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The Effect of Socioeconomic Status and Maternal Race-Ethnicity on Prenatal
Diagnosis and Birth Outcomes among Pregnancies with Birth Defects in
Metropolitan Atlanta from 1995 to 2008

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Abstract

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By Noreen Alabi

Objectives: The purpose of this study was to assess the effect of socioeconomic status and maternal race-ethnicity on elective termination after prenatal diagnosis of a congenital anomaly. This study aims to describe the current state of elective termination after prenatal diagnosis and to highlight this relationship with regards to current prevalence estimates of congenital anomalies. **Methods:** Using population-based surveillance data from the Metropolitan Atlanta Congenital Defects Program (MACDP) from 1995 to 2008, we calculated prevalence estimates of the selected congenital anomalies. Logistic regression was used to assess the maternal age adjusted effects of socioeconomic status and maternal race-ethnicity on the odds of elective termination after prenatal diagnosis of a congenital anomaly. A standardized neighborhood deprivation index was used as a socioeconomic status measure and was measured at the census tract level. **Results:** The prevalence of the selected defects varied by maternal race-ethnicity and maternal age. Maternal race-ethnicity was associated with elective termination after prenatal diagnosis of a birth defect. Hispanic mothers are the least likely to terminate after prenatal diagnosis of a congenital anomaly (aOR = 0.46 95% CI: [0.36-0.60]) followed by non-Hispanic black mothers (aOR = 0.68 95% CI: [0.57-0.81]). Neighborhood deprivation was also associated with elective termination after prenatal diagnosis. Women in high deprivation neighborhoods are less likely than those in low deprivation neighborhoods to have an induced abortion following a prenatal diagnosis of a birth defect (aOR = 0.79 95% CI: [0.65-0.96]). There was evidence of interaction between neighborhood deprivation and maternal age. **Conclusion:** While the congenital anomaly prevalence is higher among non-Hispanic whites, non-Hispanic blacks and Hispanics are less likely to terminate a pregnancy that is known to be affected by a congenital anomaly. Women in more deprived neighborhoods are also less likely to terminate such a pregnancy. More research needs to be done to determine the etiology of racially varying congenital anomaly prevalence.

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Chapter I. Background

Introduction

Approximately 3% of all live births, or 1 in 33 live births, are affected by birth defects in America every year and they are the leading cause of infant mortality and morbidity in most developed nations worldwide (1-4). In the United States, birth defects are the cause of 21% of infant deaths (2). Although elective termination isn't the only option, morbidity and mortality at the population level associated with congenital anomalies among live births has proven to be reduced by termination of the affected fetus. However, there is limited information on what factors affect a woman's decision to terminate an affected pregnancy.

Elective termination is a very traumatic event for all parties involved and is often times stigmatized in the United States (5). Most importantly the effect of elective termination on live birth disease prevalence can be profound and result in under ascertainment of all the occurring birth defect cases when conducting epidemiologic studies. Thus it is important to identify predictors of elective termination. By identifying predictors of elective termination, prevalence estimates will be more accurate and more can be done to further improve access to care and prevent further morbidity and mortality associated with congenital anomalies.

Prenatal Screening

What we recognize today as routine prenatal screening became the norm in the United States during the late 60s and early 70s. After the ground breaking decision made by the Supreme Court in the Roe V. Wade case (1973) protected a

woman's right to terminate a pregnancy, there was an increase in the uptake of prenatal screening specifically among high risk women who were older, had a previous abnormal pregnancy and/or had an initial screening that found the possible presence of a congenital anomaly (6). Roe V. Wade made prenatal screening more useful in that if a congenital anomaly was detected, women felt that elective termination was a safe and legal treatment option. As technology improved and access to such services became more wide spread and perceived as a woman's right to know, prenatal screening became part of normal ongoing prenatal care for all women not just those perceived as high risk.

There are many different screening and diagnostic techniques that are used for diagnosing structural, chromosomal, and non – chromosomal anomalies. Often times these techniques are utilized together and uptake may depend on a woman's access to health care, knowledge of her options, and a physician's expertise. Each technique has risks and limitations that are taken in to account when prescribed by a physician. There is a debate on how knowledgeable women are about the risks and benefits of each technique and how this affects their decision to undergo prenatal testing and/or screening (6). By far the most common screening technique utilized by women is ultrasound and this has increased the detection rate of fetal anomalies (7, 8). A pregnancy that occurred between 1997-1998 had 1.5 ultrasounds on average as compare to 2.7 between 2005-2006 (9). Approximately 46% of babies born with a defect had an abnormal ultrasound prior to delivery and for some isolated defects such as omphalocele, anencephaly, gastroschisis, and renal agenesis the percentage that are diagnosed prenatally is as high as 73%-83% (7). However there are some structural

anomalies such as clefts that are more difficult to diagnose in utero (18.9% all clefts, 33.3% cleft lip and palate, 20.6% cleft lip only) (10). There are some practitioners that believe that prenatal ultrasound allows parents to bond with a fetus thus making a decision to terminate harder and more emotional, but not necessarily less likely (11).

Prenatal Screening, Testing and Race-Ethnicity

Research indicates that the decision to be screened at all may vary by race-ethnicity and by screening technique. An amniocentesis, which is usually offered during the second trimester of pregnancy to detect chromosomal anomalies, is less likely to be utilized by Latinas of all ages after being given the option to have one done [Whites (84.0%), African Americans (82.9%), Asians (82.8%), and Hispanics (51.5%) ($p=0.003$)] (12). Prenatal ultrasound has become such a routine part of prenatal care that it is utilized by all ethnic groups at around the same rate (9). Little research has been conducted documenting the uptake of other screening techniques such as triple and quad screens by race-ethnicity.

There are two main reasons why there may be variation in screening by race-ethnicity. Either women from certain social classes and ethnic groups are less likely to be offered screening, and/or some women are less likely to undergo screening when offered (13). In order to be offered screening, a woman must have access to care. Poor access to care or access to care that only offers a small range of screening techniques are some of the many reasons a woman may find herself less likely to be offered screening at the crucial parts of her pregnancy. Timing of entry into prenatal care can also effect the screening options available to a woman. If a woman enters prenatal care close to the beginning of her third

trimester, she may not be able to utilize screening methods intended for earlier stages of a pregnancy. A woman who thoroughly understands the benefits and risks of screening techniques and the potential outcomes of the congenital anomalies that are screened for is more likely to undergo screening when offered. There are other factors apart from knowledge that affect whether a woman values the information that may be received from screening.

These factors differ by defect and screening technique. Down syndrome is an example of how these subtle nuances can affect the uptake of prenatal screening. For women aged 35 and older, prenatal screening and/or diagnostic testing for Down syndrome are a part of routine care. In this population of expecting women, Latinas [adjusted OR=0.28 95% CI:(0.09-0.83)] and African Americans [adjusted OR=0.33 95% CI:(0.10-1.10)] are at lower odds of undergoing prenatal screening, or diagnostic testing as compared to whites when all are offered the same opportunities (14). This effect is seen after adjusting for marital status, education, occupation, site of prenatal care, history of elective termination, and previous birth which demonstrates that there is something outside of socioeconomic barriers to prenatal screening relevant to race that prohibits minorities from receiving prenatal screening or testing.

