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Brief Report: Under-Representation of African Americans in Autism Genetic Research: A Rationale for Inclusion of Subjects Representing Diverse Family Structures

Claudia L. Hilton,
Department of Psychiatry, Washington University School of Medicine, 660 S. Euclid, Campus Box 8134, St Louis, MO 63110, USA

Robert T. Fitzgerald,
Department of Psychiatry, Washington University School of Medicine, 660 S. Euclid, Campus Box 8134, St Louis, MO 63110, USA

Kelley M. Jackson,
Department of Psychiatry, Washington University School of Medicine, 660 S. Euclid, Campus Box 8134, St Louis, MO 63110, USA

Rolanda A. Maxim,
Knights of Columbus Developmental Center, Saint Louis University, St Louis, MO, USA

Christopher C. Bosworth,
Department of Psychiatry, Washington University School of Medicine, 660 S. Euclid, Campus Box 8134, St Louis, MO 63110, USA

Paul T. Shattuck,
Washington University, George Warren Brown School of Social Work, St Louis, MO, USA

Daniel H. Geschwind, and
David Geffen School of Medicine at UCLA, Los Angeles, CA, USA

John N. Constantino
Department of Psychiatry, Washington University School of Medicine, 660 S. Euclid, Campus Box 8134, St Louis, MO 63110, USA

Claudia L. Hilton: hiltonc@wustl.edu

Abstract

African American children with autism are seriously under-represented in existing genetic registries and biomedical research studies of autism. We estimated the number of African American children with autism in the St. Louis region using CDC surveillance data and present the outcomes of a concerted effort to enroll approximately one-third of that population into either of two large national genetic autism registries. The results revealed that even after traditional barriers to research participation were addressed and all contacted families expressed a willingness to participate, 67% of the reachable families were disqualified from participation because of family structure alone. Comprehensive efforts—including expansion of eligibility to families of diverse structure—are warranted to facilitate the inclusion of African American children in biomedical research.

Correspondence to: Claudia L. Hilton, hiltonc@wustl.eduhiltonc@psychiatry.wustl.edu.

Keywords

Ethnicity; African American; Minority representation

Introduction

Just as disparities exist in medical care and diagnosis for minority children with autism (Thomas et al. 2007), current research in autism is not adequately representative of the African American segment of the US population. According to the United States Census (US Census Bureau 2002), African Americans represent 12.3% of the population and are thereby grossly under-represented in published autism research. For example, one of the most critical repositories of biobehavioral data on autism—the Autism Genetic Resource Exchange (AGRE) from which some of the most influential papers on autism over the past 5 years have been published, identifies only 2.3% of its 5,431 subjects as African American (AGRE 2008). The Autism Genome Project Consortium (AGPC) has reported that 85.2% of its 1,168 families have European ancestry,[1] leaving a total of 14.8% for all other ethnic backgrounds (AGPC 2007). Another critical resource, the Interactive Autism Network (IAN), a volunteer family register designed to accelerate the pace of autism research by linking researchers and families through the internet, identifies less than 5% (463) of its 9,817 persons with autism spectrum disorders (ASD) as being African American or biracial African American (Law 2009). The ethnic composition of subjects in these large research efforts indicates a disproportionately low representation of African American families, given the fact that epidemiologic studies consistently indicate a general lack of effect of ethnicity on diagnosable status for ASD.

The importance of resolving disparities in ethnic representation in genetic research samples is underscored by the fact that autism is known to be highly genetically determined (Abrahams and Geschwind 2008) and differences in underlying genetic structures between African American and Caucasian subjects could exist even when prevalence disparities do not, which has been the case for other medical and psychiatric conditions. For example, the risk of Alzheimer's disease may be modified by a specific genetic variation in apolipoprotein D which is present exclusively in African Americans (Desai et al. 2003). Ethnicity-specified genetic susceptibilities have also been implicated for Crohn's disease (Kugathasan et al. 2005), prostate cancer (Beffoe-Bonnie et al. 2006; Gudmundsson et al. 2007; Ries et al. 2008), systemic lupus erythematosus (Danchenko et al. 2006), cerebrovascular disease (Mak et al. 2005), prematurity (Wang et al. 2006), and vulnerability to the long-term adverse effects of child maltreatment (Widom and Brzustowicz 2006). Furthermore, African Americans do appear significantly more likely than Caucasians to be affected by schizophrenia (Bresnahan et al. 2007), a condition for which there is both phenotypic and genetic overlap with autism, and differences in genetic susceptibility as a function of ethnicity have been implicated in prevalence variations (Fatemi et al. 2008; Luo et al. 2004).

