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Estimates of adolescent and adult congenital heart defect prevalence in metropolitan Atlanta, 2010, using capture–recapture applied to administrative records

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ABSTRACT

Purpose: Although congenital heart defects (CHD) are one of the most common types of birth defects in the United States, subnational prevalence estimates beyond early childhood are limited.
Methods: We used capture–recapture methodology and logistic regression to estimate CHD prevalence per 1000 residents as of January 1, 2010, separately for adolescents and adults treated and living within five metropolitan Atlanta, Georgia counties, during 2008–2010.
Results: Data sources differed by age. Adolescents (n = 1621, aged 11–20 years) and adults (n = 3176, aged 21–64 years) were captured from at least one source. We estimated CHD prevalence to be 7.85 per 1000 adolescents (estimated n = 3718 [95% CI: 3471–4004]) and 6.08 per 1000 adults (estimated n = 12,969 [95% CI: 13,873–18,915]). When we included persons found in age-inappropriate sources, prevalence estimates increased to 11 per 1000 adolescents and 6.5 per 1000 adults.
Conclusions: This method for obtaining subnational prevalence estimates provided reasonable prevalence results and identified needs for service improvement. Only one half of adolescents and one-quarter of adults with CHD were in health care within a 3-year time frame, suggesting need for better access to health insurance, transition care, and an increased number of physicians specializing in CHD care.

Introduction

Congenital heart defects (CHD), including defects of the heart and/or primary vessels connected to the heart, comprise the most common type of birth defect. In administrative records, each CHD abnormality of structure or blood flow is coded separately such that multiple codes can describe a single CHD [1]. Advances over the past four decades in the diagnosis and medical treatment of infants and children with CHD have resulted in greater than 85% survival of affected individuals into adulthood [2]. However, they require lifelong cardiology care, and about half need care from cardiac specialists in CHDs, as recommended by published guidelines [3].

Although there are robust estimates of CHD prevalence detected at birth, few population-based surveillance prevalence estimates exist beyond birth and early childhood in the United States [3]. Better estimates of total and age-specific CHD prevalence across the lifespan would better characterize the CHD burden on morbidity, mortality, health care use, health care cost, disability, and non-CHD attributable costs [4]. For example, accurate estimation of the adolescent population living with CHD would aid in identifying the need for improved services for transitioning to adult care. Administrative data can identify persons who are in treatment, but those who are not in treatment will not be included. Administrative data-based estimates may be improved by applying a capture–recapture (CR) strategy, which adjusts for incomplete case ascertainment by cross-referencing or overlapping cases across distinct data sources [5].

In 2012, Congress appropriated funds to the Centers for Disease Control and Prevention (CDC) to develop a pilot CHD surveillance system using administrative records to improve information on

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survival, health care utilization, and long-term outcomes of adolescents (aged 11–20 years) and adults (aged 21–64 years) living with CHD. To accomplish this directive, CDC established cooperative agreements (FOA #DD12-1207) with three sites (Emory University School of Medicine and School of Public Health, the Massachusetts Department of Public Health, and New York State Department of Health) [6]. The Emory University site collected information on Georgia residents diagnosed with CHD. We collected data from seven adult and pediatric clinical and administrative sources and reported to CDC on persons aged 11–64 years who had been seen at least once with a CHD diagnosis from January 1, 2008, to December 31, 2010, and who were known to be alive as of January 1, 2010. For this analysis, we used the information to estimate CHD prevalence among two groups, adolescents (aged 11–20 years) and adults (aged 21–64 years) by applying CR methodology, residing in one of five metropolitan Atlanta counties.

Methods

This study was approved by Emory University's Institutional Review Board and SAS 9.4 (SAS Institute Inc., NC) was used to perform all analyses. We obtained demographic and encounter-level data for males and females with a CHD diagnosis who were aged at least 11 years and not older than 64 years by January 1, 2010. Six health services or health care systems that provide most CHD care in Georgia provided information: Emory Healthcare (adult), St. Joseph's Hospital (adult), Grady Health (adult), the Sibley Heart Center (adolescent), Pediatric Cardiology Services (PCS; adolescent), and Children's Health Care of Atlanta (CHOA; adolescent). To those administrative records, we added Georgia Medicaid claims (both adult and adolescent). We cleaned and deduplicated all data within data source and then linked across sources. We tracked data source in a "Master" Microsoft Access database table.

