

Use of Congenital Malformation Data Reported on Live Birth Certificates

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FOR A NUMBER of years many areas have been requesting information on live birth certificates concerning the presence or absence of congenital malformations in order to (a) provide a method of case detection so that services can be offered for infants and children with such malformations and their families, and (b) provide a method of surveillance of the incidence of congenital malformations.

Approximately 12 years ago, a survey was made to determine the extent to which these two objectives were being met at State and local levels (1). Since that time, the thalidomide tragedy and the recent nationwide rubella epidemic have generated increased interest in use of the live birth certificate as a tool for surveillance and service. Consequently, the survey reported here was undertaken to determine current practices in the United States with reference to the use of information on live birth certificates about congenital malformations.

Method

Early in 1965 a questionnaire was sent to the directors of maternal and child health services and of crippled children's services of the 54 States and territories and to the commissioners of health of the 130 U.S. cities having populations of 100,000 or more, according to the 1960 census.

The questionnaire asked if the live birth certificate included a question about the presence of a congenital malformation in the baby, and,

if so, whether the type of malformation was also requested. A third question attempted to determine whether the information was used for (a) epidemiologic surveillance, (b) routine statistical analysis and study, or (c) services to the baby and family. An effort was also made to determine the manner in which use of this information was accomplished.

Results

Responses to the questionnaire were received from 175 of the 184 cities, States, and territories—an overall response rate of 95 percent (table 1).

Inclusion of question on live birth certificate. Of the 175 questionnaires returned, 141, or 80 percent, stated that the question about presence of a congenital malformation is included on the live birth certificate. Fifty-two of the 175 replies were from States and territories, and all but 8 of the 52 include this question; 1 of the 8 will start including it in 1967 and 2 of the 8 have laws requiring the filing of a separate reporting form (in addition to the live birth certificate) for children with congenital malformations. The 123 replies from the various cities showed

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that 97 ask this question on the live birth certificate.

Information on type of congenital malformation. Of the 141 States, territories, and cities that ask about the presence of congenital malformations, the majority (122, or 87 percent) also request information regarding the type. In fact, all of the States and territories requiring the reporting of congenital malformations, with only two exceptions, require that the specific type of malformation be reported, either directly on the live birth certificate or, as is the case in two States, on a special reporting form.

Use of information reported. The majority of States, territories, and cities use the information in some manner. Sixty-eight percent of the cities use the information on a local level. Interestingly, the largest cities (more than 500,000 population) consistently make the most use of it for all three purposes—epidemiologic surveillance, statistical analysis, and followup services. Only 2 of the 44 States which ask about congenital malformations do not make use of the information. One of the two States

is undertaking a “one-time” analysis of 14 years’ data from live birth certificates about congenital malformations and also is re-initiating a Handicapped Children’s Register, previously not well developed, in hope that these actions will enable it to establish epidemiologic, statistical, and service programs. The other State hopes to establish programs soon but has made no definitive plans because of personnel difficulties.

Use for epidemiologic surveillance. Although 31 percent of the cities, States, and territories use the information about congenital malformations for epidemiologic surveillance, the extent and frequency of such surveillance vary widely (table 2). In several areas this surveillance is quite specialized; for example, one area uses it only for cleft palate, another area uses it only for congenital heart disease and mongolism. Other areas perform an epidemiologic review only after they become aware of the existence of a teratogenic factor; for example, 9 months after a rubella outbreak or after the thalidomide tragedy was publicized. One-third of the areas do not have definite, pre-arranged

Table 1. Replies of States, territories, and cities to questionnaire concerning presence of information about congenital malformations on live birth certificates and uses of the information

