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Survey of Obstetrician-Gynecologists in the United States About Chagas Disease

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Abstract. Chagas disease affects an estimated 300,000 people in the United States, and as many as 300 congenital infections are estimated to occur annually. The level of knowledge about Chagas disease among obstetricians-gynecologists in the United States has not been assessed. The American College of Obstetricians and Gynecologists surveyed a representative sample of 1,000 members about Chagas disease. Among 421 respondents, 68.2% (95% confidence interval [CI] = 63.5–72.6) described their knowledge level about Chagas disease as "very limited." Only 8.8% (95% CI = 6.2–12.0) knew the risk of congenital infection, and 7.4% (95% CI = 5.1–10.4) were aware that both acute and chronic maternal infections can lead to congenital transmission. The majority of respondents (77.9%; 95% CI = 73.5–81.9) reported "never" considering a diagnosis of Chagas disease among their patients from endemic countries. Most of those who did consider the diagnosis did so "rarely." Knowledge of Chagas disease among obstetricians-gynecologists in the United States is limited. Greater awareness may help to detect treatable congenital Chagas cases.

INTRODUCTION

Chagas disease, caused by infection with the vector-borne parasite *Trypanosoma cruzi*, affects an estimated 8–11 million persons throughout much of Mexico and Central and South America.[1] In endemic areas, Chagas disease is primarily transmitted by triatomine insects (i.e., kissing bugs). Infection also can occur through congenital transmission as well as through receipt of contaminated blood transfusions or organ transplantations, laboratory accidents, and ingestion of triatomine-contaminated food or drink.[2–5] If untreated, infection is life-long, with low-level intermittent parasitemia. Many chronically infected persons remain asymptomatic. However, an estimated 30% develop clinical manifestations, usually decades after the initial infection. Chronic infection may affect the cardiovascular system (leading to cardiomyopathy, arrhythmias, or sudden death), gastrointestinal system (with megaesophagus or megacolon), or rarely, both.[2,6,7]

Although much less common in the United States, it has been estimated that more than 300,000 people in the United States may have Chagas disease,[8,9] and congenital transmission occurs in 1–10% of infants born to infected mothers.[10] The majority of Chagas cases in the United States are chronically infected persons who have migrated from endemic areas where they acquired the infection; most are asymptomatic and likely unaware of their infection.[8] However, the detection of asymptomatic infections in the United States has increased after the initiation of widespread screening of the blood supply for *T. cruzi* in early 2007.[11] Many newly diagnosed chronic infections are identified among blood donors who are women of reproductive age and at risk of transmitting the infection to their newborns.

Obstetrician-gynecologists may be faced with questions from seropositive patients about the implications of testing results, treatment options, and risk of congenital transmission. In addition, obstetrician-gynecologists can facilitate prompt diagnosis and treatment of congenital Chagas cases by identifying *T. cruzi* infection in pregnant patients who are unaware of their illness. However, little is known about the level of Chagas disease knowledge among obstetricians-gynecologists in the United States.

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METHODS

A questionnaire about Chagas disease was developed by the American College of Obstetricians and Gynecologists (ACOG) and reviewed by the Centers for Disease Control and Prevention (CDC). The questionnaire included questions about the etiology, clinical manifestations, diagnosis, and risk for congenital transmission. Data were also collected on demographic characteristics, clinical practice type, and patient population served by respondents. In March 2008, the questionnaire was mailed to 1,000 ACOG members, including 600 members of the Collaborative Ambulatory Research Network (CARN) and 400 non-CARN members. CARN members are practicing obstetricians-gynecologists who voluntarily agree to participate in periodic surveys conducted by ACOG. A quasi-random sample of each group was selected. The CARN membership list was stratified into groups of 100 so that each group was representative of the ACOG membership based on gender breakdown and year of birth. Six of those groups were then randomly selected for this study. The same procedure was followed for the non-CARN sample, except that four groups were randomly selected for this study. Second, third, and fourth follow-up mailings were sent to non-respondents in May, June, and August 2008, respectively. Questionnaires were compiled, and data was entered at ACOG headquarters in Washington, DC.

Data were analyzed using SAS Enterprise Guide version 4.0 (SAS Institute Inc., Cary, NC). Response proportions were calculated for CARN and non-CARN groups. Ninety-five percent confidence intervals were calculated using the Clopper-Pearson method, and proportions were compared using the Fisher's exact test. Associations between respondent characteristics and knowledge about Chagas disease were investigated using logistic regression. Findings with a P value of < 0.05 were considered significant.

