



HHS Public Access

Author manuscript

Sex Transm Dis. Author manuscript; available in PMC 2023 May 04.

Published in final edited form as:

Sex Transm Dis. 2019 February ; 46(2): 139–142. doi:10.1097/OLQ.0000000000000909.

Preventing Congenital Syphilis – Opportunities Identified by Congenital Syphilis Case Review Boards

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Abstract

Background: Louisiana has had the highest rates of congenital syphilis (CS) in the nation since 2012. CS Case Review Boards were established statewide in 2016 to study CS cases and identify interventions.

Methods: We summarized the findings of CS review boards, assessed which cases were preventable by prenatal care providers, reviewed recommended interventions, and assessed subsequent improvement in provider practices.

Results: All 79 CS cases reported January 2016--July 2017 were reviewed by boards during August 2016--August 2017.

Twenty-six cases (33%) that could have been prevented by prenatal care providers had: lack of rescreening at 28-32 weeks (n=15), lack of any screening (n=5), treatment delay (n=4), or incorrect interpretation of test results (n=2).

Twenty-one cases (27%) were possibly preventable by providers including: mother did not return for follow-up and treatment (n=19), late third trimester reactive test with premature delivery (n=1), or incomplete treatment and lack of follow-up by health department staff (n=1).

Thirty-two cases (40%) that were unlikely to be prevented by providers had: non-reactive test at 28-32 weeks then reactive test <30 days before delivery (n=10), no prenatal care (n=9), mother adequately treated, case by infant criteria (n=8), first/second trimester non-reactive, reactive at preterm delivery (n=4), or mother adequately treated, reinfected before delivery (n=1). Providers were advised to adhere to CDC recommended syphilis screening and treatment protocols and rapidly report pregnant women with syphilis. Many providers changed their procedures.

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Conflicts of Interest: None

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Conclusions: CS case review boards identified practices with inadequate screening, treatment, or reporting. Sharing these findings with providers changed practices and may prevent future cases.

Summary:

Congenital Syphilis Case Review Boards in Louisiana identified many preventable cases. Strategies for reducing these congenital syphilis cases were developed and implemented.

Introduction:

Syphilis during pregnancy can cause stillbirth, perinatal death, prematurity, and developmental disabilities. Untreated early syphilis in pregnant women results in infection of the fetus in 80% of cases and leads to fetal loss, stillbirth, or neonatal death in 30% cases.¹ Congenital Syphilis (CS) is usually preventable if women are screened and adequately treated early in pregnancy.^{2, 3} CS is a sentinel event that suggests a failure of both public health and the health care systems to prevent an adverse birth outcome.⁴

Nationally, the rate of CS decreased from 10.5 to 8.4 cases per 100,000 live births during 2008-2012, then increased each year during 2013-2016. In 2016, there were 628 reported cases (15.7 cases per 100,000 live births) in the USA.⁵ Since 2012, Louisiana has ranked number one in the nation for CS case rates. In 2015, Louisiana's CS rate rose to an all-time high of 83.9 cases per 100,000 live births (54 cases), which was over six times higher than the national rate. Even though there was a small decline in 2016, the rate in Louisiana (75.2 cases per 100,000 live births) was still five times higher than the national rate.⁵

Prenatal care is provided by medical doctors, nurse practitioners, certified nurse midwives, or certified professional midwives in practice clinics or clinics within the hospitals. Based on CDC recommendations,⁶ since June 2014 Louisiana laws have mandated screening pregnant women for syphilis and HIV: during the first trimester (or first prenatal visit), again early in the third trimester, and at delivery if at high risk.⁷ The Louisiana Public Health Sanitary Code requires providers and labs to report reactive syphilis tests and new syphilis cases to the health department within one business day.⁸ Reporting can be done electronically or on a paper form which can be sent by mail, fax, or hand delivery. Reports are investigated by health department disease intervention specialists (DIS) who may contact providers to ensure that patients and their partners are treated. Reporting of pregnancy status is not required by the sanitary code, and is often missing from provider and lab reports. Therefore, DIS also ensure that women with syphilis have a pregnancy test.

