

Meningococcal disease and the law: does non-notification really happen?

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Abstract

In Victoria, legislation clearly makes the notification of clinical or confirmed cases of meningococcal disease mandatory. Statistical modelling suggests that meningococcal disease is significantly under-notified, and that incorrect codes might be being ascribed to some in-patient episodes. The aims of this study were (i) to test the assumption that cases identified as non-notified cases were true cases, and (ii) to identify the reasons for non-detection on the hospital separation database and non-notification to the infectious diseases unit. Of 26 cases not identified on the in-patient dataset, the main causes were either being given completely incorrect ICD-9-CM codes (11 cases) or being given codes for a different type of meningitis (8 cases). Of 29 non-notified admissions, most were clinically (17) or microbiologically (6) confirmed cases, although 5 were coded in error and were not cases of meningococcal disease. Therefore, although the allocation of incorrect ICD-9-CM codes at separation was a major reason for discrepancy, non-notification was a real and recent problem. It is also possible that some clinical staff did not understand the relationship between *Neisseria meningitidis* and meningococcal disease, the public health implications of this infection, or the law relating to it. *Commun Dis Intell* 1999;23:97-101.

Introduction

Following European settlement, fear of imported diseases crossing state boundaries resulted in the introduction of state public health acts,^{1,2} which were mainly adapted British public health law, to assist with quarantine and control of population movement. Eventually the 1908 Commonwealth Quarantine Act³ brought about the protection of national boundaries from imported diseases. The Quarantine Act states that the Governor General (GG) may provide, or arrange for the provision of:

'..... teaching, research and advisory service for or in relation to the improvement of health or the prevention of disease'

Clause 35A(2) provided the GG with the ability to nominate any disease as subject to quarantine if it was judged necessary. Today, in each of the States and Territories, this responsibility is delegated to the Chief General Manager (CGM).

The States developed their own internal mechanisms for the notification and control of communicable and infectious diseases. In Victoria, the relevant legislation relating to infectious and communicable disease is contained in the Victorian Health Act 1958⁴ and amendments (Part VI Division 3 Clauses 121 and 126, and Division 9 Clause 138; Part VIII Clause 146 and Division 4 Clauses 421 and 142). Clause 9 of the Victorian Health Act, which relates to disease notification, states that:

'The CGM may make regulations for or with respect to - (a) prescribing diseases the occurrence or existence of which must be notified to the CGM';

The Regulations referred to are the Health (Infectious Diseases) Regulations 1990,⁵ Schedule 2, which includes meningococcal infections on the list of Group A diseases. Group A diseases ...

'.... should be notified to the Health Department Victoria by telephone or fax upon initial diagnosis (presumptive or confirmed) with written confirmation to follow within seven days.'

In addition, in 1996 the National Health and Medical Research Council produced Australian guidelines for meningococcal disease control which further set out the process of notification of the disease in this country.⁶

If all doctors understood and abided by the law, all cases of meningococcal disease (whether clinical or microbiologically confirmed), would be notified to the Infectious Diseases Unit promptly, and there would be no non-notified cases. Non-notification of communicable diseases, including meningococcal disease, has been noted as a problem in some communities internationally.^{7,8,9}

In 1996 a study was conducted in Victoria to determine the extent of under-notification of meningococcal disease.¹¹ The study compared three datasets, which should have comprehensively and independently recorded cases of meningococcal disease:

- the then Department of Human Services Infectious Diseases Unit's Infectious Diseases Epidemiology Surveillance System (IDESS);
- the Melbourne University Microbiological Diagnostic Unit's (MDU) Victorian Hospitals Pathogen Surveillance System (VHPSS); and
- the Department of Human Services Epidemiology Unit's Victorian Inpatient Minimum Dataset (VIMD), where one of the first three listed International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes indicated that the admission was for meningococcal infection (036.0-036.9).

