The Full Spectrum: Hispanic Understanding of Autism in Southern Arizona

by

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ABSTRACT

The purpose of this study is to explore the knowledge and attitudes about autism spectrum disorders among Hispanics in the Southwest. The study will also examine perceived barriers in obtaining resources and preferences in accessing health care. Participants ($N = 169$) were surveyed using the *Autism Awareness Survey*, which was developed specifically for this research. Significant differences were found between individuals with high acculturation and low acculturation in exposure to autism, knowledge about autism, perceived barriers to obtaining resources and health care, and attitudes towards people with autism. Additionally, the findings also suggest that although the surveyed population was knowledgeable about the symptoms associated with autism, less well known is the etiology and course of the disorder. The research underscores the serious need for both Spanish educational resources and Spanish-speaking health care providers to address the needs of Hispanics with regards to autism, especially with individuals with low levels of acculturation.

ACKNOWLEDGMENTS

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INTRODUCTION

According to the Centers for Disease Control and Prevention, autism is a developmental disorder related to atypical biology and chemistry within the brain (Centers for Disease Control and Prevention, 2009). Symptoms vary, but include problems with social skills such as making friends and showing empathy, as well as difficulty with verbal and nonverbal communication. Because an early, intensive, and appropriate treatment program greatly improves the outlook for most people with autism, it is crucial that children are correctly diagnosed when they are still young, preferably before the age of three (Centers for Disease Control and Prevention, 2009).

Autism prevalence statistics in the U.S. reveal that about 1 child in every 127 of Hispanic ethnicity has an autism spectrum disorder (Centers for Disease Control and Prevention, 2012). When compared to the general population prevalence of 1 out of 88 children diagnosed with autism, however, it is uncertain whether Hispanic children are actually less affected by autism or if the lack of access to appropriate health care and autism services among Hispanic families cause this disparity in diagnosis (Centers for Disease Control and Prevention, 2012; Global Autism Public Health, 2010). While it is understood that the prevalence of autism spectrum disorders is dramatically increasing, current literature does not document Hispanic understanding or awareness of autism spectrum disorders. Additionally, the literature does not delineate if Hispanics with low levels of acculturation have more difficulty accessing health care services than Hispanics with high levels of acculturation. It is possible that

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families do not seek treatment or care because they do not understand the symptoms or they do not have access to information concerning autism in their preferred language. Due to the paucity of literature in this area, research on this topic will contribute to both the knowledge base concerning Hispanic understanding of autism and will help agencies more effectively tailor their services to meet the needs of this specific population.

REVIEW OF LITERATURE

Although the rate of autism diagnosis for Hispanics is lower than that of the general population, the literature indicates that this is because of socio-culture and economic factors, which include cultural stigma attached to diagnosis, dense population in high poverty areas with less access to care, fear of deportation, and language complications (Centers for Disease Control and Prevention, 2009; Durkin et al., 2010; Bearman & Fountain, 2011). It is important to note that the literature shows that Hispanics with higher socioeconomic status have the *same* diagnosis rate for autism as white, non-Hispanics, which could indicate that the disparity in autism prevalence rates is greatly dependent on access to quality healthcare (Bearman & Fountain, 2011; Durkin et al., 2010). The research, however, does not explore how an individual's level of acculturation might impact the cultural and economic barriers to accessing health care services.

BARRIERS TO CARE

According to the literature, there are a variety of issues that act as barriers to Hispanic populations accessing health care resources, which include but are not

limited to: Hispanic attitudes towards a system they perceive to be prejudiced, a lack of culturally and linguistically competent agencies and workers, and a lack of resources in areas of high need (Alvarado, 2005; Bearman & Fountain, 2011; Durkin et al., 2010; Flores, 1984; Kraemer, 2010; Flores, Abreu, Oliver, & Kastner, 1998; Graf, Blackenship, Sanchez, & Carlson, 2007; Guendelsberger, 1992).

