Accuracy of Birth Certificate Data for Detecting Facial Cleft Defects in Arkansas Children

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A comparison of facial cleft defects reported on birth certificates during the period 1943 to 1974 that were reported on birth certificates was made with records maintained by the Arkansas Crippled Childrens Services (CCS). A total of 506 cases were reported of which 331 (65%) were recorded on the birth certificate. Moreover, the accuracy of the reporting was not good. Only 243 (48%) cleft malformations were correctly classified on the birth certificate. Birth certificate information is an inadequate measure of the true facial cleft occurrence in Arkansas. Caution must be exercised when this data source is used in epidemiological surveys because over one-third of such defects were not recorded. These findings serve to reemphasize the national need to improve the quality of such vital health statistics sources.

Introduction

Thorough and well-designed epidemiologic studies are desirable from the standpoint of scientific accuracy and precision, but many health care programs are designed with only the most primitive and economical of data bases as a point of departure.

Health programs are particularly subject to dependence upon vital records. Capitation grants, matching funds, and categorical aid programs are based in large part upon knowledge of populations and the incidence and/or prevalence of various conditions and diseases. If case ascertainment is incomplete, then we underestimate the burden imposed upon communities by the conditions and, therefore, do not plan for programs of adequate magnitude or scope.

One example of the vital records upon which health planning depends is the birth certificate. In the United States, revision of the format, along with increased attention to detail in completion of the form, has resulted in an improved document of considerable import. However, the birth certificate is not without its problems. The accuracy and completeness of the information varies from time to time, from place to place, and from informant to informant.

One use to which birth certificate data have been put is the determination of the incidence of congenital defects. A numbers of studies have pointed out the error of accepting birth certificate entries for this purpose (Lillienfield et al., 1951; Oppenheimer et al., 1957; Montgomery et al., 1962; and Ivy, 1963). The major problem, that of under-reporting, has been demonstrated for both obvious and subtle anomalies. Even the grosser, more easily recognized malformations which are noted more frequently (Bock and Zimmerman, 1967; Khalili et al., 1970; Mackeprang and Hay, 1972) may not be recorded on the certificate. In fact, some states do not require the reporting of congenital malformations on the birth certificate. Khalili and co-workers (1970) pointed out that under-reporting cannot be explained simply by assuming the defect to be either unapparent at birth or a manifestation of postnatal development.

Investigators have demonstrated this problem by comparison of birth certificate information with actual hospital records (Oppenheimer et al., 1957; Montgomery et al., 1962;
Bock and Zimmerman, 1967; Babbott and Ingalls, 1962; Gullen et al., 1967; Mackeprang et al., 1972) with infant death certificates (Khalili et al., 1970), with hospital diagnostic indices (Milham, 1963), with treatment program records (Milham, 1963; Venters et al., 1976), or with a combination of sources (Emanuel et al., 1973).

We were interested in evaluating the possible causative role of a chemical agent in cases of cleft palate, and we attempted to discover the incidence of this disorder in the state of Arkansas. Armed with frequency data generated in the present study, we planned to proceed with epidemiologic analysis to determine the effect (or lack thereof) of the agent. We had planned to ascertain cases by extracting information about the occurrence of the defect from birth certificates in the belief that cleft palate would be noted with a reasonable degree of accuracy and completeness on birth certificates in Arkansas.

Previous surveys of birth certificate entries for facial clefts, however, were not reassuring. In 1962, Babbott and Ingalls found that over half of the cases were not reported in two small samples. Milham noted in 1963 that birth certificates identified only 63% of these cases. Khalili et al. (1970) discovered that only 57% of the total facial cleft cases were recorded on birth certificates. Emanuel and coworkers (1973) reported that 67% of cases of facial cleft were found by a search of birth certificates, and Mackeprang et al. (1972) found that, even when clefts were reported, up to 12% contained inaccurate descriptions of the anomaly. Meskin and Pruzansky (1967) pointed out that completeness of reporting increased with the severity of the cleft defect.

In an effort to ascertain the adequacy of the birth certificate for determining incidence of facial clefts in Arkansas, we chose to compare data from this source with an entirely independent source. Evaluation and comparison of the two sources were performed with respect to the birth certificate having recorded the occurrence of cleft lip or palate, which would be noticeable upon any reasonable examination of the newly-born infant.

Materials and Methods

In addition to the birth certificates as filed in the Vital Records Section of the Arkansas Department of Health, we reviewed records of the Crippled Children's Services (CCS), a division of the Arkansas Department of Social and Rehabilitative Services. Many children with facial clefts are evaluated and treated under the CCS program, and children with such defects in all parts of the state are likely to be referred to the program.

Cases of cleft lip and/or cleft palate were obtained from CCS records dating from 1943 to 1974, yielding 506 Arkansas-born children.

