

UNDERSTANDING THE CONCEPTUALIZATION
OF AUTISM IN HISPANIC CULTURES

THESIS

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by

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To my baby sister Delaney Quinn Hoover, who may never
realize the extent to which she inspired this project.

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LIST OF ABBREVIATIONS

Abbreviation	Page
1. Center for Disease Control (CDC).....	1
2. Autism Spectrum Disorder (ASD).....	1
3. American Psychiatric Association (APA)	2
4. National Institute of Mental Health (NIMH).....	2
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ABSTRACT

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Although the rate of autism diagnoses is rising, Hispanic children are diagnosed at a disproportionately low rate. For Hispanic children to receive equal access to autism services, it is important to understand the reasons for disparity in diagnosis rates. The main hypothesis of the current study is that there are differences in the amount of knowledge about autism among Hispanic parents of high and low acculturation levels, and that a combination of demographic and cultural factors impacts autism knowledge. The present study examined survey responses from 42 Hispanic patients at a clinic in Austin, Texas. Socioeconomic status (SES), social support, fatalistic beliefs, religious importance, and parenting experience were found to be significant predictors of autism knowledge as assessed by the General Beliefs About Autism subscale of the

Autism Survey (Stone, 1986), accounting for 41.8% of variance. Acculturation was not a significant predictor, however this may have been due to multicollinearity with other predictor variables, especially SES and religious importance in particular. Examination of the qualitative differences in the group definitions of autism allowed for an assessment of a general conceptualization of autism across levels of acculturation. Differences in knowledge of autism, as assessed by self-reported definitions of autism, between high and low acculturation groups were statistically significant ($p = .032$). Those in the higher acculturation group correctly described more characteristics of autism than those in the low acculturation group. Additionally, those in the low acculturation group described higher amounts of unrelated or incorrect information than those in the high acculturation group. Overall, social features of autism were most commonly described by all participants. By adding to the literature regarding conceptualization of autism within Hispanic cultures, this study will enable professionals to better identify and communicate with at-risk Hispanic families in order that children can be identified earlier and can receive early intervention, leading to more positive treatment outcomes.

CHAPTER 1

INTRODUCTION

Dr. Leo Kanner, a psychiatrist, was the first to identify and label autism as a specific disorder in 1942 (Centers for Disease Control, 2008a). Dr. Kanner's report of autism, entitled "autistic disturbances of affective disorder" (Kanner, 1942, p. 217), was based on a group of 11 children, all displaying what Kanner labeled a "unique syndrome, not heretofore reported, which seems to be rare enough, yet is probably more frequent than the paucity of observed cases (Kanner, 1942, p. 242)." Autism is now considered the most serious developmental disability after mental retardation. The Centers for Disease Control (CDC; CDC, 2009b) currently estimates that 1% of children in the United States will be diagnosed with an autism spectrum disorder (ASD).

Although the presentation of autism differs among individuals (CDC, 2008a), autism is characterized by deficits in three essential areas: social, communication, and behavioral. Individuals with autism display social impairments that are severe enough to cause difficulties in everyday life, such as being disinterested in or being unable to interact in an age-appropriate way with other people, and difficulty making and maintaining eye contact (National Institutes of Health, 2009). In addition, children with autism often have difficulty with emotional expression and perception, including the ability to understand their own and other people's feelings (CDC, 2008a). The second key feature of autistic disorder, formerly infantile autism as defined by Kanner (1942), is difficulty with communication skills, though the degree of difficulty with language and communication varies among individuals (CDC, 2008a). For example, some

children may have relatively good language skills, and experience only a slight delay, but in other cases a child may not speak at all, or will have a limited interest and ability to communicate; some children develop language normally, and then regress, losing words, or totally stop talking (CDC, 2008a). Other unusual characteristics of children with autism include echolalia, the repetition of what others say, and difficulty understanding body gestures, body language, and tone of voice (CDC, 2008a). According to the American Psychiatric Association (APA; 2000), autism is also marked by a lack of “spontaneous make-believe play or social imitative play appropriate to developmental level” (APA, 2000, p. 75).

Cognitive deficits of individuals with autism are displayed through behavioral characteristics and include a range of unusual behaviors and routines (CDC, 2008a), such as becoming preoccupied with a stereotyped or restricted pattern of interest or behavior that is “unusual in intensity or focus” (APA, 2000, p. 75). An example of this is lining up toy cars for hours instead of using them for pretend play. In addition, these individuals may become “inflexibly adherent” to a “nonfunctional, specific routine” (APA, 2000, p. 75). This is thought to be a result of needing order and sameness to lend a sense of stability to an otherwise confusing world (National Institutes of Health, 2009). Having difficulty with appropriate imitation as well as “stereotyped and repetitive motor mannerisms”, such as hand flapping, and a “persistent preoccupation with parts of objects” are also common autistic traits (APA, 2000, p. 75).

Although there is no known cause or cure for autism, (CDC, 2009A) ASDs can often be reliably identified and diagnosed by three years of age (National Institutes of Mental Health, 2009), and some children can be identified as early as 18 months (Filipek et al., 1999). According to the National Institute of Mental Health (NIMH; NIMH, 2009), parents are usually adept at noticing developmental problems in their children, although they may not fully realize the extent, severity, or nature of the problem. Early, intensive treatment and intervention can help children with autism make significant gains, or even reach the full potential of a normally developing child. Thus both the CDC (2008a) and the NIMH (2009) stress the importance of having a child

evaluated by a professional as soon as warning signs for an ASD appear, making it critical that parents know the signs of autism and understand the importance of seeking professional diagnosis.

In spite of the growing rates of autism, the number of Hispanic children diagnosed with this disorder has been shown to be disproportionately low compared to other racial groups (Dyches, Wilder, Sudweeks, Obiakore, & Algozzine, 2004). For example, a study by the U.S. Department of Education (2002; as cited in Overton, Fielding & Garcia de Alba, 2007) found that the three states in the United States with the highest Hispanic population, Texas, California, and New Mexico, seem to have lower than expected rates of children identified with autism. Consistent with these findings, an analysis of data from the National Survey of Children's Health (Liptak et al., 2008) shows the prevalence rate in those classified as Hispanics was only 26 out of 10,000, in comparison to the prevalence rate of 51 out of 10,000 for non-Hispanics.

Conversely, there is a higher percentage of children from traditionally underserved populations who are classified as having severe autism, and Hispanic parents were more likely to rate their child's autism as more severe than non-Hispanic parents (Liptak et al., 2008). Thus, their symptoms magnify to the severe range before treatment is sought. This finding could mean that Hispanic children in the less severe range are not being identified early and so are not provided with early intervention. Children who are younger than 4-5 years of age when early intervention starts have the most significant improvement (Corsello, 2005). Additionally, Hispanic children have previously been found to have low rates of mental health service use in general, which could lead to lower overall diagnosed rates of autism (Liptak et al., 2008).

Although there are no known differences by race or ethnicity in the epidemiology of autism, it has been suggested that children may be assigned diagnoses differentially according to ethnicity (Mandell, Iitenbach, Levy, & Pinto-Martin, 2006). In a recent study, Mandell et al. (2006) found that African-American children were nearly three times more likely than Caucasian children to receive one or more incorrect diagnoses prior to the ultimate diagnosis of autism. In

an analysis of multicultural concerns in autism, Dyches et al. (2004) found that Black or Asian/Pacific Islander children were being served under the label of autism at approximately twice the rate of those who were American Indian/Alaskan or Hispanic. Discrepancies in age of diagnosis are also quite significant. One study found that among Medicaid-eligible children in Philadelphia, Hispanic children received diagnosis at an average age of 8.8, two years later than white children whose average age of diagnosis was 6.3 years of age, and one year later than African-American children diagnosed at an average of age 7.9 (Mandell, Listerud, Levy & Pinto-Martin, 2002).

Dyches et al. (2004) point out that although the literature has thoroughly explored how families adapt to raising a child with developmental disabilities, few delineate autism from other disabilities. It is paramount to explore autism by itself since it has been shown to be more debilitating than many other disorders. This is because it has the possibility of affecting family members' adaptation differently than other disorders (Dyches et al., 2004). To explain, many children with an ASD are born without any physical abnormalities, so parents have "normal" expectations and are not anticipating the challenge of raising a child with autism (Dyches et al., 2004).

Due to the importance of early diagnosis and effective treatment, explaining the discrepancies in autism diagnosis between ethnic, cultural, and minority groups is paramount. It is possible that a lack of knowledge about autism within minority cultures could explain both the discrepancies in rate of diagnosis between ethnic groups, as well as the differences in age of diagnoses between different cultures. For this reason, it is important to understand what parents of different cultures know about autism, and how they understand this disorder. If this were better understood, it is possible that some of the discrepancies between cultures would be eliminated. For example, if cultural beliefs are affecting diagnosis, professionals could focus on how to alter these beliefs, or find congruence between cultural beliefs and treatment needs. If SES is affecting diagnosis and treatment, professionals should be able to purposefully focus on low SES families

in order that needs are met. The current study specifically seeks to understand knowledge of autism in Hispanic cultures within the United States, and what types of cultural and individual variables affect this knowledge. The following sections of this chapter will individually describe the literature that is related to each factor hypothesized to affect knowledge of autism in Hispanic cultures, with specific emphasis on the study hypotheses.

The Influence of Socioeconomic Status, Education, and Parenting Experience

Demographic factors, such as socioeconomic status (SES), which includes family income and education level, may play a role in autism knowledge, but should not be mistaken for differences specific to Hispanic cultures. Zhang and Bennet (2003) identified having a diverse ethnic or cultural background and a very low family income as two of the most important determinants for under use of early intervention services for children less than five years of age. Likewise, Thomas et al. (2007) found that access to care was limited for racial and ethnic minority families, those living in nonmetropolitan areas, and those with low levels of education.

Family income is the first component of socioeconomic status that could affect knowledge of autism as well as diagnosis. Medicaid eligibility is one way to evaluate income, since Medicaid is a form of health insurance available to low-income families. In a study of Medicaid eligible children in Philadelphia, researchers found that children eligible for Medicaid for more than one year were 3.4 times more likely to first receive a diagnosis such as attention deficit hyperactivity disorder (ADHD), conduct disorder, a cognitive disorder, or another adjustment disorder before autism diagnosis than those who were eligible for Medicaid for less than one year (Mandell, et al., 2006). One hypothesis to explain this discrepancy is that wealthier families obtained a diagnosis for their children prior to obtaining Medicaid (Mandell, et al., 2006), which is available to all children with a diagnosis of autism, no matter the family income. This finding is important since it illustrates the impact of low income on identification and diagnosis of autism; specifically, families who are in a higher income bracket, and therefore do

not qualify for Medicaid, seem to receive a more timely and accurate diagnosis of autism than low-income families.

In addition to diagnosis, family income has previously been shown to affect autism treatment utilization. One study found that although poor and non-poor families have similar rates of autism overall, children of poor families are receiving services in preschool at a disproportionate rate (Liptak et al., 2008). Moreover, Thomas et al. (2007) found that racial and ethnic minority families were less likely to use more costly autism interventions; specifically they had half the odds of using a case manager, and only a quarter the odds of using a psychologist, developmental pediatrician, and sensory integration therapy as compared to Caucasian children. Also, low income families accessing care via Medicaid were more likely to use only services viewed as medically necessary, families with private insurance were more likely to access supplemental services, and families without health insurance were most likely to use a case manager (Thomas et al., 2007). Thomas et al. (2007) speculate that this last, somewhat contradictory finding occurs because children using a case manager are new to services, and the case manager will likely facilitate enrollment in Medicaid or other access to services (Thomas et al., 2007).

Education is the second component of socioeconomic status that could affect autism knowledge. Thomas et al. (2007) associated parents possessing a college or graduate degree with higher use of a neurologist and other forms of specialized therapy. This finding could be due to both higher overall socioeconomic status associated with higher education, and more knowledge about treatment options. Additionally, educational level is important because it is paramount that families understand the significance of symptoms of autism, the implications of this diagnosis, and treatment needs for a child with a diagnosis of autism (Liptak et al., 2008). Therefore, a low level of education might affect the type of knowledge parents have about autism, as well as the amount of knowledge parents have about autism.

A third demographic variable that could affect autism knowledge is parenting experience, and the age of their children. Parenting experience could be an important predictor of autism knowledge since more parenting experience could lead to a greater likelihood of being exposed to autism information. Furthermore, more parenting experience could lead to better understanding of normal developmental trajectories, thus delays and deficits might be more likely to be recognized. In addition, age of children could be important to autism knowledge, since it is only relatively recently that autism became more commonly diagnosed, and knowledge campaigns began. For example, although Kanner first identified autism in 1942 (Kanner, 1942), it was not included as a separate category in the first version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) released in 1952 (APA, 1952) or the second version (the DSM-II), which was published in 1968 (APA, 1968). The first two versions diagnosed children with autism as schizophrenic reaction, childhood type and schizophrenic, childhood type respectively. The DSM-III, released in 1980, included autism as a separate category, entitled “infantile autism,” described by merely six characteristics (APA, 1980) and to be diagnosed with infantile autism, a child had to meet all six diagnostic criteria. With the 1987 revision of the DSM-III, the descriptor *infantile* was removed, and the category was renamed “autistic disorder” (APA, 1987). Finally, in the most recent release of the DSM, the DSM-IV, the category pervasive developmental disorders with the subtypes autism, Asperger’s disorder, Rett’s disorder, Childhood Disintegrative disorder, and Pervasive Developmental disorder Not Otherwise Specialized was added. Additionally, 16 symptoms were included, and a patient need only display six symptoms to receive diagnosis (APA, 1994). By 1994, with better diagnostic criteria, more accurate diagnosis was possible.

