Completeness of Pediatric TB Reporting in New York City

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SYNOPSIS

Objectives. Accurate surveillance of tuberculosis (TB) in children is critical because such cases represent recent transmission, but surveillance is difficult as only 10% to 50% of cases are culture-confirmed. Hospital-based sources were used to develop alternative surveillance to assess completeness of reporting for pediatric TB in northern Manhattan and Harlem from 1993 through 1995.

Methods. Alternative surveillance sources included ICD-9-CM hospital discharge codes for active TB and gastric aspirate reports. Cases identified by alternative surveillance were compared with cases previously reported to the New York City Department of Health (NYC DOH).

Results. Alternative surveillance detected 25 cases of possible pediatric TB, of which four (16%) had never been reported to the NYC DOH and three (12%) had been reported as suspect cases, but had not fulfilled the criteria for a reportable case of pediatric TB. Of these seven newly counted cases, three were detected by ICD-9-CM codes, three by a gastric aspirate log book, and one by both. In contrast, 13 other cases had been reported to the NYC DOH, but were undetected by our alternative surveillance; eight of these could be verified with available medical records. Thus, the demographic and clinical characteristics of the 25 detected and the eight undetected cases with available medical records were evaluated in this study.

Conclusions. Alternative surveillance proved effective, was complementary to the NYC DOH surveillance efforts, and increased the number of pediatric TB cases identified during the study period by 21%.

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During the late 1980s and early 1990s, the number of children reported with tuberculosis (TB) increased in New York City (NYC) as well as nationally.[1–6] Pediatric TB cases are sentinel events in public health, as children with TB disease represent recent transmission within the community, generally from family members.[4,6] While accurate surveillance of pediatric TB, including those children co-infected with HIV, is critical, the completeness of such surveillance in children has not been addressed in a systematic study.

The NYC Department of Health (NYC DOH) Bureau of TB Control requires healthcare providers to report suspected and confirmed cases of TB in adults as well as children.[7] Since the late 1980s, the Bureau of TB Control has surveyed clinical microbiology laboratories for positive cultures for *Mycobacteria tuberculosis*; however, only 10% to 50% of cases of pediatric TB are culture positive for *M. tuberculosis*.[4,8,9] The NYC DOH and the Centers for Disease Control and Prevention (CDC) have also sponsored two ongoing active surveillance programs to assess co-infection with HIV and TB in children: the Pediatric Spectrum of Disease and Pediatric AIDS Surveillance.[10,11]

To assess the completeness of reporting of pediatric TB cases to the NYC DOH Bureau of TB Control from January 1993 to December 1995, hospital-based alternative surveillance was developed to detect previously unreported cases of TB in children in our targeted surveillance area. The TB and TB/HIV cases identified by alternative surveillance were compared with cases previously reported to the NYC DOH during the same time period.

METHODS

Study design

This was a hospital-based, retrospective case-finding study to identify children younger than 15 years of age with TB disease who were diagnosed with TB from January 1993 to December 1995. Institutional Review Board approval was secured from the CDC, NYC DOH, Columbia University, Harlem Hospital, and St. Luke's-Roosevelt Medical Center.

Study sites

The study was conducted in health care facilities located in Northern Manhattan and Harlem, including Babies & Children's Hospital of the New York-Presbyterian Medical Center, Harlem Hospital, St. Luke's-Roosevelt Hospital Center, Incarnation Children's Center (a residential treatment center for HIV-infected children), and the Washington Heights NYC DOH Chest Clinic. In 1990, the population served by these five institutions was 52% Hispanic and 22% were children younger than 15 years of age.[11]