Alvarado (2005) reports that Hispanic families tend to distrust professionals and authorities (Alvarado, 2005). The research suggests that this mistrust arises out of a fear of deportation and an aversion to being marginalized and discriminated against (Alvarado, 2005; Bearman & Fountain, 2011; Durkin et al., 2010; Flores, 1984; Graf et al., 2007; Kraemer, 2010). One study in particular from Southern California substantiates this distrust. Bearman and Fountain (2011) have shown a direct correlation between heated political campaigns regarding immigration issues and lower diagnosis of ASD among Hispanic populations (Bearman & Fountain, 2011). Once the political fervor dies down, diagnosis numbers rise. Although the impact of political repression on the use of services by children in immigrant families is not specific to autism, this disorder might be particularly vulnerable because the diagnosis is based on behavioral symptoms (Bearman & Fountain, 2011; Mandell & Novak, 2005).

Further, inequalities in the U.S. healthcare system create the likelihood of under-diagnosis among children of low-income parents (Alvarado, 2005; Durkin et al., 2010; Kraemer, 2010). A study done by Durkin et al. (2010) found that children diagnosed with ASD are *less* likely to reside in census block groups

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classified as areas of poverty, and *more* likely to live in block groups with higher adult educational achievement and a higher medium household income (Durkin et al., 2010). It is notable that the study also indicates that Black and Hispanic children are more likely to live in areas of poverty, which suggests that Black and Hispanic children are systematically *less* likely to be diagnosed with autism. The implication is that the lower overall prevalence of autism among these population groups is correlated to the lack of appropriate medical attention because areas of higher poverty are less likely to offer high quality medical services (Durkin et al. 2010; Mandell et al., 2009).

High-poverty communities in which children with ASD are identified are often unprepared to meet the children's needs (Jacobson & Mulick, 2000; Mundell & Novak, 2005; Newschaffer & Curran, 2003). Schools in wealthy sectors are able to hire professionals proficient in assessing students, as well as offering superior facilities that cater to the particular needs of the students (Kraemer, 2010). Schools in poor sectors generally cannot afford to offer such care. Other services fall into a similar predicament- hospitals, clinics, and social work agencies in these poorer areas do not have the staffing or funding to offer the full spectrum of care (Alvarado, 2005; Kraemer, 2010). Hispanics are twice as likely to report long delays in waiting rooms and unresponsive healthcare workers (Alvarado, 2005; Kraemer, 2010). Even if the resources are available, Hispanic families often lack the health insurance and transportation necessary to take advantage of these health care programs (Flores, 1998).

Many Mexican Americans report that the number one barrier to accessing health care services has to do with the inability to communicate with health care professionals (Alvarado, 2005; Flores, Abreu, Oliver & Kastner, 1998; Mandell & Novak, 2005). Although many of these Spanish-speaking individuals qualify for assistance, they often are not aware of the availability of services because they cannot communicate with those who are knowledgeable about the programs or with the professionals once on-site. Language miscommunications in a hospital setting can result in adverse health consequences, which include poor medical care, misdiagnosis, and inappropriate medication and hospitalization (Flores, Abreu, Oliver & Kastner, 1998).

There are many gaps in the literature pertaining to Hispanic families and autism spectrum disorders. One area that merits further study is whether Hispanic populations are familiar with autism and its symptoms. The literature does not address Hispanic awareness of autism nor does it discuss whether or how people from a Hispanic background might perceive the symptoms of autism differently from mainstream Anglo culture. Ethnic minorities may be less likely to view symptoms of autism as related to a health condition and, therefore, may be less likely to seek care through public medical systems. Moreover, Hispanics could perceive autism as socially embarrassing and could be less likely to seek assistance. Additionally, the literature does not thoroughly examine if autism prevalence is truly higher among non-Hispanics or if non-Hispanics are simply more frequently diagnosed. There has been insufficient research comparing the prevalence rates of autism diagnosis among Hispanics and non-Hispanics of equal

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socioeconomic status. Finally, the literature does not address how Hispanic's

acculturation levels may impact their awareness of autism. It could be that

Hispanic families that are more highly acculturated would have a better

understanding of autism than a family that has newly immigrated to the United

States. The identified socio-culture and economic barriers could be far more

insurmountable for Hispanics with low levels of acculturation as compared to

Hispanics with high levels of acculturation. This research will examine the

relationship between acculturation and autism awareness, knowledge about

symptoms associated with and etiology of autism, and attitudes towards

individuals with autism. Additionally, the study will seek greater understanding

concerning how Hispanics perceive access to health care services.

