findings

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among the cases (10). De Boer et al. (11) in one study on validity of self-reported causes of subfertility with medical records reported that tubal and male subfertility were highly accurate but other causes had low to moderate accuracy.

Twin studies often use self-reported data when assessing reasons for individual differences in terms of genetic and environmental influences of a trait or disease. The validity of self-reported hyperthyroidism and hypothyroidism when comparing self-reported questionnaire data in twins with medical records was shown to be unsatisfactorily low (12), but higher rates of agreement were found for osteoarthritis based on self-reported data in twins with clinical and radiographic classification criteria for osteoarthritis (13). One recent study compared self-reported social security data in a Swedish twin cohort with national insurance registry data to assess the validity of the self-reported data. That study showed that self-reported disability pension data may be very useful in studies when registry information is not available, but registry data was preferred, especially for long-term sickness absences (14).

To our knowledge, no reports are available on the validity and reliability of self-reported endometriosis and endometriosis-related questions using national inpatient registers. Therefore, we examined the validity of self-reported endometriosis for improving the reliability of questionnaires by including endometriosis-related questions in a sample of female twins aged 20 to 60 years in the Swedish Twin Registry (STR) who had endometriosis diagnoses in the Swedish National Inpatient Registry (IPR).

MATERIALS AND METHODS

Data Sources

We obtained data from the nationwide population-based STR and the IPR. The STR is the largest twin registry in the world and includes all twins born in Sweden since 1886, constituting more than 194,000 twins and more than 75,000 twin pairs (15). We used data from two previous cross sectional surveys conducted at STR: the Screening Across the Lifespan Twin (SALT) Study (16) performed from 1998 to 2002 via telephone interviews among twins born between 1926 and 1958 (aged >40 years at the time of data collection), and the Swedish Twin Study of Adults' Genes and Environments (STAGE) (17) performed from 2005 to 2006 by way of a Web-based questionnaire among twins born between 1959 and 1985 (aged 20–40 years at the time of data collection). The IPR includes patients treated through inpatient care in public hospitals in Sweden. This register was initiated in 1964, covered 60% of the Swedish population in 1969, 85% in 1983, and close to 100% since 1987. The discharge diagnoses of endometriosis in the IPR are coded according to the International Classification of Diseases 8, 9, and 10 (ICD 8–10), which are listed in Supplemental Table 1 (available online).

Linkage between the registers was made by use of Personal Identity Numbers (PINs), which are unique identifiers specific to each individual in Sweden (18). One recent study from Sweden compared diagnoses between medical records and diagnoses in the IPR and reported that 98% had a correct endometriosis diagnosis in the IPR, and 99.5% had an

TABLE 1

Response of self-reported endometriosis and endometriosis-related questions among women aged 20–60 years in Swedish Twin Registry with endometriosis diagnosis in the Swedish National Inpatient Registry.

Questionnaire in STR	Endometriosis in IPR		
	Yes, n (%)	No, n (%)	Missing values, n (%)
Age at interview, y			
20–30	8 (1.33)	4,835 (18.4)	0 (0)
31–40	52 (8.6)	4,826 (18.4)	0 (0)
41–50	213 (35.4)	7,962 (30.28)	0 (0)
51–60	329 (54.65)	8,673 (33.0)	0 (0)
Self-reported endometriosis			
Yes	372/602 (61.8)	796/26,296 (3.0)	0 (0)
No	230/602 (38.2)	25,500/26,296 (97.0)	0 (0)
Severe dysmenorrhea			
Yes	123/602 (20.4)	5,680/26,296 (21.6)	
No	91/602 (15.1)	12,990/26,296 (49.4)	8,014 (30.5)
Chronic pelvic pain			
Yes	53/602 (8.8)	2,029/26,296 (7.7)	8,014 (30.5)
No	161/602 (26.7)	16,641/26,296 (63.3)	
Dyspareunia			
Yes	34/602 (5.7)	752/26,296 (2.9)	8,014 (30.5)
No	180/602 (3.0)	17,918/26,296 (68.1)	
Infertility			
Yes	167/602 (27.7)	1,900/26,296 (7.2)	0 (0)
No	435/602 (72.3)	24,392/26,296 (92.8)	0 (0)
Oral pill as contraceptive			
Yes	99/602 (16.5)	5,297/26,296 (20.1)	0 (0)
No	503/602 (83.6)	20,999/26,296 (79.9)	0 (0)

Note: IPR = Swedish National Inpatient Registry; STR = Swedish Twin Registry.

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