| Factor | Number States and territories | Total number cities | Cities with populations of— | | | |
|---|-------------------------------|---------------------|-----------------------------|-----------------|-----------------|-----------------|
| | | | 100,000–149,999 | 150,000–249,999 | 250,000–499,999 | 500,000 or more |
| Questionnaires: | | | | | | |
| Total sent..... | 54 | 130 | 49 | 30 | 30 | 21 |
| Total responses..... | 52 | 123 | 43 | 30 | 29 | 21 |
| Birth certificates: | | | | | | |
| Query on presence of congenital malformation..... | 44 | 97 | 30 | 25 | 22 | 20 |
| Query on type of congenital malformation..... | 40 | 82 | 26 | 22 | 16 | 18 |
| Use of information on congenital malformations: | | | | | | |
| Total using information..... | 42 | 66 | 20 | 17 | 15 | 14 |
| Epidemiologic surveillance..... | 18 | 24 | 7 | 5 | 4 | 8 |
| Statistical surveillance..... | 27 | 37 | 10 | 8 | 8 | 11 |
| Followup service..... | 32 | 58 | 19 | 13 | 12 | 14 |
| Not answered..... | 0 | 1 | 1 | 0 | 0 | 0 |
| Type of followup: | | | | | | |
| Routine, all newborns..... | 0 | 3 | 1 | 1 | 0 | 1 |
| Routine, all congenital malformations..... | 9 | 25 | 8 | 9 | 6 | 2 |
| Partial, some malformations: | | | | | | |
| Socioeconomic factors..... | 2 | 11 | 6 | 3 | 1 | 1 |
| Condition of infant..... | 8 | 4 | 0 | 0 | 1 | 3 |
| Combined factors..... | 4 | 9 | 3 | 0 | 2 | 4 |
| Administrative factors..... | 7 | 2 | 1 | 0 | 0 | 1 |
| To initiate followup..... | 2 | 4 | 0 | 0 | 2 | 2 |
| No followup service..... | 12 | 38 | 10 | 12 | 10 | 6 |

Table 2. Frequency of use of live birth certificate information about congenital malformations

| Frequency | States and territories | Cities with populations of— | | | |
|---------------------------------------|------------------------|-----------------------------|-----------------|-----------------|------------------|
| | | 100,000–149,999 | 150,000–249,999 | 250,000–499,999 | 500,000 and over |
| Review for epidemiologic surveillance | | | | | |
| Every 5 years..... | 0 | 0 | 0 | 0 | 0 |
| Annually..... | 2 | 1 | 2 | 0 | 2 |
| Semiannually..... | 0 | 0 | 0 | 0 | 0 |
| Quarterly..... | 0 | 0 | 0 | 0 | 1 |
| Monthly..... | 7 | 1 | 0 | 1 | 0 |
| Weekly..... | 0 | 2 | 0 | 1 | 0 |
| Continuous..... | 0 | 0 | 0 | 0 | 0 |
| Periodic..... | ¹ 2 | 0 | 0 | 0 | 1 |
| No definite interval..... | 4 | 2 | 1 | 1 | 2 |
| Not stated..... | 4 | 1 | 2 | 1 | 2 |
| Total..... | 19 | 7 | 5 | 4 | 8 |
| Review for statistical analysis | | | | | |
| Every 5 years..... | 0 | 1 | 0 | 0 | 0 |
| Annually..... | 17 | 1 | 2 | 4 | 6 |
| Semiannually..... | 2 | 0 | 0 | 0 | 0 |
| Quarterly..... | 0 | 1 | 0 | 1 | 1 |
| Monthly..... | 2 | 0 | 0 | 1 | 0 |
| Weekly..... | 0 | 1 | 0 | 0 | 0 |
| Continuous..... | 1 | 0 | 1 | 0 | 0 |
| Periodic..... | ² 2 | 1 | 1 | 0 | 1 |
| No definite interval..... | 1 | 3 | 0 | 1 | 1 |
| Not stated..... | 2 | 2 | 4 | 1 | 2 |
| Total..... | 27 | 10 | 8 | 8 | 11 |

¹ Includes 1 State where maternal and child health does quarterly review and crippled children's service does monthly review.

² Includes 1 State where 1 director stated yearly tabulation and the other director stated monthly; and 1 State where crippled children's service does continuous review and maternal and child health does annual review

intervals between reviews. In one State, epidemiologic studies are carried out only on special request from an agency or other interested group; in another State they are undertaken under the supervision, and at the discretion, of the medical school.

One State has been making epidemiologic studies annually since 1957. These studies are financed by a 10-year grant from the National Institutes of Health, Public Health Service. No mention was made of whether the studies would be continued if the grant is not renewed.

A variety of persons review the data (table 3); a physician performs this function in about one-third of the areas, but elsewhere it is done by statisticians, directors of maternal and child

health and crippled children's services, nurses, and other personnel.

Use for statistical analysis and study. The information is used for statistical analysis and study in 45 percent of the areas queried (table 1). Again, this is more commonly true of the States and territories (61 percent) than of the cities (38 percent). Also, the frequency of analysis and the types of personnel who perform this function vary widely (tables 2 and 3). Most areas analyze the data routinely at regular intervals; however, a few areas have no predetermined routine and perform their analyses at irregular intervals. Of the areas performing routine statistical analyses, about one-half do this annually; the replies of the remaining

areas ranged from "continuously" to "every 5 years." This function is performed most commonly by a statistician alone or in conjunction with other personnel—physicians, maternal and child health directors, and nurses (table 3). Several respondents anticipate new or increased use of the information for statistical analysis when they obtain data processing equipment.