Additionally, increased diagnosis of autism has led to more media attention. For example, between 2000 and 2003, 650 books about autism were published, accounting for 20 percent of books ever published on the subject (Hennessey, 2005). Information about autism is also increasingly becoming more readily available via the Internet, and from organizations like Autism Speaks, which was founded in February 2005 (Autism Speaks Inc., 2008). So, due to

better diagnosis, more media attention, and increased availability of information via the Internet and autism advocacy organizations, it is possible that parents who have young children are more likely to know about autism than those who have older children who grew up before autism was prevalent in the media.

To summarize, although these factors are not unique to Hispanic cultures in the United States, both components used to determine socioeconomic status, family income and education level, have been shown to affect autism diagnosis and treatment utilization. Additionally, parenting experience and age of children could impact knowledge of autism. By using SES, as measured by income and education, as a variable in the regression equation, and parenting experience as measured by summing the ages of all of each parent's children, as well as dividing parents with younger and older children, it will be possible to understand how much these demographic variables contribute to specific Hispanic cultural variables affecting knowledge of autism.

Cultural Beliefs, Acculturation, and Language

Culture can influence knowledge about illness and disability, treatment decisions, and general beliefs about health and illness. Mandell and Novak (2005) conducted a review of the literature regarding cultural influences on childhood health conditions in order to identify possible reasons for disparities in diagnosis of autism. Themes such as acculturation, culture and interactions with the healthcare system, and cultural attitudes toward disabilities were addressed (Mandell & Novak, 2005).

Differences in beliefs about illness and disability can lead to clashes between families of minority cultures and professionals in the majority culture. This clash of beliefs could affect diagnosis and treatment. Supporting this idea, study results show that cultural beliefs of parents from minority groups can impact how symptoms are interpreted, as well as how these interpretations differ from the opinions of members of the dominant culture (Mandell & Novak, 2005). For example, Lau et al. (2004; as cited in Mandell & Novak, 2005) found that

Asian/Pacific Islander and African-American parents were less likely than Caucasian parents to agree with a teacher that their children's behavior was symptomatic of an underlying disorder. Other studies support the idea that familiarity with majority culture, known as acculturation, could be a predictor for accessing services for children with disabilities (Dyches et al., 2004).

In order to understand the reasons for disparity in diagnosis, and the importance of acculturation, it is important to understand the way disabilities are conceptualized in Hispanic cultures. The relationship between beliefs about etiology and treatment of autism has not been examined, but researchers have examined cultural beliefs about childhood health conditions in general (Mandell & Novak, 2005). In Catholic-based Puerto Rican cultures, mothers are blamed by society if they give birth to a disabled child (Dyches et al., 2004). The child is viewed as penance for the mother's sins, or a curse placed on a woman or family by an enemy (Rogers-Adkinson, Ochoa, & Delgado, 2003). However, research by Connors and Donnellan (1998; as cited in Dyches et al., 2004) addressing this belief shows that younger Latina women in the United States, who are likely more acculturated, report less adherence to this belief than women from older generations. Some young Latina mothers accept the disabled child as a blessing or a gift from God, and view having the child as a challenge to become a better person (Dyches et al., 2004).

Another study of Puerto Rican parents' perception of their mentally disabled children lends support to the idea that disabilities are culturally defined (Harry, 1992), and in the case of other childhood disorders such as ADHD, some families attribute symptoms to causes other than a health related condition, for example "willfulness" or other usual behaviors that are still within the bounds of normalcy (Mandell & Novak, 2005). Therefore, to understand the significance parents give to their children's symptoms, their beliefs about the causes of symptoms, and chosen treatment courses, culture must be taken into account.

Research also suggests that symptoms of autism most commonly recognized by parents, and the interpretation of those symptoms, could vary according to the cultural background of the

family. In a study of how Indian parents first recognized their children's autistic symptoms, researchers found that social difficulties were the most commonly recognized (45%), whereas fewer families (31.6%) noticed a delay in speech (Daley, 2004). In contrast, one study found that typical Caucasian American parents are more likely to recognize general developmental delays or regression in language skills rather than social and communicative deficiencies (Coonrod & Stone, 2004). It is possible that the Indian cultural emphasis on social conformity could explain why social difficulties were first recognized. Indians primarily stress conformity to social norms and place high value on social relatedness. Therefore, a disorder that is largely one of social relatedness will have a unique significance in this culture (Daley, 2004). Since traditional Hispanic culture is similar to Indian culture in its emphasis on family unity and social structure, it is possible that social symptoms will be more commonly recognized as problematic than other categories of symptoms. However, it is important to note that Western professionals also strongly emphasize deficits in social symptoms. The word autism, originally coined by Kanner in 1942 (Kanner, 1942), means "self" or a "tendency to view life in terms of one's own needs and desires" (Dictionary.com, 2010). So, according to Kanner (1942), autism was originally conceptualized as a disorder of social relatedness. Thus, although many Caucasian parents may first notice communicative difficulties (Coonrod & Stone, 2004) social symptoms are also very noteworthy in Western cultures, despite individualistic tendencies. Therefore, it is possible that it is not the collectivist culture that makes social symptoms more remarkable in these cultures; instead, these are symptoms noteworthy in collective and individualistic cultures alike.

The expectations parents have regarding children's behavior and development could be influenced by culture as well (Liptak et al., 2008). Therefore, one possible way to explain the apparent disparity in diagnosis in Hispanic populations is that the concept of autism is not well understood in this minority group, so the symptoms of autism may not be recognized early as problematic. Liptak et al. (2008) found that Hispanic parents were more likely to rate their child's autism as more severe than non-Hispanic parents. This study supports the idea that beliefs about

development and behavior are shaped by culture, and one explanation of more severe ratings of autism by Hispanic parents could be that signal detection criterion is different between cultural groups, and only severe symptoms are considered noteworthy.

In addition, level of acculturation might be important in treatment seeking. For example, Pachter and Weller (1993; as cited in Mandell & Novak, 2005) also found among families of the same culture, those who are more acculturated show better adherence to physician-prescribed treatments. Levy et al. (2003) found that parents of Hispanic children recently diagnosed with autism were six times more likely than children of other ethnicities to use nontraditional treatment (as cited in Mandell & Novak, 2005).

Two specific aspects of acculturation, language use and mainstream media (Marin & Sabogal, 1987), could also affect autism knowledge.

The Significance of Language in Autism Diagnosis. The Spanish language is one important part of Hispanic culture that needs to be taken into account; being unable to speak the same language as the professionals diagnosing their children could put Hispanic parents at a significant disadvantage. For example, according to Hanson et al. (1990) in the context of understanding and receiving diagnosis and treatment “families with limited English proficiency are seriously disadvantaged” (p. 124). Another study found that controlling for language ability reduced the differences in types of care between Hispanic and Caucasian children diagnosed with autism (Liptak et al., 2008).

One of the primary diagnostic criteria for autistic disorder is a delay in, or total lack of, the development of spoken language (APA, 2000) However, Ortiz and Barrera (1997; as cited in Skiba et al., 2008) found that differentiating between language acquisition difficulties for English Language Learners and a language disability complicates autism diagnosis in Hispanic children. In one study, parents of children with autism stated that they did not know a language delay was symptomatic of a developmental disorder because language acquisition was slightly delayed in their other children or relatives as well (Overton et al., 2007). Additionally, many parents believe

that their children will experience a delay in language due to dual language learning, and parenting literature perpetuates this idea (King & Fogle, 2006). However, the research does not support the idea that bilingualism causes a language delay (King & Fogle, 2006). Still, even if families do notice a problem in the language domain, it is likely that they, or professionals, will write it off as a cultural difference, when, in fact, it could be an important symptom of autism.

Specifically, it has been suggested that not speaking English and bilingualism could affect diagnosis and treatment of autism. First, linguistic differences could affect the way families understand the diagnosis of autism. While some languages have no word for autism, the Spanish language simply adapts the English word *autism* to the Spanish word *autismo* (Wilder, Dyches, Obiakor, & Algozzine, 2004). Although we see similarities in language like this in many other Spanish/English word pairs, such as the English word *television* as compared to the Spanish word *televisión*, this type of difference is particularly important in a concept such as autism. In the previous example, the word television, it is easy to explain and understand the concept of the object. A television is something that can be seen and talked about; it is an item now familiar to most homes. However, autism is a concept that is only beginning to be understood, and cannot be readily explained. Without a correct understanding of the vocabulary, families may not understand the implications of this disability.

Communication between professionals and families is also very important in regard to diagnosis and treatment. Hanson et al. (1990; as cited in Zhang & Bennet, 2003) stated that families with limited English proficiency have been labeled “seriously disadvantaged” in regard to the diagnosis and treatment process. To explain, having limited English proficiency makes it less likely that families will understand the professional jargon, body language, timing of silence, pacing of speech, and pitch and tone within conversations with professionals (Zhang & Bennet, 2003). In summary, families who do not speak English proficiently will be less likely to comprehend professional vocabulary and truly understand the diagnosis their child is receiving. In addition, they may not understand the warning signs if a doctor explains them, and will be less

likely to report a problem with their child's development. This means the child probably will not be diagnosed at a young age, or parents may not understand the diagnosis, so early intervention services are less likely to be utilized. Because the outcome of children who are diagnosed early and receive early intervention services has been shown to be better than those who are not diagnosed or are diagnosed later and do not have the benefit of early intervention, it is paramount that children be diagnosed as young as possible and receive early intervention right away. For this reason, it is crucial that parents know about autism, understand the diagnosis and the signs, and seek treatment as early as possible.

Use of Mainstream Media. It is possible that acculturation and language not only affect diagnosis and treatment utilization, but autism knowledge in general as well. "Learn the Signs. Act Early." is an initiative operated federally through the CDC (CDC, 2008a). This campaign is aimed at families and health care providers, with the intent to promote awareness about child development in general, and ASD symptoms in particular. The CDC website provides information in both Spanish and English, which can be downloaded and used in clinic settings via their website. Although information is available in Spanish, it is questionable as to whether Hispanic populations are accessing it. In a pilot project to include children and youth with disabilities in community activities with nondisabled peers, researchers found that utilization by Hispanic families was low, despite information being presented in Spanish, and a high Hispanic population in the target region (Fennick & Royle, 2003). Information was circulated through radio stations, newspapers, public access stations, and school district notices, but it was suggested that diverse cultural and ethnic groups might not access mainstream sources such as these. See Fennick and Royle (2003) for a review alternative sources of information that might be useful to Hispanic and African American minority groups. Therefore, although mainstream sources may be providing access to knowledge about autism, parents who are less acculturated may not be accessing this information. This also lends support to the idea that lower levels of acculturation in Hispanic populations will predict less knowledge of autism.

Accessing treatment is also thought to be affected by language because some Hispanic parents are most comfortable in settings where only Spanish is spoken, and so will be more likely to seek treatment at Spanish-speaking facilities (Fennick & Royle, 2003). However, bilingual and bicultural early intervention and special education providers are in great shortage (Zhang & Bennet, 2003). Thus, even if Hispanic parents do notice problems with their child's development, they may not seek treatment due the lack of bilingual professionals.

The previous examples illustrate how acculturation and culture in general could be affecting perceptions of and knowledge about childhood development in general, and autism knowledge specifically. This could negatively impact the identification of problem behaviors and autistic symptoms, as well as perception of the behaviors and treatment seeking. Taken together, these varying ways culture shapes knowledge and perception of development and disability could in part cause the discrepancies in autism diagnosis in Hispanic minority cultures. Theoretically, those who are more familiar with the majority culture and adhere less to traditional minority culture (highly acculturated), could have more knowledge of autism than those less familiar with the majority culture (low acculturation). Although previous research illustrates the importance of culture and acculturation in other specific illnesses, there is little research exploring the role of acculturation on knowledge of autism specifically. The current study seeks to assess the concept of autism within Hispanic cultures and the impact of acculturation. Specifically, it is important to understand how Hispanic cultures conceptualize autism, and what factors influence quantitative knowledge about autism. This information is essential in order to examine barriers and solutions to successful cross-cultural practice involving Hispanic children with autism and their families (Wilder, 2004). The current study also recognizes the importance of language in autism diagnosis; the qualitative component explored the linguistic concept of "el autismo" in Hispanic cultures.

The Impact of Family and Social Structure, and Religion

The role of social support in autism knowledge, diagnosis, and treatment seeking is critical to recognize. Hispanic families tend to have a strong sense of family cohesion (Dyches et al., 2004), known as “familismo”. Having a strong social support system could impede diagnosis and initial early intervention, and high reliance on family support might lead to less reliance on organizational support systems (Dyches et al., 2004). Specifically, Blacher, Lopez, Shapiro, and Fusco (1997; as cited in Dyches et al., 2004) found that strong family structures might reduce the use of professional services by mothers of children with mental retardation. Instead of relying on organizational support, families rely on extended family members to share responsibility and gain support (Zhang & Bennet, 2003). Although there is some research on general developmental disabilities (Skinner et al., 1999) linking Hispanic family support and formal support, it is critical that further research distinguish autism from other developmental disorders due to its “intense and enduring” challenges (Dyches et al., 2004, p. 220).

