ACCESS TO CARE FACTORS CONNECTED TO AGE AT EVALUATION FOR CHILDREN ASSESSED FOR AUTISM SPECTRUM DISORDERS

by

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Abstract

The early identification of children with an autism spectrum disorder (ASD) is important for intervention programs to take place. The goal of this study was to examine the combination of several sociodemographic factors that research has indicated influence the age at which children are evaluated for ASDs. Primary variables of interest included sex, race/ethnicity, urbanicity, maternal education and severity of symptoms. This study analyzed 71 children ranging from 22 to 94 months as part of a database collected by the Autism Clinic at Children's Medical Center Dallas. We found that male children with higher Childhood Autism Rating scores were evaluated at an earlier age. For children diagnosed with ASD, maternal education was the strongest predictor of when a child would be evaluated. There were no differences between boys and girls in symptom severity at the time of evaluation. Implications for early identification of ASD are discussed.

Introduction

Autism has received considerable media attention over the past decade. The disorder, which began to draw attention in the 1940s, is characterized by a cluster of symptoms in children who are noticeably atypical or impaired. Autistic traits can affect social interaction, communication, activities, and interests (American Psychiatric Association [APA], 2000). Physicians Leo Kanner and Hans Asperger first operationalized the disorder in the early 1900s. Since that time, researchers have sought to understand the many facets of autism (Asperger, 1992; Kanner, 1943).

Before Kanner differentiated autism disorder, American children with autism often received diagnoses of psychosis or other debilitating disorders (Maxmen, Ward, & Kilgus, 2009). According to Wing and Potter (2002), much of the original philosophy surrounding autism in the 1940s was developed within the context of psychoanalytics. It was not until the 1960s, when parent advocacy groups were formed and scientific research began to proliferate, that the public began to view autism as a developmental disorder with causes outside of parental control (Wing & Potter, 2002). The diagnosis of autism and its associated traits has taken many forms over the years as evaluators strive to restructure diagnostic criteria to include a spectrum of disorders. Kanner and Asperger originally described autism as encompassing a triad of symptoms associated with

impairment in social interaction and communication and repetitive and restrictive activities (Landa, 2007; Matson, 2007).

Defining Autism Spectrum Disorder

The characteristics and deficits associated with autism often vary in terms of severity and degree of symptoms, thus warranting classification into a spectrum of associated diagnoses. The group of disorders shares common developmental deficits, referred to as autism spectrum disorders (ASDs). Specifically, ASDs are a group of neurodevelopmental disorders related to a variety of impairments in social interaction, communication, behavior, development, cognitive functioning, and sensory processing (Newschaffer et al., 2007; Yeargin-Allsopp et al., 2003). The overarching characteristics of ASD include impairment in developing social and communication skills, as well as propensities that are specific to each disorder and are often associated with some form of cognitive deficit, such as mental retardation (APA, 2000). Although clinical patterns vary depending on severity, all children with ASD demonstrate some degree of qualitative impairment in reciprocal social interaction and communication and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (Committee on Children With Disabilities, 2001).

DSM-III-R was the first publication to associate autism with a spectrum and delineated autistic subgroups to support the criteria utilized in current research (APA, 1980). According to current standards, such as those outlined in

DSM-IV-TR, autism disorder; Asperger's syndrome; Rhett's disorder; and pervasive developmental disorder, not otherwise specified (PDD NOS), all meet the criteria to justify a diagnosis of ASD (APA, 2000). The ASD diagnosis covers a variety of degrees of severity, impairments, and times of onset of key traits (Charman, 2002). Variability in the genetic and phenotypic structures associated with ASD makes causal identification and diagnostic evaluation of the disorder challenging (Johnson, Myers, & Council on Children With Disabilities, 2007; Volkmar, Chawarska, & Klin, 2005). These difficulties may overlap in various areas and in terms of associated impairments, which may inhibit autism research.

Currently, a large body of research is focused on expanding the available information on subjects related to ASD. This study examined the factors that influence the age at which children receive evaluation services from autism clinical specialists. Specifically, patients utilizing diagnostic evaluation services at a centralized northern Texas medical center were studied to explore the relationship between the age of evaluation and the relevant sociologic and demographic factors, as well as the severity of the disorder. To expand on the limited research available, the demographic factors that influence the age at which a child is first evaluated for ASD were examined in order to better analyze the factors that might delay the evaluation of ASD in children.

Review of Literature

Rates of Autism

Complex diagnostic criteria and classification systems have created much debate over the true occurrence rates of ASD in the population. Researchers' beliefs regarding prevalence rates have changed dramatically in the past several decades. Initially, studies of autism estimated prevalence rates between 2 and 5 per 10,000 and as much as 2.5 times higher for ASDs (Wing & Potter, 2002; Yeargin-Allsopp et al., 2003). However, recent studies have indicated that ASD is one of the most prevalent developmental disorders in children, second only to mental retardation (Newschaffer et al., 2007). The US Centers for Disease Control and Prevention (CDC; 2009) suggested that as many as 1 in 110 may warrant a diagnosis of some form of ASD.

However, there are other notable delineations in prevalence rates due to the many factors that may contribute to the variability in assessing prevalence rates. The lack of availability of reliable and stable diagnostic criteria, research methods, and materials for early detection of ASD may contribute to the changing prevalence rates (Johnson et al., 2007; Newschaffer et al., 2007). Wing and Potter (2002) suggested several factors that potentially contribute to the increase in prevalence: greater awareness among parents, professionals, and the general public; the association of ASD with other mental health conditions; the development of specialist services; and a probable increase in occurrence.

It is unclear to what extent any one factor has contributed to the increase in prevalence of ASD. Because it is impossible to use the current standard criteria to retroactively diagnose children in previous studies, researchers cannot definitively determine whether the prevalence of ASD is increasing or was inaccurately assessed in the past (Wing & Potter, 2002). Therefore, it is vital that future studies of incidence-related ASD determine factors that influence evaluation and diagnosis for individual clients, as well as environmental variables that may prevent or delay identification and evaluation of ASDs.