In the same population of women aged 35 or older at the time of delivery with regards to prenatal screening and/or diagnostic testing for Down syndrome, evidence supports the notion that African American women are more likely to have some religious faith and a more fatalistic view towards prenatal testing and birth outcomes than white women (15). Similarly, there is evidence to support that blacks and Hispanics feel that motherhood is the most important role a

woman is to play and have a sense that we (as humans) are supposed to take what we have been given as compared to non-Hispanic whites and Asians(16). For these reasons, African Americans and Latinas may not perceive there to be any benefit from obtaining prenatal screening or diagnostic testing, especially if the results would not change their decision to continue the pregnancy be it for religious or fatalistic reasons. These ideologies can be attributed to culture which may be similar amongst individuals of the same ethnic group.

Prenatal Screening, Testing and Socioeconomic Predictors

Research examining socioeconomic factors and prenatal screening conducted in the United States is difficult to come by. Many times variables like education, occupation, and payer status are used to proxy socioeconomic status and assess any association that may exist. It has been documented that women with more than 12 years of education as compared to those with fewer are more than 2 times more likely (95% CI [1.25-4.30]) to undergo prenatal diagnostic testing (14). Similar results have been discovered comparing unemployed women to blue collar, white collar, and professionals individually. A large part of this may be due to access to care. Women who are unemployed, work blue collar jobs, or have a partner who does may find it difficult to make it to prenatal care visits. They are less likely to have health insurance, which can make prenatal care unaffordable, and may struggle to find child care and/or transportation in order to make it to visits.

Leveling the Playing Field

Research indicates that when women are randomized to an educational program that helps them understand the benefits of prenatal screening and some of the dangers of diagnostic testing, women who receive the education are more likely to receive prenatal screening than those who do not have this extra information when going through this process regardless of race-ethnicity, maternal education, and income (17). Many of the disparities in screening are more likely attributed to lack of knowledge about the procedure and patient risk, and may be mediated by generalized education. When provided education on prenatal screening procedures before they take place, there is little to no association between race-ethnicity, income, or maternal education and whether or not a woman decides to be screened, but being 35 or older, which in the case of Down syndrome is a risk factor, and the willingness to terminate were associated with increased likelihood of screening (18). This equal knowledge across the board can be granted through proper prenatal care. Since minorities have less formal education on average than whites, it is possible that lack of knowledge on maternal health issues reduces their likelihood to be diagnosed prenatally. In turn, this effects the likelihood that a minority woman would even have the opportunity to have an induced abortion in the event that their fetus is affected by a congenital anomaly.

Race-Ethnicity, Socioeconomic Status and Birth Defects

Due to extensive research, it is a relatively common concept that the prevalence of birth defects differs by race-ethnicity. For example, neural tube defects are more common in Latinos as compared to non-Hispanic whites and Down

syndrome is more prevalent in non-Hispanic whites as compared to non-Hispanic blacks even after adjusting for maternal age (19). Some of the most drastic variation is seen in anotia and microtia, malformations of the outer ear, which is 6 times more prevalent in American Indians/Alaska natives as compared to non-Hispanic blacks (20). In general, the prevalence of all birth defects in metropolitan Atlanta is lower in blacks (PR = 0.94, CI = 0.93--0.95) and Hispanics (PR = 0.89, CI = 0.86--0.93) as compared to whites (4). There is little research on the relationship between socioeconomic status and birth defects. Socioeconomic status has been associated with a specific type of Down syndrome. However, whether or not this has to do with environmental exposures, poor nutrition or some other factor associated with socioeconomic status is unknown (21).

Decision Making after Detection of Fetal Anomaly

Women generally have three options after receiving a positive prenatal diagnosis of a fetal anomaly. They can choose to continue the pregnancy and use the diagnosis to prepare for medical for the child after delivery, potentially try treatment *in utero* for a few defects, or they can terminate the pregnancy (6, 8). A study conducted in Sweden identified specific subgroups of concerns for parents and determined that the severity and/or prognosis of a defect is the primary determining factor as to whether or not to continue a pregnancy, followed by some secondary factors ranging from sibling disruption to education/employment, and inadequate/adequate economic resources (8). This differed from other studies that found religious factors and cultural background to be determinants, but authors speculate this may be due to the secular nature of

Sweden as a country (8). Religious factors most likely play a role in how parents view their likelihood to terminate a pregnancy and through this route may have an effect on decision making. Similarly, researchers in America determined that the severity of a condition plays a larger role than the gestational age at diagnosis in the process of deciding to continue a pregnancy or to terminate (11). Severity of the diagnosed condition is so important, that having an uncertain diagnosis often results in parents deciding to continue the pregnancy in hopes of a favorable outcome rather than terminating (22).

When analyzing how this decision making is distributed amongst ethnic groups, both non-Hispanic blacks [OR=0.50 95% CI: (0.36-0.70)] and Hispanics [OR=0.49 95% CI: (0.27-0.88)] have lower odds of terminating a pregnancy after a prenatal diagnosis for Down syndrome, but non-Hispanic blacks [PR=0.77 95% CI: (0.64-0.93)] and Hispanics [PR=0.91 95% CI: (0.72-1.2)] still have a lower prevalence of live births with the disease when compared to non-Hispanic whites after controlling for maternal age and the year of the index pregnancy (23).

Consistently it is noted that Hispanics are least likely to decide to terminate when compared to non-Hispanic whites (24). Such evidence confirms that some of the intra-racial differences in prevalence of some defects, especially chromosomal and genetic defects, may have little to do with termination rates at all. These defects are probably caused by genes that may vary by race-ethnicity, or other epigenetic factors that some racial groups are at higher risk for exposure to.

Elective Termination and Live Birth Prevalence

Rates of elective termination are also differential by defect, but often result in significant effects on disease prevalence. In metropolitan Atlanta, the inclusion of

prenatally diagnosed cases increased the prevalence of all defects by 6.9% and the addition of elective terminations increased the prevalence by 6.4% (25). Some evidence shows that as many as 83% of prenatally diagnosed cases of anencephaly and 63% of prenatally diagnosed cases of spina bifida are terminated (26). Defects of the central nervous system are typically shown to have the highest rate of termination (26, 27). These numbers represent a significant proportion of cases and would have a profound effect on the overall prevalence of disease in a population. Elective termination rates have an effect on studies done examining the relationships between specific exposures and disease if live birth prevalence is used as the outcome of interest. In order to assess causality, it is necessary to know the complete incidence of the congenital anomaly and not just those that result in a live birth. This will understate an association, miss one all together, or possibly exaggerate what is actually occurring. In an example based on a study illustrating the relationship between race and risk of anencephaly, the differential termination rates of 64% for whites and 38% for blacks were applied to a study. This led to a an OR (blacks to whites) biased towards the null (1.33 vs 2.30), but a more precise estimate (28). This demonstrates how inclusion of terminated cases not only made for a more precise estimate, but almost eliminated the association between race and risk of anencephaly. Blacks were having more affected live births, because they were terminating at half the rate of whites. For this reason, it is important to include all diagnoses of a condition and to have a firm understanding of demographic traits that may lead to elective termination.

Race-Ethnicity, Socioeconomic Status, and Termination

Very little research had been conducted analyzing elective termination in relation to race-ethnicity and socioeconomic status and most research that has been conducted thus far has taken place in Europe. In Paris, France, researchers discovered that women of African origins had a ten-fold lower odds of terminating a pregnancy affected by a congenital heart defect than a woman of French origin [OR=0.1, 95% CI: (0.02 – 0.4)] but did not discover an association between odds of termination and maternal occupation [OR=0.7, 95% CI: (0.2 – 2.2)] (29). It has been documented in the UK that women in the most deprived situations terminate at a lower rate than those of higher socioeconomic status [rate ratio = 0.80, 95% CI: (0.65 – 0.970)], and this has contributed to higher rates of stillbirth, neonatal mortality and live birth prevalence of a child with an anomaly among the most deprived women which was only exaggerated when controlling for maternal age (30). A trend of this nature can lead to disparities especially when those most affected may have limited access to care already and may not be able to get their children the care that they need. In Atlanta, Georgia, researchers noted the presence of interaction occurring between race-ethnicity and socioeconomic status on the presence of a birth defect, as determined by census tract poverty variables, but did not have enough data to interpret results for most defects and those with enough data did not demonstrate a consistent pattern (1). For some defects, there was a negative linear relationship that was insignificant, but for others the relationship did not follow any pattern.