METHOD

INSTRUMENTATION

The *Autism Awareness Survey* was constructed based on part by questions

used in previous studies (*Questions about Disability Survey*, Graf, Blankenship,

Sanchez, & Carlson, 2007; *British Social Attitudes Survey*, Staniland, 2009; *The*

Acculturation Rating Scale for Mexican Americans- Short Form, Dawson, Crano,

& Burgoon, 1996), as well as questions reflective of commonly held attitudes and

understandings concerning autism. The survey is composed of 53 questions and

addresses people's understanding of key characteristics or behaviors associated

with autism, exposure to people with autism, awareness and attitudes towards

health services, and acculturation levels. Five yes or no questions and one fill-in-

the-blank question at the beginning of the survey seek to establish people's exposure to autism (see Table 1). The first and third sections of the survey consist of eighteen Likert-scale questions (rated on a five point scale of *Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree*, and *Strongly Agree*), which seek to determine perceived attitudes towards people with autism (see Table 2) and perceived barriers to accessing resources and healthcare (see Table 3). Twelve true or false questions ascertain levels of knowledge about autism (see Table 4). Section four is an eleven-question acculturation rating scale that aims to establish people's level of acculturation to mainstream English-speaking Anglo culture in the United States and includes questions related to language, activity preferences, and group identity (rated on a five point scale of *None, Sometimes, Moderate, A lot or Very Often, Very Much* and *All the Time*) (Dawson, Crano, & Burgoon, 1996). This scale is based off of the *Acculturation Rating Scale for Mexican Americans- Short Form* (Dawson, Crano, & Burgoon, 1996), which is a standardized measure specifically geared for the Mexican American population and has strong reliability ($\alpha = .96$).

Once the *Autism Awareness Survey* was completed, the researchers developed a Spanish version of the instrument so as to meet the linguistic needs of the intended population group. A native Spanish-speaking researcher completed the initial translation of the survey. Two other native Spanish-speaking professionals then reviewed the survey, with special attention being given to word choice (with the intention of incorporating local dialect) and sentence construction (with the intention of decreasing the formality of the language). A forwards and

backwards translation of the survey instrument was also completed in attempt to minimize translation errors.

STATISTICAL ANALYSIS

The researchers completed a primarily descriptive analysis of the data. A reliability analysis was conducted and used to create five scales. First, a scale was created to address *perceived barriers* to accessing resources and health care, with higher scores indicating greater perceived barriers (3 items; $\alpha = .75$). The questions included in this scale were: "I would know where to go for help if my child were diagnosed with autism," "I would be able to find health services that really care about my family," and "I would be able to get the care I need for my child." Next, a scale was created to examine *preferences* concerning health care services (4 items; $\alpha = .68$). Questions in this scale included the items: "I would want service professionals to speak Spanish," "I would be concerned that I would not be able to afford health care if my child were diagnosed with autism," "I would be concerned that professionals would not listen to the family's opinion," and "I would be concerned that professionals wouldn't spend the necessary time to provide my family the help we needed." A third scale was used to investigate perceived *negative attitudes* towards people with autism (10 items; $\alpha = .80$). The questions on this scale were modeled after a survey done Graf, Blankenship, Sanchez, and Carlson, (2007) entitled *Questions about Disability Survey*. Items on this scale included questions such as, "People with autism are ignored by other people" and "People feel sorry for people with autism." The fourth scale examined the participant's *knowledge* about the symptoms and etiology of autism

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(12 items). The scale was a sum score of responses, with correct answers receiving a 1 and incorrect answers receiving a 0. Finally, the fifth scale addressed the respondent's level of *acculturation* (11 items, α = .96). Items on this scale include questions like, "I enjoy speaking English," and "My thinking is done in the Spanish language." More positive scores (rating 0 or above on the scale) indicate high levels of acculturation, while low scores (below a rating of 0) indicate low levels of acculturation.