Inconsistency between concerns about ASD traits initially expressed by parents and formal evaluations for ASD may also contribute to uncertainty about the accuracy of previously reported prevalence rates (Inglese, 2009; Osterling, Dawson, & Munson, 2002; Reznick, Baranek, Reavis, Watson, & Crais, 2006). The Committee on Children With Disabilities (2001) suggested that primary care physician's limited knowledge and experience with ASD may limit formal evaluation and diagnosis. Parents of children diagnosed with ASDs have reported that general medical providers did not address their concerns about their child's symptoms (De Giacomo & Fombonne, 1998; Inglese, 2009). Lag time between concerns about initial symptoms and formal evaluation often delays helpful intervention for children with ASD (Inglese, 2009; Osterling et al., 2002; Reznick et al., 2006).

To reduce lag time between symptom onset and evaluation, researchers have emphasized standardization of diagnosis and development of quality resource materials for parents, pediatricians, teachers, and other community service providers (Crane & Winsler, 2008). Because children are particularly sensitive to environmental influences and interventions during their first few years of life, accessible diagnostic practitioners and evaluations are essential to correctly diagnosing and treating ASDs (Crane & Winsler, 2008; Ramey & Ramey, 1998). Although the accuracy of reported prevalence rates may be debated, researchers have determined several key sociodemographic factors that can help to accurately identify ASDs.

Symptom Variability and Diagnosis

The array of symptoms that may be present in children who warrant evaluation for ASDs often delays accurate and timely evaluation and diagnosis (Crane & Winsler, 2008; Volkmar et al., 2005). How ASDs are defined can exacerbate difficulties in diagnosing the variations in the triad of ASD-related impairments. The behavioral patterns of children with ASDs are not universal and may fall into several categories on the autism spectrum: autistic disorder, Asperger's syndrome, Rhett's disorder, and PDD NOS. The ASD spectrum encompasses an array of social behaviors, motor patterns, language delays, and deficits, which are exhibited differently in each child (Lord et al., 2005).

Lack of a definitive biological test or genetic marker to diagnose ASD in children compounds the variability of ASD symptoms (Wing & Potter, 2002). Research has suggested that there are significant biological factors and behaviors linked to ASD, although there may be variability in impairments. Biological variables, such as sex (CDC, 2009), have been shown to highly correlate with ASD diagnosis. Many studies (CDC, 2009; Johnson et al., 2007; Newschaffer et al., 2007; Wing & Potter, 2002; Yeargin-Allsopp et al., 2003) have shown that males are more likely to be diagnosed with autism than females—one of the only nondebated predictors of ASD.

Other biological factors, such as race/ethnicity (Mandell, Listerud, Levy, & Pinto-Martin, 2002), have statistical significance in their correlation with when a child is evaluated for ASD, although the reason why is widely debated. Studies also have shown that environmental factors, such as maternal education (Thomas et al., 2007) and whether the child lives in an urban or rural area (Mandell et al., 2002), are potentially associated with autistic symptoms and how soon an evaluation takes place—though the correlation is not as strong as the one between biological factors and age of evaluation. Other factors associated with delays in evaluation include degree and severity of behaviors and features of the disorder (Klien-Tasman, Risi, & Lord, 2007) and primary diagnosis (Cuccaro, Wright, Round, Abramson, Walker, & Fender, 1996). Tests, such as the Childhood

Autism Rating Scale (CARS), can help to assess the severity of these symptoms and behaviors (Schopler, Reichlet, Devillis & Dely, 1980).

Along with the complexity and variability of ASD classifications, certain behavioral traits associated with ASDs may confound diagnosis of related comorbid developmental disorders, such as mental retardation, attention deficit hyperactivity disorder (ADHD), and other language delays often associated with ASDs (Cuccaro et al., 1996; Gilliberg & Ehlers, 1998; Lord et al., 2005). Early treatment for children with ASD must be specific to the disorder (Crane & Winsler, 2008; Kasari, 2002). A consistent and comprehensive definition of ASD must be instituted to best deploy treatment and resources for all involved in caring for children with ASDs (Crane & Winsler, 2008).

Age at Evaluation

Early diagnosis is critical in the implementation of behavioral and educational interventions designed to have notable and lasting outcomes in terms of improving impairments in children with ASDs (Committee on Children With Disabilities, 2001). Overall, reviews and meta-analyses have found benefits of early interventions for children with ASDs (Blackman, 2002; Crane & Winsler, 2008; Ramey & Ramey, 1998). Outside influences are particularly effective during the first years of a child's development (Crane & Winsler, 2008). Researchers have stated that early interventions that provide treatment for developmental disabilities, such as ASDs, help protect against the advancement or

worsening of additional autistic traits and symptoms that may develop and progress during the formative years (Blackman, 2002; Crane & Winsler, 2008; Ramey & Ramey, 1998). Crane and Winsler (2008) noted, early interventions cannot happen if children are not referred for services.

Factors That Affect When a Child Is Evaluated

Limited data are available on factors associated with the age of evaluation for and diagnosis of ASD, including race and ethnicity, income, and parental education, which greatly influence access to services for families of children with ASD (Flores, Bauchner, Feinstein, & Nguyen, 1999). However, researchers do not fully understand the specific influence of these factors, particularly in children (Flores et al., 1999). Research on the correlation of sociodemographic factors and ASD diagnosis often uses small or nongeneralizable samples, making it less useful in the implementation of services (Bhasin & Schendel, 2007; Larsson et al., 2005; Yeargin-Allsopp et al., 2003).

Race/ethnicity. Researchers have extensively studied the question of what role race/ethnicity plays in evaluation and diagnosis of various health conditions. However, the role that this plays in the analysis of ASD diagnosis has been inconclusive (Mandell et al., 2009; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Studies concerning the influence of ethnic/racial disparities on early ASD diagnosis have had mixed outcomes (Liptak et al., 2008, Mandell et al., 2002; Mandell, Novak, & Zubritsky, 2005). Some have suggested that there is no

evident racial/ethnic disparity for ASD evaluation and diagnosis (Fombonne, 2003; Yeargin-Allsopp et al., 2003). However, Mandell et al. (2002) found disparities for specific race/ethnicities in a study of families receiving Medicaid benefits. According to the results, Caucasian children were evaluated and diagnosed with autism an average of 18 months before African American children, who were diagnosed 11 months sooner than Latino children (Mandell et al., 2002).