Use for followup. Services for the infant and family are provided by 90 of the areas queried (64 percent of those areas with the information noted on the live birth certificate). Twelve States do not use the live birth certificate information about congenital malformations as a tool for providing services on a statewide basis. However, cities in at least 3 of the 12 States use the information locally for this purpose.

In contrast, it is established statewide policy in nine other States for the local public health

nurse to visit the homes of all infants with congenital malformation. This was checked against the replies from the large cities within those States wherever possible. Of 13 cities in 4 States, 9 cities were in agreement with State policy and only 4 cities failed to indicate local followup. In the remaining five States, there were no cities with populations of 100,000 or more, so cross verification was not possible.

Although telephone calls and letters are occasionally used to contact the family or physician, the most common procedure is for the public health nurse to make a home visit, either to all infants with congenital malformations or to a selected population (table 1).

Selection of the infants to be followed appears in several instances to be based on socioeconomic factors and the wishes of the private physician, if one is used. In other instances it is based on

Table 3. Personnel who review data about congenital malformations on live birth certificates

| Personnel | States and territories | Cities with populations of— | | | |
|------------------------------------|------------------------|-----------------------------|-------------------|-------------------|-------------------|
| | | 100, 000–149, 999 | 150, 000–249, 999 | 250, 000–499, 999 | 500, 000 and over |
| Epidemiologic surveillance | | | | | |
| Physician..... | 5 | 3 | 1 | 0 | 3 |
| Statistician..... | 1 | 0 | 0 | 1 | 2 |
| Statistician and physician..... | 3 | 0 | 0 | 0 | 0 |
| MCH director..... | 2 | 0 | 1 | 1 | 0 |
| CC director..... | 2 | 0 | 0 | 0 | 0 |
| Statistician and MCH director..... | 0 | 0 | 0 | 0 | 1 |
| Health department..... | 0 | 0 | 0 | 0 | 0 |
| Nurse..... | 0 | 1 | 1 | 0 | 0 |
| Not stated..... | 2 | 0 | 1 | 1 | 1 |
| Other..... | 4 | 3 | 1 | 1 | 1 |
| Total..... | 19 | 7 | 5 | 4 | 8 |
| Statistical analysis | | | | | |
| Physician..... | 1 | 1 | 1 | 0 | 3 |
| Statistician..... | 17 | 2 | 2 | 4 | 1 |
| Statistician and physician..... | 0 | 0 | 1 | 0 | 3 |
| MCH director..... | 0 | 0 | 1 | 0 | 0 |
| CC director..... | 0 | 0 | 0 | 0 | 0 |
| Statistician and MCH director..... | 2 | 1 | 0 | 0 | 2 |
| Health department..... | 3 | 0 | 0 | 0 | 0 |
| Nurse..... | 0 | 0 | 1 | 1 | 0 |
| Not stated..... | 1 | 2 | 2 | 3 | 2 |
| Other..... | 3 | 4 | 0 | 0 | 0 |
| Total..... | 27 | 10 | 8 | 8 | 11 |

NOTE: MCH=maternal and child health; CC=crippled children's services.

the condition of the infant and the nature and severity of the malformation or whether the condition is one eligible for application for crippled children's services, or both. In several cases, selection is based on a combination of both socioeconomic factors and the status of the infant.

Because of variation in available staffs and administrative policies, the selection of infants for followup is left to the discretion of the local health department in seven States. About 50 percent of the large cities in these States use the information locally for home nursing visits.

Difficulty in establishing rapport with private physicians was mentioned by a number of respondents. The solutions attempted vary greatly. In some areas, the first step is for the public health nurse to contact the private physician for permission to visit, prior to contacting the family. In other areas, no attempt is made to serve patients having private physicians unless the physician refers the patient to the public health nurse. Elsewhere, patients are visited routinely, and there is no established policy regarding contact with the private physician.

In addition to the variation in degree of cooperation with the private physician, there is considerable variety in the intensity with which the followup services for infants with congenital malformations are pursued. In some areas, only families of infants with specific defects are contacted; in others, all newborn infants with congenital malformations are seen by a public health nurse, and, in still other areas, there is no followup. This variation is due in part to staffing shortages in many areas as well as to administrative decisions regarding selection of patients and necessity for followup.