Two-source CR uses the number of unique individuals captured in each of two data sources (N_1 and N_2) and the number of unique individuals captured in both data sources (X_{12}) to estimate the number of individuals in the total population (N) and the number of individuals who were missed (X_0; Table 1). We made the following assumptions: (1) the population was closed during the capture period; (2) each individual was matched from capture to recapture; and (3) each individual had the same inclusion probability [7]. We used the Chapman estimator, also referred to as an "unbiased estimator," because of its optimal properties under a wide range of conditions [5]. We assessed dependency by comparing the capture rate (N_1/N) with the recapture rate (X_{12}/N_2), where positive dependency (producing an underestimate) was indicative of a recapture rate greater than the capture rate, and a negative dependency (producing an overestimate) was indicative of a capture rate greater than the recapture rate [8].

We constrained CR analyses to individuals residing in one of the five metropolitan Atlanta, Georgia counties (Clayton, Cobb, DeKalb, Fulton, and Gwinnett). A major assumption in the use of the CR method is the consistency of prespecified analytic sources. We anticipated that the patient's age was likely to affect the probability of capture in the sources and decided to stratify into two age categories based on likely source of care. The adolescent population (aged 11–20 years) derived from three sources: (1) combined CHOA and PCS; (2) Sibley; and (3) adolescent administrative (CHD Medicaid adolescents aged 11–20 years). The adult population (aged 21–64 years) came from four sources: (1) *Adult Emory* (CHD patients in Emory Healthcare); (2) *Adult Grady* (CHD patients in Grady Health); (3) *Adult St. Joe's* (CHD patients in St. Joseph's Hospital); and (4) *Adult administrative* (CHD Medicaid patients aged 21–64 years).

We conducted manual, two-source CR analyses within the age groups and tested sources for mutual independence. We chose Poisson modeling, which is appropriate assuming that capture sources are independent and captures are counted. Because the severity of the defect may affect the likelihood of being captured in more than one source, we also stratified by severity for the two-source combinations chosen for the final models. Severe CHD was defined by International Classification of Diseases, Ninth Revision, Clinical Modification codes for heart defects that typically require surgery in the first year of life [6]. We performed log-linear modeling under the Poisson distribution to derive CHD population estimates and assessed model fit through the likelihood ratio statistic, Akaike information criterion, and the deviance/df, where the lower values for each statistic indicated better model fit [5].

Once we determined the best estimate of the number of CHD cases, we calculated the prevalence of CHD in the five-county area using the U.S. Census of 2010 [9] for denominators. We assumed that the population aged 10–19 years (473,533) accurately reflected the population aged 11–20 years and the population aged 20–64 years (2,133,575) accurately reflected the population aged 21–64 years [9].

Our preliminary analysis revealed a substantial number of adults seen in CHOA, PCS, and Sibley and some adolescents seen in adult clinics. As a secondary analysis, we added those cases to obtain an upper estimate of age-specific prevalence. We also compared results using this CR/administrative records method with data from the Metropolitan Atlanta Congenital Defects Monitoring Program

Table 1
Two-source contingency table for capture–recapture method

	Source 1		
	Yes	No	
Source 2			
Yes	X_{12}	X_2	N_2
No	X_1	X_0	
	N_1		N

N = all cases occurring (estimated); N_1 = total cases in Source 1; N_2 = total cases in Source 2; X_{12} = cases found by both Source 1 and Source 2; X_1 = cases found in Source 1, but not Source 2; X_2 = cases found in; X_0 = cases not found in Source 1 or Source 2.

Table 2
Demographics of CHD patients captured between January 1, 2008, and December 31, 2010, limited to five metropolitan Atlanta counties*

Characteristic	*n* (%)
Overall	4797 (100)
Gender	
Male	2234 (46.6)
Female	2563 (53.4)
Age group	
11–20	1621 (33.8)
21–30	762 (15.9)
31–40	692 (14.4)
41–50	646 (13.5)
51–60	757 (15.8)
61–64	319 (6.7)
Race	
American Indian	1 (0.02)
Asian	26 (0.5)
Black	231 (4.8)
Hawaiian	3 (0.06)
White	425 (8.9)
Unknown	4111 (85.7)
Severity	
Severe	829 (17.3)
Not severe	3962 (82.7)
Missing	6

* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.

