Congenital Malformations: Agreement Between Diagnostic Codes in an Administrative Database and Mothers' Reports

Sophie Kulaga, MSc, PhD,[1,2] **Anick Bérard, MSc, PhD**[1,2]

[1]Faculty of Pharmacy, University of Montreal, Montreal QC

[2]Research Center, CHU Sainte-Justine, Montreal QC

Abstract

Objective: The validity of epidemiologic research on congenital malformations conducted using administrative databases relies heavily on the quality of diagnostic information. The goal of this study was to validate the diagnostic codes for major congenital malformations (MCMs) recorded in a medical service claims database against mother's report obtained by questionnaire.

Methods: Using the Quebec Pregnancy Registry, we mailed a questionnaire to women who gave birth to a baby with an MCM and to a random sample of mothers whose infants did not have any malformation. We reviewed each infant's database record for a diagnostic code for MCM, which we then compared with the corresponding mother's report.

Results: Among the 3142 mother–infant pairs there was 60% agreement regarding the presence or absence of an MCM; for 456 babies, both sources reported the presence of an MCM. For 90% of these infants the two sources of information agreed with respect to the type of malformation.

Conclusion: Overall, mothers reported fewer infants with MCM than were recorded in the database; among those for whom both sources of information indicated the presence of an MCM, a very high proportion of diagnostic codes accorded with the mother's description of the specific type of malformation.

Résumé

Objectif : La validité de la recherche épidémiologique sur les malformations congénitales menée au moyen de bases de données administratives repose grandement sur la qualité des renseignements diagnostiques. L'objectif de cette étude était de valider, en fonction du rapport de la mère obtenu par questionnaire, les codes diagnostiques des malformations congénitales majeures (MCM) consignés dans une base de données des réclamations de service médical.

Méthodes : Au moyen du Registre des grossesses du Québec, nous avons posté un questionnaire aux femmes qui ont donné naissance à un enfant présentant une MCM, ainsi qu'à un échantillon aléatoire de mères dont les enfants ne présentaient aucune malformation. Nous avons analysé le dossier de base de données de chacun de ces enfants afin d'y repérer un code diagnostique correspondant à la MCM, que nous avons alors comparé au rapport de la mère correspondant.

Résultats : Parmi les 3 142 paires mère-enfant, nous avons constaté une correspondance de 60 % à l'égard de la présence ou de l'absence d'une MCM; dans le cas de 456 enfants, les deux sources ont signalé la présence d'une MCM. Chez 90 % de ces enfants, les deux sources de renseignements indiquaient le même type de malformation.

Conclusion : De façon globale, les mères ont signalé moins d'enfants présentant une MCM que ce qui a été consigné dans la base de données; chez celles pour lesquelles les deux sources de renseignements indiquaient la présence d'une MCM, les codes diagnostiques correspondaient à la description du type particulier de malformation par la mère dans une proportion très élevée.

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INTRODUCTION

Health administrative databases are increasingly used to conduct medical research studies. Research on the occurrence of congenital malformations in relation to medication use during pregnancy is often conducted using such databases because they provide the large cohorts needed to study rare outcomes.[1–3] However, the validity of such research depends largely on the quality of the diagnostic information held within the database. While several studies[1,2,4] using the medical service claims database of the provincial health insurance program of the Province of Quebec (RAMQ) have already made important contributions to knowledge about the effects of maternal drug use during pregnancy on the health of the baby, the coding of the diagnosis of a major congenital malformation has never been validated.

The RAMQ database holds claim records for visits or procedures performed by physicians; each medical service claim requires the specification of a diagnostic code. While the procedure codes are verified because they are linked to the level of reimbursement, the diagnostic codes are not routinely reviewed.[3] The diagnostic codes held by this database have previously been validated against medical charts for a number of conditions.[3,5] To our knowledge there has not been a study addressing the accuracy and comprehensiveness of congenital malformation codes in the RAMQ database. As the prevalence of congenital malformations is low, estimated at 3% to 5% in the general population,[6] the validity of such physician-based codes within the RAMQ is essential for the production of robust estimates from research studies.