Independent *t*-tests were used to examine differences between the responses of individuals with high acculturation in comparison with those with low acculturation on the variables that measure knowledge about autism, perceived negative attitudes towards people with autism, perceived barriers that prevent access to resources and health care and preferences concerning health care services. Chi-square tests were used to compare individuals with high and low levels of acculturation concerning exposure to people with autism.

PROCEDURE

The research team consisted of one researcher and three research assistants who are bilingual (Spanish and English) and one research assistant who is monolingual (Spanish). The research team created a list of public locations in a variety of areas in Tucson, Arizona, with the intention of collecting data from individuals with disparate socio-economic, education, and acculturation levels. Some of the collection areas included grocery stores, fast food restaurants, department and outlet stores, and a local mall. Each member of the research team was responsible for different areas so as to cover a broad geographical area.

Inclusion criteria for the survey included being over the age of eighteen and self-identifying as Hispanic or Latino. The researchers approached potential participants and asked if they spoke English or Spanish and if they would be interested in taking part in a survey designed to help social service and health care agencies offer better care to the population living in Southern Arizona. If the individual met the inclusion criteria of being over the age of eighteen, the individual was invited to complete the survey. Before completing the survey, the participants were given an informed consent letter, as required by the International Review Board at Arizona State University. The researchers made themselves available to participants in order to answer questions, read aloud the surveys if requested, and collect the surveys. Seven participants asked the researchers to read aloud the survey. In all seven cases, the Spanish version of the survey was requested. Two participants cited poor vision and five participants cited low literacy as the reason for the requested accommodation. After the survey was completed, the researchers held aside 41 surveys from people who did not meet inclusion criteria (one was set aside because the participant did not meet the age requirement, 40 were set aside because the participants did not self-identify as Hispanic or Latino).

RESULTS

Of the 169 surveys completed by individuals who self-identified as Hispanic, 108 (63.9%) were completed in Spanish and 61 (36.1%) were completed in English. Of those individuals with high acculturation, 58.1% choose

to complete the survey in English, while of those individuals with low acculturation, only 13.4% chose to complete the survey in English. The results presented below include descriptive statistics of the demographics of the participants and of questions related to exposure to autism. Additionally, frequency data and significant differences between responses of individuals with high acculturation and low acculturation are also presented pertaining to attitudes towards people with autism, barriers to accessing resources and health services, and knowledge about autism.

PARTICIPANT DEMOGRAPHICS

Descriptive statistics were performed to examine the age, gender, education, employment and marital status of the participants. The sample was largely female (81.1%). The youngest participant was 18 while the oldest was 79. The mean age of participants was 40. In terms of marital status, 47.9% were married, 5.3% had a domestic partner, 32% were single, 7.1% were divorced, 5.9% were separated, and 1.8% did not respond. Levels of education ranged from having completed only grades 1-5 to having completed graduate level work. Forty-four percent of the participants reported having only completed through grade 12 or less. Of those with high acculturation, 70.9% had completed some college or more, as compared to those with low acculturation where only 40.2% had completed some college or more. In regards to employment, 39.1% worked full time, 13.6% worked part time, 12.4% were unemployed, 30.2% were homemakers and 4.7% did not respond to the question.

EXPOSURE TO AUTISM

The first section of the Autism Awareness Survey related to exposure to autism (see Table 1). The overwhelming majority (89.3%) indicated that they had heard of autism, while only 57.1% reported that they personally knew someone with autism. Significantly more people reported having heard about autism on T.V. (82%) than having read about autism in a magazine or newspaper (59.8%). In response to the question, "What percentage of people do you think get autism," the average response was 25.7% of the population, which is far above the actual rate of diagnosis of .09% of the population.