Specifically, the influence of social support is important to recognize, because families who are not accessing services outside the home and family, may not be exposed to information about autism and knowledge campaigns such as “Learn the Signs. Act Early.” (CDC, 2008a). Therefore, if no child with autism exists within the family structure and social support network, the family may have no concept of autism and/or related signs and symptoms. The current study recognizes the possible impact of social support on autism knowledge in Hispanic families, and seeks to evaluate its influence on autism knowledge.

In addition to social support, religion has traditionally played a significant role in the daily lives of Hispanic individuals (Smith, 2009). Roman Catholicism is of particular importance in the Spanish-speaking world, and the church influences family life and community affairs, as well as provides spiritual meaning to Hispanic cultural (Clutter & Neito, 2009). The church’s influence on family affairs is important (Smith, 2009) and relates specifically to autism diagnosis and treatment utilization, since high reliance on religion might cause parents to be more accepting

of a child (Dyches, et al., 2004), thus less likely to seek treatment or diagnosis at an early age (Rogers-Adkinson, 2003). For example, families embracing beliefs such as “fatalismo,” the belief that one can do little about his fate, are less likely to seek medical care and more likely to seek harmful treatments (Mandell & Novak, 2005), or assistance through prayer or a *spiritista* (Rogers-Adkinson et al., 2003), a faith-healer who is consulted for healing through prayer. Because of the importance of religion and religious tradition to Hispanic families, it is essential to explore the effect of high religiosity within Hispanic parents on knowledge of autism. Additionally, the specific impact of fatalistic beliefs on autism knowledge was explored in the current study.

If professionals in the field of autism understood the way that families utilize social support and religion, and how this relates to need for organizational support, more effective diagnosis and treatment of Hispanic children with autism might be possible (Dyches et al., 2004). Parents relying more on their familial and social support systems, as well as on guidance and assistance from religious affiliations instead of from hospitals, clinics, and treatment centers, could contribute to lack of knowledge about autism, and less likelihood to utilize health care resources and receive effective treatment. For this reason, the current study seeks to specifically investigate the influence of social and religious support networks, as well as fatalistic beliefs, on autism knowledge.

Study Rationale

Studies identifying how families choose pathways to diagnosis and treatment of autism, as well as their perception of, attitudes toward, and experience within the system, are crucial (Thomas et al., 2007). Understanding what is known about autism in Hispanic cultures within the United States and how autism is viewed within family systems will allow for better understanding of diagnosis and treatment paths that may be taken. Specifically, the current study aims to identify whether there is a disproportional lack of knowledge about autism within Hispanic families, especially those of low acculturation that could be influencing diagnosis and initial

treatment usage. This chapter sought to examine the possible reasons for disparities in autism diagnoses in Hispanic cultures in the United States. It is important to understand the possible reasons for disproportionate rates of autism in Hispanic cultures, and delineate the factors that most significantly make a Hispanic child at risk for missed diagnosis. Early diagnosis makes it possible for children to receive early intervention at the youngest age possible; therefore, if parents do not know the signs and symptoms of autism, or do not seek treatment for their child at all, or at a later age, it is likely that the child will not achieve potential positive outcomes.

Although studies calling for more information about factors that affect autism knowledge, and explaining the reasons for discrepancies in diagnosis in minority cultures exist, there are no known studies that empirically explore these issues. The present study is an exploratory study seeking to expand the limited research available regarding knowledge of autism in Hispanic cultures, and the individual demographic and cultural variables that affect this knowledge.

The present study evaluated the amount of autism knowledge between high and low acculturation groups in order to understand if there is a difference in knowledge that is accounted for solely by acculturation status. Next, correlational analyses served to give a foundational understanding of factors affecting autism knowledge. Finally, a regression equation was created to explain the combination of cultural and demographic factors that affect autism knowledge. A qualitative component explored domains of autism knowledge that exist within Hispanic participants and between acculturation groups.

The present study used survey data obtained from patients in a waiting room at a clinic in central Texas. The possible reasons for disparities in autism diagnoses identified in this chapter and evaluated by the survey were; the influence of SES as measured by income and education, parenting experience, the significance of acculturation, the impact of family and social support structures, religiosity, and fatalistic beliefs. This study expands existing literature regarding autism in Hispanic cultures and could serve to help close the knowledge gap associated with this topic using both qualitative and quantitative measures.

Research Questions and Hypotheses

The present study seeks to answer three main research questions using exploratory analyses. The first question is: Are there quantitative differences in autism knowledge between highly acculturated Hispanic communities and Hispanic communities of low acculturation? The first hypothesis is that there will be differences between Hispanic participants of low acculturation and highly acculturated Hispanic participant's knowledge of autism as assessed by the Autism Survey (Stone, 1986). Specifically, Hispanic participants of low acculturation will indicate less knowledge of autism than the highly acculturated Hispanic participants.

The second research question is: What cultural and demographic variables best predict autism knowledge in Hispanic populations? Hypothesis two, three, four, and five will be used to explain how cultural differences affect knowledge of autism. Specifically, hypothesis two predicts that SES will be significantly related to autism knowledge. Hypothesis three is that high degrees of religiosity will correlate negatively with knowledge about autism. Hypothesis four is that Hispanic families endorsing a high degree of dependence on family and social support systems will have less knowledge of autism. The role of social support systems in Hispanic cultures is expected to mediate the use of services where knowledge could be gained, and necessary for both diagnosis and evaluation. Finally, hypothesis five is that participants endorsing fatalistic beliefs will indicate less knowledge of autism than those who do not. Specifically, those endorsing disability or problems as a sign from God will indicate less knowledge of autism than those who do not. In addition, the general descriptive features subscale of the Autism Survey will be used to clarify the relationship between the proposed cultural and demographic variables and autism knowledge.

The final research question is: Are there qualitative differences in accuracy of the description or in the characteristics of autism described by Hispanic participants of high and low acculturation? The sixth hypothesis is that Hispanic participants of low acculturation will provide a less accurate definition and description of autism than highly acculturated participants.

Additionally, Hispanic participants are predicted to more accurately describe social characteristics of autism than communicative or behavioral characteristics.

CHAPTER II

METHOD

This chapter describes the hypotheses, research methodology, research instruments, and participant selection used in this study. The purpose of this study was to explore the connection between individual demographic and cultural factors in relation to knowledge of autism, as well as to understand the contributions of specific aspects of Hispanic cultures that could influence knowledge about autism, and therefore impede early identification of autistic symptoms by parents and diagnosis by professionals. The basic design of this study was exploratory, quasi-experimental, survey research. The study was largely quantitative with a small qualitative component. Surveys made up the quantitative component, and a definition of autism provided by each participant provided the qualitative component. This combined design allowed for a more comprehensive understanding of the research questions.

Participants

The present study collected survey data in the months of September and October, 2009 from a sample of clients at El Buen Samaritano, an Episcopal Mission that provides integrated health care, emergency food, advocacy, leadership, development, and basic education for working-poor Hispanic families in Austin, Texas. Patients in the waiting room were asked if they would volunteer to participate in this study.

Sixty-seven participants filled out the survey form. Three (0.04%) were excluded from analyses because they were not of Hispanic ethnicity. The resulting sample (N = 64) ranged in

age from 18 to 65 years old ($M = 33.38$, $S.D. = 10.69$). The majority of participants were parents (86%) and female (84%). The average number of children of each participant was 1.83 ($S.D. = 1.28$) with an average age of 7.08 ($S.D. = 8.83$) for the youngest child of each participant. No other exclusion criteria were used. Participants were specifically asked if they had a child who was ever diagnosed with or referred for autism diagnosis, since these participants were likely to be different from those who do not have a child with autism. None of the participants indicated ever having a child diagnosed with autism. See Table 1 for complete demographic information for the resulting sample.

Table 1.

Summary of Participant Demographic Information (N = 64)

Gender	
Male	16%
Female	84%
Parenting Status	
Parents	86%
Not Parents	14%
Number of Children	1.83 (1.28; where applicable)
Age of Youngest Child	7.08 (8.83; where applicable)
Level of Education	
6 th Grade or Less	7.8%
7 th or 8 th Grade	15.6%
Some High School	12.5%
Completed High School	28.1%
Some College	20.3%
Graduated from College	9.3%
Post Graduate Degree	6.2%

Fifty-one participants responded to the question for the qualitative component of the study asking for a description or definition of autism in the participant's own words. Of the 51

respondents, seven answered with some form of “I do not know what autism is” and were excluded from further analysis. Two respondents were not of Hispanic ethnicity, and so were also eliminated. Therefore, the final sample for the qualitative component of analysis included 42 participant responses. It is unknown as to why the remainder of the original sample did not respond to the question. The lack of response could have been due to lack of time and interest since the question took more effort to complete, inability to write, or being unsure of the answer.

Measures

The data were collected using a four-section questionnaire consisting of 60 questions developed for this study. Each of these sections served to measure a separate variable identified in the purpose of the study, which was to explore the connection between individual demographic and cultural factors and knowledge of autism, as well as to specifically understand the contributions of aspects of Hispanic culture that could impede early identification of autistic symptoms by parents and diagnosis by professionals.

The consent form and questionnaire were translated into English and Spanish and both versions were available at the data collection site. To ensure accurate translation, the English copy of the survey and consent forms were first translated into Spanish by a bilingual speaker. Another bilingual speaker then translated the survey back into English. The two versions were checked for consistency, and errors were corrected. In addition, at the data collection site the principal investigator was available to read the questionnaires in Spanish or English to participants unable to read.

The first section of the questionnaire consisted of a survey that assessed the basic demographic information relevant to the research questions: age, occupation, number of children, age of children, and years of education (see Appendix A). In order to estimate SES from occupation and years of education, Hollingshead’s formula was used (Hollingshead, 1957). Occupations were divided into one of nine classes according Hollingshead’s categories (Hollingshead, 1957). Then, using Hollingshead’s weighted formula (Hollingshead, 1957) each

participant's SES score was obtained by adding the occupation value, which has a weight of 5, and the education value, which has a weight of 3. Parenting experience was calculated by adding the total ages of each participant's children. Participants were also asked whether they ever had a child diagnosed with an ASD, since parents who had experience with an autistic child were more likely to know more about it. These demographic variables were used to better understand the similarities and differences inherent in each participant that could affect results of the study and better understand which specific demographic variables affect knowledge of autism.

The final question on the first section of the survey form asked participants to give a definition of autism in their own words (See Appendix A). This question formed the qualitative component of the study and served to answer whether the definitions of autism by Hispanic parents of low acculturation and highly acculturated Hispanic parents are qualitatively different.

The second section of the survey was the Short Acculturation Scale for Hispanics (SASH; see Appendix B; Marin, 1986). This 12 question scale measured the level of acculturation, which is adoption of the dominant culture, including language, values, identities, attitudes, and behaviors by a minority group. Marin, et al. (1986) previously validated the SASH on 363 Hispanic and 228 Caucasian whites with similar sociodemographic characteristics. In order to develop the scale, responses to 17 behavioral acculturation items from previous scales were analyzed via exploratory principal components factor analysis (Marin et al., 1986). Factor analysis of responses revealed three factors with eigenvalues higher than 1.0: Language Use and Ethnic Loyalty, Media, and Ethnic Social Relations (Marin et al., 1986). A weight of 6.0 was used as a cutoff score and items loading heavily in more than one factor were removed, leaving 12 items with similar factor structures for Hispanic and Caucasians (Marin et al., 1986). The 12 remaining items showed very good reliability (Cronbach's $\alpha = .92$; Marin et al., 1986). Within the subscales, internal consistency was also high (Language: $\alpha = .90$; Media: $\alpha = .86$; Ethnic Social Relations $\alpha = .78$; Marin et al., 1986). Validity of the scale was found by comparing the 12-item

scale and factors with the participant's generation ($r = .66, p < .001$), proportion of time spent living in the United States ($r = .70, p < .001$), and the participant's self-evaluation of acculturation ($r = .76, p < .001$; Marin et al., 1986). Also, the power of the scale to discriminate between Hispanic and Caucasians was measured by a *t*-test, which showed that Caucasians ($M = 4.63$) differed significantly from Hispanics ($M = 2.72$; Marin et al., 1986). Overall, the reliability of this scale compares with the reliability and validity of other published acculturation scales, and was shown to be especially reliable for Mexican Americans and Central Americans (Marin et al., 1986). This part of the survey assessed acculturation level, and was used to understand differences in knowledge of autism between high and low acculturation groups.

Section three of the survey packet sought to aid in understanding of the way religiosity differentially affects knowledge of autism by race. Three single-item measures were used to assess three dimensions of religiosity: amount of institutional emphasis on religious faith, amount of religious faith, and religious preference. Gorsuch and McFarland (1972) investigated the validity of these single-item measures in comparison to multiple-item measures of religiosity. Factor analysis revealed an acceptable correlation between the single and multiple-item measures ($r = .6$; Gorsuch & McFarland, 1972). In addition, validity of single versus multiple-item measures of religiosity was assessed by examining correlations between religiosity and another variable of potential interest when measuring religiosity, ethical values. Both single and multiple-item scales showed the same number of significant relationships with ethical values (14; Gorsuch & McFarland, 1972). According to Gorsuch and McFarland (1972), the single and multiple-item scales are generally equal. In addition, single-item scales are ideal when determining the existence of a relationship rather than an estimate of the size of relationship (Gorsuch & McFarland, 1972).