Initial matching of cases was undertaken using the hospital unit record (UR) - number, gender, date of birth and age, postcode of residence, and admitting hospital. In addition

name codes (derived from a combination of first and second name initial letters) were available from the IDESS and VIMD datasets. Using log-linear modelling, for the years 1988 -1994, a significant under-notification was demonstrated. Whilst 576 cases were identified overall, only 251 cases (43.6%) were identified in all three datasets, and initial modelling suggested an under-notification of 90 cases (95%, CI 58.2,139.3).¹¹ However, when the model was applied to 1995 and 1996 data, it became very unstable, resulting in an inability to produce a clear and unambiguous estimate of the total number of cases. This effect probably occurred because a productive collaboration between the Infectious Diseases Unit and Microbiological Diagnostic Unit had been established, and IDESS and VHPSS were no longer independent of each other. However, the application of techniques such as capture-recapture to these data suggested that there was still significant under-notification. Detection was estimated as only 94.9% of all probable cases (95%, limits 92.7% - 97.2%).

Although several studies have been designed to estimate the total number of cases of meningococcal disease by using modelling techniques such as capture-recapture methods, in only one has an attempt been made to validate their datasets.¹⁰ However, the authors of this American study included only cases which were confirmed by positive microbiology or microscopy, ignoring clinical cases. In Victoria in 1996, 26% of notified cases of meningococcal disease had no positive laboratory confirmed results, and were therefore considered to be clinical cases. It is important that clinical cases be included in case counts. Overall, in Australia 12% of cases of meningococcal disease included in the National Notifiable Diseases Surveillance System were unconfirmed.⁶

The current study was designed to (i) test the assumption that cases identified as non-notified cases were true cases, (ii) identify reasons why these cases were not notified despite clear legislation, and (iii) identify the reasons why some notified cases escaped detection on the hospital separation database. As the issue of notification to VHPSS is now a historical problem, VHPSS-only cases were not included in this study.

Methods

To be identified on the IDESS, a person must be notified to the Infectious Diseases Unit as having a provisional or

confirmed diagnosis of meningococcal disease. To be identified in the VIMD, a person must have an ICD-9-CM relating to meningococcal infection (codes 036.0-036.9). People who have meningococcal disease should appear on both of these data sets.

In this study, a case was a person with meningococcal disease who was either

- notified to IDESS but not identified on the VIMD; or
- identified on the VIMD but not notified to the IDESS.

A data collection form was developed which captured key information relating to the remaining discrepant admissions, including clinical signs and symptoms, diagnostic tests, results, and discharge ICD-9-CM codes.

Ethical approval for this study was given by the Human Ethics Committee of the Department of Human Services, and in addition was noted by the Human Ethics Committees of the participating hospitals.

Results

For the years 1990 -1995, of 483 notifications and admissions for meningococcal disease, there were 121 which were known only to either IDESS or VIMD.

Of these, 4 were not hospitalised in Victoria, and were therefore not eligible for inclusion on the VIMD, accounting for this discrepancy. Access to their records was not sought. A further 24 cases were excluded from the study as they were either admitted to a private hospital (where record access is difficult), or could not be identified at the admitting hospital, or the admitting hospital could not be identified. Therefore 93 discrepant cases remained for inclusion in this study (Table 1).

On retrieving the hospital records, 19 pairs were matched with complete information (including complete name, and listed ICD-9-CM codes 36.0-9), making 55 unmatched cases and 19 matched cases. Therefore the identified sample of 93 cases was reduced to 74 records, of which 19 were no longer discrepant.

The remaining 55 discrepant admissions are discussed below, and summarised in Table 2.

Twenty-six cases were known to IDESS but not identified on VIMD for one of the following reasons:

- Eight people had codes that attributed their disease to other types of bacterial or viral infections. Some of

Table 1. Summary of records of meningococcal disease in this study sample

Total identified discrepant notifications and admissions	121
• Ineligible for inclusion to VIMD (never admitted or hospitalised interstate), therefore reason for discrepancy already clear	4
• Admitted to private hospital (logistic and legal problems relate to the retrieval of information relating to private patients admitted to private hospitals in Victoria)	6
• Records unidentifiable at admitting hospital	15
• No record of admitting hospital	3
Total number of records not requested for reasons of access or identification	28
• Known to IDESS, not identified on VIMD	45
• Identified on VIMD, not notified to IDESS	48
Total number of records for which access was requested	93

Table 2. Reasons for dataset discrepancies, meningococcal disease, Victoria, 1990-1995

	(b) Known only to IDESS	(a) Known only to VIMD	TOTAL
Matched with complete details	19	19	19/2
ICD-9-CM code differs from ascribed code; data entry error	11	5	16
ICD-9-CM code for different type of meningitis	8		8
Meningococcal disease not listed on problem ICD-9-CM coding summary	2		2
Microbiologically shown not to be a case	2		2
ICD-9-CM codes not listed	2		2
Clinical case with meningococcal disease ICD-9-CM code		17	17
Culture +ve case, not notified (including 1 recrudescence)		6	6
Clinical record states case notified, but not notified to IDESS		1	1

these were to the wrong organism (pneumococcus, for example) and others to an unspecified organism. Two of these had (incorrect) codes indicative of systemic gonococcal infection.

