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SURVEY OF PEDIATRIC INFECTIOUS DISEASES SOCIETY MEMBERS ABOUT CONGENITAL CHAGAS DISEASE

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Abstract

Participants in a survey about congenital Chagas disease, distributed electronically to Pediatric Infectious Diseases Society members, perceived having limited knowledge about congenital *Trypanosoma cruzi* infection. Most rarely or never consider the diagnosis in infants born to parents from Latin America. Improved awareness of congenital Chagas disease and assessment of at-risk infants is needed.

Keywords

Chagas disease; *Trypanosoma cruzi* ; congenital infection; newborn infant

Chagas disease, caused by the protozoan parasite, *Trypanosoma cruzi*, is an emerging infection in the United States, but there is a paucity of information regarding the US Chagas disease clinical burden.[1] It is estimated that 300,000 persons in the United States, including approximately 40,000 women in the childbearing years, have chronic Chagas disease and that 63–315 cases of congenital Chagas disease occur annually.[1,2] Approximately 10%–40% of congenitally infected infants are symptomatic at birth.[3,4] Congenitally infected infants can present with prematurity, hepatosplenomegaly, jaundice, anemia and thrombocytopenia, which might suggest congenital infection, but clinical features are not specific to Chagas disease. Other manifestations of congenital Chagas disease include hydrops fetalis, pneumonitis and meningoencephalitis. Even severe disease can go undetected because of the lack of pathognomonic clinical features and of awareness and suspicion for this diagnosis. With the exception of 2 confirmed cases in infants born to immigrant mothers, there are no reports of congenital Chagas disease in the US birth cohort.[5,6]

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Healthy appearing congenitally infected infants usually do well in infancy, but 20%–30% of children with untreated Chagas disease, both with and without symptoms, develop irreversible life-threatening and often fatal heart disease after years or decades of silent infection.[7] Conduction system abnormalities are an early manifestation of Chagas heart involvement. Cardiac arrhythmias, apical or ventricular aneurysms and progressive dilated cardiomyopathy with congestive heart failure carry a high risk of sudden death.[8] Gastrointestinal tract manifestations include megaesophagus, megacolon or both.

We hypothesized that infants with congenital Chagas disease are not identified in part because this infection is not suspected in at-risk infants. To assess knowledge of congenital Chagas disease and to enhance awareness of *T. cruzi* infection among members of the Pediatric Infectious Diseases Society (PIDS), a survey was developed and distributed to the society membership.

METHODS

A congenital Chagas disease questionnaire was reviewed and approved by PIDS Clinical Affairs and Executive Committees. The survey included 5 demographic questions and 12 regarding general awareness, clinical features and management of congenital Chagas disease. The survey was approved by the Baylor College of Medicine Institutional Review Board for Human Research. The survey was announced through “PIDSNews,” a monthly update provided online to PIDS members, in the January through March 2016 issues, and a link was provided directing those interested to access the survey at https://www.surveymonkey.com. Messages were posted on the PIDS Facebook page asking members to complete the survey, and participation requests through e-mail were sent to Infectious Disease Division Heads and Program Directors. The survey was closed in June 2016, and the results were analyzed descriptively.

RESULTS

Among 1108 active members of PIDS, 204 (18.4%) completed the survey. Most respondents (97.0%) were US-based and described their PIDS membership category as a pediatric infectious disease specialist (75.1%) or fellow-in-training (22.9%). Participants resided in 28 states or the District of Colombia. More responses were received from Texas (13.3%), California (10.2%), Ohio (7.8%), New York (7.8%) and Massachusetts (7.0% of responses) than from other states. More than two-thirds (67.7%) of participants cited patient care in an academic setting as best describing their professional activities; others cited clinical research (11.0%), basic research (6.4%), patient care in a private or group setting (5.0%), infection control/epidemiology (2.0%), teaching/education (1.5%), public health (1.0%) or other (5.5%). Respondents devoted greater than 10% but less than to one-fourth of their time (29.4%), one-fourth to one-half of their time (31.3%) or greater than one-half of their time (26.4%) to direct patient care.

