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Validation of the Finnish Care register for Health Care diagnoses for preeclampsia, gestational diabetes and preterm delivery

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ABSTRACT

Background: Centrally collected Finnish national health register data on adverse pregnancy outcomes are available for research, but the validity of the data is largely unknown. Our aim was to compare the diagnoses of preeclampsia (PE), gestational diabetes (GDM), and preterm delivery from hospital records with the registry based diagnoses from the Finnish Care Register for Health Care (FCR). Data on gestational age at delivery from the Medical Birth Registry (MBR) was also studied.

Methods: The Finnish Genetics of Pre-eclampsia Consortium (FINNPEC) Study cohort was used as a data source. Each diagnosis was ascertained from electronic hospital records. The validity of diagnoses obtained by record linkage of FCR and MBR was assessed against the classification previously confirmed independently by a research nurse and a study physician.

Results: Sensitivity of PE diagnoses in FCR was 80.3 % (95 % CI 78.3 % to 82.2 %) and specificity 95.3 % (95 % CI 93.9 % to 96.4 %). Sensitivity for GDM was 64.1 % (95 % CI: 58.7 % – 69.3 %) and specificity 98.5 % (95 % CI: 97.9 % – 98.9 %), whereas sensitivity and specificity for preterm delivery were 32.4 % (95 % CI: 29.0 % – 36.0 %) and 99.7 % (95 % CI: 99.3 % – 99.9 %). Sensitivity of preterm delivery in the MBR was 99.1 % and specificity 99.9 %.

Conclusions: FCR registry diagnoses for PE have satisfactory sensitivity and high specificity. Diagnoses for GDM and preterm delivery have lower sensitivity limiting their use in studies, and data from MBR should be preferred when studying preterm deliveries.

1. Introduction

Pre-eclampsia (PE) and gestational diabetes (GDM) are common pregnancy complications that affect both the ongoing pregnancy as well as the long-term health of the mother and the offspring [1,2]. Preterm delivery is globally the leading cause of death in children and causes significant morbidity and mortality also in high-resource countries [3]. Epidemiological studies can utilize data from administrative registers which contain diagnostic codes. The usability of these registers is highly dependent on the validity of the register data.

In this study we aimed to investigate the validity of the Finnish Care Register for Health Care (FCR) diagnoses of PE, GDM, and preterm delivery, as well as data on preterm deliveries in the Medical Birth Register (MBR), in the Finnish Genetics of Pre-eclampsia Consortium (FINNPEC)

Abbreviations: PE, preeclampsia; FCR, Finnish Care Register for Health Care; FINNPEC, The Finnish Genetics of Pre-eclampsia Consortium; ICD, International Classification of Diseases; ACOG, American College for Obstetricians and Gynecologists; ISSHP, International Society for the Study of Hypertension in Pregnancy.

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Study cohort, in which the diagnoses have been verified from hospital records. The differences between the FCR or the MBR and the verified data from the study cohort were further analyzed to find potential sources of diagnostic discrepancies.

2. Materials and methods

2.1. Finnish Care Register for Health Care

Since 1969, data on all hospitalizations in Finland have been collected in the Finnish Care Register for Health Care (FCR), which contains nationwide linkable data on all inpatient hospital discharges with personal identification code [4]. Beginning in 1998, the register also contains data on outpatient visits in specialized health care. The diagnoses are coded according to the International Classification of Diseases (ICD) codes. Physicians responsible for the patient's care assign the codes for hospitalizations. FCR database has been evaluated regarding several disorders and is considered to have good coverage and reliability [4,5]. However, data is recorded for administrative purposes and may not be accurate enough to be used in scientific studies [5].

The Medical Birth Register records data on deliveries and newborns since 1987. The data is provided primarily to research and development purposes.

2.2. Study cohort and data collection; FINNPEC study

FINNPEC is a cross-sectional case-control multicentre study originally set up to investigate and search genetic variants predisposing to PE, with particular focus on detailed clinical characterization of PE phenotypes [6]. This study is based on the FINNPEC data of 1641 women with PE and 1149 control women who had given birth in Finnish university hospitals (Helsinki, Kuopio, Oulu, Tampere and Turku). Women were recruited both prospectively during 2008 to 2011 as well as invited to participate after delivery in the retrospective arm of the study. After recruiting a PE patient, a control woman was recruited from the same hospital. In the retrospective part of the study, women who had been diagnosed with PE during their pregnancies were identified from medical records of the study hospitals. These women had delivered in 2000–2008 in other hospitals and in 1990–2008 in the Kuopio University Hospital.