In addition to the single-item measures of religiosity, one question from a measure used to assess the impact of religiosity on parents of children with Fragile X syndrome as well as examine the role of religion in Mexican and Puerto Rican parents of children with developmental

delays (Skinner et al., 2001) was included. This question was included because it specifically addressed the impact of religious beliefs on having a child with a disability, as well as the impact of Hispanic cultural beliefs linked to religiosity such as *fatalismo*.

The fourth section of the survey is a 12-item Multidimensional Scale of Perceived Social Support (MPSS; Appendix E; Zimet et al., 1988). The MPSS is useful in measuring social support because it addresses the subjective aspect of social support adequacy, using three subscales: family, friends, and significant others. In addition, Zimet et al. (1998) found that it is psychometrically sound, having good reliability ($\alpha = .88$), factorial validity, and adequate construct validity. The factorial validity was assessed using confirmatory factor analysis, which revealed high factor loadings along the three dimensions of the subscales with minimal cross-loadings (Zimet, et al., 1998). Zimet et al. (1998) also assessed construct validity by comparing the MPSS subscales with the Depression and Anxiety subscales of the Hopkins Symptoms Checklist (HSCL). Correlations between these two instruments showed that Perceived Support from Family was significantly inversely related to depression ($r = -.24, p < .01$), and anxiety ($r = -.18, p < .01$; Zimet et al., 1988). Depression symptoms and Perceived Support from Friends were related ($r = -.24, p < .01$; Zimet et al., 1988). There was a minimal significant negative relation between depression and the Significant Other subscale ($r = -.13, p < .05$; Zimet et al., 1988). The scale as a whole was also minimally but significantly negatively related to depression ($r = -.25, p < .01$; Zimet et al., 1988). The MPSS is also simple to use, and a quick measure to administer.

In the present study, the sum total of this measure, rather than the individual subscales, was used to quantify social support via multiple regression, however the subscales were analyzed by correlation in order to better understand specific parts of social support affecting autism knowledge. This measure was compared with autism knowledge in order to better understand how social support systems utilized by Hispanic parents affect autism knowledge.

The final section of the survey packet was an edited version of the Autism Survey by Stone (1986). The original 2-part survey consisting of 31 items was developed to assess beliefs

about etiology, diagnosis, and specific features of autism (Stone, 1986). It has been used on variety of populations such as parents of children with autism, teachers, and autism specialists (Stone & Rosenbaum, 1988). The Autism survey asks participants to rate on a 6-point likert scale how much they agree with statements reflecting misconceptions as well as true features of autism. Internal consistency of the Autism Survey is moderate ($\alpha = .66$; Campbell, Reichle, & Bourgondien, 1996), but acceptable.

Schwartz and Drager (2008) modified the original Autism Survey to investigate knowledge of autism among speech-language pathologists. This version has 20 items, and was changed in part to a true or false format. For the purpose of the current research study, 20 questions from the first section of the original survey (Stone, 1986) were used, but changed to true/false formatting similar to Schwartz and Dagger's (2008) version, and updated to reflect current knowledge about autism similar to adaptations by Daley et al. (2002), Schwartz and Dagger (2008), and the Christian Sarkine Autism Treatment Center (2005).

In the current study, the original subscales: general beliefs about autism, socio-emotional features, and cognitive features, were maintained. The General Beliefs About Autism subscale was used in current statistical analyses because it was thought that this scale might be a more accurate measure of autism knowledge. For example, this subscale included primarily information targeted to parents through campaigns such as Autism Speaks (2008) and descriptions of autism provided by the Autism Society of America (2009; e.g. "Autism can occur in mild as well as extreme forms"), instead of questions regarding information necessary for diagnosis and the DSM-IV (2000) criteria included in the socio-emotional (e.g. "Children with autism have poor eye contact") and cognitive subscales (e.g. "Children with autism have behaviors and interests that are repetitive and stereotyped"). So, the information included on the General Beliefs About Autism subscale might be more widely available to the average parent. Additionally, it has the most questions and was therefore the most statistically sound and most reliable for use with the small sample size of this study.

The Autism Survey (Stone, 1986) was used to explore the primary and secondary research questions, attempting to answer whether there are differences in knowledge, understanding, and conceptualization of autism between highly acculturated Hispanic parents and Hispanic parents of low acculturation, and aid in understanding what types of cultural and individual characteristics affect that knowledge. Both Total Autism Knowledge (the sum total of the measure) and General Beliefs About Autism (subscale) were used to measure knowledge of autism.

Procedures

This study involved collection of survey data from a sample of patients in the waiting room at El Buen Samaritano Episcopal Mission. First the informed consent document was presented and reviewed by the patient with the aid of the principal investigator. After signing the informed consent document, the participant was given a copy of the survey form, with the option of reading it and filling it out individually, or with the aid of the investigator. Completion of the survey document took an average of 10-15 minutes.

In return for participation in the study, participants were provided with a packet of information about autism in Spanish or English. The packet included information from the Autism Society of America (2009), the CDC (2008a), and the National Institutes of Health (NIH; 2009). Brochures from these organizations regarding the signs and symptoms of autism, treatment options, and the importance of early intervention will benefit participants in that they will be better informed about autism. This was particularly important to the targeted group of participants since lack of information could be a key reason for disparity in diagnosis. Also, additional copies of the information packets were provided to El Buen Samaritano to distribute to clients who did not participate in the study.

Procedures for human subjects and consent materials were approved by the Institutional Review Board at Texas State University. No identifiable private data that could violate privacy rights of the patients was obtained, and all surveys were coded to ensure confidentiality.

Analytic Strategy

In the present study, all quantitative data were statistically analyzed using SPSS v17.0 software. The analytic strategy for the present study was fourfold. In the first part of analysis, a correlation matrix for Total Autism Knowledge was utilized for preliminary descriptive analysis and to explore relationships between variables. A correlation matrix for General Beliefs About Autism was also used to identify significant relationships between more general autism knowledge and individual cultural and demographic variables. Correlation matrixes were used due to the exploratory nature of the current study. It was important to use these matrixes to identify correlations between demographic and cultural variables that should be included in later multiple regression analyses.

In the second part of the analyses *t*-tests were used to identify whether there was a main effect for acculturation between participant autism knowledge groups as measured by Total Autism Knowledge. A *t*-test was the most appropriate method of analysis due to the necessity to analyze between-subjects variables. Before conducting the first independent samples *t*-test analysis, group membership of each participant was determined based on responses to the autism knowledge scale. The group median was used as the dividing factor. The between-subjects, independent variable is the group status based on the each participant's Total Autism Knowledge (Stone, 1986). One dependent variable, acculturation, a discrete quantitative variable, was measured as the sum total of responses to the SASH (Marin & Sabogal, 1987). In this stage of analysis, there was one possible main effect. A main effect by group would suggest that differences in knowledge between highly acculturated Hispanic parents and Hispanic parents of low acculturation exist. This effect relates directly to the first hypothesis, Hispanic parents of low acculturation will indicate less knowledge of autism highly acculturated Hispanic parents as assessed by the Autism Survey (Stone, 1986).

T-tests between Total Autism Knowledge groups on the demographic variables parenting experience and SES were also conducted in order to determine demographic similarity between

groups. Parenting experience was measured using two separate *t*-tests. First the sum total of years of parenting experience was used as a dependent variable with Total Autism Knowledge group as the independent variable. Next, participants were divided into groups based on age of child: parents of children 12 and younger, and parents of children older than 12. These groups were used as the grouping variable, and Total Autism Knowledge was the dependent variable.

For the second set of independent samples *t*-test analyses, group membership was determined based on responses to the General Beliefs About Autism subscale. This was done because it is possible that this subscale contains less error and is a better measure of autism knowledge. The group median was used as the dividing factor. The between-subjects, independent variable is the group status based on each participant's General Beliefs About Autism. Acculturation as measured by the SASH (Marin & Sabogal, 1987), again served as the dependent variable. A main effect by group would suggest that there are differences in autism knowledge as measured by General Beliefs About Autism between highly acculturated participants and participants of low acculturation. This also directly relates to the first hypothesis: Hispanic participants of low acculturation will indicate less knowledge of autism than highly acculturated parents as assessed by the Autism Survey (Stone, 1986).

Next, *t*-tests between General Beliefs About Autism groups on the demographic variables parenting experience and SES were conducted in order to determine demographic similarity between high and low General Beliefs About Autism groups. Parenting experience was again measured using two separate *t*-tests. First the sum total of years of parenting experience was used as a dependent variable with General Beliefs About Autism group as the independent variable. Next, participants were divided into groups based on age of child: parents of children 12 and younger, and parents of children older than 12. These groups were used as the grouping variable, and General Beliefs About Autism was the dependent variable.

The third part of the analysis was completely exploratory in nature, and used SPSS to perform a multiple regression equation in order to better understand what combination of

variables that best predicts knowledge of autism. The primary purpose of the regression analysis procedures used in the present study was to develop an equation made up of demographic and cultural variables that can be used for predicting values of the dependent variable, Total Autism Knowledge, for all members of the population (Mertler & Vannatta, 2005). A stepwise multiple regression was used since it is most appropriate for exploratory studies (Mertler & Vannatta, 2005). There were five independent variables used in the regression equation: SES, acculturation as a continuous variable, parenting experience, religiosity as measured by religious importance, and problem as a sign from God. Independent variables were chosen based on the hypotheses of the present study and the correlation matrices. Due to the small sample size of the present study, it was important to keep the number of predictor variables low so as to improve the case to variable ratio and maintain predictive power (Mertler & Vannatta, 2005). The dependent variable was Total Autism Knowledge.

A second regression equation was then used to explore relationships indicated by the first equation. This additional exploratory analysis used the same independent predictor variables, with the addition of social support, and in this analysis, the dependent variable autism knowledge was measured by General Beliefs About Autism. This dependent variable was used because this subscale contained information specifically targeted to parents through Autism Speaks (2008) and the Autism Society of America (2009); therefore, the responses to this subscale might contain less error, and it is possible that it provides a truer evaluation of actual autism knowledge of each participant.

The fourth part of data analysis involved the qualitative component of the study. This was analyzed via thematic analysis in order to better understand commonalities and differences in the dominant themes emerging between participants. Thematic analysis also allows for better understanding of ideas because it allows for control (Aronson, 1994). The first step of thematic analysis is collecting data, which was the definition of autism provided by each participant. After data was collected, broad patterns were identified and broken down into themes. Themes are

“units derived from patterns such as conversation topics, vocabulary, recurring activities, meanings, feelings, or folk sayings and proverbs” (Aronson, 1994, “Performing a Thematic Analysis”, para. 5). Themes should bring together fragments or parts of ideas that are meaningless by themselves; they are pieced together to form a collective experience (Aronson, 1994). Next, related patterns of themes are combined and catalogued into sub-themes, which provide a comprehensive view of the information (Aronson, 1994). Expected themes should be derived from the literature surrounding the topic, for the current study, anticipated themes include references to the three necessary categories of symptoms for autism diagnosis, social, communicative, and behavioral, as well as references to related common misconceptions, and general information about autism. References to cognitive, developmental, and neurological symptoms were expected subthemes. For this study, data were analyzed similar to the way in which Daley (2004) analyzed interview data from Indian parents in which responses were collapsed across five broad categories: social difficulties, speech and language, typical autistic behaviors, behaviors not specific to autism, and medical or developmental difficulties (Daley, 2004).

Three trained researchers independently coded the data for thematic analysis. The researchers were provided with the DSM-IV-TR diagnostic criteria for autism (APA, 2000), as well as the definition of autism provided to the public by the Autism Society of America (2009). They then coded each definition or description on a 6-point likert scale for accuracy of the definition according to the provided descriptions. Next, these researchers were provided with a list of words and phrases in the categories social, cognitive, communication, behavioral, developmental, neurological, general knowledge, and common misconceptions or symptoms unrelated to autism. By tallying the frequency that these words or phrases are used, domains in knowledge available or lacking in each definition were identified.

This part of the analysis was expected to support the hypothesis that Hispanic participants with low levels of acculturation would provide a less qualitatively accurate definition and

description of autism than Hispanic participants of higher acculturation levels. An independent samples *t*-test was used to test this hypothesis. Hispanic participants in general were expected to provide a definition focusing more on the social aspects as well as general information about autism than on the cognitive and language symptoms. These hypotheses were further analyzed by calculating percent totals for each domain, as analyzed by Daley (2002) using descriptive statistics, in order to recognize which categories were more understood by participants. This design did not allow for between subjects (high and low acculturation groups) statistical analysis, but was used to understand the autism knowledge domains within high and low acculturation groups.

Summary

This chapter focused on the way the research would be collected, organized, and analyzed. Both qualitative and quantitative components are part of this study, in order to provide a more comprehensive understanding regarding autism knowledge in Hispanic cultures. Also, a variety of statistical procedures were employed in order to provide a more thorough understanding than a single approach would provide. For a summary of hypothesis, measures, and statistical methods, see Table 2.