Due to the high CS rates, the Louisiana Department of Health STD/HIV Program formed CS case review boards to study CS cases and identify opportunities for intervention. The aims of this investigation are to: summarize the activities and findings of the CS case review boards, assess whether or not the cases were preventable, describe the interventions recommended by the boards, and assess changes that providers made in their practices to prevent future CS cases.

Materials and Methods:

Louisiana is divided into nine administrative public health regions. There was one CS review board per region. The CS review board was comprised of staff from: the Louisiana STD/HIV Program (Director, Associate Director, STD Medical Director, Surveillance Manager, CDC Field Epidemiologist, CDC Public Health Advisor, Perinatal Surveillance Coordinator, Regional Operations Manager); and the Public Health Regional Office (Regional Medical Director / Regional Administrator, Disease Intervention Specialist (DIS), and DIS Supervisor). CS review boards met once per quarter or more depending on reported cases and they reviewed every case. Participation in the review board was mandatory for all board members. Prior to the meeting, a summary of each case within the region was sent to all members of the board. During the meeting, CS case records and STD Program notes were reviewed and discussed including treatment of the mothers' partners. Each case was discussed in detail to identify practices by providers and DIS that might have prevented the CS case. Recommendations for providers and health department staff were recorded and members of the boards were assigned to communicate with specific providers, if immediate action was necessary. These records and recommendations were reviewed and sorted by the authors according to their estimates of the likelihood that the cases could have been prevented by the prenatal care providers.

A review board member contacted providers 3-4 months after recommendations were made to see if changes had been implemented. The STD database was used to corroborate changes reported by providers. Responses to the recommendations were discussed at the next CS review board meeting.

Results:

All 79 CS case reported between January 2016 and July 2017 were reviewed during a total of 13 board meetings between August 2016 and August 2017. The mothers of these babies had: primary (3), secondary (12), early latent (29), high titer (1:32) late latent (14), and low titer (<1:32) late latent syphilis (21). The reviews suggested 26 cases (33%) were preventable by prenatal care providers if screening and treatment recommendations and law were followed, 21 cases (27%) were potentially preventable by providers if barriers were overcome, and 32 cases (40%) were unlikely to be preventable by the prenatal care providers.

The 26 cases that had high potential for prevention by providers were most often due to lack of syphilis rescreening at 28-32 weeks of gestation (15 cases), or lack of any syphilis screening during pregnancy (5 cases) (Table 1). Six cases were detected by screening, but not treated in time to prevent CS because: the initial test results were not interpreted correctly (2 cases); or there were excessive delays in treatment after positive tests (4 cases) (one mother had tested reactive in the 2nd trimester, two tested reactive at 28-32 weeks, and one was referred to another provider due to lack of bicillin on-site).

There were 21 cases that were possibly preventable by the concerted effort that CS merits from providers and health departments. Among these, 19 mothers did not return for

treatment, including 2 mothers who reported difficulties arranging transportation. Twelve of the 19 had delayed reporting to the health department because the provider depended on the lab to report and the labs used paper-based reports which were delayed. One mother had a reactive syphilis screening late in the 3rd trimester, diagnosed as secondary syphilis, was treated, but gave birth prematurely at 36 weeks (less than 30 days after treatment). Another mother reported that she was going to terminate her pregnancy after getting first dose of bicillin, then changed her mind, and delivered without completing her treatment and without further prenatal care.

There were 32 cases considered unlikely to have been prevented by the prenatal care providers. Ten mothers screened non-reactive during 28-32 weeks but then reactive less than 30 days before delivery or at delivery. Nine mothers did not have any prenatal care. Eight mothers were adequately treated 30 or more days before delivery but their babies still met the infant criteria for congenital syphilis.⁹ Four mothers had non-reactive initial screening results, but had evidence of infection at 28-32 weeks screening; all 4 mothers delivered prematurely within 30 days of treatment. One mother was treated early but later was determined to be re-infected based on symptoms and titer increase prior to delivery. A partner who was not named initially was diagnosed and treated after the reinfection of the mother.