The survey was determined to be exempt from review by the institutional review boards at ACOG and CDC.

RESULTS

Of the 1,000 ACOG members who were mailed the survey, a total of 421 (42%) responded, including 277 (46%) CARN members and 144 (36%) non-CARN respondents. The 421 respondents included residents of 49 states. Respondents had been in practice for a median of 18 years, and 51% were male.

Responses to questions about Chagas disease are presented in Table 1. There were no significant differences in responses between CARN and non-CARN members. Overall, most respondents (77%) described their knowledge level about Chagas disease as "very limited" or "never heard of it." Although 66.9% reported that at least 1% of their patient population is from Mexico or Central or South America (Chagas-endemic areas), the majority of respondents (78%) reported "never" considering a diagnosis of Chagas disease among their patients from those regions. Those serving a population where > 10% of patients are from endemic areas more frequently reported ever considering the diagnosis of Chagas disease (N = 28, 35%) compared with those with fewer patients from endemic areas (N = 60, 19%; P value = 0.002). Males more frequently reported ever considering the diagnosis (N = 55, 28%) compared with females (N = 32, 16%; P value = 0.008). However, among all those who ever considered the diagnosis (N = 88), 90% did so "rarely."

Although 58% of all respondents reported that Chagas is caused by a parasite, 32% correctly identified the various possible clinical manifestations of Chagas disease. Only 8.8% correctly reported that the risk of congenital transmission from a mother with chronic Chagas disease to her child is 1–10%, and only 7.4% were aware that both acute and chronic maternal infections can lead to infection in the newborn. Regarding testing for Chagas disease, 20.2% correctly responded that when Chagas disease is suspected in a pregnant patient, testing should be performed on the mother, her newborn, and any other children of the mother.

For five questions with defined correct answers (Table 1), 61% (N = 257) provided at least one correct response. Only 1% (N = 5) of participants gave correct answers to all five questions. Characteristics associated with providing correct answers to each question are presented in Table 2. Respondents serving a population where > 10% of the patients are from Mexico and Central and South America more commonly reported that Chagas disease is caused by a parasite compared with those who care for a smaller proportion of patients from Chagas-endemic areas. On univariate analysis, both male gender and having completed residency at least 20 yr prior were associated with knowing that Chagas can be transmitted congenitally if the mother became infected at any point during or before the pregnancy; however, on multivariate analysis, only duration since completing residency remained significantly associated. Male gender was significantly associated with correctly reporting the risk of transmission from a mother with chronic Chagas to her newborn.

When asked about sources where respondents would seek information about Chagas disease, the most frequent responses were infectious disease specialist, Medline/Pubmed search, and medical text books (Table 1).

DISCUSSION

Our study showed a very limited level of knowledge about Chagas disease among practicing obstetricians-gynecologists in the United States. The most common response to our survey questions was "I don't know," suggesting a lack of information rather than misinformation. Based on our data, obstetricians-gynecologists rarely consider the possibility of Chagas disease, even when their patient population includes people from endemic countries in Latin America. Also, most respondents reported that they did not know the risk of congenital transmission for Chagas disease or testing procedures for at-risk mothers and infants when the disease is suspected.

We found that serving a population where > 10% of patients are from Chagas-endemic areas, having completed residency more than 20 years ago, and male gender were associated with knowledge about congenital transmission of Chagas disease. Obstetricians-gynecologists providing care for substantial numbers of patients from endemic areas may have had more opportunities to learn about Chagas disease through their clinical experiences. Similarly, those who trained more than two decades ago may have had more opportunities to encounter cases of Chagas during their years of clinical practice; alternatively, the association between years since training and correct responses may reflect a change in medical school or residency curricula over time. Although the difference in Chagas disease knowledge by gender was statistically different, we investigated the role of gender primarily to adjust for the increasing proportion of female obstetrician-gynecologists over time as we examined the impact of years since completing training. The observed association between gender and knowledge about Chagas disease may be the result of unmeasured confounders. Overall, even among the groups with more frequent correct responses, the level of knowledge and index of suspicion for Chagas disease were suboptimal.