Although disparities have been found between African American and Caucasian children in the use of medical services, the differences between other major racial/ethnic groups, such as Hispanics/Latinos, Native Americans, and Asian/Pacific Islanders, have not been extensively researched (Flores et al., 1999; Reznick et al., 2006). This gap particularly affects attempts to generalize research findings to areas that serve a variety of racial/ethnic populations. Moreover, researchers have exclusively examined individuals who have been identified as meeting criteria for ASD, which presents limitations (Mandell et al., 2009). In other words, it is impossible to study undocumented cases of ASD, which raises the question of whether discrepancies can be attributed to racial/ethnic disparities or actual prevalence within the racial/ethnic groups (Mandell et al., 2009).

Maternal education. The relationship between socioeconomic disparities and use of mental health services has been well documented. The various effects of parental education on child development have been extensively studied,

although research concerning how parental education influences ASD evaluation and diagnosis is inconclusive (Flores et al., 1999). The literature on achievement has consistently shown that parental education is an important factor in predicting a child's success in attaining developmental milestones (Davis-Kean, 2005; Haveman & Wolfe, 1995; Klebanov, Brooks-Gunn, & Duncan, 1994). Thomas et al. (2007) suggested that not only can parental education affect a child's ultimate achievement, but low levels of parental education are often a significant barrier in access to medical care for families seeking services, such as ASD evaluations, as well.

Although researchers have tried to determine how maternal education affects whether children with ASD obtain timely evaluation and diagnosis, their findings have raised many questions. Seeking to assess how social class, defined by occupation, education, or intellect, may serve as a risk factor for autism and other associated disorders, researchers have produced inconsistent findings (Bhasin & Schendel, 2006; Croen, Najjar, Fireman, & Grether, 2007; Mandell et al., 2009). Nevertheless, research on the correlation between maternal education and diagnosis of ASD has found associations between specific factors, such as a high level of maternal education and family income and the presence of mental retardation and autism (Bhasin & Schendel, 2006; Croen et al., 2007). The degree to which these individual factors are significant, however, is widely debated (Bhasin & Schendel, 2006; Croen et al., 2007).

Retrospective studies, such as those conducted by Croen et al. (2007) and Mandell et al. (2009), have suggested that children with an ASD diagnosis are more likely to have parents who are better educated than a control group, which may suggest that educated parents have better access to evaluation services. The significance of the association between maternal education and ASD diagnosis has been questioned by researchers who suggest that confounding factors, such as a child's cognitive ability and socioeconomic disparity, may better explain the associated between a mother's education and delays in obtaining an ASD evaluation and correct diagnosis (Bhasin & Schendel, 2006; Mandell et al., 2009).

Urbanicity. The distance that a family must travel to obtain mental health care may affect its utilization of diagnostic and evaluative services (Mandell et al., 2007). Specialized and consistent health care is often limited for children from rural areas (Mandell et al., 2005); thus, living in a rural area can interfere with access to autism-related services and delay diagnosis (Thomas et al., 2007). Researchers have suggested that rural dwellers receive ASD diagnoses significantly later than children who live in large cities (Mandell et al., 2005; Shevell, Majnemer, Rosenbaum, & Abrahamowicz, 2001; Smith, Chung, & Vostanis, 1994; Thomas et al., 2007). The most widely accessed method of diagnostic evaluation is the school system (Shevell et al., 2001; Smith et al., 1994), which calls into question the evaluation methods schools use. Palmer, Blanchard, Jean, and Mandell (2005) concluded that school districts with greater

financial resources identified more children with autism than schools with fewer resources.

Public health and government agencies classify the terms *rural* and *urban* in different ways. Thus, researchers have sought to mainstream the terms and the systems used to designate rural and urban areas in order to advance public health research (WWAMI Rural Health Research Center, n.d.). Mainstreaming the definitions of *rural* and *urban* may aid future researchers in better assessing the barriers that exist for people with ASD.

Severity of symptoms. Parents often become concerned about their child's behavior before their child receives an ASD evaluation. Researchers have suggested that as much as 49% of parents are dissatisfied with the evaluation their child has received (Bertrand et al., 2001; Goin-Kochel, Mackintosh, & Myers, 2006).Which traits and symptoms a child is exhibiting may expedite when parents seek an ASD evaluation (Goin-Kochel, Mackintosh, & Myers, 2006).Children with more severe or distressing symptoms may be evaluated sooner than children whose symptoms are milder. Researchers have sought to standardize the diagnostic process to better address how a child's specific symptoms play a role in when they receive an ASD evaluation.

Lord, Rutter, DiLavore, and Risi (1999) first implemented the Autism Diagnostic Observation Schedule (ADOS) to rate and standardize the diagnostic

procedure for ASDs and to streamline the identification and evaluation process. Tests, such as the ADOS, were designed to mimic a social world in which behaviors related to ASD could be observed and better diagnosed (Klien-Tasman et al., 2007). The ADOS incorporates both structured and unstructured activities to test the major domains of language, communication, and reciprocal social interaction in children to address if a child's symptoms warrant an ASD diagnosis. It uses a standardized examination and applies clinical observations to an algorithm for the spectrum of disorders (Klien-Tasman et al., 2007).

Increased standardization of the diagnosis process has led to the need for insight into how symptoms and behaviors associated with ASD play a role in when a child will be evaluated. Best practices for diagnosis involve a multimethod assessment approach to evaluating children, including observation of the child, such as with ADOS (Lord et al., 1999) and CARS (Schopler, Reichler, & Renner, 1988), parental interviews and history; and developmental assessment.