Hypothesis

Given the preliminary research done on this subject, I hypothesize that maternal race-ethnicity and socioeconomic status will be associated with elective termination after prenatal diagnosis of a congenital anomaly among a population of expectant women residing in metropolitan Atlanta between 1995 and 2008. I anticipate that non-Hispanic white women will have the highest live birth prevalence of all congenital anomalies compared to all other race-ethnic groups, but whites will also have higher odds of terminating as compared to other ethnic groups. This is a trend that has been noted in the research. Those of higher socioeconomic status will also be more likely to terminate a pregnancy than those of lower socioeconomic status due to better access to healthcare.

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Chapter II. Manuscript

Abstract

Objectives: The purpose of this study was to assess the effect of socioeconomic status and maternal race-ethnicity on elective termination after prenatal diagnosis of a congenital anomaly. This study aims to describe the current state of elective termination after prenatal diagnosis and to highlight this relationship with regards to current prevalence estimates of congenital anomalies. **Methods:** Using population-based surveillance data from the Metropolitan Atlanta Congenital Defects Program (MACDP) from 1995 to 2008, we calculated prevalence estimates of the selected congenital anomalies. Logistic regression was used to assess the maternal age adjusted effects of socioeconomic status and maternal race-ethnicity on the odds of elective termination after prenatal diagnosis of a congenital anomaly. A standardized neighborhood deprivation index was used as a socioeconomic status measure and was measured at the census tract level. **Results:** The prevalence of the selected defects varied by maternal race-ethnicity and maternal age. Maternal race-ethnicity was associated with elective termination after prenatal diagnosis of a birth defect. Hispanic mothers are the least likely to terminate after prenatal diagnosis of a congenital anomaly (aOR = 0.46 95% CI: [0.36-0.60]) followed by non-Hispanic black mothers (aOR = 0.68 95% CI: [0.57-0.81]). Neighborhood deprivation was also associated with elective termination after prenatal diagnosis. Women in high deprivation neighborhoods are less likely than those in low deprivation neighborhoods to have an induced abortion following a prenatal diagnosis of a birth defect (aOR = 0.79 95% CI: [0.65-0.96]). There was evidence of interaction

between neighborhood deprivation and maternal age. **Conclusion:** While the congenital anomaly prevalence is higher among non-Hispanic whites, non-Hispanic blacks and Hispanics are less likely to terminate a pregnancy that is known to be affected by a congenital anomaly. Women in more deprived neighborhoods are also less likely to terminate such a pregnancy. More research needs to be done to determine the etiology of racially varying congenital anomaly prevalence.

Introduction

Approximately 3% of all live births, or 1 in 33 births, are affected by birth defects in America every year and they are the leading cause of infant mortality and morbidity in most developed nations worldwide (1-4). In the United States, birth defects are the cause of about 21% of infant deaths (2). Morbidity and mortality related to congenital anomalies has proven to be reduced by elective termination of the affected fetus. In order for termination to be an option, a fetus must be diagnosed before it is born. Modern prenatal screening has been around from the 70s and has been key in allowing women to have that option, but little is known about why women choose to terminate following prenatal diagnosis of congenital anomalies (6).

A person's perception of prenatal screening will not only play a role in whether they are likely to get screened, but may also be related to how an individual would value and subsequently use such information. There is evidence of varying uptake of prenatal screening by race-ethnicity whether it be for cultural or socioeconomic reasons (15, 16). However, research suggests when knowledge

about screening techniques is given to women in an organized fashion such that disparities disappear (17). Once a woman is screened and possibly undergone further diagnostic testing to receive a firm diagnosis, she generally has the option to continue a pregnancy, undergo treatment *in utero* for some conditions, or terminate the pregnancy. This decision is often based on the severity of the diagnosis and at what point in gestation diagnosis occurs (8, 11, 22). Yet evidence shows that other factors such as race-ethnicity and socioeconomic status also play a role. Non-Hispanic whites have higher odds of termination than minority groups after prenatal diagnosis (23, 29). Women of higher socioeconomic status have also been noted as more likely to terminate after a prenatal diagnosis as compared to women of lower socioeconomic status (30).

Elective termination poses a huge problem when conducting epidemiologic studies. Cases lost when ascertainment only occurs among live births can greatly affect the reported prevalence of disease and subsequently the direction of an association in an epidemiologic study (26, 28). This is even more important when a candidate exposure is confounded by an unknown covariate. This study aims to determine if there is a relationship between socioeconomic status and race-ethnicity on elective termination after prenatal diagnosis of a congenital anomaly in a population of diverse women in metropolitan Atlanta.

Methods

Population and Sample

The sample population was infants born to women who resided in five counties in central metropolitan Atlanta, at the time of delivery between 1995 and 2008 and received a prenatal diagnosis of one of the selected anomalies in table 1. Data

from the Metropolitan Atlanta Congenital Defects Program (MACDP) was used in the analysis to derive cases. A description of MACDP is published elsewhere (2). In brief, MACDP is an active case finding surveillance system for birth defects and genetic conditions in the metropolitan Atlanta area (2). Established in 1967, MACDP includes information on all babies and pregnancies diagnosed with a birth defect and whose mothers resided in the metropolitan area (Fulton, Dekalb, Gwinnett, Clayton, and Cobb counties) at the time of delivery (2). In order to qualify for MACDP, the infant must be diagnosed with a congenital anomaly from the MACDP six-digit code defect list. Liveborn infants and stillborn fetus' must be at least 20 weeks gestation and elected terminations must have defects, but can be any age gestation(31). Liveborn infants must also be diagnosed with a defect before their sixth birthday. Denominator data was taken from vital statistics information and includes all live born infants whose mother resided in the five previously mentioned metropolitan Atlanta counties at the time of delivery. Since there is limited information on all pregnancies occurring in a given state, and because stillbirths of 20 weeks or greater and elective terminations for defects make up a relatively small proportion of all pregnancies, it is common practice to use live born infants for denominator data when making prevalence calculations (2). The time period 1995 through 2008 was chosen because 1995 is the first full year for which MACDP ascertained defects that were prenatally diagnosed from out-patient perinatology offices and maternal-fetal medicine departments serving the Atlanta area. In addition, 2008 is the last year for which MACDP data have been fully cleaned and are available for analysis.