Reports in the literature show that cases of Chagas disease among pregnant women in the United States have been newly diagnosed by their obstetric providers.[12,13] Although there have been no documented cases of congenitally acquired Chagas in the United States, it is likely that such transmission has occurred. Studies of Chagas disease among blood donors in the United States have identified three suspect cases of congenital transmission; however, the source of infection could not be confirmed.[14,15] A cross-sectional study of pregnant women in Houston, Texas by Di Pentima and others[16] found that 0.4% of Hispanic pregnant women had antibodies to *T. cruzi* present in their sera. Based on census data and an assumed congenital transmission rate of 1–4%, the authors estimated that ~10–40 cases of congenital Chagas disease occur annually in the state of Texas. Buekens and others[17] used the seroprevalence reported by Di Pentimi and others[16] and national data on live births of Hispanic origin to estimate that 189 cases of congenital Chagas disease occur annually in the United States.[17] Bern and Montgomery[9] applied country-specific seroprevalence and birth rates to estimated populations of authorized and unauthorized immigrants from endemic countries residing in the United States and assumed a congenital transmission rate of 1–5%; the authors estimated that each year, there are 63–315 new cases of congenital Chagas in the United States.[9] Cases of congenital transmission of Chagas disease have been documented in other non-endemic areas, including Spain,[18,19] Switzerland,[20] and areas in South America with no vectorial transmission.[21,22]

Congenital Chagas disease cases are most commonly asymptomatic or may present with non-specific findings such as low birth weight, hepatosplenomegaly, or respiratory distress.[23] The lack of defining clinical characteristics in infected newborns highlights the importance of detecting *T. cruzi* infection among pregnant women. If a mother is known to be infected, her baby can be promptly tested and treated, if necessary. Cord blood or a blood sample from the newborn should be tested by culture, smear, serology, and polymerase chain reaction (PCR; if available); if initial results are negative, testing should be

TABLE 1
Responses from obstetricians-gynecologists in the United States to a survey about Chagas disease