Case definitions

The NYC DOH Bureau of TB Control uses the following case definitions for adults and children with suspected TB. A *verified case of TB* has laboratory confirmation of *M. tuberculosis* or meets the CDC clinical case definition.[13] The clinical case definition includes all of the following: a positive tuberculin skin test (TST); other signs and symptoms compatible with TB, such as an abnormal, unstable (worsening or improving) chest X-ray or clinical evidence of disease; treatment with two or more anti-tuberculosis medications; and a completed diagnostic evaluation. A *provider diagnosis of TB* is assigned to a patient who does not fulfill the CDC clinical case definition, but is being treated with two or more anti-tuberculosis drugs that the Bureau of TB Control Surveillance Unit has determined to be medically justified. For example, a patient with a negative TST and negative cultures but a clinical and radiographic picture consistent with active TB who improves on treatment is assigned a provider diagnosis of TB. During the study period from 1993 to 1995, 74% of TB cases in children were assigned a provider diagnosis.[14] A patient is labeled a *suspect case of TB* by the NYC DOH if the patient is reported by a physician or health care facility as a suspect case of TB, but never confirmed by the Bureau of TB Control as a verified or provider diagnosis case, and remains uncounted. Ultimately, all suspect cases are deemed TB disease, TB infection, or alternative diagnoses (i.e., may closely resemble TB disease such as a case of *M. avium* complex or other mycobacteria).

Verified and provider diagnosis cases are given Report of Verified Case of Tuberculosis (RVCT) numbers by the NYC DOH (i.e., they are counted) and reported to the CDC.[15–17] Suspect cases are not assigned RVCT numbers.

All children who are receiving treatment for tuberculosis in New York City should be reported to the NYC DOH; if these children reside outside the city, the NYC DOH will report them to the health department in the jurisdiction in which they reside, and they will be reported to the CDC as confirmed TB cases by that jurisdiction.

Alternative surveillance sources

Possible cases of pediatric TB were elicited from several hospital-based alternative surveillance sources. These sources included the International Classification of Diseases, 9th Code Modification (ICD-9-CM) codes for TB (010.0 to 018.9, inclusive);[18,19] physician

interviews held in 1996 to 1997 with specialists in pediatric HIV, infectious diseases, or pulmonology; and gastric aspirate log books (when available) from the participating clinical microbiology laboratories. The study team reviewed the medical records of children identified by these alternative surveillance sources, including those who had one or more gastric aspirate cultures obtained. Diagnostic studies (e.g., TSTs, chest X-rays and mycobacteriology cultures) and response to treatment were collected to confirm the diagnosis of TB.

Community-based surveillance was performed by administering a questionnaire to community physicians to inquire if they had cared for a pediatric patient with active TB. This one-time survey was conducted at a free continuing medical education (CME) course on pediatric TB held in March 1998, co-sponsored by the authors and the NYC DOH.

Matching strategy

The names, birth dates, and gender of children identified by alternative surveillance whose medical records supported the diagnosis of TB were submitted to the Bureau of TB Control; a search of the entire TB Registry was conducted to determine whether or not the children were ever reported to the NYC DOH and confirmed as TB cases by the NYC DOH. TB Control program staff determined whether or not children detected by alternative surveillance should be confirmed as TB cases and assigned RVCT numbers on the basis of review of information in the TB Registry and any additional information yielded in the alternative surveillance process.

The study team also identified children included on the TB Registry 14 years of age and younger who were reported between 1993 and 1995 by hospitals included in the study, but not identified by alternative surveillance. Reasons that alternative surveillance failed to detect these cases were assessed.

Data collection and analysis

A relational database was created in Microsoft Access® 97 (Redmond, WA).[20] Data collected included demographic information, alternative surveillance sources, HIV or AIDS diagnosis, medical evaluation, and treatment for TB. Final diagnosis was assigned by the study team (LS) according to the case definitions of the NYC DOH. A test of proportions based on marginal homogeneity[21] was done to compare the alternative surveillance sources and the data sources reviewed for previously confirmed vs. newly counted cases.

Missing demographic data

The demographic characteristics for several cases were missing from the data sources reviewed, as these were unavailable or incomplete. Thus, to more completely assess the demographic composition of children that ultimately qualified as TB cases, missing information, when available, was obtained from the RVCT records in the Tuberculosis Information Management System (TIMS).[22]