There are many contributing factors to the under-representation of African Americans in genetic research on autism. Epidemiologic research has revealed significant delays in diagnosis on the order of 1.6 years (Mandell et al. 2002) and African American children are 2.6 times less likely than Caucasian children to receive an autism diagnosis on their first specialty care visit, instead often diagnosed with conduct disorder or adjustment disorder (Mandell et al. 2007). Recent analysis of data from 14 Autism and Developmental

[1]It should be noted that this study included many sites based in Europe, so was not exclusively representative of the United States population.

Disabilities Monitoring (ADDM) sites indicated that African Americans meeting criteria for an ASD were less likely to have a diagnosis than Caucasians (Mandell et al. 2009). In addition, the *motivation* to participate in biomedical research is also associated with the extent to which a given condition is perceived as having a negative impact: it has been reported that African American mothers perceive lower levels of negative impact from having a child with ASD than do Caucasian mothers (Bishop et al. 2007).

Moreover, issues that are not specific to autism, but that generally compromise the participation rates of African Americans in biomedical research are highly relevant (Armstrong et al. 1999). Successful recruitment efforts often require attention to transportation, child care, incentives (monetary and nonmonetary), inclusion of persons from ethnic minorities on the research team, specifically targeted media advertisement, and addressing the many competing obligations and stressors that are particularly pronounced in communities in which minority status is correlated with social disadvantage and/or single parent households (DeBaun et al. 2009; Farmer et al. 2007; Levkoff and Sanchez 2003; Lovato et al. 1997; Marquez et al. 2003; Neill and Chessa 1998; Patterson et al. 2008; Rogers 2002). In general, refusal to participate in epidemiological studies of mental health is more common among families of lower socioeconomic status (Perez et al. 2007), and lower educational level is associated with lower willingness to participate in research (Henderson et al. 2008; Skinner et al. 2008).

Finally, power differences (defined by situations of unequal levels of authority and influence between the researcher and research participants) are also important barriers to participation in research by African Americans (Alvarez et al. 2006; Dancy et al. 2004), especially to the extent that participants perceive themselves as exploited by researchers (Franklin 1991; Jones 1981, Moynihan 1965; Smedley et al. 2002). Current economic related power differences include limitations in job opportunities, access to quality education, and inequality in housing (Smedley et al. 2002).

Given a sizeable African American population in the St. Louis metropolitan area (see Table 1), and a pressing need to improve the representation of African Americans in existing autism genetic registries, we launched a concerted effort to enroll African American families in either of two national registries (AGRE and the Simons Simplex Collection) and describe in this report the outcome of that effort. Specifically, we sought to determine whether addressing known contributing factors to under-representation of African American families in our community would result in rates of active participation in autism genetic research that would help substantiate an agenda for feasible resolution of the under-representation problem nationally. An advantage of our project was that data regarding the actual prevalence of ASD among African Americans in our community was available from an ongoing autism epidemiologic surveillance program, the Autism and Developmental Disabilities Monitoring Network (ADDM), U.S. Centers for Disease Control and Prevention, which provided us an understanding of the large proportion of the population represented by our sample.

Methods

Sample

Recruitment was focused on a trusted source of medical care for minority families in metropolitan St. Louis area, the Knights of Columbus Developmental Center (KOC) at Saint Louis University, where the total enrollment of age-eligible African American children with autism was approximately one-third of the entire pool of ASD-affected African American patients in metropolitan St. Louis (estimated from the Centers for Disease Control surveillance program, see “Estimating Base Prevalence”).

Patient records from the six most recent years including 2002–2007 were reviewed and records with DSM-IV-TR (American Psychiatric Association 2000) diagnostic codes, 299.00 Autistic Disorder, 299.80 Asperger's Disorder, and 299.80 Pervasive Developmental Disorder—Not Otherwise Specified, and an African American race code were identified for recruitment. A total of 493 patients with an ASD diagnosis were seen between 2002 and 2007 at the developmental center. Seventy-three (16%) were identified as African American (68 African American and five biracial African American) in the appropriate age range, 5–18 years, for the Autism Genetic Resource Exchange (AGRE) and Simons Simplex Family Collection (SSC) registries during the time of our study.

