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Social Vulnerability in Congenital Syphilis Case Mothers: Qualitative Assessment of Cases in Indiana, 2014–2016

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Abstract

Background—Congenital syphilis occurs when a pregnant woman with syphilis is not diagnosed or treated and the infection is passed in utero, causing severe infant morbidity and mortality. Congenital syphilis is easily prevented if women receive timely and adequate prenatal care. Cases of congenital syphilis are considered indicators of problems in the safety net. However, maternal social and behavioral factors can impede women’s care, even when providers follow guidelines.

Methods—We reviewed case interviews and maternal records for 23 congenital syphilis cases reported to CDC from Indiana between 2014 and 2016. We used qualitative methods to analyze narrative notes from maternal interviews to learn more about factors that potentially contributed to CS cases.

Results—All providers followed CDC and state recommendations for screening and treatment of pregnant women with syphilis. Twenty-one of 23 women had health insurance. The number of prenatal care visits women had was suboptimal; more than one third of women had no prenatal care. Nearly one third of women’s only risk factor was sex with a primary male sex partner. The majority of women suffered social vulnerabilities, including homelessness, substance abuse, and incarceration.

Conclusions—Despite provider adherence to guidelines and health insurance availability, some pregnant women with syphilis are unlikely to receive timely diagnosis and treatment. Pregnant women at high risk for syphilis may need additional social and material support to prevent a CS case. Additional efforts are needed to reach the male partners of vulnerable females with syphilis.

Introduction

Congenital syphilis (CS) is the transmission of a syphilis infection from an untreated pregnant woman to the fetus. It can result in miscarriage, stillbirth, and severe physical and neurological impairments in the infant. Early detection and treatment of the mother are critical to prevention of CS; for this reason CS is regarded as “a sentinel health event; its occurrence marks the failure of both the syphilis control program and the prenatal care

system.”¹ Following a period of decrease from 2008 to 2012, congenital syphilis rates in the US have since increased every year. In 2016, there were 628 cases of CS and a case rate of 15.7 cases per 100,000 births, which is a 86.9% increase over 2012.² In Indiana, no cases of congenital syphilis were reported between 2008 and 2013; the three subsequent years (2014–2016) yielded 23 cases.³

The rise in congenital syphilis incidence is part of a larger trend of increased syphilis infections. Once slated for eradication, syphilis has resurged into a pressing public health threat. Between 2015 and 2016, the rate of primary and secondary syphilis infections increased from 7.5 to 8.7 cases per 100,000 in the US, the highest rate since 1993.² While men make up the majority of the increase in syphilis cases, specifically men who have sex with men, cases among women have also increased. During 2015 – 2016, states reported an increase of 35.7% in primary and secondary syphilis among women.² Among women in Indiana, primary and secondary syphilis cases increased 154% from 2014 to 2015 and 29% from 2015 to 2016.³

The Centers for Disease Control and Prevention (CDC) recommends screening of all pregnant women for syphilis at the first prenatal care visit. In areas or populations where the risk of syphilis is high, CDC recommends testing women again during the 3rd trimester and at delivery.⁴ Most states, including Indiana, require first trimester testing; fewer states require testing later in pregnancy or at delivery.⁵

CS cases are associated with late initiation and lack of prenatal care, with most cases occurring among Black and Hispanic mothers and in the US South. In an analysis of 6,383 CS cases reported to the CDC from 1999–2013, more than a fourth (28%) of women had no prenatal care, and only 23% of women had a first prenatal care visit early in pregnancy. Relatively few women had 10 or more prenatal care visits; the fewer visits women had, the more likely they were to experience severe infection, infant morbidity or infant death.⁶