When this study was initiated and questionnaires were sent to the directors of maternal and child health and crippled children's services of various States and territories, it was postulated that there might be a significant difference in current practice if the directors' positions were vacant compared with positions that were filled full time by physicians. It was also postulated that if the two positions were in different State agencies, there might be less communication and coordination between them than if both positions were either in the department of health or under the directorship of a single person. It

was thought possible that separation of maternal and child health and crippled children's divisions might be reflected by significantly less use of the live birth certificate information or by discrepancies in the replies from the two directors. All of these factors were considered when the data were analyzed. No significant differences or discrepancies were found, except in one State where the maternal and child health and crippled children's directors disagreed as to whether the live birth certificate contained a question about the presence of congenital malformations.

The replies from the State directors were also compared with the replies from the cities within each State and again almost all the replies agreed. The only discrepancy of note was in a reply from a large eastern city, which stated categorically that epidemiologic surveillance, statistical analysis, and services to the infant and family were all carried out statewide by the State board of health, while the reply received from the State denied the use of the information for anything other than statistical analysis.

The data from States and territories were also analyzed by regions, in an attempt to detect any possible patterns or trends. No significant trends were found.

Because a similar survey was performed in 1953, the data from that survey were compared with the current practices of States and territories (table 4). The patterns were strikingly similar with respect to the number of States and territories which did not request congenital mal-

Table 4. Followup services by public health nurses for infants with congenital malformations, 1953 and 1965

| Followup | Number States and territories | |
|---|-------------------------------|------|
| | 1953 | 1965 |
| Some type of routine followup on all reported congenital malformations..... | 9 | 9 |
| Partial followup on some reported congenital malformations..... | 20 | 21 |
| No followup..... | 13 | 12 |
| No item on live birth certificates about congenital malformations.. | 6 | 8 |
| No response..... | 4 | 2 |
| Initiating followup services..... | 0 | 2 |

formation information on their live birth certificates and the use of information obtained for followup services.

Discussion and Recommendations

A belief shared by many persons (2-7) is that, despite limitations, live birth certificates can be a useful source of data; they can provide a minimum estimate of the extent of a problem and can also represent an important source of cases for early detection. For this reason, we believe that a request on the live birth certificate for information regarding presence of congenital malformations is justified and should be recommended.

However, with the use of live birth certificate information many difficulties arise which should be resolved in order for the resultant data to be meaningful. Foremost is the problem of incompleteness of reporting, a matter commented on by a number of our respondents and discussed by many experts (5-10). This incompleteness is due to a number of factors, among which are the following.

1. Because of the early age of the infant when the live birth certificates are filled out, the defect may not be apparent at that time.

2. Confusion as to what constitutes a congenital malformation.

3. Reluctance to stigmatize a child with the diagnosis of a congenital malformation.

4. Lack of communication between the physician and the person filling out the live birth certificate (often a nurse or a clerk).

5. Lack of awareness of the value of accurate and complete reporting because little of the total data collected and its statistical and epidemiologic importance has become generally known.

The following are some of the numerous suggestions made to encourage completeness and accuracy of reporting on live birth certificates (6, 8, 10).

1. The number of items requested and the time required to complete the certificate should not be excessive.

2. For many questions, a check-box design is desirable. This is probably true for determining the presence or absence of a congenital malformation. However, whether a checklist would be of value in determining the type of

malformation is a matter for further investigation (11).

3. The health information section of the certificate should be readily visible to the recorder of the information.

4. The medical information should be confidential, and it should not appear on the copy of the certificate given to the parents nor be open for public inspection. This policy should be made clear to the medical community.

5. The questions asked should be periodically reviewed, so that obsolete items may be deleted and new ones added as medical progress is achieved.

6. The questions should be carefully worded to avoid ambiguity.

7. The hospital staffs concerned should be periodically oriented as to the meaning of the terms employed. In conjunction with this, an operational definition for congenital malformations should be developed.

8. In some areas (6), the completeness of reporting is periodically tabulated by hospital, and the list showing the relative deficiencies in reporting is sent to the hospitals for review at hospital staff meetings. Similar procedures may be effective elsewhere.

9. Periodically, a validity check of a random sample of live birth certificates with the hospital records should be made to determine the degree of underreporting.