Primary Diagnosis. Autism spectrum disorders often share behavioral features with other childhood developmental disorders, such as mental retardation, ADHD, and language delays (Cuccaro et al., 1996; Gilliberg & Ehlers, 1998; Lord et al., 2005). When abnormal behaviors or impairments are shared as common features of several disorders it can be difficult for parents and pediatricians to differentiate if an ASD specific evaluation is needed (Cuccaro et al., 1996). Children may be evaluated for different common developmental

disorders prior to seeking and ASD specific evaluation. A specific diagnosis allows for the primary feature of the child's problems to be appropriately addressed through evaluation and treatment.

Rationale for the Current Study

Few studies have examined access to evaluation services in a population similar to that of northern Texas. Previous research has included a limited array of racial/ethnic groups. Specifically, previous studies have used small Hispanic and Latino groups, which make up large percentages of the general population of the area served by the Children's Medical Center (CMC) Dallas. Thus, the research on access to evaluation services has limited generalizability of findings to other geographic areas, specifically ones that include Hispanic populations.

In order to address this oversight, researchers should select a sample from areas where ethnic minorities are more heavily represented. The use of parental reports in retrospective research studies may reflect discrepancies in racial/ethnic groups used in current research (Palmer et al., 2005). Relying heavily on parental surveys to obtain information may result in bias toward families who have sufficient resources and knowledge to obtain and complete the surveys (Palmer et al., 2005). Palmer et al. (2005) suggested that this discrepancy could reflect a bias in terms of not only economic disparities, but also a higher concentration of certain racial/ethnic minorities reflected in current research (Palmer et al., 2005).

When seeking to provide services to a wide variety of people, practitioners should consider the implications of demographic factors. “Because the occurrence of neuro-developmental disorders varies markedly between countries or across geographic boundaries, the lack of disease-specific descriptive epidemiology may lead to a poor understanding of the needs of those affected” (Fombonne, 2005). Health disparities associated with race/ethnicity, residency, and parental education support the need for further development of practices that adequately respond to barriers to ASD evaluations and services (Mandell & Palmer, 2005).

Limited research has addressed factors that affect the age at which children receive evaluation, and possibly diagnosis, for ASD. Although previous research has examined locations that provide a wide variety of autism services (Thomas et al., 2007), results may not be generalizable to the services available in northern Texas (Liptak et al., 2008, Mandell et al., 2002, 2005). Research on ASD diagnostic evaluation in geographic areas similar to Texas has been limited to analysis of evaluation and diagnostic services obtained through local school systems, with limited to no information about other available diagnostic programs (Palmer et al., 2005).

Additional data regarding under examined regions are needed to identify and address barriers to specific steps in the care process, such as diagnostic evaluation. Additional research will aid the development of appropriate ASD health care for treatment sites, including improved evaluation services. In this

study, the effect that sex, race/ethnicity, maternal education, urbanicity, primary diagnosis, and severity of symptoms have on the age at which families access higher-level diagnostic services for ASD evaluation at an autism clinic at a northern Texas medical center were examined. Previous research has shown that Caucasian, well educated families who live in metropolitan areas and have children that display more severe ASD symptoms will be evaluated at the youngest age. The primary aim of the study was to determine the bivariate association between each of these variables and age at evaluation. The second aim was to examine whether sociodemographic variables associated have a unique contribution to the prediction of when a child will be evaluated when combined. An exploratory aim was to determine if those given an ASD diagnosis have different demographic and clinical characteristics than those who were diagnosed with non-ASD disorders.

Methods

Participants

A community sample of participants who attended the autism clinic at CMC between October 1, 2007, and March 31, 2010 was used for analysis. The participants' information was obtained from the database used at CMC for clinical purposes. The sample was based on a population from a single city, and the study did not incorporate multisite data as other studies have (CDC, 2009). Nevertheless, CMC is accessed by a diverse population due to its comprehensive health services system for young children. The clinic is one of the few available options for many families in North Texas that offers a variety of multidisciplinary services by well-trained staff. CMC receives autism clinic referrals from physicians in Dallas, as well as from outlying communities, which allows it to collect information on clients from a wide variety of rural and urban locations (CMC, 2010).

This study was designed to provide an understanding of the factors that influence utilization of evaluation services for ASD in an outpatient clinic setting. The autism clinic staff determined on a case-by-case basis the need to administer each assessment in a full autism evaluation battery. A total of 89 participants were seen in the AUC clinic at the time data was collected, eighteen participants did not complete a full battery, including the CARS, or had missing data. Therefore only 71 participants were included in further analysis.

Data Collection

The autism clinic at CMC collected documentation on each child assessed in the evaluation clinic. All identifying information was removed from the database, and subjects were coded for multiple demographic characteristics and sociological variables.

Instruments and Outcome Measures

Demographic characteristics. Demographic characteristics, specifically primary diagnosis, age at evaluation, sex, and race/ethnicity, were obtained from the autism clinic database. Age at evaluation was treated as a continuous variable and was expressed in months. Race/ethnicity was coded as a categorical variable. Participants' parents identified the child's race/ethnicity using one of the following options: Caucasian/non-Hispanic, African American/Black, Hispanic/Latino, Asian/Pacific Islander, or Other. Maternal education (i.e., some high school, high school or GED, some college, college, some graduate school, or a graduate degree) was categorized as an ordinal variable. All children received a primary diagnosis after evaluation, which was categorized by the following options: ASDs, mood disorders, ADHD, and cognitive disorders.

Urbanicity. In the present study participants' degree of urbanicity was measured using the Rural–Urban Commuting Areas (RUCA) system developed by the University of Washington Rural Health Research Center and the USDA Economic Research Service. Funding for RUCA was provided through the federal

office of Rural Health Policy, Health Resources, and Services Administration (Hart et al., 2005; WWAMI Rural Health Research Center, n.d.). Although government agencies classify the terms *rural* and *urban* in different ways, RUCA delineates the terms for use in public health research (WWAMI Rural Health Research Center, n.d.). The system was designed to account for census data and correlate urbanization, population density, and commuting patterns (Danaher, Hart, McKay, & Severson, 2007; Washington State Department of Health, 2004). RUCA designers estimate road travel times and distances by using the most efficient commuting pattern to the closest city; data are calculated from the nearest road to corresponding zip code category (Washington State Department of Health, 2004). (See Appendix A for RUCA's use of US zip code areas by category and rural/urban portions of cities and counties.)

