

Rubella

Some Comments on the 1964-65 Epidemic in California

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■ *The rubella epidemic of 1964-1965 resulted in the birth of a group of children with defects of vision, of hearing or of the heart. In this study of cases known to five Los Angeles agencies, it was found that about half of those affected have more than one defect. Findings demonstrate a need for more sensitive communicable disease surveillance and for the development of services for the multiple handicapped child.*

THIS IS A REPORT of a small and limited survey of some of the consequences of the 1964-1965 rubella epidemic in California. The survey was conducted to provide information regarding deficits and needs in the public health program. Because of the small number of cases studied and the manner in which they were selected, survey data cannot be considered definitive. It may be useful, however, in demonstrating the need for additional means of communicable disease surveillance and for special services for the multiple handicapped child.

Method

Study cases were identified by a medical social worker who reviewed the records of five agencies in the Los Angeles area. Information was gathered on children born between October 1962 and March 1966 with hearing, speech, eye or heart defects (or mention of maternal rubella) seen by these agencies before January 1967. The agencies were a hearing and speech center operated by a voluntary agency, three hospitals serving children who had

ocular or cardiac handicaps, and the State Department of Education's program which provides visiting teachers for the blind. Information was obtained from agency records about specific diagnoses and whether there was a history of rubella during the mother's pregnancy. Also, the problems faced by these facilities in serving this group of children and their families were discussed. It became apparent that the management of children with multiple handicaps was difficult for agencies that were prepared to deal only with single handicaps. Descriptive information was obtained through interviews with 13 of the families whose children had more than one defect.

Description of Cases

A total of 215 cases meeting survey criteria were found in the agencies' records, and they were classified according to the presumed cause of the patients' handicaps:

151 had defects due to rubella (record noted rubella as etiologic factor, based on maternal history or child's clinical syndrome).

45 had defects possibly due to rubella (records did not state rubella but it was considered possibly a factor by two reviewing physicians).

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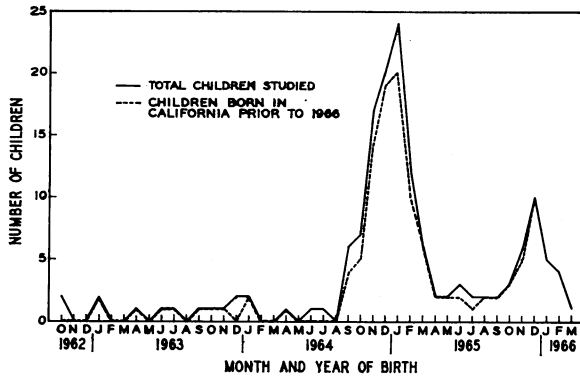


Chart 1.—Month and year of birth of children with defects attributed to rubella.

19 had defects which reviewing physicians considered either not due to rubella or of very questionable relationship to rubella.

It was decided not to include the “possible” or “questionable” cases because of the ways in which they differed from the 151 cases in which rubella was considered the cause of handicap.

The distribution of the birthdates of the 151 children in whom rubella was a factor followed an “epidemic curve” (discussed in a later section). This was not true of the cases considered possibly due to rubella, or of those which were questionable (see Charts 1 and 2). Only 11 percent of those who had handicap related to rubella were born before September 1964—that is, with the first trimester occurring before the epidemic year 1964. In approximately 42 percent of the “possible” and about 63 percent of the “questionable” cases, birth was earlier than the epidemic year 1964.

While almost half of the patients with handicap attributed to rubella had more than one defect recorded (Table 1), only one of the 45 in the “possible” and two of the 19 in the “questionable” category had more than one.

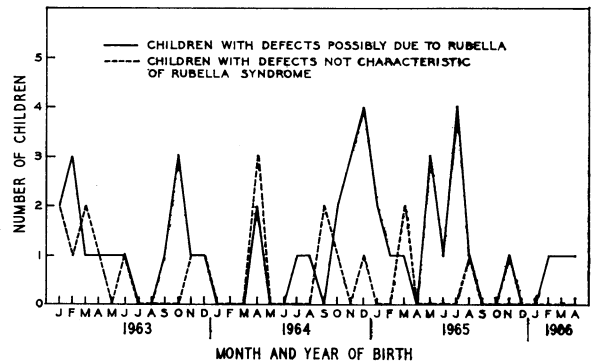


Chart 2.—Data on children with defects possibly due to rubella and those with defects not characteristic of rubella syndrome, related to month and year of birth.

