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Official information systems for cryptococcal meningitis, state of Rio de Janeiro, Southeastern Brazil

ABSTRACT

The study aimed to compare the epidemiological profile of crytococcal meningitis in different information systems, thus assessing to what extent the profile available in the *Sistema de Informação de Agravos de Notificação* (Information System for Notifiable Diseases) reflected cryptococcal meningitis occurrences in the state of Rio de Janeiro, Southeastern Brazil, between 2002 and 2004. That database was compared to a new database comprised of cryptococcal meningitis cases from this System, from the *Assessoria de Meningite da Secretaria de Saúde do Estado do Rio de Janeiro* (State Department of Health Meningitis Advisory Committee), and from the *Instituto Estadual de Infectologia São Sebastião* (State Institute of Infectious Diseases) laboratory records. The System detected 65.7% of the cases present in the new database. The percentage of patients with AIDS as a pre-existing disease was similar in both databases (26% and 24.9%). Thus, even though cryptococcal meningitis incidence is underreported in the System, the profile of notified cases reflects the profile of the total number of cases.

DESCRIPTORS: Meningitis, epidemiology. Disease Notification. Registries. Information Systems. Underregistration. Epidemiologic Surveillance.

INTRODUCTION

The *Sistema de Informação de Agravos de Notificação* (SINAN – Information System for Notifiable Diseases) began to be established in 1993, and was regulated by a ministerial decree in 1998. This system aims to collect and spread data on notifiable diseases, which helps to analyze epidemiological surveillance information. It can be used as the main source of information about the disease's natural history[4] and as an estimation of its magnitude as a health problem in a population.

Infectious meningitis is an important public health problem. Meningitis is the main clinical manifestation in 85% of cryptococcosis cases, an infection that has shown a drastic increase with the AIDS epidemic, with 80% of cases occurring in HIV infected patients.

In the state of Rio de Janeiro, records of cryptococcal meningitis first appear in the SINAN in 1998, with only six cases recorded in 1998 and nine in 1999. From 2000 on, the number of records in the SINAN becomes similar to that reported by the *Assessoria de Meningite da Secretaria de Saúde do Estado do Rio de Janeiro* (SES-RJ – State of Rio de Janeiro Department of Health Meningitis Advisory Committee).

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This study aimed to compare the epidemiological profile of cryptococcal meningitis in different information systems, thus assessing to what extent the SINAN reflected cryptococcal meningitis occurrences.

METHODS

Data on cryptococcal meningitis notifications from individuals living in the state of Rio de Janeiro, Southeastern Brazil, between 2000 and 2004, in the SINAN and the SES-RJ Meningitis Advisory Committee databases and data on positive *Cryptococcus* sp. cerebrospinal fluid (CSF) tests, recorded in the *Instituto Estadual de Infectologia São Sebastião* (IEISS – São Sebastião State Institute of Infectious Diseases), were used. The Advisory Committee is a division of the SES-RJ Epidemiological Surveillance Center and the IEISS is a referral center for meningitis in the state of Rio de Janeiro. The first case notification with laboratorial confirmation of cryptococcal meningitis present in at least one of SINAN or the Advisory Committee databases or yet in the IEISS laboratory records during this period was adopted as definition of an incident case.

SINAN data were compared with data from a new database, named "extended database", comprised by data from the three databases. In order to create the "extended database", the three databases were compared, considering age and cerebrospinal fluid puncture date, in addition to patients' names, to avoid duplicities caused by different spellings of a patient's name. The same variables were considered to compare the SINAN to the new database. Chi-square test was used to compare proportions and Student's t test was used to compare means, adopting a 5% statistical significance level.

RESULTS

The Figure shows cryptococcal meningitis cases from the three databases, in the period studied. Of all the 352 cases notified to the Advisory Committee, 32% (113 cases) were not recorded in the SINAN, and of all the 288 cases notified to the SINAN, 17% (49 cases) were not recorded in the Advisory Committee. The SINAN and the Advisory Committee did not identify 37.8% and 32.8% of the 177 cases detected in the IEISS respectively. A total of 37 cases (8.4% of the total) were diagnosed in the IEISS laboratory, but were not detected by the surveillance system. The "extended database" was comprised of 438 cases.

Of all the 92 cities in the state of Rio de Janeiro, 29 notified cryptococcal meningitis cases to the SINAN and 34 to the "extended database". The city of Rio de Janeiro contributed with 55% of all the 288 cases in the state notified to the SINAN, and with 60% of all the 438 cases of the "extended database". Other cities with the highest percentages of cases showed similar results in both databases.

Between 2000 and 2004, the SINAN detected 65.7% of the cases present in the "extended database". The percentages of cases detected by the SINAN were 67%, 52.3%, 64.7%, 73.3% and 69.5% for each year respectively. The annual cryptococcal meningitis incidence rate per 100,000 inhabitants varied from 0.30 in 2002 to 0.50 in 2003 in the SINAN, and from 0.46 in 2002 to 0.68 in 2003 in the "extended database". There was a 33.3% underestimation in the mean incidence rate in the period. The male sex predominated in both databases in the entire period (p=0.49). The entire sample of cases in the SINAN showed a mean age of 35.7 years (sd=12.6) and median of 35.5 years, while in the "extended database" the mean was 35.6 years (sd=12.6) and the median was 35 years (p=0.93).