Social vulnerability and deprivation in mothers often is associated with an increased risk of inadequate prenatal care,^{7,8} and “socioeconomic factors interfere more with prenatal care and are most responsible by the lack of adequate treatment...for maternal syphilis.”⁹ Lack of timely and adequate prenatal care is related to numerous structural, psychosocial and behavioral factors, including lack of or late enrollment in insurance or Medicaid, cost of co-pays, lack of transportation or child care, unawareness of the pregnancy, unwanted or unplanned pregnancy, and mental health and substance abuse issues.^{10–19} In recent decades, increased attention has been paid in public health to the interactions among structural barriers, social conditions, and disease; and the way that these interactions often concentrate or combine to negatively affect both individual and population health. Factors such as poverty, violence, and inequality often compound and increase the adverse effects of disease conditions. Such may well be the case with CS.²⁰

We evaluated maternal characteristics of congenital syphilis cases meeting the surveillance case definition reported to the Indiana State Department of Health (ISDH) between 2014 and 2016. Few published studies have attempted to understand the etiology of congenital syphilis through qualitative examination of case mother characteristics and behavior. In this study,

we use qualitative methods to examine each case in detail and to identify common themes regarding factors that potentially contributed to Indiana's 23 cases. Gaining a better understanding of maternal, in addition to provider, factors implicated in CS transmission will allow us to better tailor interventions to mitigate these factors.

Methods

Using the STD surveillance database, we examined syphilis case interview notes and the maternal records on mothers of congenital syphilis cases reported to CDC between 2014 and 2016 (N= 23). Case interview notes contain information pertaining to medical and social history, risks for syphilis, sex partners, health insurance status, HIV status, and demographics. Maternal records contain information specific to reproductive history and prenatal care. Interviews were conducted by Disease Intervention Specialists (DIS) in the normal course of syphilis case investigations. DIS are public health workers specially trained to intervene in the spread of syphilis. We first checked each case for evidence of health care provider adherence to CDC and ISDH screening and treatment recommendations. Next, we reviewed notes and structured content from the DIS interviews and maternal records. We developed a codebook using both a priori and emergent codes, and applied these codes across all 23 cases to capture concepts and themes. Previous large-scale studies in the UK and France^{7, 8} used indices formed from individual or group factors for the purpose of classifying maternal vulnerability, referred to as the Social Deprivation Index and Index of Multiple Deprivation, respectively. Factors considered in these studies include: social isolation; poor or insecure housing; no work-related household income; inadequate or no health insurance; level of health in area of residence; employment; education; crime in area of residence. Social vulnerability in this analysis is comprised of several factors that might impede a person's ability to obtain adequate health care. We coded for factors such as demographics, syphilis diagnosis, prenatal care, HIV status, housing stability, domestic violence, incarceration, drug use, health insurance status, and whether the named male sex partner was also a case of syphilis.

Results

Our review did not find any instance of a health care provider failing to prescribe treatment or test according to recommendations. Twenty-one of the twenty-three case mothers indicated they were enrolled in health insurance during pregnancy, with 86% covered by Medicaid or an Affordable Care Act (ACA) marketplace plan. (Table 1) All of the CS cases reported in this time period were attributable to factors associated with the mother.

Mean age was 26.1 years with a median age of 25 and a range of 18–38 years. Race was Caucasian (48%); African-American (48%); and multi-racial (4%). All mothers were of non-Hispanic ethnicity. Blacks are overrepresented among our case mothers with Black race comprising 10% of Indiana population. Whites and Hispanics are underrepresented among our case mothers with Indiana population comprised of 80% Whites and 7% Hispanics, respectively.²¹ (Table 1) Fourteen cases of syphilis less than one year's duration and eleven cases of late syphilis were represented in this group. Two maternal cases were infected with

syphilis twice during the same pregnancy, most likely by the same partner based on results of DIS investigation. (Table 2)

Eight women had no prenatal care (Table 3). Women who had any prenatal care had a median of 4 visits, with a mean of 7.9 and a range of 1 to 33 visits. Using the total number of prenatal care visits and weeks gestation at birth, we classified mothers with full-term births and less than nine visits as inadequate, and those with nine or greater as adequate, per American Council of Obstetricians and Gynecologists (ACOG) guidelines.²² Among our fifteen mothers with prenatal care, ten are classified as inadequate (67%) and five as adequate (33%). Three stillbirths and one infant born alive and then died are represented in this group. Among the mothers of stillborn infants, one had no prenatal care and two are classified as inadequate.

