Validation of ICD 10 on congenital anomalies in the state of Penang

Leela Anthony[1], Nagarajah Lee[2], Stephen Ambu[3], Lokman Hakim[1]

Background: Database on hospital records like discharge data, birth and death certificates are widely used for epidemiological and research studies. However there are a very few validation studies on these data. The aim of this study was to validate and assess the accuracy of the ICD 10 database on congenital anomalies in the state of Penang. This study was carried out for three years, from 2002 to 2004.

Methods: The list of cases coded under the general coding "Q" was extracted and approximately 30% of cases were randomly selected from the list. Medical records for the selected cases were checked and discrepancies for the diagnoses between the medical records and the ICD 10 data base were recorded for three years. Verification was done for basic demographic variables and the coding of the diseases. Discrepancies, sensitivity and specificity were calculated.

Results: The ICD 10 database for congenital anomalies are classified into two types: Type 1 and Type 2. Discrepancies on demographic information were found among the age of patients (babies with congenital anomalies). In Type 1, there was a discrepancy of about 0.02 % to 0.05% probability that a congenital anomaly case can be recorded as non congenital anomaly in the ICD 10. In Type 2 there was a discrepancy that a non-congenital anomaly was classified as congenital anomaly and this ranged from 26.7% to 50.0%. The sensitivity ranged from 96.85% to 97.98%, thus it can be concluded the ICD 10 database is highly sensitive while the specificity ranged from 50.00% to 78.57 %. In other words the ICD 10 is not accurate when classifying the non- congenital anomaly cases. A fair percentage of non-congenital anomaly cases were classified as CA in the ICD 10 database.

Conclusion: Even though hospital databases are used as a baseline data for a number of research and epidemiological studies it cannot be used at face value. Validation of these data is necessary before any conclusions can be drawn or intervention measures are undertaken.

IeJSME 2011: 5(2): 12-17

Key words : Congenital Anomalies, Validation , ICD 10.

Introduction

Health data obtained from hospital discharge sheets can be a useful source of information. This population based data can be used for public health programmes, health interventions, research and control programmes, strategic and budget planning for appropriate policy changes[1,2]. Upon the discharge of the patient, the cases are coded according to the diagnoses and this coding has to be accurate and correct. The World Health Organization (WHO) has come out with a guideline, known as the International Classification of Diseases (ICD) where diseases are coded under various categories for diagnostic information, epidemiological analysis and comparative research that can be used internationally[3]. The ICD uses a uniform system of coding, in which diseases are classified using an established system of categories of morbid conditions. The categories are limited so that it is manageable, relevant, and can be statistically acceptable and comparable.

The latest of the series of classification is ICD 10, which is the "Tenth Revision of International Statistical Classification of Diseases and Related Health Problems. There are three volumes to this 10th revision (Volume 1, 2 and 3). Volume 1 contains the tabular list, Volume 2 the instructional manual and Volume 3 the alphabetical index to the tabular list of Volume 1. Volume 3 also contains an additional number of diagnostic terms and an expanded instruction on how to use them.

Volume 2 consists of a complete review of the historical background of the diseases. It is an instructional manual and contains guidelines for coding and recoding. This volume gives a detailed account of the diagnoses, where the main code is sub-coded according to the organs, symptoms, complications, type of infections, specific sites, etc. It also includes inclusion and exclusion criteria. Besides the main diagnosis this volume includes medical and surgical procedures and disablement.

[1]Environmental Health Research Center, Institute for Medical Research, Jalan Pahang, 50588 Kuala Lumpur, MALAYSIA
[2]Open University, Kuala Lumpur, Jalan Tun Ismail, 50480 Kuala Lumpur, MALAYSIA
[3]International Medical University, 126 Jalan Jalil Perkas 19, Bukit Jalil, 57000 Kuala Lumpur, MALAYSIA

Address for Correspondence:

Prof Dr Stephen Ambu, International Medical University, 126, Jalan Jalil Perkasa 19, Bukit Jalil, 57000 Kuala Lumpur, MALAYSIA
Email: stephen_ambu@imu.edu.my

Many researchers use the ICD 10 database to get the raw data for their respective studies and each researcher will extract the respective code to get their baseline data for further research. For example if we take the neonatal hospital discharge data, they have been used widely[4,5] but there are not many published data pertaining to the accuracy of these data and the codes[6]. Hence there is a need to validate the data for its accuracy. Thus the objective of this study was to determine the validity and the accuracy of coding in the ICD 10 database to the diagnostic code for congenital anomaly as stated in the medical records in a population based health-care setting (hospitalization database) and to identify any discrepancies or weakness if any and give recommendations to improve the quality of data in ICD 10.

