Implementing a Chronic, Noninfectious Disease Surveillance System:
A Pilot Study Focusing on Childhood Asthma

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Introduction

In order to continually assess the health of the population the United States or the Federal Government operates a public health surveillance or disease monitoring system. This surveillance system grew out of concerns in the early 20th century about potential infectious disease outbreaks (Brownson, Remington, and Davis, 1993). Today, the main morbidity surveillance systems centers on the national compilation of notifiable infectious disorders. The Council of State and Territorial Epidemiologists in collaboration with the Centers for Disease Control and Prevention (CDC) decides what conditions are "notifiable." Diseases such as sexually transmitted diseases and influenza are examples of the type of infectious disorders included. Health care practitioners are required by law to report such diagnosed conditions to their state department of public health. The states in turn report these disorders to the CDC. Weekly reports on disease incidence (Morbidity and Mortality Weekly Reports or MMWR) are compiled and released both as hard copy and now on the Internet by CDC. These data provide an effective means of monitoring infectious disease patterns and to identify potential outbreaks or epidemics (Stroup and Tevtsch, 1998). However effective, this system only involves infectious disorders. We have recently seen some efforts at the national level to monitor noninfectious conditions. For example, cancer registries are becoming more widespread. We have also seen an effort to monitor risk factors in our population as evidenced by the Behavioral Risk Factor Surveillance System (CDC, 2000). Other national data sources exist such as the
National Health Interview Survey (MMWR, 2000). None of the above mentioned activities, however, contain the three essential characteristics needed for to have an effective chronic noninfectious disease surveillance system: 1) total coverage, 2) fast turnaround time, and 3) a focus on the specific disorder in question. Overall, when one examines all of the attributes needed for a disease surveillance you would see that a functional system is dependent on:

1) the inclusiveness of the reporting;

2) a centralized analysis and reporting system;

3) quality control for data collection and transmission;

4) rapid turnaround or reporting time; and

5) data focus and data utility.

Examining one specific chronic noninfectious condition may help to illustrate some of the inherent problems with our currently available system. Asthma is one of the most common chronic, noninfectious disorders among children and a leading cause of disability in this age cohort (MMWR, 1995). The main source of data we have available on asthma in children comes from the National Health Interview Survey (MMWR, 2000). The National Health Interview Survey (NHIS) is a patient or household interview survey. NHIS does not examine medical records or conduct an abstracting of clinical data. Rather, a sample of households in the U.S. is randomly selected and interviewed. Prior to 1997 a classification of asthma in a child was based on the question, "During the prior 12 months did anyone in the family have asthma?"

All of our estimates indicating a significant rise or increase in the prevalence of asthma in children was based on these reports. In 1997 NHIS was redesigned and focused on a diagnosed case. Specifically, the question was stated now as, "Has a doctor or other health professional ever told you that your child has asthma?"
Based on this change of question wording we witnessed a dramatic down turn in asthma prevalence from 1996 to 1997. The point of this example is that to establish accurate estimates of a disease prevalence clinical records are needed. Survey data, although an adequate snapshot of the health status of a population, do not provide accurate measurements. In essence there are no true disease monitoring system exists in the U.S. which would provide us timely data on changes in chronic, noninfectious disease prevalence rates.

A traditional view point might be that unlike infectious disorders whose prevalence could change quickly based on the classic outcome in the agent - host - environment interchange, chronic noninfectious conditions are not as dynamic and reflect a more stable rate. Consequently, a surveillance system is unnecessary. Two particular points, however, can be raised to counter that traditional argument. First, certain conditions, such as childhood asthma, are felt to have etiological connections to the environment (Institute of Medicine, 1999). If changes in the relevant part of the environment alters the disease rates themselves could correspondingly alter. Without a disease surveillance system we would not know. Second, since we have not had operational a clinical-based records system monitoring chronic, noninfectious diseases it is not known accurately how static or dynamic true prevalence estimates are. Remember, we witnessed a drop in prevalence in childhood asthma between 1996 and 1997 based on a change of question wording made in the NHIS.

**Design and Methods**

A number of chronic, noninfectious disease in this country are perceived to be on the rise. For example, both Parkinson's Disease and childhood asthma are estimated to have significantly higher prevalence rates now than 15 years ago. But, as stated earlier, we actually
have no way of accurately assessing the changes in the prevalence at the state level of such conditions. How difficult would it be to design and implement such a system? In order to determine how such a system could be implemented an exploratory investigation was designed and launched.