From the narrative review we identified three interrelated themes: social vulnerability, lack of engagement in health care, and male sex partner risk.

Social Vulnerability

Among our 23 cases, there were several examples of factors that are associated with women's social vulnerability. Six of the case mothers were homeless at the point they were diagnosed with syphilis, a designation which includes living in a shelter. Three more had a living situation we characterized as unstable. For example, a mother experienced two or more moves in the past year, underwent an eviction in the past year, or she and her family (male partner and other children) were temporarily living in a parents' house after having lost their own housing.

Eight case mothers reported that either they or their partner were incarcerated. Among four case mothers, one was incarcerated during the pregnancy resulting in the CS case, another had been incarcerated within the past year, and two had been incarcerated within the past two years (Table 4). Two male sex partners were currently incarcerated. There were also two instances in which both the case mother and her male partner reported incarceration; in both, she had history of incarceration within the past year and he was currently incarcerated. While reason for incarceration is not solicited in a routine syphilis interview, several women acknowledged that drug use was the underlying reason for their current or previous incarceration; some reported having had their children removed from their custody due to drug use.

Lack of engagement in health care

In addition to missing prenatal care visits, the coded interview narratives indicated that case mothers were unable to follow through with preventive health measures adequate to prevent the CS case. Some women did not obtain physician-ordered off-site syphilis testing. Some women did not return to the health care provider for syphilis treatment when contacted, even after numerous follow-up calls. Reasons for these gaps in care are poorly understood since this is not part of a routine syphilis case investigation. In one case though, the mother stated she was unable to take time off from her minimum-wage job for lab work or prenatal appointments due to a lack of paid leave.

Male Partner Risk

Nearly a third of the case mothers' only identified risk for contracting syphilis was from her primary male sex partner. Seven male sex partners were newly-identified as cases as a result of women's initial interviews with a DIS. Two case mothers were each re-infected by their primary male partners during pregnancy, despite DIS intervention. An additional four case mothers each had a negative syphilis test earlier in pregnancy but were infected by the time of delivery. DIS were unable to identify the male partners who infected these four women. Two primary male partners of the case mothers refused to get syphilis testing or prophylactic treatment even after repeated attempts by the DIS and the provider to facilitate this.

Discussion

Our descriptive qualitative analysis of 23 cases indicates that despite provider adherence to guidelines, and despite women having health insurance, some women remain at risk for CS due to other factors. The majority of women had fewer than the recommended number of prenatal care visits; over one-third of women received no prenatal care. Analysis of interview notes indicates that factors associated with maternal social deprivation such as housing instability and homelessness, a history of incarceration, and substance use may interfere with recommended care during pregnancy.

According to the literature on social determinants of health, people lacking basic economic and social support may be overwhelmed with routine life demands, may also have challenging or chaotic interpersonal relationships, and be less likely to consume health care as needed.^{23, 24} Bradley and Taylor remark that "Poverty, social isolation, lack of control in one's life and work life, and other psychological stresses, risky lifestyle choices, food insecurity, lack of educational support and housing, and job insecurity have all been shown to compromise health."²⁴

The most effective method of ensuring CS prevention is for women to have regular prenatal care visits so that appropriate screening, diagnosis and treatment may occur. Additional support may be needed for pregnant women who are socially vulnerable or at high risk for syphilis infection and re-infection to ensure continuity of care. STD programs can consider conducting targeted outreach to providers serving vulnerable women to provide special assistance in cases where women do not obtain laboratory testing or who drop out of prenatal care. In some areas, it may be feasible or advisable to use DIS or public health nurses as case managers who can help return women to care. In addition, STD programs can establish links with programs that serve vulnerable women, such as W.I.C., maternal and child health programs, substance abuse treatment, domestic violence programs, and homeless service organizations. Strengthening links in the social and health safety net can help facilitate early identification of pregnant women with syphilis who may benefit from supportive case management. Jails and prisons could consider requiring a specific care plan when releasing a pregnant inmate to improve her linkage to needed community services including prenatal care, and STD testing and follow-up.