Table 2.

Summary of Hypotheses, Measures, and Statistical Analyses.

Hypothesis	IV ^a	DV ^b	Statistical Analysis
1. There are quantitative differences in acculturation between high and low autism knowledge groups.	Autism Knowledge	Acculturation	Correlation <i>t</i> -test
2. Socioeconomic status will significantly affect autism knowledge.	SES	Total Autism Knowledge, General Beliefs About Autism	Correlation Multiple Regression
3. High degrees of religiosity within Hispanic groups will correlate negatively with knowledge of autism.	Single-item measures of religiosity	Total Autism Knowledge, General Beliefs About Autism	Correlation Multiple Regression
4. Hispanic participants endorsing a high degree of dependence on family and social support systems will have less knowledge of autism.	Social Support Total	Total Autism Knowledge, General Beliefs About Autism	Correlation Multiple Regression
5. Hispanic participants endorsing fatalistic beliefs will have less knowledge of autism than those who do not endorse fatalistic beliefs.	Problem as a sign from God	Total Autism Knowledge, General Beliefs About Autism	Correlation Multiple Regression
6. Hispanic families of low acculturation will provide a less accurate definition and description of autism than highly acculturated Hispanic parents.	Acculturation	Definition of Autism	Thematic Analysis <i>t</i> -test percent total

a. independent variable (or predictor)

b. dependent variable (or criterion)

CHAPTER III

RESULTS

Preliminary Analyses

Scale reliability for each measure used was assessed before any further analyses could be completed. Missing data were replaced by the participant's average score on each scale, or subscale if applicable. In the current study, the reliability of the SASH for the sample ($N = 63$, Cronbach's $\alpha = .947$) was slightly higher than original full-scale reliability (Marin et al., 1986). Subscale reliability (Language: $\alpha = .922$; Media: $\alpha = .939$; Ethnic Social Relations: $\alpha = .788$) was also slightly higher than original subscale reliability estimates (Marin et al., 1986). Reliability of the MPSS ($\alpha = .889$) was similar to original reliability estimates (Zimet et al., 1998). All three subscales of the MPSS also showed higher inter-item reliability (Significant Other: $\alpha = .827$; Family: $\alpha = .877$; Friend: $\alpha = .911$) than original reliability estimates (Zimet et al., 1998). In the current study, the internal consistency of the full Autism Survey ($\alpha = .521$) was lower than original reliability analyses (Stone et al., 1986). However, item-total statistics revealed that removing three items (1, 3, 4) would improve reliability considerably, causing the reliability estimate to approximate original scale reliability estimates (α with items removed = .641). In the present study, the General Beliefs About Autism subscale had low but acceptable reliability ($\alpha = .539$). Within this subscale, Cronbach's α would not improve with deletion of any items. Lower

reliability for General Beliefs About Autism subscale as compared to the Total Autism Knowledge was expected due to the lower number of items. Additionally the true/false formatting of the responses limited variability and decreased reliability of both the full scale and subscale.

Descriptive analyses. A correlation matrix was created for Total Autism Knowledge to determine which variables were significantly correlated with overall autism knowledge.

Correlations at the 0.05 significance level were considered noteworthy, and used in further analyses. Total Autism Knowledge was negatively correlated with religious importance ($r = -.266, p = .035$) and problem as a sign from God ($r = -.329, p = .008$). Total Autism Knowledge was positively correlated with acculturation total ($r = .241, p = .057$) and SES ($r = .304, p = .016$). The social support scale as a whole did not significantly correlate with autism knowledge ($r = .140, p = .274$). See Table 3 for a summary of correlations between demographic, full scale, and subscale variables and Total Autism Knowledge.

The correlation matrix for General Beliefs About Autism supported correlations found for Total Autism Knowledge, as well as revealed other significant variables related to autism knowledge. General Beliefs About Autism was negatively correlated with religious importance ($r = -.309, p = .014$) and problem as a sign from God ($r = -.367, p = .003$). Additionally, parenting experience ($r = -.280, p = .026$) was negatively correlated with the General Beliefs About Autism, although this variable did not significantly correlate with Total Autism Knowledge. General Beliefs About Autism was positively correlated with acculturation total ($r = .367, p = .003$), SES ($r = .331, p = .008$), and Social Support total ($r = .303, p = .016$). The positive correlation with social support total is noteworthy because although the correlation is in the same direction, it did not reach significance in the previous correlation matrix. See Table 3 for a summary of the correlational relationships between demographic, full scale, and subscale totals with General Beliefs About Autism.

Table 3.

Summary of Correlational Relationships Between Total Autism Knowledge and General Knowledge about Autism and Individual and Cultural Variables

	Total Autism Knowledge	General Beliefs About Autism
Religious Importance	-.266*	-.309*
Problem as a Sign from God	-.329**	-.367**
Social Support Total	.140	.301*
Acculturation Total	.241*	.367*
SES	.304*	.331**
Parenting Experience	-.226	-.280*
Social Support Significant Other subscale	-.031	.141
Social Support Family Subscale	-.018	.094
Social Support Friend Subscale	.233	.362**
Acculturation Language Subscale	.235	.359**
Acculturation Media Subscale	.249*	.365*
Acculturation Ethnic Social Relations Subscale	.163	.270*

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

Parametric Analyses

T-tests. A *t*-test of mean differences in acculturation between participants of low and high Total Autism Knowledge was conducted. Participants were split into high and low autism knowledge groups based on a median split ($Mdn = 28$) of each participant's Total Autism Knowledge. Twenty-nine participants fell into the high knowledge group. 34 participants were included in the low knowledge group. Throughout analyses, Levene's Test for Equality of Variances was not significant unless reported, so equal variances were assumed. The *t*-test of mean differences in acculturation between participants in the high knowledge group (Acculturation $M = 31.14$, $SD = 12.141$) and participants in the low knowledge group (Acculturation $M = 26.03$, $SD = 9.734$) neared significance, $t(61) = -1.853$, $p = .069$; the high knowledge group had marginally higher acculturation scores compared to the low knowledge group.

Additional *t*-tests were conducted in order to ensure that differences were not accounted for by demographic variables such as SES or parenting experience. The same autism knowledge groups were used to test if there was a mean difference in SES between participant groups. Levene's test for equality of variance was significant in this analysis, $F(1, 61) = 12.306$, $p = .001$, so equal variances were not assumed. With adjustment to account for unequal variances, the SES *t*-test was not significant, $t(61) = -1.585$, $p = .134$.

Parenting experience was explored via two separate *t*-tests. First, the same autism knowledge groups were used to test whether there is a mean difference in total parenting experience between those in high and low autism knowledge groups. The *t*-test of mean differences in total parenting experience between those in high and low knowledge groups was not significant, $t(61) = .189$, $p = .851$. Additionally, participants were split into two groups, those with a child 12 and under (19 participants), and those with children older than 12 (44 participants), to test for mean differences in autism knowledge (measured as a continuous

variable) between parents with children younger than and older than 12. The *t*-test for mean differences in autism knowledge between participants with children 12 or younger and older than 12 was not significant, $t(52) = 1.409, p = .164$.

A *t*-test of mean differences in acculturation between participants of low and high autism knowledge as measured by General Beliefs About Autism was conducted in order to determine if there is a mean difference in acculturation between participant groups. Participants were split into high and low autism knowledge groups based on a median split ($Mdn = 6$) of each participants General Beliefs About Autism. Twenty-six participants fell into the low knowledge group. Thirty-seven participants were included in the high knowledge group. Levene's Test of Equality of Variances was significant $F(1,61) = 11.239, p = .001$ so equal variances were not assumed. With adjustment for unequal variances, the *t*-test of mean differences in acculturation between participants in the high knowledge group (Acculturation $M = 30.92, SD = 12.354$) and the participants in the low knowledge group (Acculturation $M = 24.77, SD = 7.977$) on the General Beliefs About Autism scale was significant $t(60.647) = -2.399, p = .020$, the high knowledge group had higher acculturation scores relative to the low knowledge group.

Like the previous set of analyses, additional *t*-tests were conducted to ensure that differences were not accounted for by the demographic variables SES or parenting experience. The autism knowledge groups as measured by General Beliefs About Autism were used to test if there was a mean difference in SES between participant groups. Levene's test for equality of variance was significant in this analysis $F(1,61) = 14.888, p = .000$, so equal variances were not assumed. With adjustment to account for unequal variances, the SES *t*-test was significant, $t(55.887) = -2.834, p = .006$.

In the first *t*-test to explore parenting experience, the same General Beliefs About Autism knowledge groups were used as the independent variable, with parenting experience as the dependent variable. Levene's Test for Equality of Variances was significant $F(1,61) = 7.066, p = .010$, so equal variances were not assumed. With adjustment to account for unequal variances, the

parenting experience t -test was not significant $t(36.925) = 1.466, p = .151$. The same parenting groups as in previous analyses were then used as the independent, grouping variable, with General Beliefs About Autism as the dependent variable. The t -test of mean differences in autism knowledge as measured by General Beliefs About Autism between participants with children 12 or younger and older than 12 was not significant $t(52) = -.036, p = .971$.

Multiple Regression. To determine which, if any, of the hypothesized demographic and cultural variables were predictors of autism knowledge, stepwise multiple regressions were conducted. The first stepwise multiple regression explored the independent variables previously significantly correlated with (SES, problem as a sign from God, acculturation total, religious importance), or nearing significant correlation with (parenting experience) total autism knowledge. Because of the restrictions of a small sample size and in order to increase predictive power, acculturation and social support subscales previously correlated with overall autism knowledge were not included in the regression. Results of this model indicate that SES and problem as a sign from God were predictive of Total Autism Knowledge, $F(1,61) = 6.041, p = .004$. However, only a minimal amount of variance is accounted for in this model ($R^2 = .168$). Beta weights for the resulting model indicate that as SES increases, Total Autism Knowledge increases as well, $\beta = .036, t(61) = 2.065, p = .043$, where as when belief in problems as a sign from God is supported, Total Autism Knowledge decreases $\beta = -1.818, t(61) = -2.330, p = .023$.

A second stepwise multiple regression using General Beliefs About Autism as the dependent variable was conducted to clarify relationships between variables and autism knowledge, and try to provide a better fitting model. Variables previously significantly correlated with the general descriptive features subscale of autism knowledge were included in the model (parenting, religious importance, problem as a sign from God, social support total, acculturation total, and SES). As in the previous model, acculturation and social support subscales were not included in the model due to the restrictions of a small sample size and the necessity to maintain

power. The resulting model revealed that SES, social support total, problem as a sign from God, religious importance, and parenting experience were significant predictors of General Beliefs About Autism, $F(1,61) = 8.190, p = .000$, accounting for 41% of variance in the dependent variable ($R^2 = .418$). Beta weights suggest that as SES and social support increase, knowledge of autism, as measured by General Beliefs About Autism, increases, $\beta = .016, t(61) = 1.704, p = .094$; $\beta = .036, t(61) = 3.258, p = .004$, respectively. With increased religious importance, parenting experience, and support of the belief that problems are a sign from God, knowledge of autism as measured by General Beliefs About Autism decreases, $\beta = -.336, t(61) = -2.187, p = .033$; $\beta = -.013, t(61) = -2.143, p = .036$; $\beta = -1.262, t(61) = -3.074, p = .003$, respectively.

Posthoc Analyses

Post hoc analyses were conducted on the variable problem as a sign from God due to its importance throughout previous analyses. This variable differs from other variables in that it was not an ordinal or interval variable and there were unequal sample sizes, and it should be interpreted with caution. Two *t*-tests of mean differences were used to better understand this variable. Participants were grouped based on response to the problem as sign from God variable: 48 participants did not indicate support for this belief, 15 participants supported this belief. The first *t*-test measured whether there is a difference in Total Autism Knowledge based on belief in problem as a sign from God. The *t*-test was significant, $t(61) = 2.724, p = .008$ indicating that there is a mean difference in Total Autism Knowledge between participants who did and did not believe in problems as a sign from God. A second *t*-test was conducted using the same grouping variable, but with General Beliefs About Autism used as the dependent variable. This test was also significant, $t(61) = 3.079, p = .003$, indicating that there is a difference in knowledge in General Beliefs About Autism between participants who believe and do not believe problems to be a sign from God.

Additionally, since acculturation should be important to autism knowledge, yet did not enter into any of the regression equations, multicollinearity between acculturation and two of the main predictor variables was thought to be a problem. Correlational analyses were conducted between acculturation total and these variables to better understand this relationship. Significant correlations between acculturation and SES ($r = .674, p = .000$), and acculturation and religious importance ($r = -.255, p = .043$) were found.

Qualitative Analyses

Data were coded and analyzed independently by 3 trained coders. Minor differences in coding were discussed and resolved between coder. Overall, only 7% of responses had a discrepancy in rating. In cases in which agreement was not reached between all three coders, the most common response was used (i.e. two out of three researchers agreed and so their coding was used in further analyses; overall 7%). Total interrater agreement across all categories was calculated by averaging Cohen's Kappas for each rater pair (Uebersex, 2002). This method is acceptable for the current study because all raters rated every case, and so averaging Kappa's for each rater pair created a Kappa statistic similar to a multirater generalization of Cohen's Kappa, and more accurate than Fleiss's Kappa (Uebersex, 2002). Interrater reliability was very high (average $\kappa = .888$).