Materials And Methods

Procedure for coding

Upon discharge, the patient's discharge sheet is filled by the doctor in the ward and this sheet is than sent to the record office the following day. The record office receives all the discharge summaries from every ward and coding is done after each discharge according to the final diagnosis made by the doctor. The coding is done by the record officer using the ICD 10, volume 1 to 3. The key words or the lead words of the diagnosis are first identified and than the reference number is searched for in the ICD 10, Volume 3. A reference is further made in Volume 1 to check for inclusion and exclusion criteria. The coding is than made accordingly. Volume 2 is an instructional manual and used as a guideline and is referred to when needed. If there are more than one diagnosis than the coding is done based on the main diagnosis and the discipline for which the patient has been admitted. These record officers are trained by the Ministry of Health Malaysia. The coding is done electronically using a soft-ware that has been prepared by the Ministry of Health for the Medical Care Information System (MCIS 7).

The ICD 10 raw data from 1999 to 2004 for a health-care setting was obtained from the Information Data System (IDS) Unit of the Ministry of Health. This data contained the biodata of the patient which included: name, date of birth, sex, race, address, identification card number (ICN). If the patient was less than 12 years, the father's ICN was used. It also contained other information namely, the date of admission, date of discharge, ward number, diagnostic coding according to the main diagnosis upon discharge, etc. This data is stored/retained at national level as it is obtained from all government hospitals' admissions records in Malaysia. Each Health Office compiles the records from hospitals in their state.

The principal diagnostic code for congenital anomalies (CA) is "Q", thus only diseases coded under "Q" were retained from the main database and the rest were deleted. For this study, only data from a particular health setting was selected. After the initial selection, the data was further cleaned for double or multiple entries which occurred at every admission and therefore was duplicated each time the same patient was admitted during various times for the same health problem. As the objective of this study was to determine the number of cases of CA and not the number of times the patient was admitted, the multiple entries of each patient's entry data was deleted. The criteria for deleting multiple entries was based on the name of the patient, address and ICN; only the latest entry at admission was selected and retained. The medical records of patients were randomly selected and all discrepancies in code assignment for each patient was than compared with the ICD 10 as a verification process to ascertain whether the code assignment was same or different.

The total number of cases selected from the hospital records differed from year to year. About 20 to 30 % of the total number of cases was randomly selected. The list was used to trace the case notes or medical records. If a particular case sheet from a selected name was not available than the next case was selected and if that was not traceable, than the next one was selected and so on.

However for the year 2002, this process was discontinued as the medical records were all stacked in bundles and not accessible for review, only some were available. Therefore all the case sheets that were available for the year 2002 were selected.

The patient was selected from the original ICD 10 database. The name, address, date of birth, sex, ethnicity, identification card number of the patient or that of the patient's parents was checked with that given in database against the case notes. This biodata was digitized and uploaded to a computer programme managed by the admissions department. This process verified the accuracy of the patients' data in the case sheets to that of the ICD 10 database. The coding for the main diagnoses from this ICD 10 database was than counter-checked with that given in ICD 10 three character categories guidelines book by the World Health Organization (WHO).

Results

Congenital anomaly cases from three consecutive years (2002-2004) were randomly selected from the ICD 10 database and the information was checked against the hospital record, which were hard copy documents. Table 1 summarizes the population, sample and the percentage of cases verified.

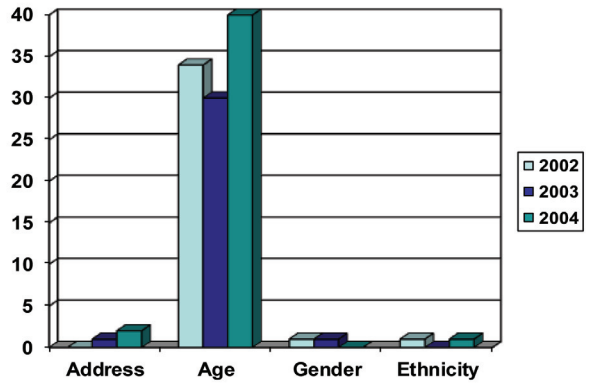
Table 1: Percentage of cases sampled and verified from 2002 to 2004

Year	Population	Sample	Percentage
2002	885	191	21.6%
2003	690	198	28.7%
2004	746	234	31.4%

Among the parameters verified for error were: patients' addresses, age, gender, ethnicity, ICD code, and description of the abnormalities. The discrepancies were categorized into two broad categories: patients' demographics and ICD coding for congenital anomalies.