Table 3
Number of captures for unique CHD cases in the five metropolitan Atlanta counties*, 11–64 years ($n = 4797$)

Number of captures for a unique CHD case	Count of CHD patients captured	Percentage
1	3678	76.7
2	832	17.3
3	210	4.4
4	60	1.3
5	17	0.4

* Five metropolitan-Atlanta counties: Clayton, Cobb, DeKalb, Fulton & Gwinnett.

(MACDP), which has collected information on cases prevalent at birth through 5 years of age for the five metropolitan Atlanta counties we included in this study. The first year of life is the most critical period of survival for an infant with a CHD, after which survival probabilities for infants and children vary by type of CHD with up to 8-year survival ranging from 50% to 85% [10,11]. Assuming that all MACDP cases of CHD had survived and were still resident, we compared our results with MACDP CHD cases (2186 adolescents as of January 1, 2010, and 3085 adults, aged 21–42 years, since births before 1967 occurred before the initiation of the MACDP).

Results

Most cases were below the age of 41 years (64.1%), female (53.4%), and did not have a race identified (86%; Table 2). The number of individuals captured by provider source varied in size (range 11–2556 CHD cases), percent male (range 36%–62%), and mean age (range 18–48 years). The proportion of severe cases was identical for adolescents and adults, both at 17.3% (eAppendix Table A). When stratified by age group (adolescents and adults) and data source, the proportion of cases diagnosed as severe varied from 16.1% to 21.0% (eAppendix, Table B).

Of the 4797 unique CHD cases identified in the five counties, most cases were captured in only one source (76.7%; Table 3). As the number of capture sources increased, the percentage of captured individuals decreased, with only 17 unique CHD cases captured in five of eight sources, including the MACDP, which we used only to increase information about already-identified cases.

We assessed dependence to 0.005. The three tests between the three adolescent data sources showed no dependence. Stratification by case severity for the two-source combination of Sibley and CHOA/PCS used in the final adolescent model also showed no dependence (eAppendix, Table C). The six tests between the four adult data sources resulted in no dependencies between each of the two-source CR calculations. Stratification by case severity for the two-source combination used in the final adult model also indicated no dependence (eAppendix, Table C).

In two-source manual calculations, the estimated CHD population ranged from 600 to 1903 individuals aged 11–20 years and from 1560 to 86,769 individuals aged 21–64 years (Table 4). Some models resulted in estimates that were fewer than the unique number of captured individuals (i.e., Model 3 in the adolescent analysis and Models 3 and 6 in the adult analysis; Table 4).

In our multiple Poisson models using combined data and interaction terms to control for possible dependencies between sources, the best model for estimating prevalence among adolescents (Model 4 in Table 5) controls for dependency between combined CHOA/PCS and Medicaid and estimates the number of missing CHD cases to be 1860 for a total CHD adolescent population aged 11–20 years estimated to be 3718 (95% confidence interval [CI], 3471–4004). The adult Model 4 is the best controlling for dependency between Emory and Medicaid and estimating the number of missing adult CHD cases to be 12,969 for a total adult CHD population of 16,152 (95% CI, 13,873–18,915; Table 5). Using the estimates from these models, we calculated the prevalence to be 7.85 (95% CI, 7.33–8.45) per 1000 residents aged 10–20 years in 2010 and 6.08 (95% CI, 5.22–7.12) per 1000 residents aged 21–64 years in the five-county metropolitan Atlanta area.

In the secondary analysis that retained those cases whose age fell outside the mission of the data source, meaning adults found in the adolescent data sources or adolescents found in the adult data sources, CHD population estimates increased by roughly 1500 and 1000 in the adolescent and adult populations, respectively. When we add these to the CR estimates, CHD prevalence is approximately 11 per 1000 adolescents and 6.5 per 1000 adults.