The 8 cases where mothers were adequately treated but their babies met the infant criteria were studied in detail. The mothers were staged as secondary (2), early latent (2), high titer (1:32) late latent (2) and low titer (< 1:32) late latent (2). Five were treated in the first trimester, 2 (with secondary syphilis) were treated in early third trimester, and one (with late latent syphilis) was treated during the third trimester. All but one were treated with 7.2 million units of Benzathine Penicillin G. The infants met one or more of the criteria including: elevated CSF protein (5), elevated CSF white blood cell count (2), reactive CSF VDRL (2), jaundice (2), and abnormal long bone x-rays (1). None had an ultrasound done during pregnancy.

The CS case review boards made several recommendations based on findings from these meetings. A letter from the Louisiana Secretary of Health mentioning the mandatory third trimester screening law was sent to all providers. Health department staff provided targeted outreach to providers including medical doctors, nurse practitioners, certified nurse midwives, certified professional midwives and infection control personnel in all regions promoting: adherence to screening and reporting guidelines and law, regular use of the pregnancy reporting form (pregnant women with positive syphilis or HIV test should be immediately reported to the health department), and seeking health department assistance when patients do not return for treatment. Providers were also advised to make treatment appointments for the patients as soon as their results were available (fast track appointment). Providers were also asked to seek health department DIS assistance when patients are unable to return for treatment due to lack of transportation or when a bicillin shortage delays timely treatment.

Among the 79 reviewed CS cases, 70 had prenatal care from 39 different prenatal care providers or groups. Only 5 of these groups reported 3 or more cases. One large group

reported 12 cases. During follow-up interviews which took place 3 to 4 months after the CS review board recommendations, all providers confirmed receipt of syphilis screening guidelines, agreed with the need for timely reporting, and agreed to seek DIS help when required. Our review of the STD database identified 28 new maternal investigations (pregnant women with syphilis) related to the top 5 provider groups that occurred from August to December 2017. Twenty four of those mothers were screened for syphilis between 28-32 weeks of pregnancy suggesting that re-screening had improved. The provider group with the highest number of cases had been using both paper reports and electronic reports for cases and lab reports. Because paper reports were causing delay in reporting, the provider had switched to full electronic reporting. The top 5 provider groups reported 2,392 positive syphilis tests (among women and men) from August to December 2017 and all were reported electronically. The average time between specimen collection and receipt of test results at the health department ranged between 4 to 7 days, suggesting timely reporting of positive results.

Discussion:

Among the cases reviewed by the Louisiana CS review boards, 59% were considered preventable or somewhat preventable if patients had received good prenatal care. These cases might have been prevented if providers: routinely screened all pregnant women early in pregnancy and again at 28-32 weeks, responded urgently to reactive tests, and promptly notified the health department so that it could help assure treatment of reluctant patients. Several studies have found that early screening, rescreening, and timely appropriate treatment of maternal syphilis cases are instrumental in preventing CS.^{10, 11, 12} The review boards' findings suggested that lack of adherence to screening recommendations and law resulted in 22 CS cases.

There were 8 cases that might have been prevented if providers had taken steps to ensure treatment. These mothers had: delayed treatment by the provider (4), referral elsewhere due to bicillin shortage at the screening provider (1), reactive screening results erroneously interpreted as serofast by the provider (1) and lack of transportation by the mother to return for treatment (2). The health department could have helped with transportation and with securing bicillin for treatment. One provider did not schedule fast-track (priority) appointments for pregnant women with syphilis which can facilitate timely treatment.

Despite efforts from the providers, 17 infected women did not return for treatment. The Louisiana sanitary code requires reporting of reactive syphilis tests and new cases of syphilis within one business day. There were reporting delays for 12 out of these 17 women. If the health department had known about these cases through timely reporting, DIS could have intervened to ensure timely treatment. In addition, rapid syphilis screening tests are now available that might be helpful in some settings. Pregnant women may be more willing for further evaluation and treatment if they know they have a reactive rapid test.