It has been shown in several studies[7,8] that maternal reports of babies' characteristics such as birth weight, for which a gold standard source of information exists, are valid, reliable and accurate. Considering the universal concern of mothers with the health of the newborn, a mother's report about the presence or absence of a major congenital malformation in her baby can be expected to be similarly reliable and accurate.

Therefore, the objective of our study was to quantify the level of agreement between physician-based diagnostic codes of congenital malformations, as recorded in the provincial health administrative databases of the province of Quebec (RAMQ), and maternal reports from a self-administered questionnaire.

METHODS

The Quebec Pregnancy Registry resulted from the linkage of three administrative databases of the Province of Quebec: RAMQ, MedEcho, and ISQ. This registry has been in existence since 1998. The RAMQ database contains information on physician-based medical services (diagnoses and procedures) received by all Quebec residents as well as medication use for a subgroup of residents. Diagnoses specified by physicians are classified according to the ICD-9. The diagnostic codes are entered on claims for reimbursement forms following a visit or procedure and are therefore completed prospectively. The MedEcho database records acute care hospitalization data for all Quebec residents and is a source of data about congenital malformations; it also records gestational age for deliveries. ISQ provides demographic information about the mother, father, and baby, as well as birth weight and gestational age for live births and stillbirths.

ABBREVIATIONS

ISQ	Institut de la Statistique du Quebec
RAMQ	Régie de l'assurance maladie du Québec
SD	standard deviation

To form the Quebec Pregnancy Registry, a linkage was made between the RAMQ and MedEcho databases using the health insurance number, which is a unique personal identifier for each person living in Quebec. Linkage between the RAMQ and ISQ databases was made using the mothers' and infants' names, family names, and dates of birth. Linkage between RAMQ and ISQ databases was possible in 73% of instances. Each mother–infant pair was also linked with MedEcho and ISQ databases to obtain hospital discharge information and sociodemographic characteristics of the mother. The Quebec Pregnancy Registry contains information on all pregnancies that had a first day of gestation (date of last menstrual period) between January 1, 1997, and December 31, 2003.

A questionnaire was developed by a group of experts in perinatal epidemiology and genetics to collect information not routinely available from the Quebec Pregnancy Registry and to validate congenital malformation codes. The questionnaire was first developed in French and translated into English; it was further back-translated into French. The questionnaire was pre-tested on a group of 20 pregnant women attending the obstetrics department at Sainte-Justine Hospital, and face validity was established by pregnant women, obstetricians, and pediatricians. Questionnaires were sent to mothers in either English or French according to the preferred language of correspondence indicated to the RAMQ by subjects. Mothers were asked a number of questions including whether their child had been given a diagnosis of a major congenital malformation, and if so, to specify the type of malformation. The specific questions that were the focus of this study were: "Was this child or were these children (twins/triplets) born with one or more birth defects? If yes, which birth defect(s)?" or "Est-ce que votre enfant (ou vos enfants s'il s'agit de jumeaux, triplets) a une ou plusieurs malformation(s) congénitale(s)? Si oui, laquelle/lesquelles?"

Women in the Quebec Pregnancy Registry were eligible for this validation study if they had given birth to a baby with a major congenital malformation, or if they had a previous diagnosis of diabetes or psychiatric disorder. Major congenital malformations are defined as ICD-9 categories 740.0–759.9: anomalies of the central nervous system, eye, ear, cardiovascular system, orofacial, gastrointestinal, genitourinary, musculoskeletal or chromosomal but excluding, as minor, malformations of the eyelids, lacrimalsystem and orbit (ICD-9 743.6); accessory auricle, macrotia or microtia, branchial cleft cyst or fistula, preauricular sinus (ICD-9 744.1–744.4); macrocheilia, microcheilia, macrostomia, microstomia (ICD-9 744.8); not otherwise specified anomalies of face and neck (ICD-9 744.9), patent ductus arteriosis (ICD-9 747.0), absence or