Table 1

Response to Items Relating to Exposure to Autism

	Yes		No	
Item	*(%)*	*n*	*(%)*	*n*
1. Have you ever heard of autism?	(89.3)	150	(10.7)	18
2. Have you ever met anyone with autism?	(63.7)	107	(36.3)	61
3. Have you ever read about autism in a magazine or newspaper?	(59.8)	98	(40.2)	66
4. Have you ever heard anyone on T.V. talk about autism?	(82)	137	(18)	30
5. Do you know anyone with autism?	(57.1)	92	(42.9)	69

* Valid Percentages are used in the table; 1-5 responses missing for each question

Chi square comparisons were performed to assess the differences in exposure to autism between individuals with high acculturation and individuals with low acculturation. Significant differences were found in the comparisons of the responses between those with high acculturation and low acculturation for the

question pertaining to having met someone with autism (see Figure 1). The number of people with low acculturation that had met someone with autism (56.1%) was significantly lower than those with high acculturation (71.8%), $x^2(1) = 4.45$, $p = .04$, *Phi* = .16. There was also a significant difference found in the comparison of responses to the question that asks if they have read about autism in a magazine or newspaper (see Figure 2). Those with low acculturation had less affirmative responses (50.6%) then those with high acculturation (67.9%), $x^2(1) = 5.01$, $p = .02$, *Phi* = .18. A trend toward significance was found in the comparisons of the question about personally knowing anyone with autism (see Figure 3). Those with high acculturation reported knowing people with autism more often (64.3%) than those with low acculturation (50%), $x^2(1) = 3.33$, $p = .07$, *Phi* = .14. There were no significant differences between the responses of those with high acculturation and of those with low acculturation in the questions of having heard of autism (89.4% vs 89%), hearing anyone on T.V. talk about autism (79.8% vs 84.1%), and the percentages of people they think have autism (mean age of 25 vs mean age of 26).
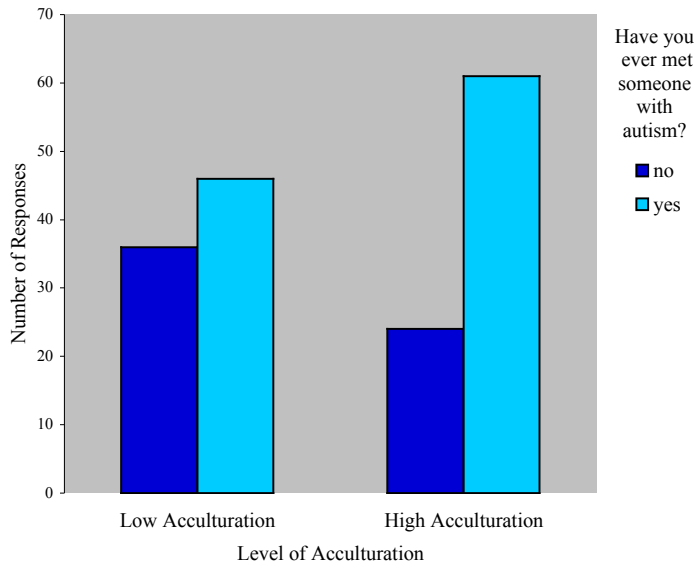
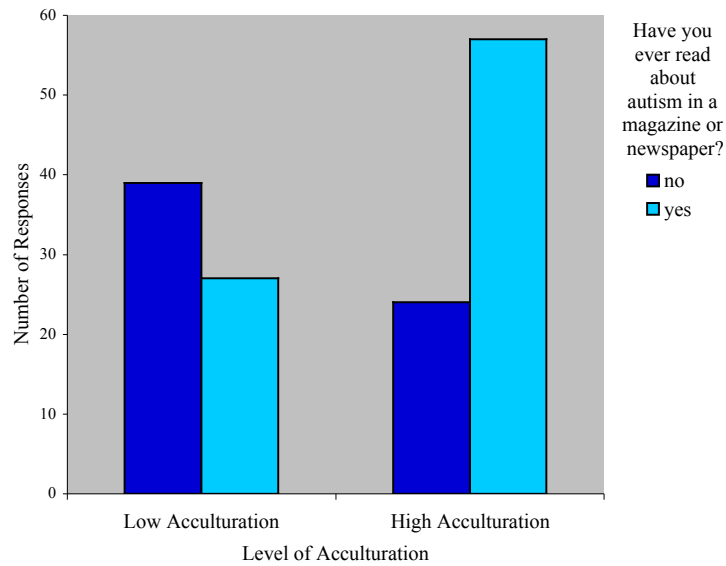*Figure 1.* Comparison of Responses to Having Met Someone with Autism

