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Childhood Asthma Surveillance Using Computerized Billing Records: A Pilot Study

SYNOPSIS

Objective. This paper describes a pilot project to develop and implement a lowcost system for ongoing surveillance of childhood asthma in Milwaukee County, Wisconsin.

Methods. The authors organized a planning workshop to solicit information and ideas for an asthma surveillance system, bringing together national experts with Milwaukee professionals and community representatives involved in the prevention and treatment of asthma. Based on recommendations from the workshop, a pilot surveillance project was implemented in Milwaukee County using records of emergency room visits and hospital admissions for asthma abstracted from the computerized billing records of the Children's Hospital of Wisconsin (CHW), retrospectively for 1993 and prospectively for 1994. Retrospective data were also sought from the other hospital emergency departments in Milwaukee County to evaluate the representativeness of the CHW data. Surveillance data were used to evaluate utilization of care by patient subgroups and to describe temporal patterns in emergency room visits.

Results. Of the emergency department visits for asthma in Milwaukee County in 1993, CHW accounted for 94% among infants less than 1 year of age, 89% among children ages 1 through 5 years, and only 59% among children between the ages of 6 and 18 years. In 1994, the 7% of asthmatic children with repeat hospital admissions accounted for 38% of all hospital admissions for asthma and the 20% with repeat emergency department visits accounted for 50% of all emergency visits. Emergency visits for asthma showed clear seasonality, with a peak in the fall and a smaller peak in the spring.

Conclusions. Computerized medical billing data provide an opportunity for asthma surveillance at a relatively low cost. The data obtained are useful for tracking trends in exacerbations of asthma and the use of medical services for asthma care and should prove valuable in targeting interventions.



sthma is the most common chronic disease of childhood, affecting an estimated 4.8 million children in the United States.¹ Increasing asthma morbidity and mortality in this country have been well documented.²⁻⁶ In particular, asthma has emerged as a major health problem among the children of America's inner cities.⁷⁻¹⁰

Exacerbations of asthma cause 470,000 hospitalizations annually.¹¹ We lack good data on the number of emergency department visits for asthma, but it is certainly far greater than the number of hospitalizations. These severe instances of acute exacerbation have major adverse effects on the health and

finances of people with asthma and their families. Current evidence also suggests that exacerbations of asthma can induce irreversible changes in the airways.^{12,13} Adequate control of airway inflammation can both reduce the need for costly emergency department visits and hospitalizations and reduce the acute and chronic effects of the disease. Furthermore, control of an acute exacerbation requires higher doses of potentially harmful medication than prevention of the exacerbation.^{14,15}

A central goal of any effort to control asthma should be to reduce the rates of emergency department visits and hospital admissions. Therefore, an accurate characterization of patterns of emergency care and hospitalizations for asthma in a particular community is extremely important in the design and implementation of prevention programs as well as critical in evaluating the long-term impact of these programs.¹⁶

Systematic asthma surveillance is not currently practiced in the United States. Occasionally, astute clinicians may recognize epidemics of asthma exacerbations such as those occurring in New Orleans in the 1950s and 1960s¹⁷ and Barcelona in the 1980s.¹⁸ In each of these cases, as typically occurs, the outbreak did not come to the attention of public health agencies until well after it began, limiting opportunities for rapid public health interventions. Passive reporting provides only sporadic information, may miss important outbreaks, and does not provide ongoing information to the community. Active surveillance based on extraction of data from medical records can provide more continuous data on exacerbations of asthma, but is costly and

labor-intensive.¹⁹ In addition, the time required for manual extraction of records may mean that data can not be made available to public health decision makers in a timely manner.

This paper describes a collaboration between the Wisconsin State Division of Health and the Medical College of Wisconsin to develop a system for childhood asthma surveillance in Milwaukee that might be adapted for use in other cities in the United States. We sought to develop a low-cost system for surveillance of asthma exacerbations that could provide useful, timely information to those providing care for children with asthma. In what follows, we describe the development of a protocol for asthma surveillance, the implementation of that protocol, and the type of data that were generated through surveillance. Finally, we offer a set of recommendations for the implementation of a surveillance program based on medical billing data.