Recruitment Methods

After securing Institutional Review Board approval, recruitment letters and study information were mailed to the potential study participant parents for inclusion in either of the two genetic research programs: AGRE, for families with two or more children affected by autism, and SSC, for families with a single affected child. Parents who did not respond to the mailing were telephoned and multiple attempts were made to contact them. African American members of the research team were included in the recruitment efforts and participated in the design of flyers and written materials that reached the families. Families who agreed to participate were provided with monetary incentives, with test results (to share with their children's physicians) when requested, and with information about other services available to them in the community. For families whose time, child care, or transportation were limiters, the research team set up evening, weekend and in-home assessment opportunities, and reimbursed families for any child care expenses.

Autism Genetic Registries

Autism Genetic Resource Exchange is a national registry that collects genetic, clinical and medical information, preferentially enrolling families in which two or more full biological siblings are affected by autism. The SSC is a 13-site North American autism genetic registry focused on the accrual of data and biomaterials from families in which a single individual, age 5–18 years, is affected by ASD. During the time of this study, both registries required an ASD-affected child, a full biological sibling (co-affected in AGRE, unaffected in SSC), and participation by both biological parents of the children.

Estimating Base Prevalence in Our Population

Prevalence data from the Missouri site of the Centers for Disease Control and Prevention Autism and Developmental Disorders Monitoring Network (ADDM) were used to estimate the actual number of African American children living in the St. Louis metropolitan area with an ASD. The ADDM surveillance system identified 8-year-olds in successive even-numbered years (beginning in 2002) who had at least one parent/guardian residing in the study area and met the surveillance case definition for ASD which includes a clinically established diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder-not otherwise specified (PDD-NOS; Centers for Disease Control 2007). Missouri ADDM reported an ASD prevalence of 4.7/1000 (47% had a documented clinical diagnosis, 53% were ascertained based on behavioral descriptions documented in medical or non-medical sources in the absence of a clinical diagnosis) for non-Hispanic African American 8-year-olds in metropolitan St. Louis in 2002 (Centers for Disease Control 2007). The proportion of children with a clinical diagnosis was extrapolated to the range of ages eligible for inclusion in the genetic registries, correcting for timing of diagnosis. First, the non-Hispanic African-American prevalence estimate was applied to age-specific (for ages 5–18) 2007 post-censal population data (Mandell et al. 2007) for St. Louis City and St. Louis County to generate the number of expected ASD cases for each age stratum. Since ADDM only collects data through the eighth year of life, the proportion of 8 year-olds with a

documented clinical diagnosis (47%) was used for the 9–18 age strata. Next, because many ASD-affected children younger than the age of 8 years are not diagnosed until a later age, the proportion of children identified by Missouri ADDM with a documented clinical diagnosis by the end of each year of life (ages 5–8 years) was applied to the corresponding age-specific stratum of expected ASD cases resulting in an estimate of the number of ASD cases that would have a clinical diagnosis.

In this way, we derived a 2007 estimate of 201 non-Hispanic African American children with a medically documented ASD diagnosis residing in metropolitan St. Louis and eligible for one of the genetic studies for which we were recruiting subjects. Given this estimate, the total number of age-eligible African American children with autism identified in the KOC records encompassed 36% of the total count of age-eligible clinically diagnosed ASD-affected African American children estimated to be residing in our region. There were no identifiable biases with respect to diagnostic severity, category, or gender for the subset of 8-year-olds ascertained through the KOC Developmental Center, in comparison to the total group ascertained by ADDM.

Disparities between Caucasians and African Americans with respect to key demographic variables relevant to research participation are shown for St. Louis County and St. Louis City in Table 1. As is indicated in the table, St. Louis African Americans in both the City and the County have higher rates of births to teen mothers, births to unmarried mothers, preterm births, and child poverty rates compared to Caucasians.

Data Analysis

Proportions of subjects whose families were reached, eligible for inclusion, and willing to participate in either of the two genetic registries were calculated and further examined with respect to categories of non-eligibility that disproportionately affect African Americans in the community.

Results

A summary of the results of our effort to enroll all eligible African American families into the genetic registries is provided in Table 2. Of 58 reachable families, ALL expressed willingness to participate in a study. Due to the various exclusion criteria for the respective genetic data collections, however, only eight families qualified for enrollment in the SSC and five qualified for the AGRE registry. Lack of a full sibling and/or lack of one or both parents were the most frequent disqualifying factors. Paternal unavailability occurred on the basis of unwillingness to participate (4), lack of contact with family (3), geographical distance (2), incarceration (1), or death (1). Fathers who were unwilling to participate were not married to the mothers, and in each case, the mothers were the legal custodians of the children and were willing to participate. Three of the families reported that they were adoptive parents and had no contact with the biological parents. One child was being raised by a grandmother who had no contact with the biological mother. The designated sibling in one family was out of the required age range for either study. In six of the families, the child with autism had been born prematurely or had a comorbid condition that constituted a specific exclusion from the genetic registries.