- Two had chronic conditions that were listed in detail, and meningococcal infection codes were ignored.
- Eleven had codes unrelated to meningococcal disease or any other type of meningitis. Most ascribed codes related to the main presenting symptoms; convulsions or diarrhoea, for example. Several had codes incorrectly transcribed, such as '36.0' instead of '036.0'.
- Two cases had no ICD-9-CM codes listed on the separation sheet.
- One was ascribed a code completely unrelated to any signs, symptoms, or final diagnosis.
- Two people were eventually shown to not have meningococcal disease (for example, one child had echovirus type 30 on CSF culture). Although these two were no longer cases they were not 'un-notified'.

Twenty-nine cases were known to VIMD but not identified on IDESS for one of the following reasons:

- An incorrect ICD-9-CM code was assigned or entered for 5 people who did not have meningococcal disease, and who should have had codes of '036' instead of '36' (heart vessel procedure) or '8361' (knee reconstruction).
- One culture positive case was recorded in the patient record as having been notified, but the Department had no record of the communication.
- Seventeen people had clinical meningococcal disease, and technically should have had a code related to bacterial meningitis of unknown origin.
- Six cases were microbiologically confirmed (either culture positive or gram-negative diplococci identified microscopically) but were not notified. In examining these case records, it was not clear whether the consultant staff were unaware of the regulations concerning this infection, or whether there was no understanding of the connection between '*Neisseria meningitidis*' and 'meningococcal disease', for example:

'... grew *Neisseria meningitidis* from CSF and blood; however antigen negative therefore ? cause of (this person)'s bacterial septicaemia....'

The problem of non-notification is not simply historical (Table 3). For instance, in the most recent study year, 1995, 5 cases were not notified. None had a lumbar puncture performed, although all had blood cultures collected, of which one was culture-positive. Two of these presented with unusual and interesting clinical histories. Three had a characteristic rash, 3 had a severe headache and 1 had neurological signs. All recovered with the administration of penicillin and ceftriaxone, however no mention was made in any of the case notes suggesting that any close contacts had received prophylaxis. Two cases should have had particularly careful public health management; one was a recurrent case, and the other a secondary, or possibly co-primary case.

Table 3. Number of discrepant cases of meningococcal disease, 1990-1995, by year and dataset record

	Notified to HACS, not identified on VIMD	Identified on VIMD, not notified to IDESS	TOTAL
1990	2	2	4
1991		1	2
1992	7	13	29
1993	7	4	17
1994	5	3	9
1995	5	6	13
TOTAL	26	29	74

Several comments on the patient records demonstrated a reluctance on the part of staff to divulge any information about their patients to the Infectious Diseases Unit, which needed it for outbreak control, for example:

' Dr phoned from the (Health Department. He) wanted to know however I told him that only the patient could give permission for this information to be released

Discussion

An assumption in the use of log-linear modelling and capture-recapture techniques for the estimation of total populations and events, is that all cases occurring in more than one dataset are matched. Despite carefully matching criteria, 19 people who could not be matched in the original project,¹¹ were matched in this study with more complete information.

Four cases were not admitted to hospital in Victoria, making it impossible for inclusion on the VIMD. It is possible that other Victorian residents may have been admitted to hospital interstate, or were not admitted to hospital at all, who were also not notified to IDESS.

Inaccurate public hospital discharge data have previously been noted to be a problem in terms of both epidemiological accuracy¹² and financial remuneration.¹³ Incorrectly being assigned an ICD-9-CM code for meningococcal disease accounted for 5 of 29 VIMD 'cases'. It is interesting that on the VIMD, 17 non-notified clinical cases were identified only because they were given a technically incorrect code; the code for bacterial meningitis or septicaemia caused by unknown organism (ICD-9-CM codes 320.9 or 038.9) would have been more accurate. It is likely that other non-notified clinical cases of meningococcal disease have occurred, who were given the correct ICD-9-CM code (such as 320.9 or 038.9), and who were not identifiable by the methods used in this study.