The number of CHD cases projected based on 100% survival of the MACDP cohorts is less than the estimated CHD cases in comparable age groups now residing in the five-county metropolitan-Atlanta area (2186 adolescents compared with our estimate of 3718, and 3085 adults aged 21–42 years compared with our estimate of 6210). We noted that only 12% of the MACDP cases were located in clinical and billing or administrative records from 2008 to 2010, perhaps as a result of deaths, or some in the MACDP cohort not having obtained health care during this period or some having moved out of the area. We conducted a search of a sample of CHD cases in the MACDP cohort, but not in the administrative data, to determine if these cases still resided in the state of Georgia. Preliminary results revealed that although 19% of cases had moved out of state, 48% remained in state with 68% of those still residing in the five-county MACDP catchment area.

Table 4
Manual CR analysis of both the adolescent and adult populations using two sources in the five metropolitan-Atlanta counties*

Model	Source 1	Source 2	Total population					
			Source 1 (N_1)	Source 2 (N_2)	Both (X_{12})	Estimated missing	CR estimated total	95% CI total
Two adolescent sources								
1	Sibley	CHOA/PCS†	1384	396	288	411	1903	1801–2005
2	Sibley	MCAID‡	1384	70	52	453	1855	1606–2104
3	CHOA/PCS†	MCAID‡	396	70	46	180	600	505–694
Two adult sources								
1	Emory	STJOE	2290	278	19	29,411	31,960	18,157–45,762
2	Emory	Grady	2290	310	36	16,693	19,257	13,398–25,116
3	Emory	MCAID§	2290	305	241	543	2897	2739–3055
4	St. Joseph	Grady	278	310	0	86,181	86,769	—
5	St. Joseph	MCAID§	278	305	10	7188	7761	3113–12,410
6	Grady	MCAID§	310	305	60	1005	1560	1243–1877

* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.
† CHOA ($n = 394$) and PCS ($n = 10$) combined into one source. Eight CHD cases found in both sources leaving 396 total.
‡ Medicaid administrative data for adolescents limited to ages 11–20 years.
§ Medicaid administrative data for adults limited to ages 21–64 years.

Table 5
Separate CR analyses using Poisson modeling of three adolescent sources and four adult sources to estimate missing and total CHD cases (adolescent and adult) in five metropolitan Atlanta counties*

Model	Interaction terms†	AIC	G^2	Deviance/ df	Predicted missing	95% CI missing	Estimated total‡	95% CI total
Adolescent population analysis								
1‖	None	114	12534	19	1610	1406–1843	3468	3263–3701
2	S1*S2	104	12539	23	1049	784–1403	2907	2642–3261
3	S1*S3	115	12534	29	1589	1367–1846	3447	3225–3704
4	S2*S3	58	12562	0.3	1860	1613–2146	3718	3471–4004
5	S1*S2 S1*S3	92	12547	32	600	408–881	2458	2266–2739
6	S1*S2 S2*S3	60	12562	0.6	1866	1298–2681	3724	3156–4539
7	S1*S3 S2*S3	60	12563	0.3	1896	1615–2227	3754	3473–4085
8	S1*S3 S2*S3	62	12563	—	2220	1245–3957	4078	3103–5815
Model	Interaction terms†	AIC	G^2	Deviance/ df	Predicted missing	95% CI missing	Estimated total§	95% CI total
Adult population analysis								
1‖	None	386	20,882	35	6406	5665–7244	9589	8848–10,427
2	S1*S2	287	20,933	27	4830	4231–5515	8013	7414–8698
3	S1*S3	319	20,917	31	4828	4209–5537	8011	7392–8720
4	S1*S4	265	20,944	24	12,969	10,690–15,732	16,152	13,873–18,915
5	S2*S3	360	20,896	36	6163	5449–6970	9346	8632–10,153
6	S2*S4	382	20,885	38	6236	5506–7063	9419	8689–10,246
7	S3*S4	317	20,918	30	7499	6567–8562	10,682	9750–11,745
8	S1*S2 S1*S3	169	20,992	13	3096	2663–3599	6279	5846–6782
9	S1*S2 S1*S4	232	20,961	22	8903	7149–11,086	12,086	10,332–14,269
10	S1*S2 S2*S3	255	20,950	26	4585	4014–5237	7768	7197–8420
11	S1*S2 S2*S4	288	20,933	30	4795	4198–5478	7978	7381–8661
12	S1*S2 S3*S4	237	20,959	23	5630	4880–6494	8813	8063–9677
13	S2*S3 S2*S4	357	20,899	40	6009	5304–6808	9192	8487–9991
14	S2*S3 S3*S4	294	20,930	31	7192	6298–8213	10,375	9481–11,396
15	S1*S2 S1*S3 S1*S4	171	20,993	15	3299	2502–4349	6482	5685–7532
16	S1*S2 S2*S3 S2*S4	257	20,950	30	4576	4006–5228	7759	7189–8411
17	S1*S3 S2*S4 S2*S3	279	20,939	34	4375	3803–5032	7558	6986–8215
18	S1*S2 S2*S3 S3*S4	208	20,974	22	5319	4609–6138	8502	7792–9321
19	S1*S2 S2*S4 S3*S4	236	20,960	26	5571	4829–6428	8754	8012–9611