It appeared, then, that these two categories should not be included and the analysis here is limited to the 151 cases in which rubella was presumptively established as the cause.

Table 1 shows the types of defects found among children in the study group. Seventy of them had two or more defects involving the heart, vision or hearing; of the 70, 41 had additional defects or were observed to be slow in physical and mental development. Among the children with only one defect of the heart, vision or hearing, defects in hearing were the most frequent (65 cases).

Age of the patient when he first came to one of the participating centers varied with the type and number of defects. In general, patients with more than one condition and those with heart defects were known to agencies earlier than those requiring care for eye and hearing defects only (Table 1). Of the children with multiple defects (and whose records included date of first visit or admission), 82 percent were seen in their first year, compared with only 25 percent of children with no other defect than deafness recorded.

Type of Defects	Age At First Visit Or Admission			
	Total	Under 1 Year	1 Year or More	Not Recorded
Total Children in Study*	151	80	58	13
Defects of the Heart, Vision, and/or Hearing†				
Multiple Defects	70‡	54	12	4
Single Defect	76	21	46	9
Heart only	6	5	1	
Vision only	5	2	2	1
Hearing only	65	14	43	8
Other Congenital Malformations	4	4		
Not Recorded	1	1		

*Includes children born from October, 1962 to March, 1966 who were known to at least one of five agencies in Los Angeles County before January, 1967.

†Includes children with additional congenital malformations and/or retarded mental and physical development.

‡Children with multiple defects include 60 with heart, 55 with vision and 43 with hearing defects.

TABLE 2.—Occupation Group of Fathers of Children with Defects Attributed to Rubella Born in California before 1966

Occupation Group of Father	Total Children Born in California Prior to 1966		At Least One Parent Born in California		Neither Parent Born in California		10 Percent Sample All Live Births California, 1959
	Number	Percent	Number	Percent	Number	Percent	
Total Children in Study*	120	100.0	75	100.0	45	100.0	100.0
Professional	18	15.0	11	14.7	7	15.6	7.9
Technical, Administrative, Managerial	21	17.5	14	18.7	7	15.6	11.7
Clerical, Sales and Skilled	37	30.8	24	32.0	13	28.9	31.6
Semiskilled	22	18.3	14	18.7	8	17.8	18.9
Laborer (Except farm and mine)	10	8.3	7	9.3	3	6.7	10.3
Farm Laborers and Foremen							3.4
Farmers and Farm Managers							1.2
Student	5	4.2			5	11.1	2.1
Military							10.6
Not Recorded, Unknown	7	5.8	5	6.7	2	4.4	2.3

*Includes children born from October, 1962 to March, 1966 who were known to at least one of five agencies in Los Angeles County before January, 1967.

Of the 151 patients, 12 died before the records were reviewed in January 1967.

California birth certificates were available for 120 of the children born before 1966. From a comparison of father's occupation (Table 2) of these children with the occupations of fathers in all live births, it appeared that the study group included a slightly larger proportion of children born to upper and middle income parents. This is probably due to the survey method, which used records of private agencies and hospitals which serve handicapped children: they are more likely to be utilized by the upper and middle socio-economic groups than by low income families.

Study findings cover three subject areas, which we will discuss separately:

1. Epidemic curves plotted from the birthdates of study cases.
2. Experience of patients and families in obtaining services.
3. Estimate of numbers of children born with defects as a result of the 1964-1965 rubella epidemic in California.

Epidemic Curves

Findings

When year and month of birth were plotted for children with defects attributed to rubella, there was a very definite pattern, with the major peak in January 1965 and a smaller peak in December 1965 (Chart 1). It would appear that the handicapped children we studied were the products of conceptions which occurred during two epidemics, one peaking in the late spring of 1964 and the other in the spring of 1965.

It should be noted that the smaller size of the later peak is probably related to the timing and method of studying the cases. Even among children with more than one defect of the heart, vision or hearing, 18 percent were not seen by survey agencies until after they were one year of age. Among the largest group—children needing care primarily for a hearing loss—three-fourths were not seen until after the first year.

Since records were reviewed in December 1966 and January 1967, affected infants born in late 1965 and early 1966 had only one year or less for referral to a center and inclusion in the study. So it may be assumed that if these infants had gained the same time interval for admission to the study as those born around January 1965, the second peak around December would be as high as the first.