RESULTS

Potential cases detected by alternative surveillance sources

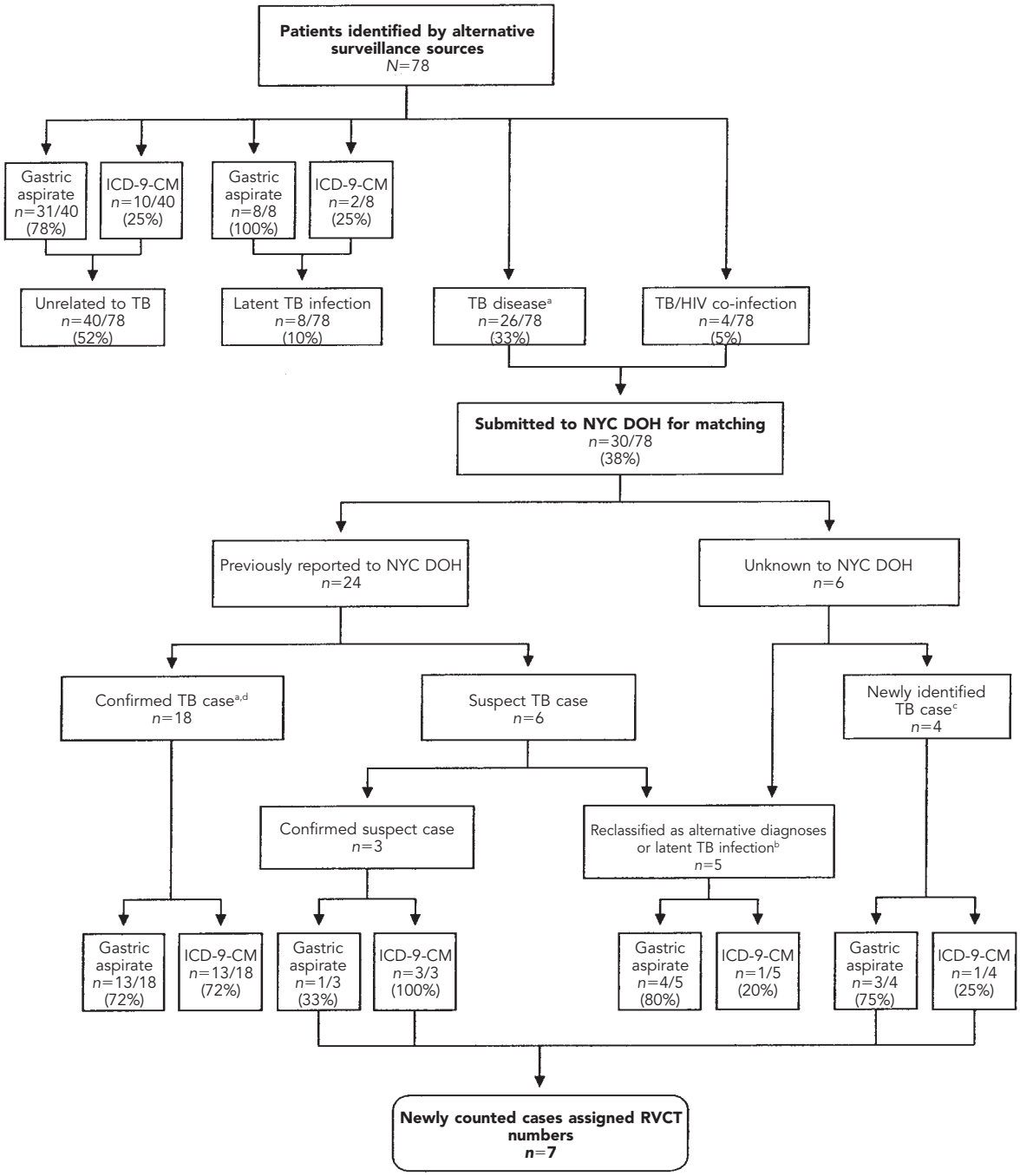
Alternative surveillance identified 78 children who were possibly evaluated for TB during the study period (see Figure). Medical record reviews indicated that 48 (62%) did not have active TB, including 40 (51%) children with diagnoses unrelated to TB and 8 (10%) children with latent TB infection (LTBI). Of these 48 children, 12 (25%) had been incorrectly assigned discharge ICD-9-CM codes for active TB. Thirty-nine (81%) of 48 were detected by review of a gastric aspirate logbook maintained by one of the laboratories. This suggests that these children had undergone evaluations for TB, but ultimately were diagnosed with conditions other than TB or LTBI. None of the community-based physicians surveyed at the CME course reported caring for a child with active TB during the study period.