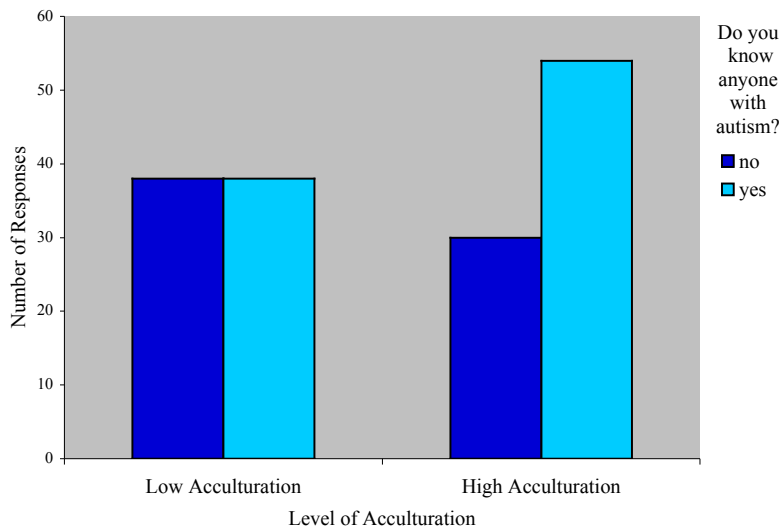*Figure 2*. Comparison of Responses to Having Read about Autism

Figure 3. Comparison of Responses to Knowing Anyone with Autism

PERCEIVED NEGATIVE ATTITUDES

The responses in the section of the survey about perceived negative attitudes towards people with autism highlighted fairly strong views about how society interacts with people with autism (see Table 2). Most notably, over sixty percent of the respondents *Agreed* or *Strongly Agreed* that that people don't know what to say to individuals with autism (66.9%) and that people with autism are isolated from others (64%). Additionally, more than half of the respondents *Agreed* or *Strongly Agreed* that people with autism are ignored by others (51.8%) and that people feel sorry for people with autism (54.8%). More than half of the respondents indicated that they believed that people with autism are discriminated against because of their condition (51.3%).

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Table 2

Responses to Items Related to Perceived Attitudes Towards People with Autism

Item	Strongly Disagree		Disagree		Neither Agree nor Disagree		Agree		Strongly Agree	
	(%)	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*
1. People with autism are ignored by other people.	(15.2)	25	(13.4)	22	(19.5)	32	(34.1)	56	(17.7)	29
2. People with autism are isolated from other people.	(9.8)	16	(11.0)	18	(15.2)	25	(39.0)	64	(25.0)	41
3. People with autism stay at home.	(11.1)	18	(35.2)	57	(24.7)	40	(24.7)	40	(4.3)	7
4. People with autism are hidden from other people.	(12.8)	21	(31.1)	51	(28.0)	46	(20.1)	33	(7.9)	13
5. People don't know what to say to people with autism.	(7.8)	13	(10.2)	17	(15.1)	25	(48.2)	80	(18.7)	31
6. People are comfortable around people with autism.	(16.9)	28	(29.5)	49	(28.9)	48	(22.3)	37	(2.4)	4
7. People avoid interacting with people with autism.	(6.6)	11	(17.5)	29	(33.1)	55	(31.9)	53	(10.8)	18
8. People feel sorry for people with autism.	(12.7)	21	(16.3)	27	(16.3)	27	(36.7)	61	(18.1)	30
9. People don't associate with people with autism because they are too different.	(12.2)	20	(26.8)	44	(23.2)	38	(28.7)	47	(9.1)	15