2.3. Definition of PE, GDM and preterm delivery and the validation procedure in the FINNPEC study cohort

PE was defined as hypertension and proteinuria occurring after 20 weeks of gestation, and eclampsia as newly onset tonic-clonic seizure in a preeclamptic patient, in accordance to the American College of Obstetricians and Gynecologists (ACOG) 2002 guidelines [7]. Superimposed PE was diagnosed in women with chronic hypertension and development of proteinuria.

Hypertension was defined as systolic blood pressure $\geq$140 mm Hg and/or diastolic blood pressure $\geq$90 mm Hg. Proteinuria was defined as the urinary excretion of $\geq$0.3 g protein in a 24-hour specimen, or 0.3 g/l, or two $\geq$1+ readings on dipstick in a random urine determination.

GDM was defined as glucose intolerance onset or recognized during pregnancy. Delivery before 37 completed gestational weeks was defined as preterm delivery.

Each diagnosis was ascertained from hospital records and confirmed independently by a research nurse and a study physician. Exclusion criteria were multiple pregnancy, maternal age less than 18 years and inability to provide an informed consent based on information in Finnish or Swedish.

2.4. Data linkage from registers

Data on PE, eclampsia, GDM and preterm delivery in the index pregnancy were collected from computerized register linkage with the FCR in collaboration with the Finnish Institute for Health and Welfare. The data linkages were performed by using the unique Finnish personal identity code (thereafter replaced by a pseudonymized study ID).

In order to validate the FCR diagnoses of PE, ICD-10 codes for PE, superimposed PE and eclampsia (O14, O11 and O15) were sought from the registry. In addition, to assess potential misdiagnosis, ICD-10 codes for other hypertensive disorders (O10 for chronic hypertension complicating pregnancy, O12 for gestational edema and proteinuria in absence of hypertension, O13 for gestational hypertension, and O16 for unspecified gestational hypertension) were also extracted. Furthermore, codes for GDM (O24.4 and O24.9), pregestational diabetes (O24.0-O24.3) and preterm delivery (O60) were evaluated. In addition, gestational age at delivery was extracted from the MBR.

2.5. Statistical analyses

The FINNPEC data on PE was used as the gold standard and compared to ICD-10 diagnoses in the FCR and preterm birth in MBR. Sensitivity and specificity and their 95 % confidence intervals (CI) were calculated using MedCalc calculator at medcalc.org.

3. Results

In the FINNPEC cohort of 1641 women with PE and 1149 women without PE, the FCR correctly identified 1319 PE women, whereas 322 women had PE according to FINNPEC but lacked diagnoses of PE in the FCR. Of women who did not have PE according to FINNPEC data, 1095 did not have PE diagnoses in FCR, and 54 were misdiagnosed with PE. The results are shown in Table 1.

The sensitivity for the FCR diagnoses was 80.4 % (95 % CI: 78.4 % – 82.3 %) and specificity 95.3 % (95 % CI: 93.9 % – 96.5 %).

Of the 54 women who had PE only according to the FCR (false positives), 53 were diagnosed with PE (ICD-10 code O14) and one with eclampsia (ICD-10 code O15). Nine of these women also had chronic hypertension (ICD-10 code O10), three had diagnosis of gestational proteinuria without hypertension (ICD-10 code O12), 20 had gestational hypertension (ICD-10 code O13) and one had undefined gestational hypertension (ICD-10 code O16). 23 women had no other diagnoses of hypertensive pregnancy disorders than PE.

Of the 322 women who had PE according to FINNPEC but did not have diagnoses of PE in the FCR (false negatives), 234 had diagnoses of hypertensive pregnancy disorders other than PE. Thirty of these women had chronic hypertension, 18 were diagnosed with gestational proteinuria without hypertension, 211 with gestational hypertension and 16 with unspecified gestational hypertension. 88 women with PE did not have any FCR diagnoses of hypertensive pregnancy disorders.