Variables for Analysis

The two main exposures of interest were maternal race-ethnicity and neighborhood deprivation. Neighborhood deprivation is being utilized as a proxy for the mother's socioeconomic status at delivery. For this analysis, race-ethnicity was categorized as non-Hispanic white, non-Hispanic black, Hispanic, Asian or Pacific Islander, and other. The other category includes mothers whose race was identified as American Indian/ Alaskan Native and those whose race was not stated. A prenatal diagnosis was determined as any defect detected prior to time of delivery. Birth outcomes were reported as live born, fetal death prior to 20 weeks gestation, elected termination after prenatal diagnosis of an anomaly, and unknown outcome. Unknown outcomes are cases that were prenatally diagnosed at a prenatal care provider office in the MACDP catchment area, but for which there are no records of live birth or other delivery within a hospital setting in the metropolitan Atlanta area. Defects for this analysis were selected from a subset of defects for which there is evidence of a significant difference in disease prevalence when stillbirths and electively terminated pregnancies are incorporated into prevalence calculations as compared to the live birth prevalence. These defects are listed in table 1. Socioeconomic status was evaluated at the census tract level. Addresses at the time of birth were geocoded and matched to the corresponding census tract for all cases. A neighborhood deprivation index was used to determine the relative socioeconomic status of mothers in each census tract. The index being utilized is comprised of 8 census variables and attributes to the composition of 6 domains: low education,

unemployment, poor housing, low occupation, poverty, and residential instability (32). The index was standardized for the state of Georgia and then dichotomized as high deprivation, which included women in the upper quartile (75th percentile and up), and low deprivation (up to the 75th percentile). Information regarding the index has previously been published. Other variables considered for this analysis were maternal age, as a continuous variable, sex of fetus (male, female, ambiguous/not stated), previous live birth (none/not stated, one, two, three or more), and previous induced abortions (yes, no).

Analysis

Prevalence estimates for the selected defects were calculated by race-ethnicity and maternal age in the MACDP catchment area. Denominator data contains information on all live births and thus does not provide information on stillbirths and elected terminations of infants with or without prenatal diagnosis of a birth defect. This is standard for live birth prevalence calculations. We estimated the prevalence of defects in the entire catchment area for all outcomes and the live birth prevalence for the catchment area during the same time period. The same prevalence estimations were then calculated for all six categories of race-ethnicity and then compared via a chi squared test.

Bivariate analyses were conducted for main exposures maternal race-ethnicity, neighborhood deprivation and all covariates, maternal age, sex of fetus, previous live birth, and previous induced abortions, with the outcome of interest induced abortion after prenatal diagnosis of at least one of the selected defects.

Last we utilized a multivariable logistic regression model to estimate the odds of termination for pregnancies with a prenatal diagnosis of a defect. Odds ratios and confidence intervals were calculated. The covariates maternal age, sex of fetus, previous live birth, and previous induced abortions were assessed for confounding. Census tract data were assigned using ArcGIS 9 (33) and all statistical analysis were completed using SAS 9.3 and OpenEpi (34, 35). IRB approval for this study was obtained through Emory University and the Centers for Disease Control and Prevention.

Results

Sample Demographics

6,813 cases were identified as having one or more of the defects listed in table 1. 18.4% of case pregnancies ended in elective termination. Cases in which a diagnosis was made after delivery were dropped from the final analysis (n =1,397). This 1,397 cases dropped from the final dataset did not differ demographically from the cases in the final analysis (n= 5,416). The demographic information for all 6,813 cases can be found in the appendix table. Of the 5,416 prenatally diagnosed cases, 1,480 (27.4%) of the mothers were 35 years of age and older and the average maternal age was 29.5, 2,273 (42.0%) of the mothers were non-Hispanic white, 4456 (85.6 %) of the mothers had never had an induced abortion, 3,887 (73.9%) mothers lived in low deprivation neighborhoods, and 3079 (59.1%) of mothers have had a previous live birth. There were more male fetuses (52.1 %) as compared to female fetuses (45.16). 65% of the 147 (2.71%) of fetuses whose sex was ambiguous or not stated were terminated. The

complete demographic information of the finalized dataset can be found in table 2.

Prevalence Estimates

Table 3 contains congenital anomaly prevalence estimates stratified by maternal race-ethnicity and maternal age. The overall prevalence of the selected defects for all birth outcomes among all women in the MACDP 5 county catchment area is 93.3 (95% CI:91.1 – 95.6) per 10,000 live births. Whereas the live birth prevalence for the selected defects is 68.6 (95% CI: 66.7-70.5) in the same area. Non-Hispanic whites have the highest congenital anomaly prevalence among women of all ages for both live birth prevalence (72.3 95% CI: 69.2-75.5) and congenital anomaly prevalence among all birth outcomes (100.9 95% CI: 97.3 - 104.7). The congenital anomaly prevalence for Non-Hispanic whites is higher than the five-county prevalence for all women and women younger than 35 years of age. The prevalence of birth defects among all birth outcomes in women of all ages is lower in non-Hispanic black women as compared to non-Hispanic whites (PR = 0.86 95% CI: 0.82-0.91), Hispanic women as compared to non-Hispanic whites (PR = 0.84 95% CI: 0.78-0.90), and Asian women as compared to non-Hispanic whites (PR = 0.76 95% CI: 0.68-0.86). A similar trend is seen in the live birth prevalence between the races. However, there is a reverse in the relationship when comparing the prevalence ratios, both all outcomes and live birth, for women under the age of 35 to those of women above the age of 35. Minority women over the age of 35 have a higher disease prevalence than non-Hispanic white women over the age of 35.

Bivariate Analysis

There is an association between elective termination and maternal age (OR = 1.051, 95% CI: [1.0 -1.1]) (table 4). The crude odds ratios illustrated an association between maternal race-ethnicity and odds of termination. Non-Hispanic Blacks OR=0.55 95%CI: [0.47 – 0.65], and Hispanics OR =0.39 95%CI: [0.30 – 0.48] were less likely to have an induced abortion after prenatal diagnosis as compared to whites. For Asian/Pacific Islanders, the odds were also lower as compared to whites OR = 0.71, but the results were marginally insignificant (95% CI: [0.50 – 1.0]). Previous live birth was also insignificantly related to the outcome of elective termination after prenatal diagnosis (OR=0.94, 95% CI [0.81 – 1.1]). In contrast neighborhood deprivation (OR=0.57, 95% CI [0.48 – 0.68]) and previous induced abortion (OR=1.50, 95% CI [1.24 – 1.81]) was significantly related to the outcome. Sex of the fetuses was also significantly related to the outcome of interest. All information pertaining to bivariate analysis is available in table 4.

Multivariable Regression Analysis

Each covariate was assessed as a potential confounder of the relationship between race-ethnicity and neighborhood deprivation and elective termination after prenatal diagnosis. The final model (M5) (table 5.) contained the two exposures of interest, race-ethnicity, neighborhood deprivation, and maternal age. The final adjusted model showed a significant relationship between race and induced abortion. Blacks (aOR= 0.68 95%CI: [0.57 – 0.81]) and Hispanics (aOR= 0.46 95%CI: [0.36 – 0.60]) are statistically significantly less likely than whites to

have an induced abortion after a prenatal diagnosis of a congenital anomaly. The relationship for Asians as compared to whites was not statistically significant (aOR = 0.75 95%CI: [0.52 – 1.1]). For the cases that had maternal race-ethnicity not stated, the odds of termination were much higher than that of whites. The other main exposure variable of interest was neighborhood deprivation. The odds of termination among mothers who resided in neighborhoods with high neighborhood deprivation were lower as compared to mothers who lived in neighborhoods with low neighborhood deprivation (aOR= 0.79 95%CI: [0.65 – 0.96]). Previous induced abortion was a great predictor of elective termination following a prenatal diagnosis of a congenital anomaly. A woman who has previously had a termination is 1.5 times more likely than one who had not to have an induced abortion after prenatal diagnosis of a congenital anomaly in the Gold Standard Model. However, this variable was removed from the final model as there was little evidence of confounding. Similar results were noted for all other covariates. These results are seen in Table 5.