AIC = Akaike information criterion.
* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.
† Adolescents, aged 11–20 years: S1 = Sibley; S2 = combined CHOA/PCS; and S3 = Medicaid. Adults, aged 21–64 years: S1 = Emory; S2 = St. Joseph; S3 = Grady; and S4 = Medicaid.
‡ Predicted missing were added to the total captured in the adolescent data sources ($n = 1858$).
§ Predicted missing were added to the total captured in the adult data sources ($n = 3183$).
‖ All models build off this original model containing S1, S2 and S3 for adolescent models and S1, S2, S3 and S4 for adult models.

Discussion

Using CR methods, we estimated prevalence of CHD in the five-county metropolitan Atlanta area as of January 1, 2010, to be 7.85 per 1000 residents aged 11–20 years and 6.08 per 1000 residents aged 21–64 years. To our knowledge, this is the first study to use CR methods applied to administrative data for estimating CHD prevalence among U.S. adults aged 21–64 years and the second such prevalence estimate for adolescents. With a similar approach, Akkaya-Hocagil et al. estimated prevalence to be 6.4 (95% CI, 6.2, 6.6) per 1000 adolescents aged 11–19 years in 11 New York counties [12]. The authors noted dependence between two of their three data sources and lack of Medicaid as a data source, which might have increased their observations by identifying CHD cases in primary care encounters. Similar to our study, insufficient information was available to estimate prevalence within race or ethnic subgroups.

Gilboa et al. [13] used 2010 age, sex, and severity-adjusted prevalence estimates of CHD from Québec, Canada, to estimate the CHD prevalence among non-Hispanic whites in the United States and the overall CHD prevalence in the United States using

correction factors for differences in survival for other race and ethnic groups. Their estimates for ages 13–17 years were 12.62 (95% CI, 12.15–13.08) for females and 10.18 (95% CI 9.78–10.59) for males. These estimates are similar to our adolescent prevalence estimate when adolescents seen in adult clinics are included.

Gilboa's estimates are higher than CHD prevalence at birth (range of 8–10 per 1000) [14,15], which may reflect CHD diagnoses at later ages that are included in administrative databases, such as those from Québec [16], New York [12], and this study. Later age at diagnosis may also account, in part, for the difference in our estimated cases and the number of cases enrolled MACDP up to 6 years of age. In addition, Atlanta's population has grown dramatically over the last few decades (more than doubling in the five counties between 1970 and 2000) [17]. Thus, in-migration of CHD survivors is another likely explanation for the discrepancy.

Our adult CR analyses yielded a prevalence estimate of 6.08 per 1000, which may fairly represent the adult CHD population who were born at a time when survival rates were lower than contemporary survival rates. Our estimate is very similar to Gilboa's estimate for the U.S. adult population aged 18 years and older (6.16 [95% CI 6.10–6.22] per 1000), which used extrapolated Canadian data.