Thus, the alternative surveillance strategy detected 30 (38%) cases of probable pediatric TB, including four with HIV or AIDS (Figure). Seventeen (57%) of these 30 children were correctly identified by ICD-9-CM codes for active TB, 17 (57%) by review of gastric aspirate logbooks, and one (3%) was detected by physician interview. The children with probable TB were more likely to have been detected by more than one alternative surveillance source (11 of 30) compared with the children without active TB (three of 48).

Cases detected by alternative surveillance sources and matched by the NYC DOH to the TB Registry

Matching with the NYC DOH TB registry revealed that 24 of 30 (80%) patients had been previously reported. Eighteen were confirmed as TB cases, 10 of whom were verified TB cases (six had positive cultures for *M. tuberculosis*) and eight of whom received a provider diagnosis of TB. Six were suspect TB cases, but were never confirmed and counted. Of the 30 cases, six (20%) had never been reported to the NYC DOH; one of these six children resided outside New York City and, while confirmed to be a TB case, would have

Figure. Classification of possible pediatric TB cases identified by alternative surveillance



This figure shows the final classification of 78 children detected by alternative surveillance sources as possible TB cases and the sources (not mutually exclusive) that yielded these cases. Cases were classified as unrelated to TB, latent TB infection (LTBI), TB disease, TB/HIV co-infection, or alternative diagnoses. In addition to the alternative surveillance sources shown, physician interviews yielded one case ([a]). The names of children with TB disease or TB/HIV co-infection were submitted to the NYC DOH Bureau of TB Control for matching with previously reported cases. Previously reported cases were classified by the Bureau as confirmed or suspect cases. Three suspect cases and two cases unknown to the Bureau were reclassified as alternative diagnosis or LTBI ([b]). The remaining suspect cases were reclassified by alternative surveillance as confirmed TB cases and, with the 4 newly identified cases confirmed by the NYC DOH, were assigned Reported Verified Case of TB (RVCT) numbers. One child ([c]), who was not a New York City resident and was treated at a city facility for less than four months, was unknown to the Bureau, while another child ([d]) was counted by another state agency but already known to the Bureau.

been countable by another jurisdiction. The diagnostic evaluations of these six suspect and six unreported cases were reviewed with the NYC DOH staff. One suspect and one unreported case were reclassified as having LTBI, three were reclassified with alternative diagnoses which included *Pneumocystis carinii* pneumonia, *Mycobacterium haemophilum* abscess and disseminated *M. avium* complex, and the remaining seven were classified as newly counted TB cases, including one case of TB/HIV co-infection previously reported to the Bureau of TB Control as a suspect case. Six children who resided in New York City were assigned RVCT numbers.

Cases not detected by alternative surveillance sources

In contrast, 19 additional children with TB had been identified by the Bureau of TB Control, but not detected by alternative surveillance. Of these, five were evaluated and treated for TB in 1991 and 1992, but added to the TB registry in 1993 and 1994 (two of these had incorrect ICD-9-CM codes assigned) and one child was older than 15 years of age. An additional five cases could not be evaluated as their medical records could not be located. Thus, the medical records of eight children younger than 15 years of age evaluated for TB from 1993 to 1995 were available for review, including one child with HIV infection. Alternative surveillance failed to detect four of these eight TB cases because the medical records department of two newly merged hospitals failed to identify them despite correctly assigned ICD-9-CM codes. The remaining four were evaluated only as outpatients and ICD-9-CM codes had not been assigned. None of the undetected cases were from the hospital that maintained a gastric aspirate logbook.

Thus, there were 33 evaluable cases of pediatric TB treated in our surveillance area from 1993 to 1995 among the five facilities in Northern Manhattan and Harlem. These included 18 (55%) confirmed cases, counted by the NYC DOH and found by our efforts; seven (21%) newly counted cases detected and/or confirmed by the alternative surveillance system; and eight (24%) cases undetected by our surveillance efforts, but previously reported to the NYC DOH.