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| 10. I believe people with autism are discriminated against because of their condition. | (14.0) 23 | (14.6) 24 | (20.1) 33 | (29.3) 48 | (22.0) 36 |

* Valid Percentages are used in the table; 3-7 responses missing for each question

To determine if there were differences in perceived attitudes towards people with autism between individuals with high acculturation and individuals with low acculturation, the questions concerning attitudes were examined using *t*-test analysis. Significant differences were found between the responses of those with high acculturation and those with low acculturation (see Graph 4). Individuals with low acculturation indicated that they perceived less negative attitudes towards people with autism (*M* = 3.03, *SD* = .69) than those with high acculturation (*M* = 3.40, *SD* = .70), *t*(164) = -3.44, *p* = .001.
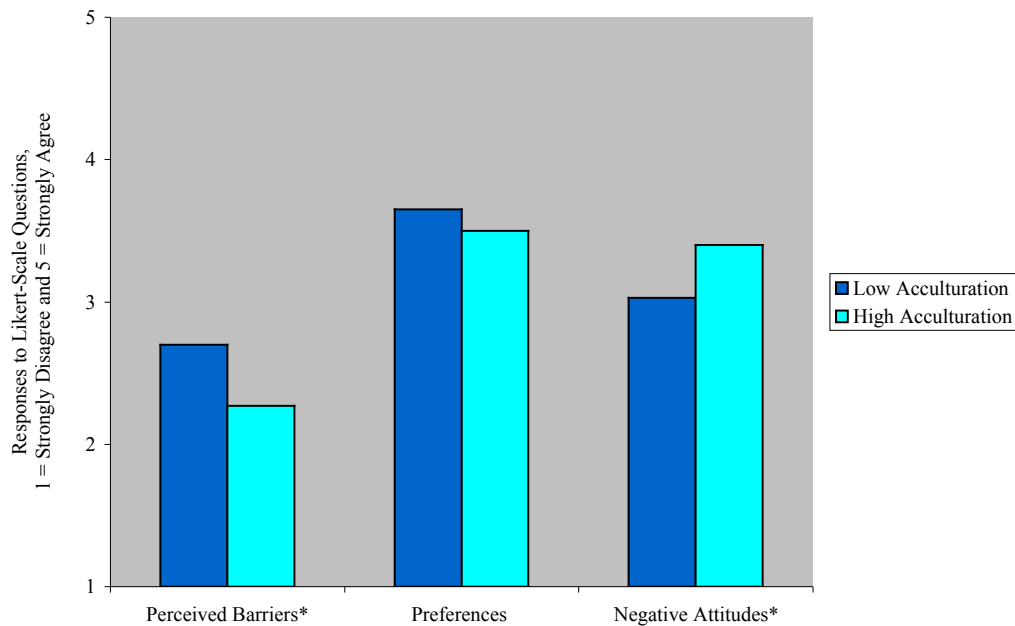
Figure 4. Comparison of Responses to Perceived Barriers, Preferences, and Negative Attitudes

PERCEIVED BARRIERS AND PREFERENCES

There were varied responses to the survey questions pertaining to perceived barriers to accessing resources and health care services (see Table 3). The largest perceived barriers pertained to finances and language. More than sixty percent of the respondents *Agreed* or *Strongly Agreed* that if their child was diagnosed with autism, they would be concerned they would not be able to afford the necessary health care services (65%) and that they would want the health care professional to speak Spanish (68.5%). Additionally, 56.6% indicated they would be concerned that the health care provider would not spent the time necessary to provide the family with quality care. On the other hand, over half the respondents indicated that they would know where to go for help if their child was diagnosed with autism (54.8%) and that they would feel confident that they would be able to get the care they needed for the child (71.3%).