Initial thematic analysis revealed five themes in participant definitions or descriptions of autism: social deficits, communicative deficits, behavioral signs, general knowledge, and symptoms or characteristics unrelated to autism. The general knowledge category was further broken down into four sub-themes: developmental, neurological, and cognitive characteristics, as well as broad general knowledge about autism.

An independent samples t -test was used to investigate whether or not there was a mean difference in total qualitative knowledge about autism reflected in definitions of autism between acculturation groups. Acculturation group was used as a categorical, grouping variable. Using a median split ($Mdn = 28$), participants who provided definitions or descriptions of autism were

divided into high (21 participants) and low (20 participants) acculturation groups. There was a significant mean difference, $t(39) = -2.224, p = .032$ between participants in the high ($M = 2.05, SD = 1.161$) and low ($M = 1.30, SD = 2.05$) acculturation groups, supporting the sixth hypothesis, that there is a difference in qualitative autism knowledge between acculturation groups, as measured by total scores on definitions and descriptions of autism.

By breaking down the coding into percent total responses in each category, similar to Daley (2002), it is possible to better understand the domains of autism knowledge within high and low acculturation groups. The highest amount of knowledge across acculturation groups was in the social symptoms category (27.14%), this was followed by equal amounts of information about cognitive characteristics (14.28%), communicative characteristics (14.28%), and general knowledge about autism (14.28%). The third and fourth most common overall categories of knowledge were developmental characteristics (12.28%) and behavioral characteristics (11.42%). The least common amount of knowledge was in the neurological disorder category (5.7%). 11.42% of participant responses described characteristics unrelated to autism. These results support the hypothesis that overall descriptions of autism in Hispanic participants would contain more information about social features than other categories of knowledge.

Within the low acculturation group, percent categories of information were similar to the overall percentages. In this group, social (22.22%) and general knowledge (22.22%) categories were described the most, followed by cognitive (14.81%) and developmental (14.81%) features. Communication (11.11%), behavioral (7.4%), and neurological (3.7%) symptoms were described the least. 18.51% of responses were unrelated to autism.

Percentages of descriptions across categories were similar in the high acculturation group as well. Social characteristics (29.54%) were described the most, followed by communication (15.9%) and behavior (15.9%). Cognitive (13.63%) and developmental (11.36%) characteristics were described in similar amounts, and general knowledge (9.09%) and neurological (6.81%)

characteristics were described the least. Notably, in the high acculturation group only 6.81% of responses were unrelated to autism.

The most notable percent differences between high and low acculturation groups were in the following categories: social (29.54 vs. 22.22 respectively), general knowledge (9.09 vs. 22.22 respectively), behavioral (15.90 vs. 7.4 respectively), and unrelated symptoms (6.81 vs. 18.51 respectively). These differences do not necessarily represent a difference in amount of knowledge in each domain between groups; instead they are representative of percent differences in knowledge domains calculated within groups. See Table 4 for a summary of percentages of knowledge across domains and acculturation groups.

Table 4.

Summary of Percentages of Autism Characteristics Described Across Domains

	High Acculturation	Low Acculturation	All Participants
Social	29.54	22.22	27.14
Cognitive	13.63	14.81	14.28
Communication	15.90	11.11	14.28
Developmental	11.36	14.8	12.28
General Knowledge	9.09	22.22	14.28
Behavioral	15.90	7.4	11.42
Neurological	6.81	3.7	5.71
Unrelated	6.81	18.51	11.42

CHAPTER IV

DISCUSSION

There is a rising rate of autism diagnosis throughout the United States, however the number of Hispanic children diagnosed with autism seems to be lower than expected (Dyches et al, 2004). The purpose of the present study was to identify and test cultural and demographic variables that could be affecting autism knowledge, and eventual diagnosis and treatment, in Hispanic populations. Previous studies have pointed to factors that could be influencing diagnosis and treatment utilization such as ethnicity (Mandell et al, 2006), acculturation (Mandell & Novak, 2005; Dyches et al., 2004), SES (Liptak et al., 2008; Zhang & Bennet, 2003), religion (Rogers-Adkinson, 2003), fatalistic beliefs (Mandell & Novak, 2005), and social support (Dyches et al., 2004; Zhang & Bennet, 2003); however no previous studies have empirically evaluated the influence of these factors on knowledge of autism. Therefore, the current study sought to empirically evaluate these variables and their effects on knowledge of autism. Data were collected from 63 Hispanic participants at a community clinic in central Texas. Preliminary analyses of correlations between autism knowledge and variables revealed some of the relationships between cultural and demographic variables and autism knowledge. In secondary analyses, forward multiple regressions were used to explore which variables could predict autism knowledge. Planned *t*-tests were conducted in order to understand if there are differences in autism knowledge accounted for by acculturation, as well as to explore differences in autism knowledge due to age of children or SES. Due to its importance throughout analyses, the variable problem as a sign from God, which represents fatalistic beliefs, was also analyzed *posthoc*.

Thematic analysis was used to better understand how the participants understand autism from a qualitative standpoint.

The first research question was: Is there a difference in autism knowledge between highly acculturated and those of low acculturation? It was hypothesized that there would be a quantitative difference in autism knowledge between highly acculturated and low acculturation Hispanic participants. Throughout the literature addressing autism diagnosis and treatment in Hispanic populations, acculturation is a recurring subject. Mandell & Novak (2005) found themes such as acculturation, culture and interactions with the health care system, and cultural attitudes toward disabilities throughout a review of literature regarding disparities in autism diagnosis. Researchers have pointed to culture as a deterrent to diagnosis and treatment due to clashes between the beliefs of minority parents and the perspective of majority culture (Mandell & Novak, 2005). Additionally, culture is thought to shape the way disabilities are viewed; Harry (1992; as cited in Dyches et al., 2004), found that those who are more familiar with majority culture, in other words more highly acculturated, adhere less to traditional cultural beliefs that could impede diagnosis and treatment.

In order to understand the influence of acculturation on autism knowledge, *t*-tests were conducted. Autism knowledge groups were created using a median split based on Total Autism Knowledge, and served as the independent variables. Acculturation served as a discrete quantitative dependent variable. This analysis was only marginally significant, suggesting that autism knowledge might be somewhat related to acculturation. Additional *t*-tests were conducted in order to ensure this marginally significant main effect was not accounted for by demographic variables. Two separate *t*-tests using the same autism knowledge groups and SES and parenting experience as the dependent variables were not significant, suggesting that the marginally significant results of the first *t*-test were not accounted for by SES or parenting experience. Additionally, since parents with younger children could have more knowledge of autism due to the relative recency of autism knowledge campaigns, an additional *t*-test was used to ensure that

this did not account for differences in autism knowledge. This test also was not significant, suggesting that there is not a difference in autism knowledge between parents of children younger than and older than 12. In summary, when acculturation and Total Autism Knowledge were compared statistically via a *t*-test, there was a marginal main effect not accounted for by other demographic factors. So, it is possible that with a larger sample size, or a more accurate measurement of autism knowledge, this result would reach significance.

Since it was thought that the General Beliefs About Autism subscale might contain less error than Total Autism Knowledge, its relationship to acculturation was also explored via *t*-test. A median split based on responses to the General Beliefs About Autism subscale was used to create high and low knowledge groups, which served as independent variables. Acculturation again served as the dependent variable. This analysis was significant, suggesting that there is a difference in acculturation by level of autism knowledge as measured by General Beliefs About Autism. *T*-tests between SES, parenting experience, and age of child, and autism knowledge as measured by General Beliefs About Autism were also conducted to ensure that this significant result is not accounted for by demographic variables. The *t*-test measuring mean differences in SES between General Beliefs About Autism knowledge groups was significant, indicating that the significant differences found between General Beliefs about Autism knowledge groups and acculturation might be accounted for by SES. These results lend support to the first hypothesis, that there are differences in acculturation by autism knowledge, however the importance of SES needs to be taken into account, as it might account for these differences.

The second research question was: What cultural and demographic variables best predict autism knowledge in Hispanic populations? In the first part of analysis, a correlation matrix was created, and Total Autism Knowledge was found to be significantly positively correlated with the variables acculturation and SES. It was significantly negatively correlated with religious importance and belief in problems as a sign from God. Based on these correlations, the relationships between autism knowledge and the variables acculturation, SES, religious

importance, and problems as a sign from God did support hypotheses; nevertheless, further analyses were needed in order to provide a clearer picture.

In order to better understand which demographic and cultural variables affect autism knowledge, a second correlation matrix was created; however, General Beliefs About Autism was used to measure autism knowledge. This subscale was used because it represents information that is theoretically thought to be more available to the average person through autism knowledge campaigns (Autism Speaks, 2008; Autism Society of America, 2009), and contains less technical information from the DSM-IV-TR (APA, 2000). The correlation matrix revealed significant positive correlations between General Beliefs About Autism and the variables acculturation total, SES, and social support total. Significant negative correlations were found between General Beliefs About Autism and the variables religious importance, problem as a sign from God, and parenting experience. Regarding the first research question: Are there quantitative differences in autism knowledge between highly acculturated and less acculturated Hispanic communities?, these correlational findings support the idea that autism knowledge and acculturation are related. Specifically, these findings lent support to the first hypothesis, that there are differences in autism knowledge between highly acculturated Hispanic participants and those of low acculturation.

The second research question sought to understand what cultural and demographic variables affect autism knowledge. Significant correlations between acculturation, SES, social support, religious importance, belief in problems as a sign from God, and parenting experience indicate that these specific cultural and demographic variables are related to autism knowledge. Specifically hypothesis two, that SES would significantly affect autism knowledge, was supported by positive correlations between SES and autism knowledge as measured by General Beliefs About Autism. Additionally, hypothesis three and five, that high degrees of religiosity would correlate negatively with autism knowledge, and that endorsement of fatalistic beliefs would negatively affect autism knowledge, respectively, were supported. Hypothesis four, that families with high degrees of social support would indicate less knowledge of autism, was not

supported. Although there was a correlation between General Beliefs About Autism and Social Support, this correlation was positive, opposite of the hypothesized relationship.

In order to answer the second research question, and specifically evaluate which demographic and cultural variables significantly affect autism knowledge, regression equations were used. Variables found to be significant in the first correlation matrix (religious importance, problem as a sign from God, acculturation total, and SES) were entered as predictors in a forward stepwise multiple regression, with Total Autism Knowledge total as the dependent variable. The resulting independent variables of central importance in this analysis were SES and problem as a sign from God. Results of this model showed that SES and problem as a sign from God, although significant, accounted for very little variance, and therefore this model did not seem to reliably predict autism knowledge and creation of a second model was necessary. Additionally, it is notable that acculturation did not enter into this model, despite the large body of literature suggesting that cultural and acculturation affect treatment seeking (Pachter & Weller, 1993; as cited in Mandell & Novak, 2005), and symptom recognition (Daley, 2004), as well as beliefs about normal childhood behavior and development (Liptak et al., 2008). Being more familiar with majority culture, that is, more highly acculturated, was expected to be a main predictor of autism knowledge, however it did not even enter into this model.

The second model created used the General Beliefs About Autism to measure autism knowledge and, similar to the previous analysis, variables significantly correlated with this subscale were entered into the equation (SES, social support total, religious importance, problem as a sign from God, parenting experience, and acculturation total). This second model had much higher predictive power than the previous model, and provided a better fit.

The variables of central importance to prediction in this model were SES, social support total, problem as a sign from God, religious importance, and parenting experience. Specifically, when SES and social support increased, knowledge of autism as measured by General Beliefs About Autism increased as well. When religious importance and parenting experience increased,

and participants indicated support of the belief that problems are a sign from God, knowledge of autism as measured by General Beliefs About Autism decreased. These relationships will be discussed further in the following sections. Additionally, and similar to the previous model, acculturation did not enter into the model as a predictor variable, despite previous research that suggests culture and acculturation could impact everything from beliefs about normal development (Liptak et al., 2008) to accessing services (Dyches et al., 2004). It is probable that acculturation was not a significant predictor in analyses in the current study because of high multicollinearity with the other predictor variables; therefore it might not be a significant predictor because it does not account for enough unique variance in the model. The significant main effect between SES and autism knowledge as measured by General Beliefs About Autism on the previous *t*-test, and *posthoc* correlational analyses supported this finding, since acculturation was highly correlated with the predictor variables SES and religious importance.

Before moving on to specific cultural factors, the influence of demographic variables must be examined. Hypothesis two, which predicted that SES would be related to autism knowledge, was supported. Previous research has identified having low income, one component of SES, as one of the most important determinants for use of early intervention in children younger than five years old (Zhang and Bennett, 2003). Additionally, both family income and education have previously been shown to affect treatment utilization (Thomas et al., 2007). So, given that SES affects intervention and treatment utilization, it is easy to understand how it could also be affecting knowledge of autism in general through an inverse relationship. Specifically, SES was positively correlated with both Total Autism Knowledge and General Beliefs About Autism, indicating that higher SES is related to more autism knowledge, and lower SES is related to lower autism knowledge. Moreover, it was the main predictor variable in both the first regression model, which used measured autism knowledge using Total Autism Knowledge, and the second and final regression model, which used General Beliefs About Autism to measure

autism knowledge. Additionally, it is highly correlated with acculturation, which could also aid in its effects on autism knowledge.