In this present study, a downloadable version of RUCA's zip code from the University of Washington Rural Health Research Center (see http://www .fammed.washington.edu/wwamirhrc and http://ww.ers.usda.gov) was used. Standard aggregation of RUCA zip codes, differentiating them by category was used to classify in four locations (urban, large rural/town, small rural/town, and isolated small rural/town) and were used as categorical variables to capture the travel time and distance for each participant (see Appendix B).

Severity of diagnosis. A multi-method approach that included child observation (Lord et al., 1999; Schopler et al., 1988), parental interviews and

history, and developmental assessment was used to evaluate the children in this study. Severity of symptoms was measured as a continuous variable based on the CARS (Schopler et al., 1988), a valid behavioral rating scale widely used as a diagnostic tool for evaluating ASDs (Garfin, McCallon, & Cox, 1988). CARS is a 15 item scale designed to rate children from one to four on their relationship to people, imitation, emotional response, body, object use, adaptation to change, visual response, listening response, taste-smell-touch response and use, fear and nervousness, verbal communication, non-verbal communication, activity level, level and consistency of intellectual response, and general impressions (Magyar & Pandolfi, 2005; Schopler et al., 1988). A composite total score ranging from 15 to 60 is obtained; higher total scores are representative of more severe ASD symptoms with a cut off score of 30 indicating a mild ASD diagnosis (Magyar & Pandolfi, 2005). The CARS is designed to measure the severity of behaviors associated with autism with high reliability (Magyar & Pandolfi, 2005; Schopler et al., 1988).

Primary diagnosis. The role primary diagnosis plays in ASD evaluation in children was investigated. ASDs often share behavioral features with other common childhood developmental disorders, such as mental retardation, ADHD, and language delays (Cuccaro et al., 1996; Gilliberg & Ehlers, 1998; Lord et al., 2005). Therefore, primary diagnosis was examined to evaluate the effect on the

age at evaluation. The primary diagnosis was indicated as ASD, ADHD, mood disorders, or cognitive disorders.

Design and Statistical Analysis

In the present study, data was collected and entered into a clinical dataset and imported and managed them in SPSS 18.0. Then descriptive statistics were computed for all of the variables (t-tests for continuous variables and chi-squares for categorical variables). Next, correlation coefficients (point biserial correlation coefficient for sex, race/ethnicity, and diagnosis; Pearson's *r* for CARS scores and age; and Spearman's Rho for maternal education and urbanicity) were computed to determine bivariate relationships to predict the age at which participants received an autism evaluation. Variables that were significantly associated with age at evaluation in the bivariate analyses were then analyzed using a multiple regression analysis to examine their unique association. Exploratory analyses were conducted to compare children diagnosed with ASD versus those who received non-ASD primary diagnoses. T-tests were used for continuous measures, and chi-squares were used for categorical measures.

Results

Descriptive Statistics

Table 1 lists the sociodemographic characteristics of the participants. Participants' ages ranged from 22 to 94 months (mean = 47.0 months; *SD* = 16.56). Most participants were male and had college-educated mothers, received an ASD diagnosis, scored in the mild-to-moderately autistic range on CARS, and lived in metropolitan areas that require less travel time and shorter distances to CMC. Table 1 includes additional frequencies of all predictor variables and additional analyses.

Correlations

Correlation coefficients (point biserial correlation coefficient for sex, linear regression for race/ethnicity and diagnosis, Pearson's *r* for CARS scores and age, and Spearman's Rho for maternal education and urbanicity) were computed to determine bivariate relationships between variables to predict the age at which children received an autism evaluation. Table 2 presents the correlation between sociodemographic and clinical test variables and age of evaluation. Being male was negatively correlated with age of evaluation such that males were evaluated at a younger age than their female counterparts, $r(88) = -.24$, $p < .05$. CARS scores were also negatively correlated with age at evaluation such that higher scores (i.e. more severe symptoms) were associated with a younger age of

evaluation $r(71) = -.27$, $p < .05$. Additional bivariate correlation can be found in Table 2.

Regression

A standard multiple regression analysis was used to evaluate whether variables associated with age of diagnosis predicted unique variance when combined. Two proposed predictors were significantly associated with the dependent variable, age at evaluation: sex and CARS scores. Table 3 presents the regression analysis wherein sex and CARS scores were significantly related to age at evaluation ($F_{(2,67)} = 5.35$, $p < .05$). The multiple correlation coefficient was .37, indicating that approximately 14% of the variance of age at evaluation could be accounted for by the combination of sex and CARS scores. Therefore, the research indicated that male participants with more severe manifestations of ASDs were more likely to be evaluated at a younger age.

To further examine the relative strength of these two factors, a stepwise regression was used to predict the age of evaluation. At Step 1, the results indicated CARS scores ($F_{(2,67)} = 5.35$, $p < .05$). The multiple correlation coefficient was .27, indicating approximately 7% of the variance of age at evaluation could be accounted for by CARS scores.

At Step 2 of the analysis, sex was entered into the regression equation and was significantly related to age at evaluation ($F_{(1,68)} = 5.38$, $p < .05$). The multiple correlation coefficient was .37, indicating approximately 6% of the variance of

age at evaluation could be accounted for by sex. Therefore, a child's symptoms contributed most in determining the age a child was evaluated (see Table 4). All previous analyses were conducted with the entire group of children who presented for evaluation in order to determine whether age of those who eventually received an ASD diagnosis showed similar patterns of associations.