Birth certificate notations of the specific defect (whether lip, palate or both) were compared with records of the (presumably) more detailed examinations by CCS personnel. The CCS diagnosis was accepted as correct when the two sources were not in agreement.

Results

During the period under study, 175 of the 506 (35%) children with facial clefts in the CCS records had no cleft defect noted on their birth certificates. This is in general agreement with the data of Milham (1963) in which 37% were missed and of Emanuel et al. (1973) in which 33% were not recognized and recorded on the birth certificates. The total number of malformations correctly identified on the birth certificates was 243 (48%). The sensitivity of the birth certificates was 58% (131/222) for cleft lip and cleft palate, 53% (56/105) for cleft lip, and 31% (56/179) for cleft palate only. (Table 1). As expected, the cleft malformations were more often noted as the seriousness of the defect increased. That is, cleft palate alone was often missed, and cleft lip with cleft palate was more often noted. None of the percentages above take into consideration the number of children who were correctly identified as not having cleft malformations. The sample is based on those children who were seen at Crippled Children's Hospital only.

We believe that there is good evidence that underreporting of these defects is a real problem. In the time period from 1943 to 1948, the cleft incidence was .525/1000 live births. This increased to 1.034/1000 live births in between 1955 and 1960. Also, considering all 1201 cases identified by either birth certificates or CCS records or both, the number of cases seen by CCS between 1943 and 1948 was only 19% of the total clefts studied. This percentage increased steadily to 67% between

<table>
<thead>
<tr>
<th>Birth Certificate Classification</th>
<th>Cleft Lip</th>
<th>Cleft Palate</th>
<th>Cleft Lip &amp; Palate</th>
<th>Percentage of Correct Recognition on Birth Certificates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft Lip</td>
<td>87</td>
<td>3</td>
<td>28</td>
<td>64.4</td>
</tr>
<tr>
<td>Cleft Palate</td>
<td>91</td>
<td>56</td>
<td>27</td>
<td>61.5</td>
</tr>
<tr>
<td>Cleft Lip &amp; Cleft Palate</td>
<td>153</td>
<td>15</td>
<td>131</td>
<td>85.6</td>
</tr>
<tr>
<td>No Cleft Malformation Noted</td>
<td>175</td>
<td>34</td>
<td>105</td>
<td>36</td>
</tr>
</tbody>
</table>

* 331 total facial cleft defects recorded.
* 506 total facial cleft defects recorded.

1968 and 1974. This probably means that more cases were referred to CCS as the capacity for managing an increased case load developed.

If one examines the percentages correctly identified on birth certificates by time periods (1943–‘48; ’49–’54; ’55–’60; ’61–’67; ’68–’74); there is a peak between 1955 and 1960 and a subsequent stabilization. The percentage correctly identified is defined as those birth certificates that agreed with the CCS records for the three malformations. The percentages for the time periods are 36%, 36%, 57%, 47% and 51%, respectively.

Discussion

At the present time in Arkansas, the examination of birth certificate data is an insufficient method of determining the incidence of cleft palate and is not much better for ascertaining the incidence of the more obvious cleft lip. Whether this is due to inadequate examination of newborn infants or whether it is attributable to a failure to record observations is a matter for further study.

Mackeprang et al. (1972) cites a number of factors leading to reduced accuracy and completeness of birth certificate data. These include: low hospital priorities for such records; loose administrative procedures; and busy physicians. Gullen and his co-workers (1967) recommended a continuing campaign to stimulate physicians and medical students to achieve “better” diagnosis and more complete reporting, including completion of the birth certificate personally. Changes in administrative procedures could make a difference. Naylor et al. (1974) noted an apparent doubling of the rate of newborns with congenital malformations subsequent to the adoption of a revised birth certificate form! It is obvious that physicians, hospital personnel, and public health authorities have room for improvement if the birth certificate is to be an accurate reflection of the occurrence of birth defects. At this time, the sole dependence on this source as an indicator of terata would result in a gross underestimation, with a possible serious consequence when heavy reliance is placed on these records for planning. Of course, even carefully filled in birth certificates will not solve the problem of measuring the incidence of more subtle defects, such as congenital palatopharyngeal incompetence, which impose burdens upon health care programs similar in nature to the more gross anomalies.
This study addressed only lip and palatal clefts. The number and variety of major and minor congenital anomalies is a significant health concern. The emotional, social, and economic impact of some of these is enormous, while others are of little consequence. It is desirable to make a concerted effort to train and motivate health care personnel appropriately. In the meantime, accurate knowledge of the incidence of birth defects is dependent upon prospective studies of pregnancies and their long-term outcomes, rather than on examination of any particular document.

References