A question that arises is: Were these infants affected by epidemics which occurred in California or did they represent infections to mothers elsewhere, who then migrated to California before delivery or brought their infants here? The eastern and central states experienced a severe epidemic in 1964 which was not observed to the same extent in Washington and Oregon (the only two Pacific states reporting rubella to the National Communicable Disease Center at that time) until 1965.⁴

Migration seems an unlikely explanation for the two epidemic peaks. Of the 141 children born before 1966, 120 were born in California, practically all of them in the Los Angeles area. (Certificates for the 1966 births were not available at the time of the study.) Thus, 85 percent were born in Cali-

fornia, and they did not appear to be children of recent migrants: in 75 cases one parent and in 25 cases both parents were born in California. This does not exclude the possibility that these mothers were out of state during early pregnancy. No information on travel was available for the total study group, but none of the 13 mothers interviewed had been out of California in the early months of pregnancy.

When the year and month of birth of California-born infants were plotted, two peaks were observed as with the total group (Chart 1); this was also true for infants with one or both parents born in the state.

The California-born infants studied were almost entirely residents of the Los Angeles area and perhaps inferences should be limited to that area. However, since the county includes almost 40 percent of the state's population, it is not unreasonable to assume that a rubella epidemic in Los Angeles would spread rapidly to show a similar pattern elsewhere in the state.

Chart 2 shows the distribution of birthdates of 45 children whose defects were possibly due to rubella, and of 19 children with conditions not characteristic of the rubella syndrome. These dates appear to be more randomly distributed than those in which rubella relationship was better established, although the "possible" cases seem to have a small increase clustered around November and December of 1964.

Discussion

During the 1964 epidemic in the eastern and central parts of the United States, an increase in cases was reported by Oregon and Washington to the National Communicable Disease Center, but the full impact was not apparent until 1965. In California, with a voluntary and fragmentary reporting system of cases seen by physicians, 2,500 cases of rubella were reported for 1964 compared with 10,500 for 1965. While the 2,500 cases that were voluntarily reported in 1964 reflected to some degree the occurrence of an epidemic, a comparison with the 10,500 cases reported in 1965 might indicate that the rubella epidemic elsewhere in the nation did not reach the West Coast in full intensity until 1965. This conclusion is contradicted by the findings of the present study, since the birthdates of affected children suggest an epidemic in 1964 of possibly the same intensity as that in 1965.

In 1966, rubella was made a reportable disease in California by the State Board of Health. But even with compulsory reporting, there still can be a significant lag between the occurrence of an epidemic and its recognition. Many of the rubella symptoms may be confused with those of other conditions. The presence of a known epidemic might influence the physician toward a diagnosis of rubella—all other factors being equal—but this would hardly speed up the recognition that an epidemic exists and the institution of plans to cope with the consequences.

Making laboratory diagnostic procedures more available would help but they are expensive and time-consuming and perhaps it is neither logistically possible nor economic to provide diagnostic tests in every case of suspected rubella. The practicing physician is most interested in procedures that directly bear on the treatment of his patient, and probably would order laboratory tests only where a clinical decision is involved, as in the case of a pregnant woman.

In addition to general reporting of cases, it would be helpful to establish surveillance posts in strategically located medical centers interested in definitive evaluation and diagnosis of diseases of current interest. The centers would be those serving populations at particular risk, or strategically located. They might include university student health services and hospitals with large maternity and outpatient departments. Frequently the first indications that an epidemic is in the making are apparent at such centers. If this intelligence could be brought into focus through provision of laboratory services and collation of information, the intervals between the disease outbreak and its recognition, and the development and implementation of plans for managing its consequences, could be considerably shortened.

Experiences of Patients and Their Families

Findings

Because no single facility has the wide variety of very specialized medical, testing, counselling, referral and educational services needed by those with multiple handicaps, the families of the 151 children studied had sought medical and rehabilitative care from numerous sources.

Information from the five agencies surveyed showed that 75 percent of the parents had been served by at least two or more community agencies

and 30 percent had used at least three or more, in addition to private physicians and other resources.

An insight into the problems of obtaining and providing care for these children was obtained through interviews with parents of 13 of those with multiple malformations attributed to rubella. The group was made up of families of children who were currently receiving services from the speech and hearing center. The records of the first 15 children requiring services for more than one defect, who were born during the period covered by the study, were selected from the case files. Two families had moved and were not available. The remaining 13 were all willing to be interviewed. While the questions were essentially open-ended, they were planned to cover the following:

- What the family was told about the possible effects on the newborn of rubella during pregnancy.
- What information was given the family on the patient's handicaps at birth, and by whom the handicap was first noted.
- The sequence of treatment, including the facilities used, how selected, any changes, and reasons for changes.
- Problems encountered.
- Information given on long-range planning.