Discussion

The results of a comprehensive effort to recruit and enroll approximately one-third of African American children, age 5–18 years, carrying an ASD diagnosis and residing in metropolitan St. Louis, revealed that even after traditional barriers to research participation of African American families were addressed by the research team, fully 67% of the

reachable families (39/58) were disqualified from participation on the basis of family structure alone (i.e. no sibling or no full siblings, only one parent or no parents available). When compounded with the problem that over half of the probable cases of ASD in African American children in the community remain undiagnosed by the age of 8 years, and the fact that prematurity (another exclusion criterion for genetic studies) is substantially more common in this subset of the population, an alarmingly low proportion of affected children met eligibility criteria for these genetic registries. The constraint that the family structure requirement specifically imposed on African American families in this study is generalizable to the United States population, in that 54% of African American children in the US reside with a single parent, in comparison to 20% of Caucasian children (U.S. Census Bureau 2008).

Remarkably, despite these substantial constraints on eligibility, all of the families who were successfully contacted were willing to enroll in one or the other of the genetic studies, including participation in the blood draw. Willingness of the families to enroll was likely influenced by efforts implemented in this project and suggested by prior studies (i.e. collaboration with a trusted source of medical care, the inclusion of African American staff on the research team, monetary incentives, test results, information about other services available in the community, evening, weekend and in-home assessment opportunities, and reimbursement for child care expenses). A limitation of this exploratory study is that we were not able to determine which of these were the most effective components of the recruitment protocol for the families. In future efforts, collection of narrative data on the families' contemporaneous views of psychiatric genetic research may help refine the implementation of such methods, and help to compare and contextualize these findings with those obtained across varying geographic regions, conditions-of-interest, ethnicities, and cultural settings.

The four-member nuclear family structure, required by these and most other genetic registries at the time of this enrollment effort, had been implemented to optimize statistical power to identify genetic susceptibility in traditional molecular genetic approaches (in which it is assessed whether marker alleles transmitted from parents segregate with affected status of the children). This requirement, however, placed enormous constraints on the achievement of ethnic diversity in our current sample. Fortunately, new case–control methodologies made possible by the development of microarray technology, and the consequent feasibility of dense genetic marker coverage across the entire genome, now provides adequate information to identify susceptibility loci without the need for full siblings or both parents, and calls for an expansion of eligibility of families of diverse structure to offset the severe under-representation that has accumulated on the basis of stringent traditional inclusion criteria.

Given the emerging evidence that causal influences are heterogeneous, multi-factorial, and interactive, and that evidence from other complex genetic disorders suggests that some of those influences vary by ancestral origin, it is critical for ongoing autism genetic studies to intensify efforts to encompass the entire range of race and ethnicity that will result in full representation of the human population. For autism research in general, these data indicate that achieving ethnically diverse samples is within reach, and therefore, a necessary target that requires attention to the costs and details of the recruitment and enrollment process described herein.

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Table 1

St. Louis, Missouri metropolitan area population demographics by ethnicity

	St. Louis County		St. Louis City	
	Non-Hispanic White	**Non-Hispanic Black**	**Non-Hispanic White**	**Non-Hispanic Black**
Population[a]	772,041	192,544	149,324	177,446
% of total[a]	76	18.9	42.9	51
% Children (0–18 years)[a]	68.8	24.6	27.6	65.4
% Births to teen mothers[b]	4.8	18.5	9	25.8
% Births to single women[b]	16.2	70	31	86.4
% Premature births[b]	11.2	20.2	12.3	22.2
% Children in poverty[b]	3.8	25.2	15.5	42.3
% Adults without high School diplomas[c]	10.6	18.5	22.2	35.3
% Adults with bachelors degree or higher[c]	38.4	17.4	28.2	8.8

Sources:

[a]United States Department of Health and Human Services 2008,

[b]State of Missouri Department of Health and Senior Services 2009,

[c]U.S. Census Bureau 2000 Census

Table 2

Recruitment/enrollment results for 73 African American families affected by autism

Results	Number of families
Qualified for enrollment in Simons simplex collection	8
Qualified for enrollment in autism genetic resource exchange	5
Family moved/not able to contact	15
Disqualified ($N = 45$)[a]	
No siblings or no full siblings	27
Only one parent available	12
Child adopted and no parents available	3
Sibling not within age range	1
Prematurity	3
Excluded comorbid diagnosis in proband	3

[a]Four families are in more than one category