In response to the query, “How would you describe your level of knowledge about congenital Chagas disease?,” responses of “excellent” (2.5%) were uncommon. Some respondents cited having “good” knowledge (26.4%), but most perceived having “limited”

(50.2%) or “very limited” (17.9%) knowledge or responded, “I didn’t know congenital infection could occur” (3.0%). Although most survey participants (80.9%) reported that at least 1% of their patients were children of immigrants from Mexico, Central America or South America, a majority (75.6%) reported that they “never” or “rarely” considered a diagnosis of congenital Chagas disease in a newborn infant born to parents from Latin America and only 8.5% “frequently” or “always” considered the diagnosis (Table 1).

Among questions with defined correct answers, 99.5% of respondents knew that Chagas disease is caused by a parasite and 90.3% knew that cure rates for congenital Chagas disease exceed 90% when treatment is instituted in the first weeks of life. The distribution of responses to additional questions is shown in Table 1. Overall, 46.5% of respondents accurately estimated the number of newborn infants with congenital *T. cruzi* infection per year in the United States, but another 39.5% were unsure of the reported disease burden. Potential modes of transmission were correctly identified by 61.5% of respondents, but less than one-half (47.0%) knew that the risk of maternal-to-infant transmission is 1%–10% and most (48.2%) underestimated or did not know (27.1%) that 10%–40% of infants with congenital Chagas disease have clinical abnormalities at birth. In contrast, 89.9% of respondents were knowledgeable regarding the approach to diagnosis and testing to perform when the diagnosis is suspected.

DISCUSSION

Among PIDS members who completed a survey of congenital Chagas disease knowledge and awareness, most never or rarely considered congenital Chagas disease a diagnostic possibility in infants born to immigrants from Latin America. Two-thirds of respondents provided patient consultation in an academic setting and cared for substantial number of children of immigrants from regions endemic for Chagas disease. As with other emerging health concerns, a shift in thinking is required to consider a diagnosis that is rarely encountered or frequently goes unrecognized at birth. The American Academy of Pediatrics recommends treatment for all cases of acute or congenital Chagas disease as well as chronic *T. cruzi* infection in children younger than 18 years of age.[9]

Data are needed to better understand the extent and distribution of Chagas disease in the United States in the approximately 40,000 women of childbearing age with the infection who are at risk of transmitting it congenitally.[10] Suspicion should be highest in Latino immigrants and those with prolonged residence in endemic regions.[11] Survey respondents demonstrated good knowledge of potential transmission routes for *T. cruzi* but were unfamiliar with the fact that 10%–40% of infants with congenital infection have clinical abnormalities at birth that could permit early treatment and cure. A high index of suspicion is important to initiate diagnostic testing. Paramount in arriving at the decision to perform testing is a maternal travel history. Risk is enhanced if the infant’s mother has lived in a Chagas disease–endemic region and if there has been a potential for prolonged exposure to triatomine bugs, for example, through residence in rural settings or living in adobe or thatched-roofed dwellings.

Although serologic tests, available commercially, can identify individuals with antibodies to *T. cruzi*, the only method to establish the diagnosis conclusively in a neonate is by detection of trypomastigotes. This can be accomplished by direct microscopy of fresh anticoagulated blood specimens or by polymerase chain reaction (PCR) testing of whole blood through the Parasitic Diseases Branch Laboratory of the Centers for Disease Control and Prevention (CDC), to detect circulating parasite DNA. The CDC reference laboratory employs a multitargeted PCR testing algorithm using *T. cruzi* minicircle TaqMan real-time PCR and nuclear *T. cruzi* mini-satellite TaqMan real-time PCR assays.[12] Positive PCR results on serial blood samples from the infant are strong evidence of congenital transmission. Results of testing usually are available within 1 week. Information regarding treatment with the medications approved for treatment of *T. cruzi* infection, nifurtimox and benznidazole, can be obtained through the CDC Drug Service (404-639-3670).

A study conducted by MedscapeCME in 2010 with technical support from CDC suggested a substantial knowledge deficit regarding Chagas disease among healthcare providers in 5 medical specialties.[13] A general lack of awareness was common across all groups, most pronounced in obstetrician–gynecologists and least pronounced in infectious disease physicians. Another questionnaire, developed by the American College of Obstetricians and Gynecologists and reviewed by the CDC, found that obstetrician–gynecologists rarely considered the possibility of Chagas disease.[14] Although enhanced awareness is needed in many arenas, PIDS members who participated in the survey had good knowledge of a number of aspects of *T. cruzi* infection. Specialists and those with an interest in pediatric infectious diseases have the opportunity to provide leadership in the medical community so that optimal evaluation and prompt treatment are provided to infants with congenital Chagas disease.