Pregnant women, particularly those without prenatal care, may greatly benefit from syphilis testing when they present for any complaint to hospital emergency departments (ED) or

urgent care centers. Several studies have shown that a substantial number of women present to EDs during their pregnancies and that many are not in prenatal care; thus, the hospital ED may be their only contact with the health system.^{9,25,26}

Some women may find it difficult to carry out physician-ordered off-site syphilis testing due to issues such as transportation, cost, employment conflicts, or competing family responsibilities. Women whom providers suspect may be at high risk for syphilis might benefit from a syphilis point-of-care, rapid test performed in the provider's office. This treponemal test is recommended for persons without a history of prior syphilis infection²⁷ and is viewed as useful for screening pregnant women or in situations where patient follow-up is difficult. The syphilis rapid test is particularly useful during pregnancy due to the severity of congenital syphilis.²⁸ Although there are drawbacks to this test, (low sensitivity and specificity, difficulty reading results, necessary training to correctly interpret results), some pregnant women may be more motivated to follow through with additional diagnostic testing at a laboratory following a preliminary positive result from a rapid test. Depending on location, it might also be reasonable to request DIS follow up for high-risk pregnant women with reactive syphilis rapid tests for field phlebotomy. If state regulations allow, syphilis treatment could also be administered in the patient's home to her and her male partner.

Our analysis highlights the role played by male sex partners in contributing to CS cases, as a substantial proportion of women in this analysis were infected during pregnancy by a primary male sex partner, and reported no other sexual risk factors, such as involvement in sex work or multiple sex partners. Among our cases, none of the men were diagnosed prior to their female partners, indicating that they likely had little if any contact with the health system. This makes them as challenging to reach as are women do not engage with prenatal care. Male partners may need to be reached through other community settings such as jails, substance abuse treatment centers, job training centers, and other local agencies where screening can occur. STD screening in correctional settings, for example, has been shown to be effective in identifying persons with undiagnosed bacterial STDs.²⁹

It is important to 1) determine if women diagnosed with syphilis are pregnant, and 2) identify pregnant women who could have been exposed to syphilis. To address this, STD programs could ensure that DIS ask males with syphilis or other STDs if they have pregnant female partners. Health care providers could also be encouraged to have this discussion with their male patients diagnosed with any STD so that their pregnant female partners may be prioritized for notification and testing.

Close review of case reports and DIS interviews provides insight into contextual factors that may contribute to CS. Other states with congenital syphilis cases may benefit from a similar qualitative review of these factors in order to understand if CS cases are attributable to health care provider missed opportunities, maternal vulnerability, or both. For example, some states now utilize periodic congenital syphilis case review boards to identify missed opportunities, gaps, and barriers. These reviews allow programs to make necessary adjustments designed to prevent future cases.

Effective intervention requires a clear understanding of the problem. State STD programs may consider revising standard DIS interviews with pregnant women with syphilis to include supplemental questions pertaining to the factors identified in this analysis to ascertain potential intervention points and causal factors. Further research may be needed to determine if a lack of understanding on the part of the women about the severity of syphilis to a fetus and the importance of receiving recommended testing contributes to the problem of CS. In addition, we need to know more about factors that facilitate and enable women to obtain prenatal care and that support follow through with syphilis testing, as well as the reasons women do not engage with care; for example, women with substance abuse histories may avoid prenatal care due to fear of being tested for drugs.