The one study, conducted in New York, designed to validate the completeness of notification of meningococcal disease by examining the records of notified and admitted cases, did not include clinical cases.¹⁰ Although the conclusion of these authors was that their combined datasets identified 93% of all cases; the inclusion criteria for both databases was identical, 'positive culture or microscopy', therefore they were not really independent of each other. In Victoria, many notified cases of meningococcal disease are not able to be confirmed by existing laboratory techniques (between 25% and 50% of cases since 1990 have not had an isolate submitted to the State Meningococcal Reference Laboratory.)¹⁴

The problem of laboratory-positive cases not being notified to the Infectious Diseases Unit accounted for 6 of 29 'un-notified' admissions. It is of concern that disease caused by *Neisseria meningitidis* is ever not recognised as being meningococcal disease, and therefore not notified. Ward staff should be aware of the importance of prompt notification of both suspected and confirmed cases of all manifestations of meningococcal disease.

It is commendable that ward staff are generally unwilling to divulge information about their patients. In this study the apparent unwillingness of ward staff to divulge information to public health staff has been noted. Some staff appear not to understand the contact tracing process involved in communicable diseases and are diffident about exposing the close contacts of cases to scrutiny. All cases, whether private patients or not, should be notified by law. The law covers issues of confidentiality and identification equally for all patients, whether being treated in private or public hospitals. The Commonwealth Privacy Act 1988¹⁵ contains legislation relevant to health personnel involved in outbreak investigations. This is a situation that is common

in the follow-up of contacts of cases of meningococcal disease, and precludes further disclosure of personal details of cases or their contacts, except in very unusual circumstances:

'... shall not disclose unless (the) record-keeper believes (disclosure) will lessen a serious and imminent threat to the life and health of the individual concerned or another person.'

Mechanisms should be explored for ensuring that private patients are afforded the same public health follow-up as their public patient counterparts, so that the former are not disadvantaged by their private patient status.

It should be noted that of the 24 clinical and confirmed but non-notified cases, 2 were secondary cases. Without consistent notification it is impossible to ascertain some important epidemiological features including; accurate counts of co-primary or secondary cases, rates of clinical versus confirmed cases, and efficacy of chemoprophylaxis and vaccination programmes.^{7,10} Some clinical staff undertake the identification of contacts and prescription of appropriate antibiotics without notifying the Health Department. In the event of an admission for meningococcal disease it is common for many people to claim to be close contacts. Whilst it is important to institute prophylactic treatment promptly, for clinical reasons it is also important to ensure that *only* close contacts are treated. In Victoria a legal clause exists in the Victorian Health Act 1958 (Division 4, Clause 421) which could be used to enforce this point:

'Every person who - (a) knowingly makes any false or misleading statement in any application, notice or report'

The last point to emphasise with regard to notification is very clear in the Victorian Health Act 1958, Clause 422:

'... Every person who does not do anything directed to be done shall be guilty of an offence against this Act.'

Therefore, as meningococcal disease is listed in Schedule 2 as a notifiable disease in Victoria, its notification is obligatory, regardless of whether cases are *suspected* or *confirmed*. Disclosure of personal details of cases or close contacts by any hospital staff, to anyone other than people closely involved with the family or health protection staff, is technically in breach of the law. The relatives of cases are likely to be upset and unable to give rational informed consent for public dissemination of distressing details. It should be impossible for health protection staff to first hear about a new case through the media or from a worried teacher or neighbour, rather than directly from a colleague.

Complete notification enables effective public health management of single cases, early identification of outbreaks and secondary cases, the distribution of appropriate information and advice for communities, and rational information for media distribution. It makes the impact of preventive programmes measurable. Without complete notification the incidence of this frightening disease will be underestimated, and consequently the costs of public health strategies and preventive programmes overestimated.

This study has shown that, despite laws which stipulate that suspected and confirmed cases of meningococcal

disease shall be notified, for several reasons, clinicians fail to always do so.

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