Information about the presence of pre-existing diseases was missing in 66% of patients registered in the SINAN and in 67.8% in the "extended database". AIDS was the most frequent pre-existing disease, afflicting 26% of the SINAN cases and 24.9% of the "extended database" cases. Of all the AIDS cases in the SINAN, 88% (66 cases) were patients notified in 2003 and 2004, with no AIDS records in 2000. In the "extended database", there was reference to AIDS in all years, with 2003 and 2004 concentrating the highest percentage (68%). The remaining diseases reported were tuberculosis, leukemia and renal transplant.

Case fatality rate of cryptococcal meningitis was 47.4%, based on SINAN data, and 48.8%, based on "extended database" data (p=0.72).
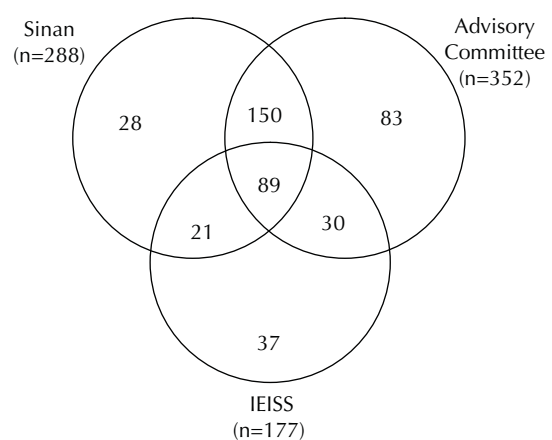
SINAN: Information System for Notifiable Diseases

Advisory Committee: State of Rio de Janeiro Department of Health Meningitis Advisory Committee

IEISS: São Sebastião State Institute of Infectious Diseases

Figure. Intersection of three cryptococcal meningitis record sources. State of Rio de Janeiro, Southeastern Brazil, 2000-2004.

DISCUSSION

One limitation to this study was the decision to consider the "extended database" to be representative of all the cases occurring in the period, as case underreporting may occur. However, for the purpose of comparing the SINAN to the "extended database", this decision would be justified, since all possible information sources had been included.

In this study, a national database and the Advisory Committee database were used, both with data input by the municipal departments of health. The fact that the SINAN and Advisory Committee databases do not coincide shows the precarious flow of information, which is generally still carried out using written files that circulate among different sectors. Cases detected by the IEISS that are not present in the SINAN point to local epidemiological surveillance difficulties.

The percentages of cases detected by the SINAN showed a variation of up to 20% among the years analyzed. According to the surveillance systems assessment criteria, despite its not showing high sensitivity, a system could be useful to follow disease tendencies, provided this sensitivity remained constant throughout time.[3]

In both databases, the variable pre-existing disease showed high percentage of missing information. The percentages of AIDS cases in the SINAN (26%) and in the "extended database" (24.9%) are well below those reported in the literature (about 80%). Data are often found to be in the medical records, but there is no careful investigation to turn them into information, thus showing their low appreciation as actual source of knowledge. In a previous study,[5] by combining the Advisory Committee cryptococcal meningitis database with the SINAN STD/AIDS database, the percentage of AIDS as pre-existing disease rose from 25.6% to 61.2% among the cases reported in the Advisory Committee.

The use of laboratories as supporting surveillance sources, such as the IEISS, is important to increase coverage and reduce underreporting. An Italian study showed a 27% increase in bacterial meningitis cases reported by the Surveillance System, when laboratories were included in the surveillance process.[2]

By analyzing infectious meningitis cases in a public hospital in the city of Rio de Janeiro with data from the SINAN, Escosteguy et al[1] found out the usefulness of the system as an instrument to analyze the clinical-epidemiological profile of different types of meningitis in hospitals. Cases were notified and investigated by the hospital's epidemiology service, which operates with both active and passive surveillance systems. Local data entry would enable inconsistencies to be reviewed more easily. This system could identify AIDS as a pre-existing disease in 84.7% of cryptococcal meningitis cases.

The incidence of cryptococcal meningitis is underreported in the SINAN, but the profile of cases notified reflects the profile of the total of cases, considering the "extended database" as a more accurate indicator of cryptococcal meningitis incidence in the state. Passive systems can be useful, despite underreporting, provided the cases are representative of the totality. By using the information generated, it is possible to identify limitations, detect errors and seek information quality improvement.

Routine assessment of surveillance systems is essential to guarantee adequate monitoring of health problems and the reliability and usefulness of the information obtained. The systematic combination of databases should be planned to enable underreporting assessment and the identification of the steps to be improved and errors to be corrected. Quality of information depends on adequate data collection where the health problem is occurring. High percentage of missing information harms the assessment of the epidemiological profile of the disease under study. There is a recommendation from SINAN that defines updating and record correcting responsibilities between the municipal and state levels. States must assess data regularity, completeness, consistency and integrity and also record duplicity, carrying out procedures to maintain database quality.[a] Finally, notification of certain health problems by laboratories should be considered as a strategy to increase surveillance system coverage.

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