Eclampsia was rare, and occurred in 13 cases only. All women with eclampsia had correct diagnoses of PE in the FCR, but only nine of them had also the diagnostic code of eclampsia, implying four false negative diagnoses of eclampsia. An incorrect diagnosis of eclampsia (false positives) was recorded in the FCR for five women, of whom three had and two did not have PE according to FINNPEC.

Regarding diagnoses of GDM, the FCR identified 211 out of the 329

Table 1
Diagnoses of preeclampsia (PE) in the Finnish Care Register for Health Care (FCR) compared to diagnoses in the Finnish Consortium for the Genetics of Preeclampsia (FINNPEC) study, the latter used as a golden standard to validate registry data.

	PE according to FINNPEC		
PE according to the FCR	Yes	No	Total
Yes	1319	54	1373
No	322	1095	1417
Total	1641	1149	2790

women with true GDM, whereas 38 were misdiagnosed with GDM (false positives). The sensitivity was 64.1 % (95 % CI: 58.7 % – 69.3 %) and specificity 98.5 % (95 % CI: 97.9 % – 98.9 %). Table 2 details the true cases of GDM and diagnoses in the FCR.

One woman had GDM according to FINNPEC but had been misdiagnosed with pregestational diabetes in the FCR; other false negative cases lacked any diabetes diagnoses. None of these women had received insulin treatment. Of the 38 false positive cases, 20 had pregestational diabetes according to FINNPEC, and these women also had the correct diagnosis code for pregestational diabetes.

703 of deliveries in FINNPEC were preterm, but only 228 of these women had the diagnosis of preterm delivery in the FCR. Seven women had delivered full-term but were misdiagnosed as having had a preterm delivery. Sensitivity was 32.4 % (95 % CI: 29.0 % – 36.0 %) and specificity 99.7 % (95 % CI: 99.3 % – 99.9 %). See Table 3 for details.

Data from MBR was available in 2751 women. 697 women had delivered before 37 gestational weeks and the MBR correctly identified 691 of them. Gestational age at delivery was incorrectly recorded as full-term in six women with preterm deliveries, and incorrectly as preterm in three women who had delivered full-term. Sensitivity was 99.1 % (95 % CI: 98.1 % – 99.7 %) and specificity 99.9 % (95 % CI: 99.6 % – 100 %).

4. Discussion

In this study, we studied the validity of diagnoses for PE, GDM, and preterm delivery in the FCR using the FINNPEC study cohort as gold standard. The specificity of diagnoses for these disorders was high at 95–99 %, but sensitivity varied widely. Data on prematurity in the MBR was very accurate.

This study suggests that the quality of the FCR is satisfactory regarding PE and GDM but poor in recognizing preterm delivery. However, incorrect and missing codes were observed also in PE and GDM.

The national guideline on diagnosing and managing PE had not been published in Finland until 2021 [8], and as several women in both false negative and false positive groups had other diagnoses of hypertensive pregnancy disorders, it could be assumed that the disorder was identified yet misclassified. Only 5.4 % of women with PE did not have any diagnoses related to hypertensive pregnancy disorders.

None of the women with GDM who lacked the diagnosis for diabetes had received insulin treatment, and their pregnancies were likely managed in the Finnish primary level maternity care, as is customary when glucose levels are controlled with diet and no additional complications arise. The FCR contains data only on specialized health care admissions and diagnoses of disorders that are managed in the primary level are missed.

The diagnosis for preterm delivery had particularly low sensitivity. In Finland, midwives manage preterm but otherwise uncomplicated deliveries independently, and although the obstetrician on duty should set the diagnosis, not participating in the delivery personally may predispose to underreporting. In complicated preterm deliveries, multiple codes are recorded, and some may simply be forgotten to document. Furthermore, as the MBR is familiar to Finnish obstetricians, the diagnosis may be seen of lesser importance compared to some other diagnoses.

Table 2
Diagnoses of gestational diabetes (GDM) in the Finnish Care Register for Health Care (FCR) compared to diagnoses in the Finnish Consortium for the Genetics of Preeclampsia (FINNPEC) study, the latter used as the gold standard to validate registry data.