Methods

Planning. In order to make the surveillance program as use-

ful as possible to the Milwaukee community, we convened a workshop in February 1994 to bring state and national experts on asthma surveillance and intervention together with members of the Milwaukee community involved in asthma prevention and control. More than 30 health care, educational, government, and community organizations were represented at the workshop. During the course of the meeting, participants met in small groups to make recommendations for a surveillance program. These recommendations were summarized on the final day of the workshop, revisions were proposed, and a surveillance protocol was endorsed by the community members.

The recommended surveillance protocol relied on the use of computerized data that were already being collected by hospitals (including emergency department records), community clinics, and health maintenance organizations (HMOs). The primary tool for ongoing surveillance were

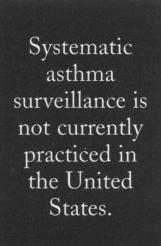
> the billing data for emergency department visits and inpatient admissions to Children's Hospital of Wisconsin (CHW). The choice of CHW was based on our analysis of data from the Hospital Discharge Data Base maintained by the Wisconsin Office of Health Care Information, which indicated that more than 90% of inpatient care for asthma in Milwaukee County in 1992 was provided by CHW.

> In addition to the prospective data from CHW, retrospective data were collected from other hospital emergency departments, community clinics, and HMOs throughout the city. These data were analyzed to: (a) evaluate how well the data from CHW represented patterns of asthma exacerbation in the entire city; (b) charac-

terize temporal patterns of asthma in Milwaukee County; and (c) describe subgroups of children with asthma according to their patterns of utilization of care.

The planning meetings also led to the establishment of an active community group. The formation of the Milwaukee Area Asthma Coalition (later renamed Fight Asthma Milwaukee) was an important but unexpected outcome of the project. This coalition was created as a direct result of the early planning meetings for the surveillance workshop and now operates independently to plan and coordinate projects to reduce the prevalence of asthma and its social, psychological, and economic costs. It has almost 300 members and has obtained outside funding for its activities, which include a major role in an inner-city asthma intervention project funded by the Centers for Disease Control and Prevention.

Prospective data collection. On the basis of recommendations from workshop participants, we decided to use CHW as the primary source of surveillance data and made arrangements to obtain current patient billing data from



CHW beginning in March 1994. We also requested retrospective data back to January 1, 1993. Once the data abstraction procedures were established, we obtained monthly datasets as soon as the billing records for each month were complete, usually two weeks after the end of the month. The following data elements were requested for each patient seen in the emergency department and given a diagnosis of asthma:

- Name and address
- Age, ethnicity, sex, and date of birth
- Admission and discharge dates
- Social Security number and medical record number
- Mother's name, address, and Social Security number
- Admission source
- Primary and secondary diagnosis
- Length of stay (for hospital admission)

By the summer of 1994, approximately six months after the start of the project, a computer operator at CHW was abstracting the desired data on a monthly basis and sending it to us on a floppy disk in standard ASCII, comma delimited, format.

Retrospective data collection. Participants in the planning workshop compiled a list of institutions in Milwaukee County providing urgent and emergency asthma care for the 259,000 children in Milwaukee County under the age of 18.²⁰ Discussions during the workshop also indicated that a full year of data for all identified institutions would be practical only for 1993, the year before the workshop.

Following the workshop, we requested data from the billing records of each of eight hospital emergency departments and four community-based clinics. We requested that each institution provide the following data elements for each visit by a patient under 19 years of age with a primary diagnosis of asthma (*ICD-9-CM* code 493):

- Diagnostic code
- Date of visit
- Medical record number
- Zip code of residence
- Sex, ethnicity, and date of birth (or age)

The workshop participants had also identified four HMOs as potential sources of relevant data. We contacted these HMOs and arranged for them to provide the same data to determine if HMO records might be useful for surveillance purposes. Because of concerns about confidentiality raised by the HMOs, we arranged for a formal Memorandum of Understanding (MOU) from the Wisconsin Division of Health based on the right of access to medical data for public health purposes.

All identified sources except one community clinic provided data. One dataset provided on a computer tape had many missing values and was presented in a format that proved extremely difficult to edit; therefore, it was not used. Five sites could provide data only in the form of computer printouts. These were scanned, but only three could be read by optical character recognition software and thus could be used in the study. Overall, 11 of the 15 potential data sources provided usable datasets.