Alternative surveillance data sources reviewed

The usefulness of the alternative surveillance sources was assessed. We compared the proportions of previously reported and confirmed TB cases with newly counted cases (i.e., unreported and suspect cases) detected by each source (Figure). Of the seven newly counted cases, three were detected by ICD-9-CM codes, three by the gastric aspirate logbook, and one by both (Figure). The proportions of both confirmed and newly counted cases found by each of the alternative surveillance sources were similar. We then analyzed the medical record sources reviewed for both groups (Table 1). The two groups had comparable proportions of hospital charts, radiography reports, and clinic charts reviewed. However, more microbiology reports were available for the counted cases than for the newly counted cases ($p=0.05$).

Comparison of demographic and diagnostic evaluations of TB cases

The demographic and clinical characteristics of the confirmed ($n=18$), newly counted ($n=7$), and undetected cases ($n=8$) were compared (Table 2). Fourteen (42%) of the 33 cases were female with a mean age of 4.8 years (range 0.25 to 13 years). Two-thirds were known to be U.S. born, although the place of birth was not found for six (18%) children. The foreign-born cases were from the Dominican Republic ($n=2$), Panama ($n=1$), Mexico ($n=1$), and Afghanistan ($n=1$). The racial composition of these children

Table 1. Medical record data sources reviewed for confirmed cases and newly counted cases of TB[a]

Data sources reviewed	*Confirmed cases (percent)* n=*18*	*Newly counted cases (percent)* n=*7*	p-*value*[b]
Hospital chart	18 (100%)	7 (100%)	1.00
Radiology	16 (89%)	6 (86%)	0.84
Microbiology reports	17 (94%)	4 (57%)	0.05
Pathology	0 (0%)	1 (14%)	0.29
Clinic chart	1 (5%)	1 (14%)	0.52

[a]Cases confirmed by NYC DOH Bureau of TB Control; newly identified cases include those unknown to the Bureau and suspect cases that were later classified as TB disease.

[b]Test of proportions.

Table 2. Comparison of demographic characteristics of confirmed, newly counted, and undetected cases of pediatric TB by alternative surveillance sources

Demographic characteristics	*Confirmed cases (n=18)*	*Newly counted cases (n=7)*	*Undetected cases*[a] *(n=8)*	*Total (n=33)*
Female (percent)	7 (39%)	5 (71%)	2 (25%)	14 (42%)
Mean age (range) in years	5.8 (1–13)	3.5 (0.25–10)	3.6 (1–9)	4.8 (0.25–13)
U.S.-born (percent)	14 (78%)	5 (71%)	3 (38%)	22 (67%)
Foreign-born[a] (percent)	4 (22%)	1 (14%)	0 (0%)	5 (15%)
Unknown (percent)	0 (0%)	1 (14%)	5 (62%)	6 (18%)
Ethnicity[a] (percent)				
Hispanic (percent)	9 (50%)	3 (43%)	4 (50%)	16 (48%)
Race[a] (percent)				
Black (percent)	8 (44%)	2 (28%)	2 (25%)	12 (36%)
Caucasian (percent)	10 (56%)	4 (56%)	0 (0%)	14 (42%)
Asian (percent)	0 (0%)	1 (14%)	2 (25%)	3 (9%)
Unknown (percent)	0 (0%)	0 (0%)	4 (50%)	4 (12%)

[a]Includes information obtained from RVCT records in NYC DOH TB registry.

was 36% black, 42% white, 9% Asian, and 12% unknown, with 48% of Hispanic ethnicity.

The diagnostic evaluations of the confirmed, newly counted, and undetected cases were also compared (Table 3). Cultures were positive for *M. tuberculosis* in seven (39%) of the confirmed cases and four (50%) of the undetected cases. None of the newly identified cases had positive cultures for *M. tuberculosis*. Overall, 27 (82%) of all cases had a positive TST. Nearly all cases had an abnormal chest radiograph (91%). Likewise, the majority of cases (85%) had abnormal physical findings. Of the 33 cases, 10 (30%) were tested for HIV, two (6%) were positive, and the results for 23 (70%) were not found. None of the children with a negative TST was known to be HIV-infected, and the two children with HIV or AIDS had a TST of ≥10 mm. Treatment with two or more TB medications was documented for all 24 patients, all of whom received three or more drugs. Identification of an infectious source case was rare in the surveillance sources reviewed.