	GDM according to FINNPEC		
GDM according to the FCR	Yes	No	Total
Yes	211	38	249
No	118	2423	2541
Total	329	2461	2790

Table 3
Diagnoses of preterm deliveries in the Finnish Care Register for Health Care (FCR) compared to diagnoses in the Finnish Consortium for the Genetics of Preeclampsia (FINNPEC) study, the latter used as the gold standard to validate registry data.

	Preterm delivery according to FINNPEC		
Preterm delivery according to the FCR	Yes	No	Total
Yes	228	7	235
No	475	2080	2555
Total	703	2087	2790

Underreporting and misclassification of PE and hypertensive disorders has been reported in the Danish National Patient Registry [9]. In that study, the gold standard diagnosis of PE (against which the ICD codes were compared) was set retrospectively, contrary to the mostly prospective FINNPEC cohort. Especially severe PE was underreported, but the authors did not investigate further whether these women were misdiagnosed with other types of PE or lacked any diagnosis of PE. We did not study different subtypes of PE, as classification into severe and mild subtypes is no longer recommended [10]. Furthermore, as Finnish national guidelines for PE recommend low-dose aspirin prophylaxis in subsequent pregnancies in all PE [8], misdiagnosis of PE subtypes will not impact later care.

An Australian group also described errors and both over- and underreporting of hypertensive disorders of pregnancy, depending on the coding system used [11]. As a solution they proposed purpose-built, disorder-specific databases that would be maintained by clinicians, a costly and time-consuming alternative.

So far, the validity of FCR has been studied only for few diagnoses in obstetrics and gynecology. Our results are partly in accordance with results found in a study assessing the quality of a legal-bound register of induced abortions and sterilizations and the quality of FCR regarding these diagnoses. In that study, the data coverage of FCR was good, as 97.5 % of the 1492 cases during the study period could be identified in the register, and only 30 false positive diagnoses were found. FCR was confirmed as being a good source in measuring volumes of hospital use as well as the main diagnoses, but the registration of single diagnoses may be less ideal for research [12].

An earlier systematic review of validation studies on the FCR included 32 studies, most of which examined the validity of vascular diseases, mental disorders or injuries. More than 95 % of hospital discharges could be identified from the register, and the completeness and accuracy in the register was concluded to vary from satisfactory to very good. Most obvious limitations in validity were poor recording of subsidiary diagnoses and other rarely used items [4].

The strength of our study was the detailed and precise data from the FINNPEC study cohort. The jury protocol used to diagnose pregnancy disorders includes multiple professionals and strict, science-based criteria in defining diagnoses, which offers an excellent gold standard for comparison against actual diagnosis codes. As the cohort was originally assembled to study PE, the prevalences of PE, GDM and preterm delivery are higher than in the general obstetric population in Finland [13]. This allowed examining a larger number of women with true pregnancy disorders and increased statistical power.

As the diagnoses in FCR are made by individual physicians in different settings, identifying the exact reasons behind incorrect diagnoses is not possible. However, multiple diagnoses of hypertensive pregnancy disorders in many women may demonstrate disease progression and the difficulty of correctly diagnosing and reporting different stages or phenotypes of the disease spectrum.

There are many steps from diagnosis-making to transferring a code to a register, and these steps are prone to pitfalls. This was studied by Rauhala and Linna, who evaluated the coding of diagnoses in Finnish

specialized health care [14]. Our experiences in clinical settings are similar. The diagnostic practices vary between different places and in different time periods. The clinicians are expected to record correct codes but the inexact nature of human physiology as well as busy clinical work can predispose physicians to imprecise recording. Rauhala emphasized that the coding practice must become more uniform and its quality must be improved. This could be achieved through education and motivation and by using tools that make coding easier. Also to reduce these problems code recordings could be done more often by a specialized department secretary [14].

Diagnostic criteria for PE have been revised after the recruitment of our cohort. However, the FINNPEC cohort has been readjusted in a previous study [15], and only a minor change in the total number of preeclamptic women was observed; the number of women with PE increased 0.8 % according to the ACOG 2013 criteria and 0.6 % according to the International Society for the Study of Hypertension in Pregnancy (ISSHP) 2014 criteria.

The results of this study showed that diagnoses for PE, GDM and preterm delivery obtained from the nationwide registry have moderate to low sensitivity, which limits their use in scientific studies. Data regarding prematurity in MBR is very accurate and should be preferred.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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