If our CR method is accurate, only one half of adolescents and one-quarter of adults with CHD living in metropolitan Atlanta were in health care within a 3-year time. Unfortunately, lack of care continuity is common, often beginning in late adolescence, and often related to issues associated with unsuccessful transition to adult care [18,19]. A major reason for gaps in care may be loss of insurance at age 18 years when many teens no longer qualify for Medicaid. Georgia has one of the highest uninsured rates in the United Studies (13%–19%) [20]. Barriers other than insurance access may also contribute to lapses in care. A Canadian study, in a population with universal health care coverage, reported that in a “usual care” group of adolescents, only 51% transitioned in the recommended 3-month time interval, a rate which increased to 68% in a nurse-led intervention model [21]. Gaps in health care may increase the risk of serious outcomes because adults with CHD must be closely monitored for complications from their structural heart defects, such as arrhythmias and pulmonary hypertension [2,3,22,23]. The larger numbers of missing adult CHD patients could be due, in part, to early mortality [24].

Limitations

We found that both the adolescent and the adult sources were independent of the other sources contained in CR analyses. This independence could be because of possible confounding variables not investigated, thereby yielding an overestimate of prevalence. Population characteristics influenced by geographic location, immigration, and missing demographics can make data sources appear independent from one another, when, in fact, they may be divergent from one another [25]. Improvements in the quality of administrative data made since 2010 should allow for better subgroup analysis, particularly for race and ethnicity, in future applications of this method.

Population estimates could be somewhat biased as the age groups were slightly different. Biased estimates of population size could also arise because of its not being closed over the observation period.

Another potential limitation was unmatched cases. We used deterministic (exact) matching with last name, first name, social security number, date of birth, and gender for seven of the eight sources. We used probabilistic matching for Medicaid, which lacked some of this information, and could have limited the number of unique captures from this source.

Conclusion

A CR approach applied to readily available administrative data from multiple sources may provide accurate, location-specific prevalence estimates of adolescents and adults living with CHD. If this CR method is accurate, only one half of Atlanta's adolescents and one-quarter of adults with CHD were in health care within a 3-year time. This information is valuable in estimating needed services such as more physicians specializing in adult CHD care, adult congenital heart care centers, assistance in transitioning from pediatric to adult care, and improved access to health insurance.

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Appendix

Table A
CHD severity for adolescents (aged 11–20 years) and adults (aged 21–64 years) pooled across sources for five metropolitan counties*

	Adolescents (aged 11–20 y) $n = 1619$ (33.8%)	Adults (aged 21–64 y) $n = 3172$ (66.2%)	Total $n = 4791$†
Severe	280 (17.3)	549 (17.3)	829 (17.3)
Not severe	1339 (82.7)	2623 (82.7)	3962 (82.7)
Total	1619 (33.8%)	3172 (66.2%)	4791†

* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.
† Six cases missing severity classification, 4797−6 = 4791.

Table B
CHD severity for adolescent (aged 11–20 years) and adult (aged 21–64 years) sources in the five metropolitan Atlanta, Georgia counties*

	Severe		Not severe	
	$n = 869$	17.5%	$n = 4095$	82.5%
Teens				
Sibley	230	16.6	1152	83.4
CHOA/PCS	71	17.6	333	82.4
Adults				
Emory	397	17.4	1890	82.6
Grady	50	16.1	260	83.9
Medicaid	64	21.0	240	79.0
St. Joseph	57	20.6	220	79.4

* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.

Table C
Dependency results of two two-source CR analyses: adolescents (aged 11–20 years) with severe CHD and not severe CHD and adults (aged 21–64 years) with severe CHD and not severe CHD in five metropolitan Atlanta, Georgia counties*

Model	Source 1	*n* (%)	Source 2	*n* (%)	Recapture rate	Capture rate	Dependence†
Adolescent model							
Severe	Sibley	230 (16.6)	CHOA/PCS	70 (17.7)	0.74285714	0.74193548	Independent
Not severe		1152 (83.4)		326 (82.3)	0.72392638	0.72407291	Independent
Adult model							
Severe	EMORY	397 (17.4)	MCAID	64 (21.0)	0.81250000	0.81352459	Independent
Not severe		1890 (82.6)		240 (79.0)	0.78333333	0.78325736	Independent

* Five metropolitan Atlanta counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett.
† Dependence was assessed to 0.005.