Two way interaction was assessed for all covariates and both exposures. There was an interaction found between neighborhood deprivation and maternal age controlling for maternal race-ethnicity. As maternal age increased, the effect of neighborhood deprivation was multiplicative. When assessing the odds of termination in a high deprivation neighborhood as compared to a low deprivation neighborhood, a woman age 25 had higher odds of termination with an adjusted OR of 0.91 [95% CI:0.74 - 1.3] as compared to a woman aged 35 who had

adjusted OR of 0.59 [95% CI:0.45-0.77] (table 6.). All other interaction terms were not significant.

Discussion

From the data, we determined that there is indeed a relationship between maternal race-ethnicity and elective termination after a prenatal diagnosis as well as between our secondary exposure of interest, neighborhood deprivation, and our outcome of interest. Non-Hispanic whites are at the highest odds of termination after prenatal diagnosis among all race/ethnic groups. This finding was similar to what is found in the literature regarding race-ethnicity and elective termination after prenatal diagnosis of a congenital anomaly (23, 24, 29). This trend might be attributed to the higher faith and fatalism demonstrated by African Americans in comparison to non-Hispanic whites and the nature with which minorities tend to regard motherhood which has an effect on their reluctance to get screened (15, 16). In our data, there was no difference in racial makeup in those with a prenatal diagnosis and the few without. However, it is likely that this reluctance to get screened seen in the minority populations of other studies might be due to the fact that the result of the screening wouldn't affect their decision to carry out the pregnancy. Thus, even when a minority women receives screening and is prenatally diagnosed with a congenital anomaly they are still less likely to terminate when compared to non-Hispanic white mothers who tend to have a more secular view on motherhood which has been associated with termination (8). Those who's race is unknown or not stated are at the highest odds of termination after prenatal diagnosis of a congenital

anomaly (aOR=2.4 95%CI: [1.5– 3.8]). This may be due to the fact that the available data for terminations that occur outside the hospital setting have more incomplete data.

There was also a relationship between our second exposure of interest, neighborhood deprivation, and elective termination after prenatal diagnosis of a congenital anomaly. Women in high deprivation neighborhoods are less likely (aOR = 0.79 95%CI: [0.65-0.96]) than those in low deprivation neighborhoods to undergo an elective termination after a prenatal diagnosis. A similar result was found in the UK where women of lower socioeconomic status were at lower odds of termination than women of higher socioeconomic status (30). There was some evidence of interaction between maternal age and neighborhood deprivation. As women aged, they were less likely to terminate following a prenatal diagnosis of a congenital anomaly when comparing odds ratios (odds of termination in a high deprivation neighborhood vs. low deprivation neighborhood). However, the effect of neighborhood deprivation was reduced as women aged. This pattern holds true to what is seen the model without interaction. It is possible that there are generational differences and older women may be more likely to have religious faith. Therefore reducing their likelihood to terminate as compared to younger women also residing in a high deprivation neighborhood.

Covariates, sex of the fetus and previous induced abortion, were strong predictors of the outcome, but were not confounders of the relationship between our exposures race-ethnicity and neighborhood deprivation and our outcome. The strongest association being seen in those where the sex of the fetus was either

unknown or ambiguous (aOR=12.1 95% CI: [8.1 – 18.2]). This is also likely due to the fact that it is more difficult to determine the sex of the fetus in the early stages of the pregnancy, but most likely due to the fact that abstracted records have incomplete data. Having a previous induced abortion was also greatly associated with outcome of interest. This might be due to the fact that a woman who has previously chosen to have an abortion for any reason is more likely open to the procedure and has fewer reservations about having an abortion.

Strengths

Majority of the strengths in this study pertain to the robust nature of MACDP. MACDP is a population based study and is a great representation of the study sample as it utilizes multiple sources for case abstraction. Cases are abstracted from birth hospitals, pediatric hospitals, specialty clinics, perinatal offices, cytogenetic laboratories, and then linked to information from vital statistics. MACDP is also an active case finding surveillance system that uses trained abstractors who know how to read and decipher medical records. Lastly, all MACDP cases undergo clinical review by clinical pediatric and genetic staff.

Limitations

One of the main limitations for this study is missing data. A number of the not stated observations are likely due to data that was not provided in the medical record. The lack of information available about gestational age at diagnosis is an obvious limitation of this study. Although there are windows of time during which specific prenatal screening methods are completed, the exact age at diagnosis may or may not have had an effect on the decision to electively

terminate. Trends associated with missing, or not stated data may have been weaker had there been a covariate pertaining to gestational age at diagnosis. Another limitation is that the exact reason for termination is not known. From the medical records and the data available in the dataset, we only know that before the decision to terminate the pregnancy there was positive prenatal diagnosis of one of the congenital anomalies listed in table 1. It would also be beneficial to have some idea about access to care. It is possible that access to care may confound the relationship between our two exposures of interest and the outcome.

III. Summary, Public Health Implications, Possible Future Directions

Summary

Little research has been conducted examining the effect of race-ethnicity or socioeconomic status has on the odds of elective termination after prenatal diagnosis of a congenital anomaly. At the population level, there is evidence of a disparity when looking at the prevalence of congenital anomalies across different race-ethnicities. There tends to be a higher prevalence of congenital anomalies amongst non-Hispanic whites as compared to minority groups and one may wonder if this can be attributed to some behavior such as elective termination. The purpose of this study was to determine if there is a relationship between neighborhood deprivation and race-ethnicity and the outcome, elective termination after prenatal diagnosis of a congenital anomaly in a diverse population of women in metropolitan Atlanta from 1995 to 2008.

From the data, we determined that there is indeed a relationship between maternal race-ethnicity and elective termination after a prenatal diagnosis as well as between our secondary exposure of interest, neighborhood deprivation, and our outcome of interest. Non-Hispanic whites are at the highest odds of termination after prenatal diagnosis among all race/ethnic groups. This finding was similar to what is found in the literature regarding race-ethnicity and elective termination after prenatal diagnosis of a congenital anomaly (23, 24, 29). This trend may be attributed to the higher faith and fatalism demonstrated by African Americans in comparison to non-Hispanic whites and the nature with which minorities tend to regard motherhood and the reluctance to which they get

screened (15, 16). In our data, there was no difference in racial makeup in those with a prenatal diagnosis and the few without. However, it is likely that this reluctance to get screened seen in the minority populations of other studies may be due to the fact that the result of the screening wouldn't affect their decision to carry out the pregnancy. Thus, even when a minority women receives screening and is prenatally diagnosed with a congenital anomaly they are still less likely to terminate when compared to non-Hispanic white mothers who tend to have a more secular view on motherhood which has been associated with termination (8).

There was also a relationship between our second exposure of interest, neighborhood deprivation, and elective termination after prenatal diagnosis of a congenital anomaly. Women in high deprivation neighborhoods are less likely than those in low deprivation neighborhoods to undergo an elective termination after a prenatal diagnosis. A similar result was found in the UK where women of lower socioeconomic status were at lower odds of termination than women of higher socioeconomic status (30). There was some evidence of interaction between maternal age and neighborhood deprivation. As women aged the effect of living in a high deprivation neighborhood decreased. A woman's overall likelihood of receiving an abortion after prenatal diagnosis of a birth defect decreased by maternal age when residing in a high deprivation neighborhood.

Strengths and Limitations

Majority of the strengths in this study pertain to the robust nature of MACDP. MACDP is a population based study and is a great representation of the study

sample as it utilizes multiple sources for case abstraction. Cases are abstracted from birth hospitals, pediatric hospitals, specialty clinics, perinatal offices, cytogenetic laboratories, and then linked to information from vital statistics. MACDP is also an active case finding surveillance system that uses trained abstractors who know how to read and decipher medical records. Lastly, all MACDP cases undergo clinical review by clinical pediatric and genetic staff.