Data analysis. We conducted descriptive data analyses with several goals: (a) to determine the extent to which the data from CHW described emergency asthma care for inner-city and non-inner-city children in Milwaukee County; (b) to describe the utilization of inpatient and outpatient asthma care in the city; (c) to examine temporal patterns of asthma exacerbations in the city.

Comparison of CHW data to data from other emergency departments. We evaluated the degree to which the CHW data represented emergency care for asthma in Milwaukee County using the retrospective data from other emergency departments in the city. We first compared the proportions of asthma care provided by CHW and by other emergency departments for inner-city and non-inner-city children in each of three age groups (younger than 1 year, 1-5, and 6-18). Children were classified as living in the inner-city if the per capita income of the zip code area of their place of residence was less than \$12,000 per year.¹⁹ We also calculated the correlation between daily counts of visits to CHW and combined daily counts of visits to all other hospital emergency departments around the city. Similar correlations were calculated after stratification into inner-city and noninner-city children.

Utilization of care by patient subgroups. We concluded, based on the predominant role that CHW plays in providing urgent care for asthma, that care at CHW was a reasonable surrogate for care in the city as a whole. We grouped children visiting CHW in 1994 into four categories defined by whether they had repeated hospital admissions, repeated emergency department visits, both, or neither. These groupings were based on the notion that repeated hospital-based care for asthma would frequently represent inappropriate use of care and that these children would be an important target for intervention. We also believed that repeated use of emergency departments without repeat hospital admissions indicated a different set of problems (such as use of emergency department facilities for primary care) from repeated hospital admissions, which represent more severe exacerbations. We used patient identifiers included in the data to determine the number of emergency department visits and hospital admissions for each child. For each of these four groups, we calculated the ratio of emergency department visits to hospital admissions.

Temporal patterns in emergency room visits. Finally, we plotted one year of emergency department visits for inner-city and non-inner-city children. We smoothed the data with a

Table 1. Emergency department visits for asthma by service provider and location of residence, Milwaukee (County,
1993	-

Age	Provider	Inner-city		Non-inner-city		Total	
		Number	Percent	Number	Percent	Number	Percent
<1	CHW	226	93	118	97	344	94
	Other	17	7	4	3	21	6
I – 5	CHW	1023	86	1000	91	2023	89
	Other	162	14	99	9	261	11
6 – 18	CHW	1042	52	743	71	1785	59
	Other	946	48	303	29	12 49	41
Total (0 – 18)		3416	100	2267	100	568	100
	CHW	2291	67	1861	82	4152	73
	Other	1125	33	406	183	1531	27

NOTE: The inner city in Milwaukee was defined as those zip code areas with an average per capita income below \$12,000.¹⁹

CHW = Children's Hospital of Wisconsin

Other = Columbia Hospital, St. Joseph's Hospital, St. Luke's Hospital, St. Mary's Hospital, Sinai-Samaritan Hospital, and West-Allis Memorial Hospital

seven-day moving average. We also plotted the data for the most recent month without smoothing.

Results

Comparison of CHW data to data from other emergency

departments. As shown in Table 1, our data confirmed that CHW provided the vast majority of asthma care for children in Milwaukee County. However, while CHW provided 89% of the emergency asthma care for children under 6 years of age, it provided only 59% of care for children older than 6.

Children from ages 6 to 18 years old who lived in the inner city received 52% of their emergency care at CHW. These numbers represent a slight overestimate of care delivered by CHW because detailed data could The 20% of children with repeated emergency department visits accounted for 50% of all emergency department visits while the 7% of children with repeated hospital admissions accounted for 38% of all admissions.

city for both inner-city and non-inner-city populations. The correlations between daily counts for CHW and counts for all other sites combined was 0.91 for the inner-city population and 0.90 for non-inner-city patients. On the basis of these data, it appears that our decision to use data from CHW for surveillance purposes was reasonable.

Utilization of care by patient subgroups. Table 2 shows the number of emergency department visits or hospital admissions attributable to four groups of asthmatic children under age 18. The largest group, with 76% of the children, Group A, had no repeat admissions or emergency department visits and accounted for about half of all admissions and emergency department visits. Group B (>1 emergency department visit, 0-1 admissions) included 17% of the children and accounted for

not be obtained from one of the seven hospital emergency departments in the city. However, the data that could be obtained from this site showed that it was a relatively small department accounting for less than 2% of the emergency asthma care in the city and its inclusion would not have altered these values significantly.