Question or statement*	Total (N = 421) Yes or affirmative n	Total (N = 421) Yes or affirmative Percent (95% CI)	CARN (N = 277) Yes or affirmative n (%)	Non-CARN (N = 144) Yes or affirmative n (%)	P value†
How would you describe you level of knowledge about Chagas disease?					
Excellent	1	0.2 (0, 1.3)	1 (0.4)	0 (0)	1.000
Good	10	2.4 (1.2, 4.4)	7 (2.5)	3 (2.1)	
Limited	84	20.1 (16.4, 24.3)	55 (19.9)	29 (20.4)	
Very limited	285	68.2 (63.5, 72.6)	188 (68.1)	97 (68.3)	
I've never heard of it	38	9.1 (6.5, 12.3)	25 (9.1)	13 (9.2)	
Chagas diseases is caused by a					
Bacterium	33	8.1 (5.6, 11.2)	24 (9.0)	9 (6.4)	0.504
Virus	2	0.5 (0, 1.8)	2 (0.8)	0 (0)	
Parasite‡	236	57.8 (52.9, 62.7)	155 (57.8)	81 (57.9)	
Fungus	1	0.2 (0, 1.4)	0 (0)	1 (0.7)	
I don't know	136	33.3 (28.8, 38.1)	87 (32.4)	49 (35.0)	
People with chronic Chagas disease may have					
Cardiac manifestations only	29	7.2 (4.9, 10.2)	19 (7.1)	10 (7.5)	0.797
Gastrointestinal manifestations only	3	0.8 (0.2, 2.2)	2 (0.8)	1 (0.8)	
No clinical manifestations	4	1.0 (0.3, 2.5)	1 (0.4)	3 (2.2)	
Cardiac or no clinical manifestations	33	8.2 (5.8, 11.4)	22 (8.3)	11 (8.2)	
Gastrointestinal or no clinical manifestations	6	1.5 (0.6, 3.2)	5 (1.9)	1 (0.8)	
Cardiac or gastrointestinal manifestations	4	1.0 (0.3, 2.5)	3 (1.1)	1 (0.8)	
Cardiac, gastrointestinal or no clinical manifestations‡	126	31.5 (27.0, 36.3)	82 (30.8)	44 (32.8)	
I don't know	195	48.8 (43.8, 53.8)	132 (49.6)	63 (47.0)	
Immigrants from Mexico or Central or South America constitute what proportion of your patient population?					
< 1%	117	28.3 (24.0, 32.9)	71 (25.9)	46 (33.1)	0.326
1–10%	168	40.7 (35.9, 45.6)	122 (44.5)	46 (33.1)	
11–25%	52	12.6 (9.6, 16.2)	33 (12.0)	19 (13.7)	
26–50%	17	4.1 (2.4, 6.5)	10 (3.6)	7 (5.0)	
> 50%	10	2.4 (1.2, 4.4)	6 (2.2)	4 (2.9)	
I don't know	49	11.9 (8.9, 15.4)	32 (11.7)	17 (12.2)	
How often do you consider a diagnosis of Chagas disease in your patients who are immigrants from Mexico or Central or South America?					
Never	310	77.9 (73.5, 81.9)	210 (79.6)	100 (74.6)	0.451
Rarely	79	19.8 (16.0, 24.1)	49 (18.6)	30 (22.4)	
Sometimes	7	1.8 (0.7, 3.6)	3 (1.1)	4 (3.0)	
Frequently	1	0.2 (0, 1.4)	1 (0.4)	0 (0)	
Always	1	0.2 (0, 1.4)	1 (0.4)	0 (0)	
Chagas disease can be transmitted congenitally if the mother became infected					
During the pregnancy	6	1.5 (0.6, 3.2)	4 (1.5)	2 (1.5)	0.512
Within 1–3 months before becoming pregnant	5	1.2 (0.4, 2.9)	5 (1.9)	0 (0)	
> 5 years before becoming pregnant	1	0.2 (0, 1.4)	1 (0.4)	0 (0)	
During the pregnancy or within 1–3 months before becoming pregnant	19	4.7 (2.8, 7.2)	13 (4.9)	6 (4.4)	
Any of the above‡	30	7.4 (5.1, 10.4)	16 (6.0)	14 (10.2)	
None of the above	3	0.7 (0.2, 2.2)	2 (0.8)	1 (0.7)	
I don't know	340	84.2 (80.2, 87.6)	226 (84.6)	114 (83.2)	
The risk of congenital transmission from a mother with chronic Chagas disease to her child is					
< 1%	5	1.2 (0.4, 2.8)	2 (0.7)	3 (2.2)	0.282
1–10%‡	36	8.8 (6.2, 12.0)	27 (9.9)	9 (6.6)	
11–25%	9	2.2 (1.0, 4.1)	6 (2.2)	3 (2.2)	
26–50%	5	1.2 (0.4, 2.8)	3 (1.1)	2 (1.5)	
> 50%	4	1.0 (0.3, 2.5)	1 (0.4)	3 (2.2)	
I don't know	350	85.6 (81.8, 88.8)	233 (85.7)	117 (85.4)	
When Chagas disease is suspected in a pregnant patient, testing should be performed on the					
Mother only	8	2.0 (0.8, 3.8)	6 (2.2)	2 (1.4)	0.927
Newborn only	0	0 (–)	0 (0)	0 (0)	
Mother and newborn	16	3.9 (2.2, 6.3)	10 (3.7)	6 (4.3)	
Mother, newborn, and any other children of the mother‡	83	20.2 (16.5, 24.5)	56 (20.7)	27 (19.3)	
I don't know	303	73.9 (69.4, 78.1)	198 (73.3)	105 (75.0)	
Indicate the sources you would use to look for information about Chagas diseases and pregnancy§					
Infectious disease specialist	244	59.5 (54.6, 64.3)	163 (60.2)	81 (58.3)	0.750
Medline/Pubmed search	223	54.4 (49.4, 59.3)	141 (52.0)	82 (59.0)	0.209
Medical text books	205	50.0 (45.0, 55.0)	139 (51.3)	66 (47.5)	0.531
Other internet	157	38.3 (33.6, 43.0)	106 (39.1)	51 (36.7)	0.668
ACOG newsletter	127	31.0 (26.5, 35.7)	84 (31.0)	43 (30.9)	1.000
Journal articles	124	30.2 (25.8, 34.9)	85 (31.4)	39 (28.1)	0.570
Colleagues in obstetrics-gynecology	111	27.1 (22.8, 31.6)	70 (25.8)	41 (29.5)	1.000
Medical conferences	25	6.1 (4.0, 8.9)	17 (6.3)	8 (5.8)	1.000

* Missing responses excluded from denominator.
† Comparing CARN vs. non-CARN using Fischer's exact test for rxc tables.
‡ Correct answer.
§ Instructed to select all that apply.