The lack of information available about gestational age at diagnosis is an obvious limitation of this study. Although there are windows of time during which specific prenatal screening methods are completed, the exact age at diagnosis may or may not have had an effect on the decision to electively terminate. Trends associated with missing, or not stated data may have been weaker had there been a covariate pertaining to gestational age at diagnosis. Another limitation is that the exact reason for termination is not known. From the medical records and the data available in the dataset, we only know that before the decision to terminate the pregnancy there was positive prenatal diagnosis of one of the congenital anomalies listed in table 1. It would also be beneficial to have some idea about access to care. It is possible that access to care may confound the relationship between our two exposures of interest and the outcome.

Public Health Implications

Despite entry into prenatal care there are still differences in decision making after prenatal diagnosis of a congenital anomaly. These differences are explained by something related to maternal race-ethnicity that has yet to be identified. Literature shows that differences in religious practice and viewpoints on fate may

have something to do with these differences. However, what's more interesting is the association between neighborhood deprivation and the decision to terminate after prenatal diagnosis. Women who live in high deprivation neighborhoods often lack the resources and the support system to care for a child with a disability. Children born to women in high deprivation neighborhoods often fare more poorly than those who are born to women in low deprivation neighborhoods. Low birth weight, increased maternal morbidity and increased infant mortality are often associated with being born to a woman from a high deprivation neighborhood. This increases the burden on taxpayers and the medical system as a whole. These mothers who are more likely to carry a child to term with a congenital defect are also the least able to afford care.

Possible Future Directions

The difference in the prevalence of congenital anomalies by race-ethnicity needs more research. There is likely something related to the etiology of certain conditions that places one race at higher risk of disease than another. More studies need to be conducted looking at social determinants and birth outcomes here in the United States. Majority of the studies examining the effects of maternal race-ethnicity and socioeconomic status on the decision to terminate after a prenatal diagnosis of a congenital anomaly have been conducted in Europe. The healthcare system and the history of minority populations here in the United States have a different effect on what is found in relation to this topic and many other maternal and child health issues such as low birth weight and preterm birth. A qualitative study is also needed in which some of these

differences between racial groups can be better addressed. Lastly, there needs to be more research looking into decision making socioeconomic status and race-ethnicity in relation to maternal and child health topics.

References

1. Kucik JE, Alverson CJ, Gilboa SM, et al. Racial/ethnic variations in the prevalence of selected major birth defects, metropolitan Atlanta, 1994-2005. *Public health reports (Washington, DC : 1974)* 2012;127(1):52-61.
2. Correa-Villasenor A, Cragan J, Kucik J, et al. The Metropolitan Atlanta Congenital Defects Program: 35 years of birth defects surveillance at the Centers for Disease Control and Prevention. *Birth defects research Part A, Clinical and molecular teratology* 2003;67(9):617-24.
3. Correa A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. *Birth defects research Part A, Clinical and molecular teratology* 2007;79(2):65-186.
4. Update on overall prevalence of major birth defects--Atlanta, Georgia, 1978-2005. *MMWR Morbidity and mortality weekly report* 2008;57(1):1-5.
5. Wool C. Systematic review of the literature: parental outcomes after diagnosis of fetal anomaly. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses* 2011;11(3):182-92.
6. Pryde PG, Drugan A, Johnson MP, et al. Prenatal diagnosis: choices women make about pursuing testing and acting on abnormal results. *Clinical obstetrics and gynecology* 1993;36(3):496-509.
7. Weedn AE, Mosley BS, Cleves MA, et al. Maternal reporting of prenatal ultrasounds among women in the National Birth Defects Prevention Study. *Birth defects research Part A, Clinical and molecular teratology* 2014;100(1):4-12.
8. Asplin N, Wessel H, Marions L, et al. Pregnant women's perspectives on decision-making when a fetal malformation is detected by ultrasound examination. *Sexual & reproductive healthcare : official journal of the Swedish Association of Midwives* 2013;4(2):79-84.
9. Siddique J, Lauderdale DS, VanderWeele TJ, et al. Trends in prenatal ultrasound use in the United States: 1995 to 2006. *Medical care* 2009;47(11):1129-35.
10. Johnson CY, Honein MA, Hobbs CA, et al. Prenatal diagnosis of orofacial clefts, National Birth Defects Prevention Study, 1998-2004. *Prenatal diagnosis* 2009;29(9):833-9.
11. Evans MI, Sobiecki MA, Krivchenia EL, et al. Parental decisions to terminate/continue following abnormal cytogenetic prenatal diagnosis: "what" is still more important than "when". *American journal of medical genetics* 1996;61(4):353-5.
12. Saucier JB, Johnston D, Wicklund CA, et al. Racial-ethnic differences in genetic amniocentesis uptake. *Journal of genetic counseling* 2005;14(3):189-95.
13. Rowe RE, Garcia J, Davidson LL. Social and ethnic inequalities in the offer and uptake of prenatal screening and diagnosis in the UK: a systematic review. *Public health* 2004;118(3):177-89.
14. Kuppermann M, Gates E, Washington AE. Racial-ethnic differences in prenatal diagnostic test use and outcomes: preferences, socioeconomics, or patient knowledge? *Obstetrics and gynecology* 1996;87(5 Pt 1):675-82.
15. Kuppermann M, Learman LA, Gates E, et al. Beyond race or ethnicity and socioeconomic status: predictors of prenatal testing for Down syndrome. *Obstetrics and gynecology* 2006;107(5):1087-97.
16. Learman LA, Kuppermann M, Gates E, et al. Social and familial context of prenatal genetic testing decisions: are there racial/ethnic differences? *American journal of medical genetics Part C, Seminars in medical genetics* 2003;119c(1):19-26.