Variations in daily counts of emergency department visits for asthma to CHW in 1993 were closely associated with daily counts from other emergency departments around the 41% of emergency visits but only 8% of hospital admissions. Group C (0-1 emergency department visit, >1 admission), with 5% of the children, accounted for 22% of hospital admissions but only 1% of emergency department visits. Finally, the 3% of children who comprised Group D, who had both repeated admissions and repeated emergency department visits, accounted for 16% of admissions and 9% of emergency department visits.

The ratio of emergency department visits to hospital

Patient group:				Total 1994 ED visits and hospital admissions						
					accounted for by patients in each group				Ratio of ED visits to	
	ED visits þer year		Patients		ED visits		Admissions			
			Number	Percent	Number	Percent	Number	Percent	admissions	
Α	0–1	0–1	2889	75.5	2036	48.2	1041	54.1	1.96	
В	>	0-1	657	17.2	1734	41.1	154	8.0	11.26	
С	0–I	>1	182	4.8	60	1.4	418	21.7	0.14	
D	>1	>1	100	2.6	390	9.2	311	16.2	1.25	
Totals .			3828	100	4220	100	1924	100	2.19	

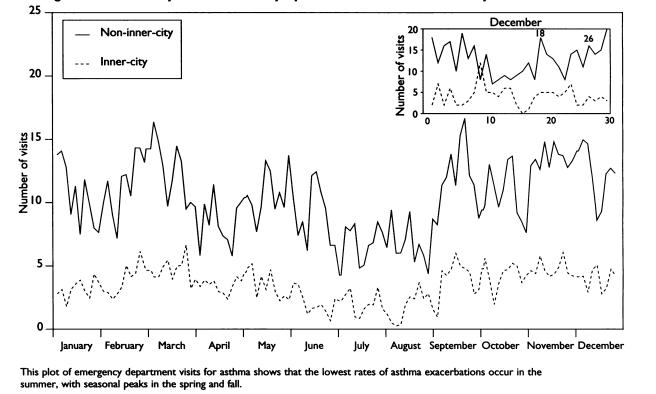
Table 2. Hospital admissions and emergency department (ED) visits for asthma by four subgroups of patients defined based on repeat admissions and repeat ED visits, Children's Hospital of Wisconsin, Milwaukee, 1994

admissions ranged from 0.14 for Group C to 11.3 for Group B. Overall, the 20% of children with repeated emergency department visits accounted for 50% of all emergency department visits while the 7% of children with repeated hospital admissions accounted for 38% of all admissions.

Temporal patterns of emergency room visits. The Figure shows the counts of daily emergency and urgent care visits to CHW for asthma in 1994. The inset shows data for the month of December without smoothing. The dates with the highest daily counts are indicated. The data showed wide fluctuations in daily counts ranging from 5 to 12 visits per day for the inner-city children and from 0 to 7 visits per day for non-inner-city children. The highest rates occurred in the spring and fall of the year. In an ongoing surveillance system, this format would be used for monthly reports to provide both a detailed picture of asthma visits over the short term and a broader picture of patterns in these rates over the long term.

Surveillance costs. Initial set-up of the system required one full-time equivalent (FTE) employee to organize data and

Figure 1. Asthma surveillance data for 1994 showing daily counts of emergency department visits for children under age 19 from inner-city and non-inner-city zip code areas in Milwaukee County



work with sites providing data, a half-time employee (1/2 FTE) for data management and analysis, and 1/4 FTE from a supervisor. Once a system is operating smoothly, we expect it would require 1/4 FTE from a data manager with occasional input from a supervisor.

Discussion

This model for asthma surveillance, designed with extensive input from members of the Milwaukee community responsible for the care of children with asthma, provided timely information on asthma exacerbations. Our initial experience in developing this model indicates that computerized billing records can provide a useful tool for asthma surveillance at a relatively low cost.