As for patient demography, most of the discrepancies were incorrect recording of patients' ages. There were also a few cases where patients' genders were wrongly recorded. Figure 1 summarizes the discrepancies in patient demography.

Figure 1: Summary of discrepancies in patient demography



Coding of the Congenital Anomalies (CA) from the ICD 10 database was checked for error. There were two common types of coding error detected: Type 1 - Congenital anomaly cases recorded as non cases (other disease), and Type 2 - Non congenital anomaly (other diseases) classified as congenital anomalies. The ICD 10 database was analyzed for the Type 1 and Type 2 discrepancies. Tables 2 (i)-(iii) summarize the analysis.

Tables 2 (i)-(iii): Sensitivity and Specificity of Type 1 and 2 Discrepancies of ICD 10 Database for Congenital Anomalies

2 (i)

ICD Classification **2002**	Actual Cases	
	Congenital Anomaly Cases	Non Congenital Anomaly Cases
CA	185	6
NCA	6	8

CA = Congenital Anomaly; NCA = Non Congenital Anomaly

Type (i) Discrepancy = $\frac{6}{191}$ = 3.14%;

Type (ii) discrepancy = $\frac{6}{14}$ = 42.86%

Sensitivity Type (i) Discrepancy = $\frac{185}{191}$ X 100 = 96.85%

Specificity Type (ii) Discrepancy = $\frac{8}{14}$ X 100= 57.14%

2 (ii)

ICD Classification **2003**	Actual Cases	
	Congenital Anomaly Cases	Non Congenital Anomaly Cases
CA	194	4
NCA	4	11

CA = Congenital Anomaly; NCA = Non Congenital Anomaly

Type (i) Discrepancy = $\frac{4}{198}$ = 2.02%;

Type (ii) discrepancy = $\frac{4}{15}$ = 26.67%

Sensitivity Type (i) Discrepancy = $\frac{194}{198}$ X 100 = 97.98 %

Specificity Type (ii) Discrepancy = $\frac{11}{15}$ X 100 = 78.57%

2 (iii)

ICD Classification **2004**	Actual Cases	
	Congenital Anomaly Cases	Non Congenital Anomaly Cases
CA	220	12
NCA	12	12

CA = Congenital Anomaly; NCA = Non Congenital Anomaly

Type (i) Discrepancy = $\frac{12}{232}$ = 5.17%;

Type (ii) discrepancy = $\frac{12}{24}$ = 50.00%

Sensitivity Type (i) Discrepancy = $\frac{220}{232}$ X 100 = 97.98%

Specificity Type (ii) Discrepancy = $\frac{12}{24}$ X 100 = 50%

The Type 1 discrepancy ranged from 2.02% to 5.17%, thus it can be concluded that the ICD 10 database had low percentages of Type 1 discrepancy. However the Type 2 discrepancy was high, ranging from 26.67 % to 50.0%. In other words the ICD 10 was not accurate when classifying the non-congenital anomaly cases.

The sensitivity and specificity was used to assess the validity of the ICD 10 data base on coding for congenital anomalies. Sensitivity here refers to the ability of the database to correctly identify those congenital anomaly cases. The sensitivity ranged from 96.85% to 97.98%, thus it can be concluded the ICD 10 database is highly sensitive. By referring to the ICD 10 database one will be able to identify the cases with high accuracy. However the specificity seems to be low, ranging from 50.00% to 78.57 %. In other words the ICD 10 is not accurate when classifying the non congenital anomaly cases. A fair percentage of non congenital anomaly cases were classified as CA in the ICD 10 database.

Discussion

In general the majority of the congenital anomalies cases were coded accurately but there were some discrepancies. This was also noted in other validation studies where they compared population health data with medical records[8]. In a nationwide study carried out by Medicare where they sampled 7050 medical records from 239 hospitals between October 1984 and March 1985. They found an error rate of 20.8% in diagnosis related coding[9]. Another validation study was carried

out by Ford, *et al.* (2007) in Australia. The aim of this study was to use hospital discharge data to identify neonatal morbidity during birth admission and compare it with data from the state audit data of selected neonatal state wide intensive care admissions. He found that the sensitivity ranged from 37% to 97.7% and the specificity was above 85%[10].

In this study, discrepancies were noted, such as, in the age of the patient where the mother's age was stated instead of the baby's and the diagnosis was given as anencephaly. The biodata of the patient and new born was entered by the administrative staff in the admission department, while the diagnostic coding was done by the officer in the record office. Therefore the problem is perpetuated and not compounded at its source. Another error encountered was in the recording of the age of the newborn. The age was stated in hours or months and coded by the abbreviated letters "H" or "B" which denotes hour or months (B stands for 'bulan' which is month in Malay). The records showed that the recording officer mistook the age of the baby that was in hours and months and interpreted it in years. Thus, for example, if a baby was 2 hours old it was stated as 2 years. This mistake was noted frequently and consistently in all the three years' records that were used for this study.