Our study has some limitations. Survey participation was relatively low and weighted toward those providing care in an academic setting, so responses might not be representative of all PIDS members. Study respondents could have been more likely than nonrespondents to be familiar with congenital Chagas disease. The multiple choice and structure of the questions may have lent itself to educated guessing by participants. The study was distributed through PIDSNews, but the survey site could have been accessed by non-PIDS members. However, none of these limitations would be expected to substantively affect awareness of congenital Chagas disease except possibly to underestimate the knowledge gap. In summary, our data suggest that enhanced awareness among PIDS members as leaders in the care of children could prompt diagnostic evaluation of at-risk infants and could lead to improved long-term outcomes from congenital Chagas disease.

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TABLE 1.

Responses to a Congenital Chagas Disease Survey by Pediatric Infectious Diseases Society Members, 2015

Question or Statement*	Total Responses (n = 204)†	
	Number	%
Respondent characteristics:		
Children of immigrants from Mexico, Central America or South America constitute what proportion of your patient population?		
<1%	27	13.2
1–10%	83	40.7
11–25%	49	24.0
26–50%	25	12.3
>50%	8	3.9
I don’t know	12	5.9
How often do you consider a diagnosis of congenital Chagas disease in a newborn infant born to immigrants from Mexico or Central America or South America?		
Never	70	34.8
Rarely	82	40.8
Sometimes	32	15.9
Frequently	10	5.0
Always	7	3.5
Respondents’ knowledge of congenital Chagas disease:		
The CDC estimates the number of newborn infants with congenital *Trypanosoma cruzi* infection per year in the United States is in the range of:		
<50	9	4.5
50–500	**93**	**46.5**
501–5000	15	7.5
>5000	4	2.0
I don’t know	79	39.5
Chagas disease can be transmitted congenitally if the mother became infected:		
During the pregnancy	7	3.5
Within 1–3 months before becoming pregnant	1	0.5
>5 years before becoming pregnant	1	0.5
During the pregnancy or within 1–3 months before becoming pregnant	29	14.5
Any of the above	**123**	**61.5**

Pediatr Infect Dis J. Author manuscript; available in PMC 2023 May 08.

Question or Statement*	Total Responses (n = 204)† Number	%
None of the above	1	0.5
I don't know	38	19.0
The risk of congenital transmission from a mother with chronic Chagas disease to her infant is:		
<1%	9	4.6
1–10%	**93**	**47.0**
11–25%	19	9.6
26–50%	3	1.5
>50%	0	0
I don't know	74	37.4
What percent of infants with congenital Chagas disease are symptomatic at birth?		
<10%	96	48.2
10–40%	**39**	**19.6**
41–75%	2	1.0
>75%	8	4.0
I don't know	54	27.1
Clinical manifestations of congenital Chagas disease may include each of the following except:		
Preterm delivery	6	3.1
Fetal hydrops	14	7.2
Respiratory failure	24	12.4
Cardiac failure	9	4.6
Hepatosplenomegaly	6	3.1
Periostitis	**107**	**55.2**
Meningoencephalitis	28	14.4
When congenital Chagas disease is suspected, testing should be performed on the:		
Mother only	2	1.0
Newborn only	2	1.0
Mother and newborn	**178**	**89.9**
I don't know	16	8.1
The diagnosis of congenital Chagas disease can be made by:		
Detection of *T. cruzi* in cord blood or peripheral blood from a newborn by the micromethod	6	3.1

Pediatr Infect Dis J. Author manuscript; available in PMC 2023 May 08.

Question or Statement*	Total Responses (n = 204)†	
	Number	%
Detection of *T. cruzi* DNA by PCR in blood from the newborn	16	8.1
Positive serologic tests for *T. cruzi* when the infant is 9–12 months of age	2	1.0
Any of the above	**173**	**87.8**

*Correct answer designated in bold.

†Total responses ranged from 194 to 204, depending upon the question.