10. Congenital malformation statistics should be periodically published by the State or local health department, along with an interpretation of trends, possible implications, and influencing factors.

11. Followup services should be provided by using the information on congenital malformations obtained from the live birth certificates, and the medical community should be made aware of this use of data.

Because of their nature, some congenital malformations (for example, many renal, gastrointestinal, and cardiac abnormalities) may not be obvious at birth and will necessarily be underreported. Acceptance of this fact should not preclude encouragement of complete reporting of other, more readily recognized abnormalities.

Once the information is reported, it becomes the responsibility of public health personnel to

assure that it is used in the most meaningful manner. Much attention has been given to this (3, 4, 11) in providing followup to bring services to the infants; in analyzing the data and reporting back to the sources of the data; and in careful, frequent, and periodic surveillance.

It has been suggested (3, 12) that the effects of thalidomide could have been detected much earlier and the extent of the resultant tragedy significantly curtailed had adequate epidemiologic surveillance programs been established. An adequate program would include the following:

1. A relatively simple codification of congenital malformations, such as those already in use (3, 13, 14), designed to indicate the occurrence of major defects at birth.

2. Communitywide coverage, thereby providing background data regarding the incidence of a specific congenital malformation in a community, its seasonal fluctuation, and geographic distribution.

3. Correlation of the particular congenital malformation with sex, race, plurality of birth, other pertinent information about the infant, and significant factors in the prenatal history. Some of this information may be reported on the birth certificate. Other factors, such as drug intake, radiation exposures, infections, and family history may not be readily available; they should be obtained by epidemiologic study, either by further study of the hospital records, by direct contact with the private physician, or from the family.

4. Relatively frequent processing of the data (monthly, or at least quarterly). Obviously, periodic processing of data, even in the absence of the occurrence of known teratogenic factors, is mandatory if outbreaks and new teratogenic agents are to be discovered.

5. Availability of adequately trained personnel (physicians, statisticians) to analyze the information received.

6. Information on congenital malformations should also be obtained from stillbirth certificates, and this information should be included in the epidemiologic surveillance.

7. Collaborative studies by neighboring States or regions might be useful.

In conjunction with epidemiologic programs, the data processing machines which are being

used in many areas are of great value in epidemiologic surveillance. They can also be useful in facilitating the rapid transfer of information from agency to agency concerned with providing services to the infant; adequate, effective service requires early casefinding and early followup.

It seems reasonable that if a visit by a public health nurse is necessary, the visit would be most effective if made early in the course of the infant's life. The nurse could assist the family in preparing for the homecoming and in caring for the infant during the first crucial days of adjustment. In one study (1) the average age of the infants at the time of the visit by the public health nurse was 36 days, and more than half of that time was consumed in transmitting the newborns' referral cards to the respective health districts for home visiting.

Followup service also includes adequate counseling and referral to the proper agencies for medical assistance, prostheses, physical therapy, schooling, or vocational training. It has been suggested that clinic registries be established to provide counsel and service as well as cohort material for further analysis of malformations as they are influenced by both genetic and environmental factors.

As to the method of selection of infants reported to have congenital malformations for followup services, it is suggested that the major criteria be the type and severity of the malformation and the needs of the family in providing care and support for the infant. Unless complete information is otherwise available, this means routine visits by public health nurses. Also, each area should periodically review its protocol of service for adequacy and effectiveness of coverage.

Summary

The thalidomide tragedy and the more recent rubella epidemic have generated increased interest in early detection and adequate care of infants with congenital malformations. Because of this, a questionnaire survey was undertaken in 1965 among States, territories, and large cities to determine the extent to which information on live birth certificates about congenital malformations is used for epidemiologic

surveillance and as a tool for service to the affected infant and family. Responses were received from 52 of 54 States and territories and 123 of 130 cities.

Of the areas queried, 80 percent ask about the presence of a congenital malformation on the live birth certificate. A majority (87 percent of those having certificates containing this question) also request information about the type of malformation.

The information is used by 31 percent of the areas for epidemiologic surveillance, by 45 percent for statistical analysis, and by 64 percent for followup services. Considerable variation was noted in the type of personnel performing the reviews and analyses and in the criteria for selection of infants for followup service.

A comparison of the 1965 findings with those obtained in a similar survey in 1953 showed strikingly similar patterns regarding the number of States and territories which did not request the reporting of congenital malformations on their live birth certificates and the use of information for followup services.

A number of suggestions for improving the completeness and accuracy of reporting congenital malformations on birth certificates are reviewed.

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