Exploratory Analyses

Approximately half of the sample evaluated for ASD were given a non-ASD primary diagnosis. To examine differences between those with and without a primary diagnosis of ASD, additional analyses were conducted on the demographic and clinical variables between the two groups. A one-sample *t* test was conducted on the ASD and non-ASD subgroups to evaluate whether the mean ages a child was evaluated were significantly different. The ASD mean age of 41.03 (SD= 12.24) was significantly different from the non-ASD subgroup mean age of 52.76 (SD=18.38) t (67)=-3.13, $p<.05$. Children who received an ASD diagnosis were evaluated significantly sooner than children who received a diagnosis other than ASD. Other demographic and clinical characteristics were similar between those with and without ASD (Table 1).

Correlation coefficients (point biserial correlation coefficient for sex, linear regression for race/ethnicity and diagnosis, Pearson's *r* for CARS scores and age, and Spearman's Rho for maternal education and urbanicity) was used to determine bivariate relationships between variables to predict the age at which

children received an autism evaluation in a subgroup of ASD children. Maternal education was positively correlated with age of evaluation such that mothers who reported a lower level of education were associated with an earlier age of evaluation ($P(44) = .42$, $p < .05$). Urbanicity was negatively correlated with age at evaluation, indicating children who travelled over a longer time and distance were evaluated at a younger age ($P(44) = –.38$, $p < .05$). Additional bivariate correlations are shown in Table 5. A *t* test failed to reveal a statistically reliable difference between the mean age of children living in an urban area (mean=48.13, SD=16.30) and children living in non-urban/rural area (mean=45.50, SD=17.71).

A standard multiple regression analysis was used to evaluate whether variables associated with age of diagnosis predicted unique variance when combined for the ASD subgroup. Two proposed predictors, maternal education and urbanicity, were significantly associated with the dependent variable, age at evaluation. Table 6 presents the regression analysis wherein maternal education was significantly related to age at evaluation.

To further examine the relative strength of maternal education, the variable was entered into a stepwise regression to predict the age of evaluation. At Step 1, the results indicated maternal education ($F_{(1,37)} = 7.55$, $p < .05$). The multiple correlation coefficient was .41, indicating approximately 17% of the variance of age at evaluation could be accounted for by maternal education.

Therefore, in the ASD subgroup, mother's education was the most important variable to contribute to age at evaluation.

A question that the primary aims of this study did not address is whether females, who are underrepresented in the population of children diagnosed with ASDs (CDC, 2009; Johnson et al., 2007; Newschaffer et al., 2007; Wing & Potter, 2002; Yeargin-Allsopp, 2003), present with different levels of symptomology. Because children who display milder levels of symptoms may present later for evaluation, age was controlled for in this analysis. An analysis of covariance was used to determine whether CARS scores, symptom severity, for male and female participants differed after adjusting for age at evaluation. Homoscedasticity of CARS scores was confirmed using Levene's test for homogeneity of variance (.002, $df = 68$, $p > .05$). The assumption of equal regression slops was tested and supported by confirming no interaction between sex and age at evaluation ($F_{2, 67} = 2.95$, $p > .05$). As indicated by the ANCOVA, sex was not significantly related to the CARS scores (females $\bar{x} = 31.96$, $SD = 7.93$; males $\bar{x} = 31.94$, $SD = 8.00$).

Conclusion and Recommendations

Discussion

The goal of this study was to examine the combination of several sociodemographic factors that research has indicated influence the age at which children are evaluated for ASDs. Participants were evaluated through a multidisciplinary team medical diagnostic evaluation in an autism clinic in Northern Texas. One finding of this study was that boys are evaluated sooner than girls. Expansion on this finding could help to explain delays in girls receiving autism evaluation. Wiggin, Baio, & Rice (2006) have suggested that there is no difference in the age at which boys and girls are evaluated for autism. Sex and CARS scores association with age of evaluation in this present study suggest that delays could be associated with the symptoms each sex exhibits prior to evaluation. Boys are more likely to display behaviors that are stereotypical of ASD traits, such as restricted, repetitive behaviors and deficits in reciprocal social interaction, whereas girls generally show communication skill defects (Hartley & Sikora, 2009), which may lead to delays in referring girls for diagnostic evaluation. Other researchers (Pilowsky el al., 1998) have questioned whether autism evaluation more accurately test symptoms exhibited by males. The differences between the sexes that exist in ASD may contribute to a bias in the referral process, affecting evaluation and correct diagnosis (Mandell et al., 2009).

Additionally, this study showed that more severe ASD symptoms, higher CARS scores, were associated with a younger age of evaluation. CARS scores (symptomology) was the most important predictor of when a child was brought in for an evaluation. Parents whose children displayed more severe ASD symptoms sought an ASD evaluation sooner. Symptoms that were not severe enough to warrant an ASD indication from the CARS at the time of initial evaluation could be missed during diagnosis. CARS is not able to assess for ASD symptoms that may become more severe over time or capture children who present with other common developmental disorders that may account for symptomatology not measured by the tool (Cuccaro et al., 1996; Gilliberg & Ehlers, 1998; Lord et al., 2005). Follow-up testing may help to assess children whose symptoms receive a borderline ASD indication on the CARS at initial evaluation.

The unique set of symptoms displayed by each child being evaluated for an ASD is an important aspect in correctly diagnosing children. Shevell et al. (2001) suggested that the severity of symptoms often prompts an earlier referral for many specialized diagnostic evaluations. Referral to a diagnostic center may help families become involved in earlier intervention strategies for many developmental disorders, which has been shown to have favorable impact on the outcome of the disorders (Pilowsky et. al., 1998). However, without proper evaluation and diagnosis the deficits cannot be treated. No exact behavior criteria for ASD diagnosis exists, therefore features of other developmental disorders

such as ADHD symptoms of inattention or impulsivity can often appear similar to stereotypical ASD behavior (American Psychiatric Association [APA], 2000). Likewise mood disorder traits such as erratic behavior and irritability can also be common features of ASD. Cognitive impairments are frequently symptoms of ASDs or can be a comorbid diagnosis of mental retardation or other impairments (American Psychiatric Association [APA], 2000, Cuccaro et al., 1996; Gilliberg & Ehlers, 1998; Lord et al., 2005). While these traits and symptoms may initially cause a parent to be concerned, the complexity may confound when and how a child is correctly evaluated and appropriately diagnosed (Cuccaro et al., 1996). Children who did not receive an ASD were evaluated at a significantly later age than those who received an ASD diagnosis. These abnormal behaviors and traits in these areas of overlap may cause pediatricians and parents to seek specialized diagnostic services to find answers. Children's Medical Center diagnostic evaluation team often serve children with more complex symptoms. Younger children with more straight forward presentations of ASDs may likely be assessed and diagnosed by pediatricians and school systems before needing a more in depth ASD evaluation.