The tracing of the relevant records was a main problem as the Records Office had recently been relocated and all the records were in bundles on the floor rather than being placed on the racks. This problem was seen to be more evident for the year 2002 as there were missing records, and in such cases we had to refer back to the case notes and that was time-consuming. Thus the total number of medical records that were traced were less than our expected target for the study.

The other problems noted were in the diagnosis of cases, such as, it was not written at all, not legibly written, or non-standardized abbreviations were used in the 'discharge summary sheet' that were attached to the case notes. In order to get the right diagnosis we had to read through the case notes to find it. That was also time-consuming.

In some cases, the mother's diagnosis was stated using the baby's coding. This had to be corrected. Sometimes the coding varied with different recording officers and admission officers. A case in point was that of a child having congenital anomaly, eg. congenital heart disease, but it was recorded as septicemia by the admission office. Another instance was a baby with an absent kidney but the admission record showed urinary tract infection (UTI), the diagnosis on the summary sheet was UTI but the coding used was for 'absent kidney'. The highlight here is that the coding was not standardized and it depended on the recording officer on duty. However the discrepancies in the records were minimal.

Although this study had a high sensitivity of above 90% and a low specificity ranging from 50% to 78.57%, the validation of medical records study had raised many issues on the need for proper coding of patient records. The recording and admission officer must work on a common platform with the relevant guidelines for efficient recording of patient data. Standardization of abbreviations and a coding checklist has to be maintained in both offices for error minimization. The consistency of the ICD 10 will provide reliable information for interested parties to be used as a retrospective database.

Conclusion

For epidemiologists and researchers, hospital discharge data are important resources for researches and health surveillance. However our study suggest that they should not solely depend on it for there are some discrepancies and some verification is necessary before undertaking any major decisions in what they wish to do.

Acknowledgements

The authors would like to thank the Director-General of Health for the permission to publish this paper. This study was supported by the research grant from NIH, Ministry of Health, Malaysia and also partly funded by IMU Grant No. 164/08.

REFERENCES

1. Stanley F.J., Croft M.L, Gibbins J. & Read A.W. A population database for maternal and child health research in Western Australia using record linkage. *Paediatric & Perinatal Epidemiology*, 1994: **8**: 433-447.
2. Roos, L.L., Sharp S.M., Cohen M.H. Comparing clinical information with claims data: some similarities and differences. *Clinical Epidemiology*, 1991: **44**: 881-888.
3. *International Statistical Classifications of Diseases and Related Health Problems*, 10th Revision (ICD-10) Volume 3, Second Edition, Geneva, World Health Organization; 2005.
4. Edmonson M.B., Stoddard J.J., Owens L.M. Early hospital discharge of newborns was not associated with feeding related hospital readmission during the first 28 days of life. *JAMA*, 1998: **278**: 299-303.
5. *Morbidity and Mortality Weekly Report: Hospital stays, hospitals charges and in hospital deaths among infants with selected birth defects-United States*, 2003. *MMWR* 2007, **56**: 25-29.
6. Gould J.B., Danielsen B., Korst L.M., Phibbs R., Chance K., Main E., Wirt-schafter D.D., Stevenson D.K. Cesarean delivery rates and neonatal morbidity in a low-risk population. *Obstetrics & Gynecology*, 2004: **104**: 11-19.
7. Lailanor b. Hj. Ibrahim. Data collection and coding in Ministry of Health (MOH) Malaysia. *NCD Malaysia*, 2004: Vol 3: No 4.
8. Lydon-Rochelle Mt., Holt V.L., Nelson J.C., Cardenas V., Gardella C., Easterling T.R., Callaghan W.M. Accuracy of reporting maternal-in hospital diagnosis and intrapartum procedures in Washington State linked birth records. *Paediatric Perinatal Epidemiol*, 2005: **19**: 460-471.
9. Hsia D. C., Krushat W. M., Fagan A. B., Tebbutt J. A., Kusserow R.P. Accuracy of Diagnostic Coding for Medicare patients under prospective –payment system. N Eng J Med 1990 May 24;322(21):1540.
10. Jane B. Ford, Christine L. Roberts, Charles S. Algert, Jennifer R. Bowen, et al. Using hospital discharge data for determining neonatal morbidity and mortality: a validity study. *BMC Health Services Research*, 2007: **7**: 188.