It is also important to consider that although the results of this study suggest that SES is related to autism knowledge, which could affect knowledge and treatment utilization, it may also be independently related to autism diagnosis and treatment. For example, although having a low SES is related to less autism knowledge, even if a person of low SES does know about autism they still may not be able to access diagnostic and treatment services. This is for a few reasons. First, treatment of autism is expensive, despite the fact that Medicaid is available to offset costs. As mentioned previously, families of children with autism accessing care via Medicaid were more likely to use only services viewed as medically necessary, whereas families who have private insurance, an indicator of higher SES, were more likely to access more costly and supplemental services (Thomas et al., 2007). Second, access to treatment and diagnostic services could be limited by geographic location, which is often linked with SES. Specifically, Thomas et al. (2007) identified living in a nonmetropolitan area as a limiting factor for access to autism care for racial and ethnic minorities. So, even if parents identify symptoms of autism in their child, specialty care might be limited due to its lack of availability.

Parenting experience was another demographic predictor variable that entered into the regression equation. Autism knowledge and parenting experience had a negative relationship, which can be explained by the way the variable was measured. Theoretically, more parenting experience should be related to greater autism knowledge, since there would be added likelihood for exposure to information about autism with greater experience. However, in this study parenting experience was measured by summing the ages of all children for each parent. So, parents with older children have more parenting experience, but might not have had young children when information about autism was readily available to parents, since autism did not receive extensive media coverage until between 2000 and 2003 (Hennessey, 2005), and one of the most prominent autism campaigns, Autism Speaks, did not begin until 2005 (Autism Speaks Inc.,

2008). This lack of information during the time when parents had young children could explain the inverse relationship.

Hypothesis four was that high degrees of social support would negatively affect autism knowledge; however social support entered into the final model and had a positive relationship with autism knowledge. So, despite previous research suggesting that high social support in Hispanic populations reduces use of treatment and services in other mental disorders (Dyches et al., 2004; Blacker et al., 1997), results of this study do not seem to suggest that high social support impedes autism knowledge in general. The results of the current study do not support the idea that higher social support will predict lower knowledge of autism as a result of strong family cohesion and dependence of family limiting access to autism knowledge through organizations.

Subscales of the social support scale contained correlations that help to better explain the role of social support in autism knowledge. Specifically, the social support subscale measuring friend support is significantly positively correlated with autism knowledge as measured by General Beliefs About Autism, and the degree of relationship is actually slightly higher than the correlation between the scale as a whole and autism knowledge as measured by General Beliefs About Autism. So, it is possible that the significant positive correlation between autism knowledge and friend social support explains why the current results are the opposite of hypothesized results and previous research; having support of friends outside the family structure could create a pathway to knowledge of autism through a greater social network and more possible sources of knowledge.

Additionally, it is possible that the strong social support systems characteristic of Hispanic cultures positively influence autism knowledge because having more social support allows parents to seek out healthcare and diagnosis. Specifically, it could affect diagnosis and treatment of a child with autism because caring for a child with autism requires a great deal of time and effort from the parents. Thus having a strong social support system, such as an extended family, could provide the parents with more people to take care of the child, therefore relieving

them and allowing them to seek out treatment and diagnosis through organizations. The results of the current study support the idea that having a strong social support system allows parents to seek help and access organizations that might provide information about autism because they might have more people available to take care of their children instead of the idea that a high degree of social support impedes knowledge by limiting access to care.

Hypothesis three stated that high degrees of religiosity would correlate negatively with autism knowledge. This hypothesis was supported, as religious importance was another predictor variable that entered into this model. The negative relationship between autism knowledge and religious importance can be explained in a few ways. First, Roman-Catholicism is historically of great importance in the Hispanic culture, especially through its influence on family life and community affairs (Clutter & Neito, 2009). It has been suggested that high reliance on religion could cause parents to be more accepting of a child and less likely to seek treatment or diagnosis (Rogers-Adkinson, et al., 2003). Additionally, seeking care through religious pathways, such as through a faith-healer or prayer could lead to less utilization of medical care in general (Rogers-Adkinson, et al., 2003), and therefore less knowledge of autism through the health care system. Additionally, it is notable that although religious importance is significantly related to autism knowledge, religious attendance is not. Skinner et al. (2001) also found that organized religion and faith were viewed differently as sources of support by Latino parents of children with Fragile X. Specifically, parents viewed their personal religious faith as more important in providing support than organized religion (Skinner et al., 2001). It is possible that this also explains why religious importance was a more salient variable in the current study.

Hypothesis five was that endorsement of fatalistic beliefs would result in less knowledge of autism, and this hypothesis was supported by results of correlational analyses, *t*-tests, and multiple regression analyses. The relationship between autism knowledge and the problem as a sign from God variable is especially interesting, since it has been important throughout analyses. Essentially, the problem as a sign from God variable measures support of fatalistic beliefs.

Fatalism is the belief that the path of fate generally cannot be changed, and that the events of life are beyond one's control (Abraido-Lanza, 2007). In the Hispanic culture, *fatalismo* is thought to be a cultural belief that can affect health behaviors (Florez, 2009). For example, there is a body of literature exploring the impact of fatalism and breast cancer beliefs in Hispanic women (Florez, 2009; Abraido-Lanza, 2007; Facione, 2002), some suggesting that support of fatalistic beliefs can negatively influence use of health care (Abraido-Lanza, et al., 2007). Traditional Puerto Rican culture illustrates an example of the expression of a fatalistic belief; traditionally, this culture blames mothers who give birth to a disabled child, and the child is viewed as penance for the mother's sins, or a curse (Rogers-Adkinson et al., 2003). In this case, treating the child is discouraged, since it is viewed as the mother's burden. Additionally, in one study *fatalismo* impacted treatment decisions in parents of autistic children (Mandell & Novak, 2005). Parent's supporting fatalistic beliefs were less likely to seek medical care, and more likely to seek harmful treatments (Mandell & Novak, 2005). So, it is understandable that supporting fatalistic beliefs could impact autism knowledge, since those supporting these beliefs seem to be less likely to utilize health care in general, and therefore may not be exposed to information about autism or normal childhood development. This idea is supported in the current model, since believing in problem as a sign from God is negatively associated with autism knowledge in multiple regression and correlational analyses; however, these results must be interpreted with caution and more systematic examination of this finding is necessary.

Additionally, since problem as a sign from God is a different kind of variable in that it was measured nominally rather than on a scale, it was explored through *posthoc* analyses as well. Significant *t*-tests exploring Total Autism Knowledge by belief in problem as a sign from God and General Beliefs About Autism by belief in problems as a sign from God again supported the importance of this variable. Parents who supported belief in problem as a sign from God seem to have different amounts of knowledge about autism than those who do not support the beliefs in problems as a sign from God.

Interpretation of Qualitative Data

The quantitative analyses used were designed to show overall patterns in autism knowledge as affected by various individual cultural and demographic variables. The analysis of participant responses to the description or definition of autism provided a more in-depth picture of autism knowledge in Hispanic populations. The third research question was: Are there qualitative differences in accuracy of the description or in the characteristics of autism described by Hispanic participants of high and low acculturation? Specifically, it was hypothesized that Hispanic participants of low acculturation would provide a less accurate qualitative definition or description of autism than highly acculturated Hispanic participants, this hypothesis was supported by the results of a *t*-test measuring qualitative autism knowledge by participant acculturation group. Definitions and descriptions of autism provided by participants revealed five main themes: social deficits, communicative deficits, behavioral abnormalities, unrelated features, and general knowledge. General knowledge was further broken down into three sub-themes: cognitive deficits, developmental characteristics, neurological etiology, and broad general knowledge about autism.

As discussed previously, the literature suggests that acculturation could play an important role in autism diagnosis and treatment seeking, and the primary research questions of the current study asks if there is a difference in autism knowledge between high and low acculturation groups. In qualitative analyses, an independent samples *t*-test of mean differences supported the hypothesis that there is a difference in qualitative knowledge between Hispanic participants of low acculturation and those of high acculturation as measured by the accuracy of participant description or definitions of autism. Specifically, this finding is important given the marginally significant differences between Total Autism Knowledge groups and acculturation level, and the significant differences found between General Beliefs About Autism knowledge groups and acculturation level found in previous analyses. It is possible that qualitative data revealed a significant difference in autism knowledge level by acculturation because of the way autism

knowledge was measured. Similar to the General Beliefs About Autism subscale, the survey items could have contained less error. Specifically, the survey items, especially in Total Autism Knowledge, which contained more specialized knowledge about autism, could have contained error due to the true/false nature of the question that could have allowed for random guessing and error to influence results. However, by asking participants to write a definition, they may have revealed their true knowledge of autism since this might not have been as affected by random guessing.

In addition to clarifying the relationship between autism knowledge and acculturation, the qualitative analyses are useful in understanding the domains of autism knowledge within participant acculturation groups. This is especially important to understand so pertinent information can be effectively targeted to Hispanic parents in the most appropriate domains.

Social Characteristics. Social characteristics, the first category of deficits described in the DSM-IV-TR (APA, 2004), were described the most in definitions and descriptions of autism overall, as well as in the high and low acculturation groups. For example, one participant described autism as; “a mental disability that disrupts our ability to interact with the world (participant 15)” and another described a child with autism as someone who “shuts down or goes into his/her own world (participant 12).” A high amount of descriptions of social characteristics was an expected finding, since previous research has stressed the importance of cultural values in autism diagnosis (Zhang & Bennet, 2003). Specifically, Daley (2004) found that social symptoms were most commonly recognized by parents in India, a collectivist culture. Notably, Hispanic cultures also tend to have strong collectivist tendencies (Taylor, 2004), which separate them from the mainstream individualistic culture. Additionally, social symptoms are one of the primary domains recognized by autism specialists in the United States, and Kanner’s original terminology for autism suggests that it has always been viewed as a socio-emotional disorder (Kanner, 1942). So, due to the emphasis on social relatedness and conformity in Hispanic, collectivist culture, as well as the emphasis placed on this domain by professionals and original conceptualization of

autism, social impairment could have a unique significance, which makes these symptoms of autism more salient.

Communication. The second category of impairment described by the DSM-IV-TR (APA, 2004) are communicative deficits. Overall, this category was one of the most often described by participants as well. For example, one participant described autistic children as “not having much communication with other children (participant 18)” and another wrote, “it is being confined in oneself and being unable to communicate (participant 19).” The importance of both professionals and parents knowing that communicative deficits could be symptomatic of autism spectrum disorders is especially important in Hispanic cultures, especially since language delays could be attributed to cultural differences and language acquisition difficulties in English language learners (Barrera, 1997).

Behavioral. The DSM-IV-TR (APA, 2004) lists behavioral deficits such as stereotyped and repetitive patterns and preoccupations as the third diagnostic category for autism diagnosis. These are some of the most notable characteristics of autistic children, yet overall they were described less than all other domains of autism knowledge with the exception of neurological etiology. The best description of these characteristics was, “The first signs [of autism] are repeating the same things and not moving on to something else (participant 47).” Previous research has suggested that Hispanic families might not access information circulated through mainstream sources (Fennick & Royle, 2003), even if it is available in Spanish. Lack of knowledge in this important, recognizable domain lends support to the idea that Hispanic parents are not accessing information through the current available sources, and should point to the necessity of knowledge campaigns to make sure they are truly reaching Hispanic parents with information about autism.

General Knowledge. All other responses, with the exception of unrelated symptoms or characteristics, were identified as sub-themes in the general knowledge domain. These included cognitive, developmental, neurological, and broad general knowledge. In the total group (both

high and low acculturation), the cognitive (ex. “they learn differently from a regular person”, participant 60) and broad general knowledge (ex. “It ranges from mild to severe”, participant 3) sub-themes had the highest amounts of descriptions within the general knowledge theme, and this pattern was similar within the low acculturation group. However, in the high acculturation group, cognitive and developmental (ex. “a disorder that a child may be born with” participant 10), participant characteristics were most commonly described. This difference is most likely due to the higher level of specific information about autism’s etiology, in the neurological and developmental domains, that is demonstrated by this group; to clarify, because the participants in the high acculturation group know more information that falls into specific domains, their general knowledge score is lower.

Unrelated Features. Alarming, 11.42% of knowledge of autism described in the definitions was incorrect or not related to autism at all, and in the low acculturation group it was even higher, 18.51%. In the high acculturation group, the percent of unrelated or incorrect information was much lower, only 9.09%. Some examples of responses unrelated to autism are, “it is a disease that can be cured (participant 36),” “I think it is a paralysis (participant 37),” and “the person is unable to control certain bodily functions (participant 6).” The salience of the unrelated features domain within the low acculturation group adds support to the hypothesis that Hispanic persons of lower acculturation will have less knowledge of autism than those in the high acculturation group in a somewhat paradoxical way; they have less knowledge, but endorse more unrelated and incorrect symptoms. Previous literature has pointed out the importance of acculturation and language to autism diagnosis and treatment, and families with limited English proficiency are at a disadvantage (Zhang & Bennet, 2003). If families do not understand the language used by professionals, they are unlikely to understand the diagnosis, and could be more likely to misunderstand symptoms and signs of autism, as evidenced in the current study.