Sex and CARS score were the only sociodemographic variables to significantly predict unique variance in age at evaluation, an expected finding due to each variables strong individual relationship with when a child will be evaluated. Further evaluation of the relationships between sex and CARS score

and age of evaluation indicated no difference between boys and girls in terms of CARS scores after accounting for age of evaluation. Regardless of the age at which a child was evaluated for ASDs, there were no significant differences between severities of symptoms. Although this study supported research by Pilowsky et al. (1998), which suggested that there were no sex-based differences related to the CARS, additional analyses support previous findings (Mandell et. al., 2009) that a referral bias may exist. It is necessary to continue educational efforts to increase parents' and practitioners' awareness that although boys are more likely to be diagnosed with ASDs this fact should not affect referral. Other developmental disorders are not specific to one sex and ASDs are best diagnosed through early evaluation.

A second goal of this study was to evaluate differences in predicting age of evaluation for children who received an ASD diagnosis. Unlike the original analyses for the full sample, rural living and lower maternal education were individually correlated to a younger age of evaluation for children diagnosed with autism. The farther away children live, the more likely they are to receive an evaluation at a younger age. Although research has suggested that services in metropolitan areas are more readily accessible to families who seek ASD evaluations (Thomas et al., 2007), the current analyses indicated that services may not be available in rural areas. Therefore, families with children who display symptomology are forced to travel to metropolitan areas to seek services, areas

that have more resources for children who have developmental delays (Shevell et al., 2001; Smith et al., 1994). Additionally, metropolitan school systems with readily available services, such as speech and special education, may provide supplementary resources that delay the need for a formal ASD evaluation in a medical setting (Palmer et al, 2005).

Although researchers have found correlations between other sociodemographic variables and the age of evaluation, maternal education appears to be the most important predictor of when a child diagnosed with ASD will be evaluated (Mandell et al., 2005). Studies have documented the link between low parental education and barriers to medical services (Thomas et al., 2007). However, this study showed that educated mothers delayed bringing their children in for an ASD evaluation. One explanation is that highly educated mothers may have a higher stress tolerance, which results in delays in bringing a child in for evaluation. In addition, mothers with more education may be more aware of resources and have the confidence and means to enroll their children in alternative developmental strategies (e.g., speech therapy, developmental therapy, increased social interaction) before bringing them for an autism evaluation. It is important to continue implementing programs that target parental influence and educate families about the importance of earlier interventions to reduce delays in evaluation.

Several limitations may have affected the results of this study. The small sample affected the generalizability of the findings, a limitation noted in studies such as by Mandell et al. (2002). The single-site nature of this study restricted the number of participants that could be included for analysis and did not provide the diversity of multiple-site studies (CDC, 2009). Restrictions in sampling families who had medical insurance could indicate a disproportionately high socioeconomic status among the participants evaluated. Therefore, the study's small sample may not provide a true representation of the ethnically diverse population in this region attempting to be sampled—a limitation noted in other studies (Mandell et al., 2002) of ethnic/racial differences in children evaluated for ASDs. The Hispanic/ Latino population sampled by the AUC clinic was half that seen by the general psychiatric clinic and even less than the total Hispanic/ Latino population seen in the hospital setting at CMC. Additionally, the absence of consistency of the measures administered to each participant limited the number of subjects available to be analyzed for this study.

In this study, the relationship between sociodemographic variables and the age at which a child was evaluated for an ASD was investigated. One of the strengths of this study was access to information about families traveling from rural areas to access medical services and the examination of specific differences between the general population of children evaluated for ASD and those diagnosed with ASD.

Future studies should consider the influence of sociodemographic factors in order to expand on this research. A better understanding why specific variables such as maternal education and sex might increase the risk for delaying evaluation is needed. Future studies may look at how specific symptoms influence when a child is evaluated for autism, along with specific differences between boys and girls that play a role in the expression of ASD symptoms.

Various sociodemograhpic factors have been shown to have inconclusive influence on when a child is evaluated. Similar to this study previous research has often been limited by small samples that are unable to fully investigate these complex variables. When looking at factors such as race/ethnicity and parental education it will be important for future studies to develop a comprehensive picture of all of the factors that may confound analyses. Conducting analyses of the components assessed to measure socioeconomic status (e.g., income, education, and occupation) could help determine which component is most important in predicting age of evaluation. It may also be helpful in assessing how medical insurance is associated with age of evaluation for an ethnically diverse population (Flores et al., 1999). Future studies may design a methodology to examine each aspect of how more complex factors influence when a child is evaluated, along with attempting to sample from populations that may be better able to target these understudied minorities.