At the local level, it may be useful for programs to assess health systems and identify structural factors that hinder women's use of prenatal care; for example, to further understand what tangible services are lacking such as transportation, child care, or availability of prenatal care providers.

Some limitations of our analysis include the following: the surveillance case definition for congenital syphilis is more sensitive than specific, so it includes both confirmed and probable cases. This may result in including mothers of non-infected newborns in our analysis. This study does not compare women with syphilis who did not deliver a congenital infant with those that did, so we are unable to say if any factor we identified was different between the two groups. DIS do not routinely collect information on the specific barriers a woman encountered that discouraged or prevented her from getting care; we cannot say for certain that the barriers described here led to a CS case. We cannot objectively evaluate from this analysis whether barriers actually exist in locations where these cases occurred. Indiana is a low morbidity state for congenital syphilis. Our findings may not be generalizable to other states with greater morbidity or a different geographic, racial, or cultural composition.

Key findings from this analysis add to the literature by providing a richer understanding of contextual factors influencing a case of congenital syphilis. Preventing congenital syphilis in the US may require a focus on both ameliorating the social vulnerabilities affecting pregnant women with syphilis, and traditional medical management.

Acknowledgments

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Short Summary

A qualitative assessment of factors contributing to cases of congenital syphilis in Indiana found no instances of missed opportunities by providers. All cases were attributable to maternal social or behavioral factors.

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Table 1

Demographic Characteristics of Mothers of 23 Congenital Syphilis Case Infants, Indiana, 2014–2016

	Number	Percent (%)
Race		
African-American	11	47.8
Caucasian	11	47.8
Multi-race	1	4.3
Ethnicity		
Hispanic	0	0.0
Non-Hispanic	23	100
Age Group		
15–19	3	13.0
20–24	8	34.8
25–29	6	26.1
30–34	2	8.7
35–39	4	17.4
40 and older	0	0.0
Health Insurance		
None	2	8.7
Commercial	3	13.0
Public	18	78.3

Table 2

Disease-Related Information for 23 Case Mothers of Congenital Syphilis Infants, Indiana, 2014–2016

	Number	Percent (%)
Stage *		
Primary	3	13.0
Secondary	1	4.3
Early Latent	10	43.5
Late Latent or Unknown Duration	11	47.8
HIV Status		
Positive at time of interview	1	4.3
Negative at time of interview	22	95.7
Male sex partner is syphilis case		
No	11	47.8
Yes	7	30.4
Unknown	5	21.7
Negative test early in pregnancy; positive later		
No	16	69.6
Yes	7	30.4
Two syphilis infections this pregnancy		
No	21	91.3
Yes	2	8.7

* Note: 25 Cases are reported among 23 case mothers because two had syphilis twice in one pregnancy

Table 3

Prenatal Care Characteristics of Mothers of 23 Congenital Syphilis Case Infants, Indiana, 2014–2016

	Number	Percent (%)
Prenatal Care		
None	8	34.8
Any	15	65.2
Trimester of first visit		
None	8	34.8
Third (>30 days before delivery)	1	4.3
Second	2	8.7
First	12	52.2
Number of Visits		
None	8	34.8
1	2	8.7
2–4	6	26.1
5–9	2	8.7
>9	5	21.7
Number of live births to case mothers		
One	8	34.8
Two	7	30.4
Three	3	13.0
>Three	5	21.7

Table 4

Social Characteristics of Mothers of 23 Congenital Syphilis Case Infants, Indiana, 2014–2016

	Number	Percent (%)
Housing		
Homeless	6	26.1
Unstable (two moves in past year or living with family)	3	13.0
Stable	14	60.9
Domestic Violence		
No	23	100
Traded Sex for Drugs, Money, Goods		
No	23	100
History of or current incarceration		
None reported	15	65.2
Case mother only	4	17.4
Male sex partner only	2	8.7
Both case mother and male sex partner	2	8.7
Drug Use		
None reported	20	87.0
Unknown	1	4.3
Yes	2	8.7