Overall, results of the qualitative analyses illustrate the importance of culture, acculturation, and language in autism knowledge. Those in the high acculturation group

demonstrated significantly more knowledge about autism, and the low acculturation group identified more incorrect or unrelated symptoms than the high acculturation group. These results indicate that knowledge campaigns should specifically focus on identifying at-risk Hispanic families, and providing information that is timely, informative, and comprehensible to them, additionally, misconceptions that might impede diagnosis need to be addressed.

Limitations

The present study has several limitations. The first is that the rating scales used were all self-report measures and, as such, are subject to random guessing and response bias. However, the scales used were all validated in previous research, and so should be reliable measures.

This study is also limited by design. Since the intent of the study is to assess conceptualization of autism in Hispanic populations, this research cannot be generalized to other ethnic and cultural groups. Also, insufficient non-Hispanic persons participated in the study, and so there was no control group available. Future studies should focus on conceptualization of autism in other minority groups, with use of a control group as well.

Additionally, a convenient and relatively small sample was used, and larger sample size would have allowed for better predictive power of all models. Moreover, the sample was obtained from a public service setting, and it is possible that those who do not access these services may have different characteristics, and were not well represented in this population. Specifically, the participants were obtained from a clinic waiting room at a facility with a religious affiliation. Thus, the participants could be biased in that they were already treatment-seeking, and so are not representative of Hispanic populations who are not accessing care or services. The clinic was also specifically for a low-income population, which further limited the demographic characteristics of the participants. These limitations make the chance of finding significant results less likely, so important relationships may have been overlooked.

A fifth limitation is that although participants were asked if they had a child diagnosed with autism, they were not asked if they had any friends or relatives who had a child with autism.

Therefore, some participants might have had additional knowledge about autism through experience with children of family or friends, which was unaccounted for in this study.

Future Directions

Although the current study had some limitations, it points toward possibilities for future research, as well as clinical application of the results. The present study showed that there are factors that impact knowledge of autism, and these results need to be more thoroughly explored through research in other samples. Due to the exploratory nature of this study, replication of the results and extension of this research is imperative. Future studies replicating these results in Hispanic communities, as well as an extension of this research to other minority groups, would add to the literature regarding knowledge of autism and conceptualization of autism in minority cultures. Additionally, using larger sample sizes in order to add predictive validity, as well as the option of adding other variables would be useful.

Clinically, replication and extension of this study is imperative, since understanding the variables associated with autism knowledge, and therefore related to diagnosis and treatment utilization, could lead to a reduction in the disparity in autism diagnosis in minority groups. Specifically, understanding how autism is viewed within minority groups, and which aspects of culture could ultimately affect diagnosis and treatment utilization, could shape the way autism knowledge campaigns target minority groups to ensure information is reaching them. Previous research has shown that mainstream media sources may not be an effective way to target Hispanic populations (Fennick & Royle, 2003), and an understanding of specific individual and cultural characteristics that affect conceptualization of autism and availability of information could make knowledge campaigns more effective. Additionally, understanding how autism is conceptualized within minority culture could help bridge gaps between minority parents and members of the majority culture, such as teachers and doctors (Mandell & Novak, 2005), and significantly impact treatment utilization and adherence.

To summarize, recommendations for future studies are that the current study be replicated and expanded upon by using other minority groups, more diverse samples, larger sample sizes, and control groups. Additionally, future studies should work to empirically validate the variables identified in the current study as well as other demographic and cultural variables that could impact autism knowledge, diagnosis, and treatment utilization. It is imperative that these variables be identified and validated so clinicians and autism advocates can effectively target information and communicate with those who have children at greatest risk for missed or late diagnosis. Ultimately, it is thought that this information could help to reduce the disparity in autism diagnosis in minority groups.

CHAPTER V

RELEVANCE TO HEALTH PSYCHOLOGY

The current study has particular relevance to health psychology research for at least two reasons. The first of these is the high prevalence of autism in the United States, and the dearth of knowledge about it in the general population as a whole. The CDC recognizes autism as the second most devastating developmental disease after mental retardation. It is estimated that 1 in 150 children has an ASD, and early intervention is key to a more positive outcome (CDC, 2009b). Health disparities research shows that being a member of a minority group is one of the factors associated with limited health care and poor health in general (CDC, 2008b). Hispanic children with autism have a disadvantage that is twofold. First, they have a disorder about which little is understood. Second, they are a member of a minority group and therefore are more likely receive poor quality health care. The present study sought to focus on both of these disadvantages by contributing important information to the body of knowledge about autism and focusing on disparity in diagnosis of Hispanic children.

The first hypothesis predicted statistically significant mean differences in acculturation between Hispanic participants with high and low autism knowledge scores as measured by the Autism Survey (Stone, 1986). Results showed a marginally significant difference in mean acculturation between high and low Total Autism Knowledge groups. A statistically significant difference in mean acculturation between high and low autism knowledge as measured by the General Beliefs About Autism subscale, which might have contained less error than the full scale, lent support to this hypothesis.

Hypothesis two, three, four, and five explored how cultural differences affect knowledge of autism. Hypothesis two predicted that SES, a combination of education and income, would significantly affect autism knowledge. This hypothesis was supported by both correlational analyses and multiple regression equations. Hypothesis three, again supported by correlational analyses and multiple regression, was that high degrees of religiosity within Hispanic groups would correlate negatively with knowledge about autism. Hypothesis four stated that Hispanic families endorsing a high degree of dependence on family and social support systems would have less knowledge of autism. The role of social support systems in Hispanic cultures was expected to mediate the use of services needed for both diagnosis and evaluation. This hypothesis was not supported, and social support and autism knowledge were positively linked through correlational analyses. However, this finding might be explained by the friends subscale of the social support scale, which was the only significant subscale, and had higher correlation with autism knowledge than the total social support scale. Finally, hypothesis five was that those endorsing fatalistic beliefs, as measured by belief in problems as a sign from God, would know less about autism than those not endorsing this belief, this hypothesis was supported by correlational analyses, multiple regression, and *t*-tests.

These hypotheses point to the importance of cultural understanding of clinicians during diagnosis and treatment and autism awareness groups who are trying to reach the public with knowledge about autism. However, the results of this study indicate that SES is more important to autism knowledge than acculturation, which never entered into the regression models as a predictor of autism knowledge, as well as other cultural and demographic variables. So, this study's findings indicate that while clinicians need to be culturally sensitive, primarily SES must be taken into account when considering autism knowledge. Taking the influence of SES into account, as well as important cultural and demographic factors such as religiosity, fatalistic beliefs, and parenting experience, could help reduce the disparity in diagnosis in Hispanic children, and give the opportunity for early intervention and services to more children.

The sixth hypothesis was that Hispanic families of low acculturation would provide a less accurate definition and description of autism than those of high acculturation. This hypothesis was supported in that results of a *t*-test showed a statistically significant mean difference in knowledge of autism as measured by the qualitative responses to the survey between acculturation groups. Additionally, Hispanic participants of low acculturation provided a greater percentage of incorrect or unrelated information about autism within their group total responses than those in the high acculturation group. Hispanic families in general were predicted to describe social characteristics of autism more than behavioral or cognitive characteristics, and this was supported by the results of the qualitative analyses. Additionally, participants in the low acculturation group provided a greater percentage of general knowledge responses within their group's knowledge domains than those in the high acculturation group. This finding could be explained by the higher percentages of more specific knowledge domains in the high acculturation group.

Results of qualitative analyses show that campaigns with the goal of educating the general public about autism need to purposefully focus on educating specific minority groups about each of the domains symptoms of autism occur. Also, general health practitioners must be educated about the way autism could be interpreted by those in the Hispanic culture, and be sensitive to differences in presentation or identification due to culture.

With information from this study, clinicians and care providers will be better equipped to identify, diagnose, and treat Hispanic children with autism, and campaigns like Know the Signs. Act Early. (CDC, 2008a) will be more effective in targeting information to Hispanic families.

APPENDIX A

Survey Part I—Demographic Information

- Are you a Mother or Father? (Circle One)
 - How old are you? _____

- How many children do you have? _____
 - How old is your child/children? _____

- Have any of your children ever been diagnosed with an autism spectrum disorder (e.g., Pervasive Developmental Disorder NOS, Aspersers, Autism, Rhett's disorder)?
 - Yes _____
 - No _____

- What is your race or ethnicity? (Check all that apply)
 - African American _____
 - Asian American _____
 - Caucasian/European American _____
 - Native American _____
 - Latin American/Hispanic _____
 - Other (please explain briefly) _____

- What is your education level? (check one)
 - 6th grade or less _____
 - 7th or 8th grade _____
 - some high school but not finished _____
 - completed high school or GED _____
 - some college but not finished _____
 - graduated from college _____
 - post graduate (Master's, Doctoral, MD, Etc.,) _____

- What is your spouse's education level? (check one)
 - 6th grade or less _____
 - 7th or 8th grade _____
 - some high school but not finished _____
 - completed high school or GED _____
 - some college but not finished _____
 - graduated from college _____
 - post graduate (Master's, Doctoral, MD, Etc.,) _____
 - don't know _____
 - NA _____

- What is your occupation/job? _____

- What is your spouse's occupation/job? _____

Please define or describe autism in your own words:

APPENDIX B

Survey Part II—Acculturation Scale

Directions: Circle one answer for each of the following questions.

1. In general, what language(s) do you read and speak?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
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2. What was the language(s) you used as a child?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
--------------	-----------------------------	--------------	-----------------------------	--------------

3. What language(s) do you usually speak at home?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
--------------	-----------------------------	--------------	-----------------------------	--------------

4. In which language(s) do you usually think?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
--------------	-----------------------------	--------------	-----------------------------	--------------

5. What language(s) do you usually speak with your friends?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
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6. In what language(s) are the T.V. programs you usually watch?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
--------------	-----------------------------	--------------	-----------------------------	--------------

7. In what language(s) are the radio programs you usually listen to?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
--------------	-----------------------------	--------------	-----------------------------	--------------

8. In general, in what language(s) are the movies, TV and radio programs you *prefer* to watch and listen to?

Only Spanish	Spanish Better than English	Both Equally	English Better than Spanish	Only English
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9. Your close friends are:

All Latinos/Hispanics	More Latinos than Anglos	About Half and Half	More Anglos than Latinos	All Anglos
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10. You prefer going to social gatherings/parties at which people are:

All Latinos/Hispanics	More Latinos than Anglos	About Half and Half	More Anglos than Latinos	All Anglos
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11. The persons you visit or who visit you are:

All Latinos/Hispanics	More Latinos than Anglos	About Half and Half	More Anglos than Latinos	All Anglos
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12. If you could choose your children's friends, you would want them to be:

All Latinos/Hispanics	More Latinos than Anglos	About Half and Half	More Anglos than Latinos	All Anglos
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APPENDIX C

Survey Part III—Religion Scale

1. Which best describes your religious membership?

- Catholic
- Protestant (list denomination, e.g., Methodist, Southern Baptist) _____
- Jewish
- Hindu
- Muslim
- Other. Please specify _____
- None

2. How often do you go to some activity of a religious organization?

- Never
- 1-5 times per year
- 6-11 times per year
- Once a month
- Twice a month
- Once a week
- More than once a week
- Not applicable

3. How important is your religious faith for you and your family? (circle)

Not important	Only a little important	Somewhat important	Important	Extremely important
1	2	3	4	5

4. Do you believe this that having a child with problems is a message or a sign from God?

- Yes _____
- No _____

APPENDIX D

Survey Part IV—Social Support Questionnaire

Please mark how strongly you agree or disagree with the following statements

	Very strongly Disagree					Very strongly Agree	
	1	2	3	4	5	6	7
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

APPENDIX E

Survey Part V—The Autism Survey

Directions: Please answer the following questions on this survey as best you can.

- | | | |
|---|------|-------|
| 1. Autism occurs only in childhood. | True | False |
| 2. Autism can occur in mild as well as extreme forms. | True | False |
| 3. Autistic children are more intelligent than test scores show. | True | False |
| 4. Autistic children do not show social attachments, even to parents. | True | False |
| 5. Most children with autism are also mentally retarded. | True | False |
| 6. Most children with autism do not talk. | True | False |
| 7. Children with autism have poor eye contact. | True | False |
| 8. Autism occurs more commonly among higher socioeconomic and educational levels. | True | False |
| 9. Autism is a developmental disorder. | True | False |
| 10. Most children with autism have special talents or abilities. | True | False |
| 11. Emotional factors play a major role in the cause of autism. | True | False |
| 12. With the right treatment, most children with autism eventually “outgrow” autism. | True | False |
| 13. Autism is more often diagnosed in males than in females. | True | False |
| 14. Children with autism are uncooperative on purpose. | True | False |
| 15. Early intervention can lead to large gains in children’s social and communication skills. | True | False |
| 16. Autism is a rare condition in Hispanic peoples as compared to Caucasians. | True | False |
| 17. It is impossible to tell if a child is autistic before four years of age. | True | False |
| 18. In most cases, the cause of autism is unknown. | True | False |
| 19. Children with autism have problems with social interaction. | True | False |
| 20. Children with autism have behaviors and interests that are repetitive and stereotyped. | True | False |

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