17. Kuppermann M, Pena S, Bishop JT, et al. Effect of enhanced information, values clarification, and removal of financial barriers on use of prenatal genetic testing: a randomized clinical trial. *Jama* 2014;312(12):1210-7.
18. Caughey AB, Washington AE, Gildengorin V, et al. Assessment of demand for prenatal diagnostic testing using willingness to pay. *Obstetrics and gynecology* 2004;103(3):539-45.
19. Canfield MA, Honein MA, Yuskiv N, et al. National estimates and race/ethnic-specific variation of selected birth defects in the United States, 1999-2001. *Birth defects research Part A, Clinical and molecular teratology* 2006;76(11):747-56.
20. Canfield MA, Mai CT, Wang Y, et al. The association between race/ethnicity and major birth defects in the United States, 1999-2007. *American journal of public health* 2014;104(9):e14-23.
21. Hunter JE, Allen EG, Shin M, et al. The association of low socioeconomic status and the risk of having a child with Down syndrome: a report from the National Down Syndrome Project. *Genetics in medicine : official journal of the American College of Medical Genetics* 2013;15(9):698-705.
22. Zlotogora J. Parental decisions to abort or continue a pregnancy with an abnormal finding after an invasive prenatal test. *Prenatal diagnosis* 2002;22(12):1102-6.
23. Jackson JM, Crider KS, Cragan JD, et al. Frequency of Prenatal Cytogenetic Diagnosis and Pregnancy Outcomes by Maternal Race-Ethnicity, and the Effect on the Prevalence of Trisomy 21, Metropolitan Atlanta, 1996 - 2005. *American Journal of Medical Genetics Part A* 2013;164A:70-6.
24. Shaffer BL, Caughey AB, Norton ME. Variation in the decision to terminate pregnancy in the setting of fetal aneuploidy. *Prenatal diagnosis* 2006;26(8):667-71.
25. Cragan JD, Gilboa SM. Including Prenatal Diagnoses in Birth Defects Monitoring: Experience of the Metropolitan Atlanta Congenital Defects Program. *Birth Defects Research (Part A): Clinical and Molecular Teratology* 2008;85(1):20-9.
26. Johnson CY, Honein MA, Dana Flanders W, et al. Pregnancy termination following prenatal diagnosis of anencephaly or spina bifida: a systematic review of the literature. *Birth defects research Part A, Clinical and molecular teratology* 2012;94(11):857-63.
27. Svensson E, Ehrenstein V, Norgaard M, et al. Estimating the proportion of all observed birth defects occurring in pregnancies terminated by a second-trimester abortion. *Epidemiology (Cambridge, Mass)* 2014;25(6):866-71.
28. Cragan JD, Khoury MJ. Effect of prenatal diagnosis on epidemiologic studies of birth defects. *Epidemiology (Cambridge, Mass)* 2000;11(6):695-9.
29. Tararbit K, Bui TT, Lelong N, et al. Clinical and socioeconomic predictors of pregnancy termination for fetuses with congenital heart defects: a population-based evaluation. *Prenatal diagnosis* 2013;33(2):179-86.
30. Smith LK, Budd JL, Field DJ, et al. Socioeconomic inequalities in outcome of pregnancy and neonatal mortality associated with congenital anomalies: population based study. *BMJ (Clinical research ed)* 2011;343:d4306.
31. Division of Birth Defects and Developmental Disabilities N, Centers for Disease Control and Prevention. Metropolitan Atlanta Congenital Defects Program. Centers for Disease Control and Prevention; 2013. (<http://www.cdc.gov/ncbddd/birthdefects/macdp.html>). (Accessed September 4, 2014 2014).
32. Messer LC, Vinikoor LC, Laraia BA, et al. Socioeconomic domains and associations with preterm birth. *Social science & medicine (1982)* 2008;67(8):1247-57.
33. ESRI. ArcGIS 9. Environmental Systems Research Institute., 2005.

34. SAS Institute I. SAS 9.3. SAS Institute Inc., 2010.
35. Dean A.G. SKM, Soe M.M. OpenEpi: Open Source Epidemiologic Statistics for Public Health. 2014. (www.openepi.com). (Accessed).

Table1. List of Selected Defects and CDC BPA^a Codes	
Defect	Codes
Cystic hygroma	228.10x ^b
Anencephalus	740.0x
Craniorachischisis	740.10x
Spina bifida	741.xxx, but not 741.985
Encephalocele	742.0xx
Conotruncal heart defects	745.00x, 745.01x, 745.10x, 745.11x, 745.13x, 745.14x, 745.15x, 745.18x, 745.19x, 745.20x, 745.21x, 747.216, 747.25x
Atrioventricular septal defect without trisomy 21	74560x, 74562x, 74563x, 74568x, 74569x, 74560x, 745487, but not 7580
Single ventricle	74530x
Cleft lip with or without cleft palate	7490xx - 7492xx
Esophageal atresia or stenosis	75030x - 75035
Bilateral renal agenesis or dysgenesis	75300x
Any cystic kidney disease	7531xx
Posterior urethral valves	75360x
Any limb deficiency	75520x - 75549x
Diaphragmatic hernia	75661x, but not 756617
Skeletal dysplasia	75640x - 75659x
Any abdominal wall defect	75670x, 75671x, 75679x
Any chromosome abnormality	75800x - 75899x, but not 75840x
Conjoined twins	7594xx
^a Full list of CDC BPA code available here http://www.cdc.gov/ncbddd/birthdefects/documents/macdpcode0807.pdf	
^b x can be any number 0-9	

Table 2. Descriptive Analysis of Women with Pregnancies Prenatally Diagnosed with a selected Congenital Anomaly in Metropolitan Atlanta between 1995 - 2008 (n=5,416)^a		
Variable	N (%)	% Terminated
Total	5, 416 (100)	18.43
Maternal Age	29.53 (7.06) ^b	N/A
Maternal Age CAT (n=5,410)		
<15	10 (0.18)	0
15-19	503 (9.30)	12.3
20-24	965 (17.8)	12.6
25-29	1158 (21.4)	14.7
30-34	1294 (23.9)	20.1
≥35	1480 (27.4)	25.9
Maternal Race		
White	2273 (42.0)	23.4
Black	1974 (36.5)	14.4
Hispanic	823 (15.2)	10.3
Asian/ Pacific Islander	224 (4.1)	17.9
Other	122 (2.2)	47.5
Neighborhood Deprivation (n=5,263)		
Low	3887 (73.86)	19.76
High	1376 (26.14)	12.28
Previous Live Birth		
None	2128 (39.3)	17
One	1678 (31.0)	18.1
Two	834 (15.4)	15.6
Three or more	567 (10.5)	11.1
Not Stated	209 (3.9)	66.5
Previous Induced Abortion (n= 5,207)		
No	4456 (85.6)	12.9
Yes	751 (14.4)	14.2
Sex of Fetus		
Male	2823 (52.12)	15.87
Female	2446 (45.16)	18.56
Ambiguous/Not Stated	147 (2.71)	65.31
^a Only cases that were prenatally diagnosed prior to termination.		
^b Mean (SD)		

Table 3. Prevalence Estimates of Selected Birth Defects Among All Pregnancy Outcomes, Live Birth Prevalence, Presented by Maternal Race-Ethnicity and Age for Metropolitan Atlanta, 1995-2008

	MACDP Five-County Region			Non-Hispanic White			Non-Hispanic Black		
	All	<35	≥35	All	<35	≥35	All	<35	≥35
Total Live Births, n	730,135	614,573	115,562	278,577	216,331	62,246	285,238	250,627	34,611
Defects, all outcomes^a, n	6813	4959	1854	2812	1854	958	2484	1911	573
Prevalence^b	93.3	80.7	160.4	100.9	85.7	153.9	87.1	76.3	165.6
95% CI	91.1-95.6	78.5-83.0	153.3-167.9	97.3-104.7	81.9-89.7	144.4-163.9	83.7-90.6	72.9-79.7	152.4-179.7
Prevalence ratio				Referent	Referent	Referent	0.86	0.89	1.1
95% CI							0.82-0.91	0.84-0.95	0.97-1.2
Defects live births^c, n	5006	3784	1222	2014	1403	611	1910	1483	427
Prevalence	68.56	61.57	105.74	72.30	64.85	98.16	66.96	59.17	123.37
95% CI	66.68-70.49	59.63-63.56	88.05-125.6	69.19-75.51	61.53-68.31	90.6-106.2	64.01-70.02	56.22-62.24	112.1-135.5
Prevalence ratio				Referent	Referent	Referent	0.93	0.91	1.3
95% CI							0.87-0.99	0.85-0.98	1.1-1.4

^aAll outcomes is the sum of live births, fetal deaths, elective terminations, and unknown outcomes

^bPrevalence per 10,000 live births in the 5 county Metropolitan Atlanta area

^cLive birth prevalence for selected defects

Table 3. (Cont'd) Prevalence Estimates of Selected Birth Defects Among All Pregnancy Outcomes, Live Birth Prevalence, Presented by Maternal Race-Ethnicity and Age for Metropolitan Atlanta, 1995-2008