TABLE 2
Characteristics associated with correct responses questions about Chagas disease

Question or statement*	Correct response *n* (%)	Incorrect response *n* (%)	OR (95% CI)	aOR† (95% CI)
Chagas disease is caused by a parasite	*N* = 236	*N* = 172		
Male gender	114 (48.5)	91 (53.2)	0.83 (0.56, 1.23)	0.74 (0.48, 1.14)
≥ 20 years since completing residency	110 (47.0)	70 (40.9)	1.28 (0.86, 1.91)	1.47 (0.96, 2.26)
> 10% of patient population from Chagas-endemic areas	59 (25.2)	19 (11.2)	2.68 (1.53, 4.70)‡	2.71 (1.54, 4.76)‡
People with chronic Chagas disease may have cardiac, gastrointestinal, or no clinical manifestations	*N* = 126	*N* = 274		
Male gender	62 (49.2)	137 (50.4)	0.96 (0.63, 1.46)	0.89 (0.57, 1.4)
≥ 20 years since completing residency	61 (48.8)	116 (42.3)	0.78 (0.51, 1.19)	1.36 (0.87, 2.12)
> 10% of patient population from Chagas-endemic areas	29 (23.2)	48 (17.6)	1.29 (0.84, 1.97)	1.42 (0.84, 2.39)
Chagas disease can be transmitted congenitally if the mother became infected during or before the pregnancy	*N* = 30	*N* = 374		
Male gender	22 (73.3)	182 (48.9)	2.87 (1.25, 6.61)‡	2.05 (0.86, 4.89)
≥ 20 years since completing residency	22 (73.3)	157 (42.2)	3.76 (1.63, 8.68)‡	3.06 (1.29, 7.27)‡
> 10% of patient population from Chagas-endemic areas	6 (20.0)	73 (19.6)	1.02 (0.40, 2.6)	0.99 (0.38, 2.56)
The risk of congenital transmission from a mother with chronic Chagas disease to her child is 1–10%	*N* = 36	*N* = 373		
Male gender	24 (66.7)	181 (48.8)	2.10 (1.02, 4.32)‡	2.22 (1.04, 4.74)‡
≥ 20 years since completing residency	16 (44.4)	166 (44.7)	0.99 (0.50, 1.97)	0.77 (0.37, 1.60)
> 10% of patient population from Chagas-endemic areas	11 (30.6)	68 (18.3)	1.96 (0.92, 4.18)	1.94 (0.90, 4.15)
When Chagas disease is suspected in a pregnant patient, testing should be performed on the mother, newborn, and any other children of the mother	*N* = 83	*N* = 327		
Male gender	46 (55.4)	158 (48.6)	1.31 (0.81, 2.13)	1.19 (0.71, 1.99)
≥ 20 years since completing residency	43 (52.4)	139 (42.8)	1.48 (0.91, 2.40)	1.39 (0.84, 2.32)
> 10% of patient population from Chagas-endemic areas	20 (24.1)	57 (17.6)	1.49 (0.83, 2.65)	1.50 (0.84, 2.68)

*Missing responses excluded from denominator.
†Adjusted for gender, years since completing residency, and proportion of patient population from Chagas-endemic areas.
‡$P < 0.005$.

repeated at 4–6 weeks, and serology should be tested again at 9–12 months.[24] Infected babies should be treated as soon as possible, because treatment is more efficacious when initiated in the first days to weeks of life.[25] Two anti-parasitic medications used for treatment of Chagas disease—nifurtimox and benznidazole—are available in the United States only through the CDC. In order for cases of congenital Chagas disease to be promptly detected and treated, obstetric providers must consider the diagnosis in their patients and be aware of the need to test pregnant women and their children. However, we found that obstetrician-gynecologists rarely suspected the diagnosis, and most were unaware of testing recommendations.

Although congenital Chagas disease is relatively rare in the United States, the estimated number of annual cases is not dissimilar from other rare diseases for which all newborns are screened, such as phenylketonuria (estimated 215 cases) or congenital adrenal hyperplasia (estimated 202 cases).[26] Because untreated congenital Chagas may lead to substantial morbidity or death and effective treatment is available, it is important for obstetric providers to be aware of the risk factors for disease among their patient population. Furthermore, there is increasing evidence that treatment of chronic asymptomatic Chagas disease in older children and adults may help prevent or halt the progression of clinical manifestations, and treatment is now advocated for a much wider group of patients with chronic Chagas disease.[27] Therefore, detection of Chagas disease among obstetric patients can facilitate treatment of the mother (generally after delivery because of potentially adverse effects of the medications on the fetus) as well as the diagnosis and treatment of Chagas disease in the newborn and any older siblings.

This study was limited by the use of self-reported data, which may be subject to social desirability bias. We also had a relatively low response rate, which may limit the ability of generalizations of the findings more broadly to all obstetrician-gynecologists. However, neither of those limitations would be expected to lead to an underestimation of respondents' knowledge about Chagas disease. Our data suggest that a greater awareness of Chagas disease may help to detect treatable congenital cases in the United States.

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