DISCUSSION

Completeness of reporting studies such as the one presented allow assessment of the accuracy of existing surveillance as well as assessment of novel ways to enhance surveillance.[23] Matching of cases to registries to assess completeness of reporting, however, does have limitations, particularly for pediatric populations: investigators, for example, may not be aware of name changes. Much of the surveillance for infectious diseases has been passive surveillance, and therefore often incomplete.[24,25] More recent surveillance efforts, particularly for TB and HIV or AIDS, have been active, and have demonstrated improved reporting rates.[26–28]

While the completeness of reporting for TB in adults has been explored,[22,29–33] this study is the first assessment of completeness of reporting performed exclusively for a pediatric population. In general, morbidity and mortality rates for children (except for young infants) with TB are less than those for adults. Therefore, surveillance sources used in adult populations may not be appropriate for children. Furthermore, only 10% to 50% of children with TB have positive cultures. Thus, active surveillance for positive cultures does not capture all pediatric cases. In this study, none of the newly identified cases had positive cultures for *M. tuberculosis*. However, the complete identification of pediatric TB cases is important, as such cases are sentinel events.[4–6]

Previous completeness of reporting studies in adults have utilized a variety of sources. These have included medical records,[33,34] billing records,[33] death certificates,[35,36] pathology[37] and autopsy reports,[29,36] pharmacy records[38,39] and ICD-9-CM codes.[23,34,36] In addition, surveys of statutory notifications and local government TB registries have been used, as have surveys of physicians and clinics, supplemented with periodic audits of medical records.[27,29,31,36] Active surveillance of microbiology laboratories for positive *M. tuberculosis* cultures

Table 3. Comparison of the diagnostic evaluation of confirmed, newly counted, and undetected cases of pediatric TB as determined by alternative surveillance sources

Diagnostic evaluations	*Confirmed cases (percent)* n=*18*	*Newly counted cases (percent)* n=*7*	*Undetected cases (percent)* n=*8*	*Total (percent)* n=*33*
Culture for *M. tuberculosis*				
Positive	7 (39%)	0 (0%)	4 (50%)	11 (33%)
Negative	11 (61%)	6 (86%)	1 (13%)	18 (55%)
Unknown	0 (0%)	1 (14%)	3 (37%)	4 (12%)
Tuberculin skin test[a]				
Positive	15 (83%)	6 (86%)	6 (74%)	27 (82%)
Negative	3 (17%)	0 (0%)	1 (13%)	4 (12%)
Unknown	0 (0%)	1 (14%)	1 (13%)	2 (6%)
Abnormal chest X-ray				
Yes	17 (94%)	6 (86%)	7 (87%)	30 (91%)
No	1 (6%)	1 (14%)	1 (13%)	3 (9%)
Abnormal physical findings[b]				
Yes	16 (89%)	6 (86%)	6 (74%)	28 (85%)
No	2 (11%)	1 (14%)	2 (26%)	5 (15%)
Treatment ≥ two drugs				
Yes	9 (50%)	6 (86%)	7 (87%)	22 (67%)
No	1 (6%)	0 (0%)	0 (0%)	1 (3%)
Unknown	8 (44%)	1 (14%)	1 (13%)	10 (30%)
Known HIV-infected	0 (0%)	1 (14%)	1 (13%)	2 (6%)
Source case identified				
Yes	4 (22%)	0 (0%)	1 (13%)	5 (15%)
No	14 (78%)	6 (86%)	6 (74%)	26 (79%)
Unknown	0 (0%)	1 (14%)	1 (13%)	2 (6%)

[a]One reported, one unreported, and one undetected case had Tine tests placed. All three Tine tests were negative.

[b]Include pulmonary findings (e.g., wheezing, tachypnea, decreased breath sounds).

and pharmacies for mycobacteriology drugs has enhanced TB case detection.[23] However, alternative methods to improve case finding for TB have been variably successful, and increased rates from 1% to 94%.[27,34] The most reliable sources have been pathology and autopsy reports, followed by laboratory records and required physician reports. Less useful sources to assess completeness of reporting included ICD-9-CM codes and local government TB registries.