As the group was not made up at random, it cannot be considered representative, but some insight into the problems facing the family and the community was gained.

All 13 mothers reported having rubella early in pregnancy; of these 11 reported the disease to their physicians in the course of prenatal care.

Five were either given no information regarding the possible consequences or were told not to worry; of the six who were informed of possible consequences, three attempted to obtain an abortion but were unsuccessful in finding a physician or facility willing to perform one.

In all but one of the 13 affected children the congenital condition was noted by the family or physician before the child was three months of age. In ten of the cases it was detected before the child was six weeks old. In one case it was not diagnosed until after the child was one year old. However, only 64 percent of the total 70 children studied with multiple defects were seen at participating centers before the child was six months old. If the experience of interviewed parents is typical, this was because families visited one or several physicians before coming into the centers, either through "shopping around" or through referral.

TABLE 3.—Children with Defects Attributed to Rubella—Problems Most Frequently Mentioned by Mothers with Regard to Handicapped Child

<i>Problems Most Frequently Mentioned</i>	<i>Number</i>
Total Mothers Interviewed	13
No Problems Reported	1
One or More Reported	12
Having to Go to So Many Facilities for Care, Difficulties with Making Appointments, Difficulties with Transportation	5
Educational Materials Do Not Meet Needs of Multiple Handicapped	4
Conflicting Advice from Professional People	4
Resources Didn't Know or Didn't Suggest CCS as a Possibility	3
Lack of Long-Range Planning	3
Acceptance by Other Family Members	3

Of the 13 mothers interviewed, seven had been in contact with two or more community agencies regarding the handicapped child's problems; five had been to three or more. These contacts were in addition to medical care for the child's various conditions from numerous medical resources:

<i>Number of Medical Resources</i>	<i>Number</i>
Total mothers interviewed	13
Only one source	—
2	1
3	3
4	5
5 or more	4

In 12 cases the families had used three or more sources of medical care. This enumeration does not reflect the difficulties encountered in obtaining services, in coordinating the treatments prescribed, in understanding and carrying out the advice given, in determining what services and assistance are available, and using them if they are available. Table 3 summarizes the most frequent responses by mothers to the interviewer's questions about some of their problems.

The difficulties encountered by families (even in an urban area such as Los Angeles with many medical community resources) may be seen from summaries of two interviews, one with a family dependent on public assistance and public medical care, the other with a family which would ordinarily use private medical care.

1. The affected child was, at the time of interview, a three-year-old girl, the youngest of six children, all under 12 years old. The family was dependent on public assistance, as the father had

deserted before this child was born. During the pregnancy the mother and children contracted rubella. The mother was told at the clinic not to worry. At birth a heart condition was found and was successfully treated surgically at one month.

Soon afterward the mother noted that the baby did not respond to sound. On examination at her insistence, deafness was diagnosed and a referral was made to a center for speech and hearing defects. But family complications interfered. About that time the mother was found to have a malignant tumor, and operation upon her and continuing disability afterward made it impossible for her to get the baby to the clinic until she was about a year old. Many lapses occurred in keeping schedules, as various medical crises arose—the mother's, the patient's, and those of the other children. (The patient was also found to have an orthopedic defect requiring regular clinic visits, and a sister is thought to have epilepsy and must be taken to the neurological clinic regularly.) Transportation and the cost of maintaining a car to get to medical care is a big problem for this family.

The patient is well accepted by the family and the mother feels her biggest problem is "getting her to understand." The child is considered to be intelligent by the otosurgical group and personnel at the hearing center.

The mother was told that it is essential for the child to start school by age three; she is now over that age, but neither the public school nor the hearing center has a vacancy.

2. The patient was an 18-month-old boy at the time of interview. His family consists of his divorced mother, a three-year-old sister, his grandmother and a ten-year-old aunt. The mother said that during her pregnancy both she and her husband had had rubella, but possible effects on the unborn child were never discussed. No handicaps were reported to the mother at birth. But at three weeks a pediatrician diagnosed blindness and a heart murmur; the patient was later found also to have a hearing defect and brain damage.

At the time of interview, eight different physicians and clinics had been involved in the child's care: a pediatrician, three eye specialists, a cardiologist, a psychologist, and two hearing centers. In addition, the child had received physical therapy. There had also been contact with Crippled Children Services, the local health department, the visiting teacher to the blind, and mental hygiene clinics.