The primary objectives of this exploratory investigation were to determine: 1) how to access the appropriate clinical data at primary care sites, and 2) the degree of difficulty in abstracting the required data. The secondary objective was to broadly assess any possible environmental connections to the disorder in question. Consequently, we selected childhood asthma (ICD 493) as the chronic, noninfectious disease for this exploratory effort. As mentioned previously, asthma is felt to environmental connections. The only environmental feature we could control for was possible agricultural pesticide exposure. Consequently, we selected two clinics from contrasting regions in Mississippi. One clinic is located in the Delta, a region of high agriculture pesticide use. The other clinic is primarily located in the non-Delta region of the state where pesticide use is documentedly lower. Although this clinic does have a small satellite site in the Delta, we abstracted place of residence to account for this. A one page abstracting form was developed. The administrators at the two sites were briefed on the diagnostic category and the abstracting form. The key independent variables collected involved residential location and family history of asthma in addition to age, age of onset, and gender. Now, it should be clearly stated that such a disease monitoring system in and of themselves can not be directly used for etiological studies or testing causal models. These data, however, can be extremely useful if continually collected over time; if incidence rates (new cases) change over time there is obviously a change occurring in the distribution of risk (causal) factors.
After training, the staff was told to conduct a point in time abstracting of all asthma cases of children 14 years and younger. This age limitation was suggested by an adolescent health specialist. The data were collected during the last two weeks of November and the first two weeks of December, 2000.

Results

The data collected were anonymous as no identifier was recorded. Both clinics received approval for this medical records search by the Executive Board. Neither clinic site has an electronic patient medical records system. The Delta site is partially computerized, while the in the non-Delta site utilized manual or hard copy medical records. Consequently, the records search took quite some time to accomplish. It should not be assumed that all small primary care clinics in this country electronically process their patient records. A meaningful proportion of these clinics still rely on manual medical records.

In order to make the data comparable between sites, rates were calculated. The numerator used was the number of actual diagnosed cases in the patient panels. The denominator in the estimated total number patients in that age cohort (< 14 years) enrolled in that particular clinic. The following table lists the results from the medical records search on childhood asthma.

Table 1

Point Prevalence Rates of Childhood (< 14 years) Asthma in Contrasting Clinical Sites

<table>
<thead>
<tr>
<th>SITE</th>
<th>LOCATION</th>
<th>RATES PER 1000 *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic A</td>
<td>Hills</td>
<td>33</td>
</tr>
<tr>
<td>Clinic A</td>
<td>Delta</td>
<td>64</td>
</tr>
<tr>
<td>Clinic B</td>
<td>Delta</td>
<td>56</td>
</tr>
</tbody>
</table>

*Estimates
These results strongly indicate an association between region of residence and the prevalence of childhood asthma with children residing in the Delta having a higher prevalence rate than children residing in the non-Delta. These findings, however, have to be viewed with some caution. First, these two (3) clinics investigated may not necessarily be representative of all rural clinics in Mississippi let alone the nation. Second, we are only dealing with a statistical association as no causal references between these rates and any independent variable, such as agriculture pesticides, can be made.

All patients at the two sites were African American. No gender difference in prevalence was observed. However, roughly 70 percent of the cases reported a family history of asthma; this is a very high proportion of the population reporting a family history. Obviously, we cannot make any reference whether there is any genetic component involved here or a lifestyle issue. The finding though is interesting.

**Discussion**

From an epidemiological perspective this exploratory study provides us with a strong basis to further investigate an environmental childhood asthma connection. That though, was our secondary objective. Our primary objectives were to develop and implement an abstracting system that would resemble a chronic, noninfectious disease surveillance system. This was accomplished but not without some difficulty.

Medical records are not easily accessible in some primary care clinics, making manual searches necessary. Transmission of the abstracting forms was done through the mail with response times varying.

If a chronic, noninfectious disease management system were implemented, a retrospective collection and analysis of data should not be required. The format should be similar
to the infectious disease system (notifiable conditions) now used by CDC. Notification or reporting could be mandated at an agreed date. Such a prospective monitoring system would be valuable to assess the point in time status of a wide range of chronic, noninfectious conditions. We would no longer have to rely on self-reported surveys or registries with less than total coverage. As stated earlier, disease surveillance systems should not be used to test etiological models of disease causation, but they provide the basis or impetus to design and launch studies.

REFERENCES CITED


Institute of Medicine, Toward Environmental Justice, National Academy Press, 1999.