Interpretation of these data requires assumptions about their validity. In our surveillance system, the strong correlation between the CHW data and the data from other emergency departments suggested that they were measuring similar aspects of asthma care, but the limited time and funding for this project did not allow for more detailed data validation. Although medical records appear to be a useful tool for asthma surveillance, additional research is needed

on the validity of billing data. Specifically, an analysis of the accuracy of diagnoses in the billing data using medical records for comparison would have been extremely useful for this project and should be undertaken in future studies.

In addition to providing information on the rates of serious asthma exacerbations, surveillance could also be used to identify subgroups of children for whom intervention would be desirable. We were able to identify different subgroups of children who make radically different use of available medical care. Only 25% of children had repeat hospital admissions or emergency department visits, but they accounted for 52% of emergency department visits and 46% of admissions. One group (Group B in Table 2) appeared to use the emergency department visits for each hospital admission. Clearly, this group should be the target of interventions to improve disease management and access to care.

We found that in Milwaukee most of the asthma care for infants and younger children was delivered by one specialized pediatric emergency department. In other cities in which this is true, interventions designed to reach parents of young children with asthma can reach a high percentage of their target population if they are conducted at these specialized facilities. Older children, on the other hand, are substantially less likely than younger children to receive their care at specialized pediatric emergency departments. Surveillance based on data from a small number of specialized emergency departments will be less representative for older children and interventions intended to reach older children will miss many children if they are limited to specialized pediatric emergency departments.

The data collected demonstrated clear seasonal variation in the exacerbation of asthma in the city. A comprehensive program to reduce the frequency of asthma exacerbations should include efforts to understand the factors responsible for these peaks and interventions to reduce them. Ongoing surveillance could be extremely useful in the planning and evaluation of any such effort. We experienced a one-month

Our initial experience in developing this model indicates that computerized billing records can provide a useful tool for asthma surveillance at a relatively low cost. time lag in the availability of data. In the future, we anticipate that surveillance data of this type could be available as soon as a patient is admitted. This would open up the possibility of public health interventions to control an outbreak of asthma exacerbations as it is occurring.

The start-up costs for the surveillance system were relatively low and the maintenance costs should be substantially lower. Costs in other cities will vary as a function of the number of

emergency departments involved and the degree to which those sites are computerized. Once the necessary database management and statistical analysis programs have been written, the costs of maintaining a surveillance system will be reduced dramatically. Data abstraction will require only a few hours each month from the medical data managers at each of the sites in the surveillance network. The data manager at the coordinating site will need from several hours to a full day or more each month to download the data, run data analyses, and distribute results—special reports or analyses will increase the time required. Additional sites and special requests for programming and analysis will increase personnel requirements.

Adapting the model to other communities. This model should be transferable to other cities in the United States. We offer the following advice to those seeking to adapt this model to their own community.

Hold a preliminary planning meeting (or meetings) with community members responsible for caring for children with asthma. This will facilitate acceptance of the project by the community, aid in the identification of contact people for the data collection process, and may provide the opportunity for ongoing collaborative efforts to control asthma (in our case, the formation of Fight Asthma Milwaukee).

It may be possible to reduce cost and complexity by limiting surveillance to a small number of large pediatric emergency departments. Each additional site from which data are required will increase the cost and complexity of the surveillance system. In many cities, a few institutions will provide the great majority of emergency asthma care. Focusing on these sites can simplify surveillance and may have little impact on the quality and completeness of the data collected.

Be prepared for problems related to the confidentiality of data. A Memorandum of Understanding from public health officials may be particularly useful in allaying concerns relating to confidentiality of the data. (The authors will provide a copy of the one used for this study on request.)

Allow at least one year for planning and development before the initial implementation of a surveillance system. Our surveillance system was not running smoothly until almost a year after planning began. A system including more hospital emergency departments should be expected to require even more time.

In the budget, include money to compensate institutions providing data for the staff time required to abstract data. We did not include these costs in our budget. As a consequence, providing data was a low priority for these institutions. We would not have been able to maintain surveillance over a longer period without some regular compensation. These costs will be relatively small.

Overall, the project described above demonstrated the ways in which medical billing data might be a valuable tool in asthma surveillance. These data are available at a relatively low cost and may provide useful information for planning and evaluating interventions to provide more efficient and effective preventive and therapeutic care for children with asthma. Improvements in the detail, quality, and accessibility of medical billing databases will increase the utility of this method for surveillance purposes.

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