The mother discussed the difficulties she had had with the large number and the sequence of medical examination, with necessary cancellations of appointments, with agency policies which affected choice of physicians, and with the differing opinions among various sources of care—all during the child's first year of life. There had been no long-range planning, which causes the mother some concern, for she believes the child will eventually need a residential school of some kind. She said that other mothers of handicapped children with whom she speaks have told her of long waiting lists at institutions. She said the hospital has been unable to provide advice about future planning, and that "everyone says, 'Don't worry'."

Discussion

Multiple handicaps in a significant number of children can be anticipated as a result of maternal infections during the 1964-1965 rubella epidemics. Of the estimated 750 to 1,500 affected infants, perhaps 300 to 600 would have more than one defect. If our survey is valid, it is obvious that several community resources are needed to treat these children. The parents of such infants face considerable difficulty in coordinating treatment recommendations and putting them into effect.

It would greatly help if services, including overall case management planning and follow-up for multiple handicapped children, could be provided through a single agency, along the pattern of the two California regional centers for evaluation and treatment of mentally retarded children.

Perhaps they could not only be used as a model but their functions extended to include such services for multiple handicapped children as evaluation, outlining a broad program of treatment, and arranging the use of available community resources for the specific services required. This would relieve the family of the decisions—which are essentially medical—regarding treatment priorities and coordination.

As with the mentally retarded, it is apparent that schools will need to provide special education facilities and services.

The value of the services would be significantly enhanced by making them available at an early age, before admission to school, and in pre-school programs. Even in these programs there is too often a lack of appropriately trained professional personnel to provide special education services.

Experience in the treatment of multiple handi-

capped children is limited, and it would be inappropriate here to discuss specific measures at great length. But it should be recognized that this problem is with us and requires attention.

Estimates of Number of Children Handicapped

Sever and coworkers,² reporting on a study of 6,000 women pregnant during the January-June 1964 epidemic (mostly in the eastern and central states) noted that by laboratory tests 9 percent of women reporting exposure to rubella in the first trimester had experienced infections, one-third of which resulted in clinical symptoms. While 10 percent of the women examined reported exposure in the first trimester, only 45 percent of the women in whom clinical rubella developed during the first trimester had been aware of—and had reported—exposure. From this it might be concluded that the actual exposure rate in early pregnancy during the epidemic was approximately 22 percent (10:45) of all pregnant women in their first trimester: Since 9 percent of women exposed showed infection, it can be estimated that approximately 2 percent of all pregnant women experience clinical or sub-clinical infection during the first trimester in an epidemic period.

Approximately 184,000 live births occurred in California during the months of September 1964 through February 1965. The first trimester of the gestation period in those infants occurred during the first six months of 1964, when presumably the epidemic was extant. Assuming an attack rate of 2 percent of infections during the first trimester for pregnant women in an epidemic period, there may have been an estimated 3,680 women with rubella infection during the first three months of pregnancy in California during the epidemic year of 1964, and perhaps a similar number in 1965. The reason an epidemic occurred in both 1964 and 1965 may have been that the first was not severe enough to build up a sufficient number of immune persons during that year to prevent its recurrence during the second year, particularly since there is evidence that infected infants remain carriers for up to six

months and serve as a reservoir of reinfection.¹ We might therefore revise our estimate downward to around 6,000 mothers with rubella infection in the first trimester during 1964 and 1965 (that is, 3,000 per year) of which perhaps 2,000 to 3,000 may have had clinical symptoms.

If we assume, as appears reasonable, that 25 percent of infants born to mothers with rubella in the first three months of pregnancy have a congenital malformation, we would estimate that around 750 to 1,500 malformed infants were born as a result of the recent epidemics of 1964 and 1965. While these estimates cannot be considered as accurately or even approximately giving the incidence of first trimester rubella, they do provide us with an order of magnitude which may be useful in planning.

On the basis of Sheridan's study of children whose mothers had rubella in early pregnancy, it is further estimated that 40 percent of the 750 to 1,500 affected children would have multiple malformations.³ Of those with one or more defects:

1. One-third would have heart defects.
2. One-third would have vision defects.
3. Sixty percent would have a significant hearing loss, including a large proportion (40 percent) in which the loss was not detected until age eight or over.

In the present study, the incidences of heart, vision and hearing defects were similar to those in the Sheridan group (Table 1). These are very general estimates but they provide some idea of what might be expected from the rubella epidemics of 1964 and 1965.

ACKNOWLEDGMENT

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