We categorized 32 (41%) cases as unlikely to be preventable by providers. Most were among women who had no prenatal care or acquired infection late in pregnancy. Lack of prenatal care has been a common contributor to CS in previous studies.^{10,13,14,15} In Upstate New

York (1988--1992) 50% of 322 mothers of CS cases had no prenatal care.¹⁶ Similarly, in Arizona (2000—2005) 40% of 131 mothers of CS cases had no prenatal care.¹⁷ On the other hand, in New York City (2000--2009) only 20% of 195 mothers of CS cases had no prenatal care.¹⁸ In our study, only 12% of the mothers of CS cases had no prenatal care. We did not interview these mothers to determine reasons for their lack of prenatal care, but clearly some of these CS cases could have been prevented if the mothers had been in care. Assuring prenatal care for all pregnant women would provide additional benefits, beyond preventing CS.

Other studies have found many cases occur after women test non-reactive in early pregnancy. In one study, 14% of 59 cases were among women who were not retested, and another 12% were among women who acquired infection after a non-reactive third trimester test.¹¹ Another study found 10% of 148 mothers initially screened non-reactive and were not rescreened at 28-32 weeks, and another 8% had a non-reactive test at 28-32 weeks and then had a subsequent infection.¹⁰ A third study found 14% of 318 women tested non-reactive early in their pregnancy and were never retested until delivery and additional 18% acquired infection late in pregnancy.¹⁶ In the United States (1992—1998) 11% of 760 syphilitic stillbirths were among women who tested non-reactive early in pregnancy.¹⁹

Finally, in our study there were 8 mothers who received timely and adequate treatment of infection, but delivered babies diagnosed with congenital syphilis based on infant criteria.⁹ Our review of these cases did not identify possible reasons for treatment failure or other conditions that might explain the clinical findings, but perhaps a larger review of more cases could provide clues.

CS review boards connected state surveillance and prevention staff with local personnel to identify and address opportunities for preventing congenital syphilis. Similar to previous studies,^{10, 17,18,20,21} CS cases reviewed in this study were often related to inadequate syphilis screening or treatment, infections acquired near delivery, or lack of prenatal care. Review boards provided recommendations to health care providers which enhanced prevention effectiveness. Many CS cases can be prevented by screening and treating women early in pregnancy, and rescreening early in the third trimester to identify infections acquired during pregnancy. Additional infections can be prevented by preventing syphilis and unintended pregnancy among all women.^{22, 23}

Acknowledgments

Source of Funding/Support: None

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Table 1: Summary of Louisiana Congenital Syphilis case review findings and recommendations for prenatal care providers

Findings	Cases	Recommendation
A. High Potential for Prevention by Prenatal Care Providers	26	
1. Early screening non-reactive, not rescreened at 28-32 weeks	15	Provider education on syphilis screening.
2. No early screening, infection detected too late (<30 day /at/ after delivery)	5	Provider education on syphilis screening.
3. Reactive at 28-32 weeks, treatment delayed	2	Treatment is urgent. Fast track appointment for treatment needed. Should not wait until next regular scheduled appointment.
4. Bicillin unavailable, patient referred elsewhere, treatment delayed	1	Notify Health Department when patient is referred to Parish Health Unit for treatment.
5. Reactive in 2 nd trimester, not treated on time	1	Provider outreach on timely treatment of maternal syphilis to prevent congenital syphilis.
6. Reactive test erroneously considered as serofast	1	Provider education on CDC diagnostic criteria for congenital syphilis.
7. Confirmatory test not done	1	Provider education on need for confirmatory test.
B. Possibly Preventable by Prenatal Care Providers	21	
8. Patient did not return for treatment along with delayed reporting by provider to health department	19	Encourage early reporting. Health Department can help find patients for treatment.
9. Early screening non-reactive, reactive at late 3 rd trimester, preterm delivery	1	Provider education on syphilis screening.
10. Incomplete treatment	1	Closer Health Department follow-up necessary.
C. Unlikely Preventable by Prenatal Care Providers	32	
11. Screened non-reactive at 28-32 weeks	10	
12. No prenatal care	9	Community engagement on promoting prenatal care.
13. Mother adequately treated, case by infant criteria	8	
14. Early screening non-reactive, reactive at 28-32 weeks, preterm delivery	4	
15. Early test reactive, treated, reinfected	1	
Total	79	