Table 1

*Demographic Characteristics of Participants (*n = *71)*

	All Participants n=71 % (n)	ASD n=35 %(n)	Non-ASD n=34 %(n)
Sex			
Male	80.9(55)	88.2 (30)	73.5 (25)
Female	19.1(13)	11.8 (4)	26.5 (9)
Age (mean, SD)	32.03±7.85	41.03 ±12.24	52.76 ±18.38*
2-5 years	92.8(64)	100 (35)	85.3 (29)
6-8 years	7.2(5)	0 (0)	14.7 (5)
Race/ethnicity			
White	58.0(40)	54.3 (19)	61.8 (21)
African American	7.2(5)	8.6 (3)	5.9(2)
Hispanic/Latino	13.0(9)	11.4 (4)	14.7 (5)
Asian/Pacific Islander	2.9(2)	0.0 (0)	5.9 (2)
Other	18.8(13)	25.7 (9)	11.8 (4)
Maternal education			
Some high school	3.2(2)	3.0 (1)	3.3 (1)
High school/GED	15.9(10)	21.2 (7)	10.0 (3)
Some college	23.8(15)	18.2 (6)	30.0 (9)
College	38.1(24)	45.5 (15)	30.0 (9)
Some graduate education	6.3(4)	6.1 (2)	6.7 (2)
Graduate education	12.7(8)	6.1 (2)	20 (6)
Urbanicity			
Urban	83.6(56)	79.4 (27)	87.9 (29)
Nonurban	16.4(11)	20.5(7)	12.6(4)
Large rural town	10.4(7)	17.6(6)	3.0(1)
Small rural town	4.5(3)	2.9(1)	6.1(2)
Isolated rural town	1.5(1)	0(0)	3.6(1)
Primary diagnosis			
ASD	50.7(35)		
ADHD	11.3(8)		
Mood disorders	22.5(16)		
Cognitive disorders	9.9(7)		
CARS total score	32.03±7.85	37.30±5.36	26.60±6.12**

*Note. ASD= Autism Spectrum Disorder,*ADHD = attention deficit hyperactivity disorder; PDDNOS = pervasive developmental disorder, not otherwise specified

*p.01

** p<.001

Table 2

Sociodemographic and Clinical Variables Correlated to Age at Evaluation

	Age
Sex	−.24*
Ethnicity	.03
Maternal Education	.19
Urbanicity	-.10
CARS total	−.27**

Note. CARS = Childhood Autism Rating Scale.

* $p \leq .05$, ** $p \leq .02$

Table 3

Summary of Multiple Regression for Sample

	β	SE B	B[a]	R^2	ΔR^2	F	p
Sex	−.25	8.76	−10.80				.029*
CARS Total	−.27	.24	−.57				.020*
				.14	.14	5.35	

[a]Standardized Beta.

*$p \leq .05$.

Table 4

Summary of Stepwise Regression for Sample

	β	SE B	B[a]	R^2	ΔR^2	F	p
Model 1				.06	.07	5.38	.023*
CARS total	−.27	.25	−.57				
Model 2				.11	.06	4.97	.020*
Sex	−.25	4.83	−10.80				.029*

[a]Standardized Beta.

*$p \leq .05$.

Table 5

Sociodemographic and Clinical Variables Correlated to Age at Evaluation for ASD Subgroup

	Age	*p* Value
Gender	−.15	.315
Ethnicity	-.02	.902
Maternal Education	.45†	.009
Urbanicity	-.38†	.012
CARS total	−.14	.419

* $p \leq .05$

† $p \leq .01$

Note. CARS = Childhood Autism Rating Scale.

Table 6

Summary of Multiple Regression for ASD Subgroup

	β	SE B	B†	R^2	ΔR^2	F	p Value
Maternal Education	.40	2.65	6.88				.014*
Urbanicity	−.12	7.10	−5.45				.448
				.14	.19	4.10	

* p value ≤ .05

† Standardized Beta

Appendix A

Rural and Urban Commuting Area Codes

1 Metropolitan area core: primary flow within an Urbanized Area (UA)
1.0 No additional code
1.1 Secondary flow 30% through 49% to a larger UA
2 Metropolitan area high commuting: primary flow 30% or more to a UA
2.0 No additional code
2.1 Secondary flow 30% through 49% to a larger UA
3 Metropolitan area low commuting: primary flow 10% through 29% to a UA
3.0 No additional code
4 Large rural area core: primary flow within an Urban Cluster (UC) of 10,000 through 49,999 (large UC)
4.0 No additional code
4.1 Secondary flow 30% through 49% to a UA
4.2 Secondary flow 10% through 29% to a UA
5 Large rural high commuting: primary flow 30% or more to a large UC
5.0 No additional code
5.1 Secondary flow 30% through 49% to a UA
5.2 Secondary flow 10% through 29% to a UA
6 Large rural low commuting: primary flow 10% through 29% to a large UC
6.0 No additional code
6.1 Secondary flow 10% through 29% to a UA
7 Small rural town core: primary flow within an Urban Cluster (UC) of 2,500 through 9,999 (small UC)
7.0 No additional code
7.1 Secondary flow 30% through 49% to a UA
7.2 Secondary flow 30% through 49% to a large UC
7.3 Secondary flow 10% through 29% to a UA
7.4 Secondary flow 10% through 29% to a large UC
8 Small rural town high commuting: primary flow 30% or more to a small UC
8.0 No additional code
8.1 Secondary flow 30% through 49% to a UA
8.2 Secondary flow 30% through 49% to a large UC
8.3 Secondary flow 10% through 29% to a UA
8.4 Secondary flow 10% through 29% to a large UC

9 Small rural town low commuting: primary flow 10% through 29% to a small UC

9.0 No additional code
9.1 Secondary flow 10% through 29% to a UA
9.2 Secondary flow 10% through 29% to a large UC

10 Isolated small rural areas: primary flow to a tract outside a UA or UC (including self)

10.0 No additional code
10.1 Secondary flow 30% through 49% to a UA
10.2 Secondary flow 30% through 49% to a large UC
10.3 Secondary flow 30% through 49% to a small UC
10.4 Secondary flow 10% through 29% to a UA
10.5 Secondary flow 10% through 29% to a large UC
10.6 Secondary flow 10% through 29% to a small UC

Appendix B

RUCA Aggregation

Groups	RUCA codes
Urban	1.0, 1.1, 2.0, 2.1, 3.0, 4.1, 5.1, 7.1, 8.1, 10.1
Large rural/town	4.0, 4.2, 5.0, 5.2, 6.0, 6.1
Small rural/town	7.0, 7.2, 7.3, 7.4, 8.0, 8.2, 8.3, 8.4, 9.0, 9.1, 9.2
Isolated small rural/town	10.0, 10.2, 10.3, 10.4, 10.5, 10.6

Note. RUCA = rural–urban commuting areas.

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