Both discharge ICD-9-CM codes and the gastric aspirate logbook proved useful in identifying cases of pediatric TB in this study. Previous studies have documented ICD-9-CM miscoding to be as high as 73%.[34] We found that ICD-9-CM codes were correctly assigned to 17 (68%) of 25 children with TB, and 36 (75%) of 48 children without TB were correctly assigned non-TB ICD-9-CM codes. In contrast, gastric aspirate records identified 17 of 25 (68%) children diagnosed with active TB, and 39 of 48 (81%) children initially suspected to have TB but ultimately diagnosed with other conditions. When compared to non-TB cases, cases of TB disease were not more likely to be identified with the surveys of gastric aspirate records ($p=0.23$). However, surveys of such records, for both negative and positive cultures, would still be helpful in timely identification of children with suspected TB to the NYC DOH. Surveys of ICD-9-CM codes could be used to assess completeness of reporting. However, these surveys are not as sensitive as active surveillance, since the assignment of diagnosis codes are made well after the management and discharge of the patient.

Co-infection with TB and HIV or AIDS has been less frequently observed in children than adults. Overall, two (6%) of 33 cases were co-infected with HIV; one of these was a previously reported (suspect) TB case, and the other was a confirmed case that had

been undetected by alternative surveillance. Numerous studies have emphasized the benefits of sharing information between healthcare agencies,[11,26,27,32] but this strategy can be difficult to implement due to patient confidentiality.[27] Previous studies have demonstrated under-notification of TB, ranging from 12% to 94%, in patients with known HIV infection or AIDS.[26,27,32] The inclusion of pulmonary TB as an opportunistic infection in the 1993 AIDS surveillance case definition improved the reporting of TB cases in adults with HIV or AIDS.[40,41] Therefore, sharing of patient identifiers between health care agencies may further improve the detection of additional cases of pediatric TB.

The NYC DOH makes continual efforts to improve surveillance for TB. Since 1986, the Bureau of TB Control has been performing active surveillance of clinical microbiology laboratories for cultures positive for *M. tuberculosis.*[42] Enhanced training of TB outreach workers, such as NYC DOH public health advisors, in performing contact investigations is a priority.[43] Educational campaigns have highlighted TB case reporting by health care professionals. In the past, the Bureau of TB Control has also identified hospital-based and community physicians specializing in HIV care, infectious diseases, and pulmonary medicine with an interest in TB to provide lists of active cases (Personal communication, M. Silin, April 2000). As shown in this study, these physicians may assist in clarifying the complete diagnostic evaluation and provide data to support an alternative diagnosis. Other efforts include the implementation of improved ICD-9-CM coding software, training of medical records personnel, and ongoing research to ensure accurate medical records management. Furthermore, targeted reviews of pathology reports for granuloma and acid-fast bacillus have been implemented recently.[44]

There are several limitations to this study. Not all alternative surveillance sources were available or complete and thus there were missing data. This limitation highlights the difficulty of using retrospective surveys to increase detection of unreported cases of TB. Not all children were tested for HIV. Although three organizations maintained lists of community-based physicians, we cannot accurately determine the proportion of such healthcare providers surveyed. Additionally, community-based and hospital-based physicians were interviewed two to five years after the study period, potentially decreasing their recollection of patients with TB. Finally, only one hospital maintained a gastric aspirate logbook, which limited our ability to fully assess the usefulness of reviewing gastric aspirate reports.

We suggest the following alternative surveillance strategies to improve case identification for pediatric TB. Periodic ICD-9-CM searches should be conducted to determine if results are more accurate now than during the study period, and the use of Current Procedural Terminology (CPT) codes[45] may supplement this strategy, particularly for children managed as outpatients. In addition, infection control personnel could periodically survey medical records administrators for cases of TB. Since most children with active TB have negative gastric aspirate cultures, surveillance of positive cultures only is insufficient. Therefore, audits of gastric aspirate logbooks, which are not universally employed but are easy to implement, might help detect potential cases (as we have shown).[46] As chest X-ray reports are frequently found in computerized medical records, reports with suggestive terms (e.g., hilar adenopathy) could trigger timely medical record review.[47,48] The same approach could be applied to laboratory data, whereby medical informatics could tag biopsy reports (e.g., granuloma or acid-fast bacilli) or gastric aspirate reports as well. Finally, joint medical chart reviews by health care professionals from hospitals, clinics, and city agencies could be reserved for equivocal cases and to assess the efficacy of the alternative surveillance methods.

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