	Hispanic			Asian			Not Stated		
	All	<35	≥35	All	<35	≥35	All	<35	≥35
Total Live Births, n	119,108	108,878	10,230	37,321	30,643	6,678	9,891	8,094	1,797
Defects, all outcomes^a, n	1009	843	166	287	200	87	221	151	70
Prevalence^b	84.7	77.4	162.3	76.9	65.3	130.3	223.4	186.6	389.5
95% CI	79.6-90.1	72.3-82.8	139-188.4	68.4-86.2	56.7-74.8	105.0-159.9	195.4-254.4	158.5-218.2	306.0-489.2
Prevalence ratio	0.84	0.94	1.1	0.76	0.76	0.85	2.2	2.2	2.5
95% CI	0.78-0.90	0.83-0.98	0.89-1.2	0.68-0.86	0.66-0.88	0.68-1.1	1.9-2.5	1.8-2.5	1.9-3.1
Defects live births^c, n	805	683	122	214	163	51	63	52	11
Prevalence	67.6	62.7	119.3	57.3	53.2	76.4	63.7	64.1	61.2
95% CI	63.0-72.4	58.2-67.6	99.5-141.9	50.0-65.4	45.5-61.9	57.5-99.6	49.4-81.0	48.5-83.6	32.2-106.4
Prevalence ratio	0.94	0.97	1.2	0.79	0.82	0.78	0.88	0.99	0.63
95% CI	0.86-1.0	0.88-1.1	1.0-1.5	0.69-0.91	0.70-0.97	0.59-1.0	0.69-1.1	0.75-1.3	0.35-1.1

^aAll outcomes is the sum of live births, fetal deaths, elective terminations, and unknown outcomes
^bPrevalence per 10,000 live births in the 5 county Metropolitan Atlanta area
^cLive birth prevalence for selected defects

Table 4. Bivariate Analysis of Selected Covariates with Termination after prenatal diagnosis (n=5,416)		
Variable	Odds Ratio	95% Confidence Interval
Maternal Age (continuous)	1.1	[1.0 – 1.1]
Race		
White	Referent	Referent
Black	0.55	[0.47 – 0.65]
Hispanic	0.38	[0.30 – 0.48]
Asian/ Pacific Islander	0.71	[0.50 – 1.0]
Other	3.0	[2.1– 4.3]
Neighborhood deprivation		
Low	Referent	Referent
High	0.57	[0.48 – 0.68]
Sex of Fetus		
Male	Referent	Referent
Female	1.2	[1.0 – 1.4]
Ambiguous/ Not Stated	10.0	[7.0 – 14.2]
Previous Live Birth		
None	Referent	Referent
One	1.1	[0.91 – 1.3]
Two	0.90	[0.72 – 1.1]
Three or more	0.61	[0.46 – 0.81]
Previous Induced Abortion		
No	Referent	referent
Yes	1.5	[1.2 – 1.8]

Table 5. Comparison of Crude Odds Ratios to the Gold Standard and Multiple Adjusted models (n=5,416)					
Variable	Crude Odds Ratio [95% CI]	M1 : Gold Standard	M2: Adjusted Odds Ratio	M3 Adjusted Odds Ratio	M5^a Adjusted Odds Ratio
Maternal Age (continuous)	1.05 [1.04 – 1.06]	1.03 [1.02 – 1.04]	1.03 [1.02 – 1.04]	1.04 [1.03 – 1.05]	1.04 [1.03 – 1.05]
Race					
White	Referent	Referent	Referent	Referent	Referent
Black	0.55 [0.47 – 0.65]	0.69 [0.57 – 0.84]	0.66 [0.56 – 0.80]	0.66 [0.55 – 0.79]	0.68 [0.57-0.81]
Hispanic	0.38 [0.30 – 0.48]	0.54 [0.41 – 0.71]	0.50 [0.38 – 0.65]	0.44 [0.34-0.57]	0.46 [0.36-0.60]
Asian/ Pacific Islander	0.71 [0.50 – 1.0]	0.74 [0.50 – 1.1]	0.74 [0.50 – 1.1]	0.74 [0.51 - 1.1]	0.75 [0.52 - 1.1]
Other	3 [2.1– 4.3]	2.4 [1.5– 3.8]	2.4 [1.5– 3.8]	2.5 [1.6-3.7]	3.2 [2.2 - 4.7]
Neighborhood deprivation					
Low	Referent	Referent	Referent	Referent	referent
High	0.57 [0.48 – 0.68]	0.85 [0.69 – 1.1]	0.82 [0.67 – 1.0]	0.78 [0.64-0.96]	0.79 [0.65-0.96]
Sex of Fetus					
Male	Referent	Referent	Referent	Referent	
Female	1.2 [1.0 – 1.4]	1.1 [0.94 – 1.3]	1.1 [0.94 – 1.3]	1.2 [0.99 - 1.3]	
Ambiguous/ Not Stated	10 [7.0 – 14.2]	12.0 [8.0 – 18.0]	12.1 [8.1 – 18.2]	10.3 [7.1-15.0]	
Previous Live Birth					
None	Referent	Referent			
One	1.1 [0.91 – 1.3]	0.97 [0.81 – 1.2]			
Two	0.9 [0.72 – 1.1]	0.89 [0.70 – 1.1]			
Three or more	0.61 [0.46 – 0.81]	0.60 [0.44– 0.82]			
Previous Induced Abortion					
No	Referent	Referent	Referent		
Yes	1.5 [1.2 – 1.8]	1.5 [1.2 – 1.8]	1.5 [1.2 – 1.9]		

^aModel M5 represents the final model

Table 6. Odds Ratio estimates reflecting evidence of interaction between Maternal Age and Neighborhood Deprivation in Metropolitan Atlanta, 1995 - 2008			
Variables	Maternal Age		
Neighborhood Deprivation	25	35	40
High Deprivation	0.91 [0.74-1.3]	0.59 [0.45-0.77]	0.47 [0.33-0.69]
Low Deprivation	Referent	Referent	Referent]
^a Model adjusted for maternal race-ethnicity, neighborhood deprivation, and maternal age (M5) with interaction term including maternal age and neighborhood deprivation.			

Appendix

Descriptive Analysis of Women with Pregnancies Diagnosed with a selected Congenital Anomaly in Metropolitan Atlanta between 1995 - 2008 (n=6,813)		
Variable	N (%)	% Terminated
Maternal Age	29.50 (7.06) ^a	N/A
Maternal Age CAT (n=6,808)		
<15	13 (0.19)	0.00
15-19	636 (9.35)	10.53
20-24	1222 (17.92)	10.83
25-29	1453 (21.36)	12.66
30-34	1630 (23.93)	17.44
>35	1854 (27.25)	22.49
Maternal Race		
White	2812 (41.27)	20.06
Black	2484 (36.46)	12.36
Hispanic	1009 (14.81)	8.92
Asian/ Pacific Islander	287 (4.21)	16.38
Other	221 (3.24)	35.29
Previous Live Birth (n=6,484)		
None	2664 (41.09)	14.49
One	2083 (32.13)	15.89
Two	1037 (15.99)	13.31
Three or more	700 (10.80)	9.29
Previous Induced Abortion(n=6,484)		
None	5564 (85.81)	13.39
One	636 (9.81)	18.08
Two	183 (2.82)	21.31
Three or more	101 (1.48)	20.79
Sex of Fetus (n=6,813)		
Male	3517 (51.62)	13.68
Female	3069 (45.05)	15.80
Ambiguous / Not Stated	227 (3.33)	52.86
Neighborhood Deprivation Index (n=6,626)		
Low Deprivation	4922(74.28)	12.62
High Deprivation	1704 (25.72)	2.78
Total		15.94
^a Mean (SD)		
^b Only cases that were prenatally diagnosed prior to termination.		