Table 3

Responses to Items Related to Perceived Barriers to Accessing Health Care

Item	Strongly Disagree (%) *n*	Disagree (%) *n*	Neither Agree nor Disagree (%) *n*	Agree (%) *n*	Strongly Agree (%) *n*
1. If my child were diagnosed	(12.2) 20	(0.6) 1	(12.2) 20	(39.6) 65	(15.2) 25

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with autism, I would know where to go for help.

2. If my child were diagnosed with autism, I would not use health services because my family is able to take care of the things I need.	(29.3) 48	(40.9) 67	(11.0) 18	(15.9) 26	(3.0) 5
3. If I needed services for my child with autism, I would be able to find health services that really care about my family.	(9.2) 15	(8.6) 14	(16.6) 27	(42.9) 70	(22.7) 37
4. If my child were diagnosed with autism, I would be able to get the care I needed for him or her.	(6.9) 11	(6.9) 11	(15.0) 24	(46.3) 74	(25.0) 40
5. If my child were diagnosed with autism, I would be concerned I wouldn't be able to afford the care he or she needs.	(7.5) 12	(13.1) 21	(14.4) 23	(39.4) 63	(25.6) 41
6. If my family needed help, I would be concerned that professionals would not listen to my opinion.	(9.4) 15	(16.4) 26	(23.9) 38	(35.2) 56	(15.1) 24
7. If my child were diagnosed with autism, I would want the service professionals to	(4.3) 7	(4.3) 7	(22.8) 37	(37.0) 60	(31.5) 51

speak Spanish.

| 8. If my family needed help from service professionals, I would be worried that they wouldn't spend the time to provide me the help I need. | (5.0) 8 | (16.1) 26 | (22.4) 36 | (37.3) 60 | (19.3) 31 |

* Valid Percentages are used in the table; 3-7 responses missing for each question

In order to examine differences in perceived barriers to accessing resources and health care services between individuals with high acculturation and individuals with low acculturation, the questions concerning access to resources and health care were examined using *t*-test analysis. Significant differences were found between the responses of those with high acculturation and those with low acculturation (see Figure 4). Individuals with low acculturation indicated that they perceived more barriers in accessing resources and health care services (*M*=2.70, *SD*=1.01) than those with high acculturation (*M* = 2.27, *SD* =.96), *t*(161) = 2.74, *p* = 007. On the other hand, there were no significant differences in the responses of those with low acculturation (*M* = 3.65, *SD* = .85) and with those with high acculturation (*M* = 3.50, *SD* = .79) addressing specific preferences about health care services (see Figure 4), *t*(160) = 1.16, *p* = .25.

KNOWLEDGE ABOUT AUTISM

Results from the true and false section of the survey demonstrated that the respondent sample had some understanding of the symptoms associated with autism (see Table 4). The majority were able to identify that children with autism had difficulty reading facial expressions (65%), often avoid eye contact (71%), often have unusual behavior patterns (79.3%), talk excessively about one or two topics (63.3%), prefer predictability (60.4%), and often resist being held or touched (66.9%). Only 42% of the respondents, however, correctly indicated that children with autism are not generally attuned to other people's feelings and emotions.

The sample responses also suggested, however, that the etiology and course of autism is less well known among the survey participants. Many respondents (60.4%) incorrectly believed that children with autism could outgrow the disorder and that trauma plays a major role in causing autism (46.2%). Additionally, only 36.1% of the respondents recognized autism as a genetic disorder. It is notable, however, that 69.8% did correctly identify that vaccines do not cause autism.

Table 4

Responses to Items Related to Knowledge About Autism

True and False Questions	% correct
1. Most children with autism have difficulty reading facial expressions. (T)	65.0%
2. With proper treatment, most children with autism "outgrow" the disorder. (F)	39.6%
3. Children with autism often avoid eye contact. (T)	71.0%

4. Children with autism often have unusual behavior patterns (like flapping their arms or tapping). (T)	79.3%
5. Children with autism often talk excessively about one or two topics. (T)	63.3%
6. Emotional trauma plays a major role in causing autism. (F)	53.8%
7. Children with autism generally prefer predictability. (T)	60.4%
8. Children with autism are generally attuned to other people's feelings and emotions. (F)	42.0%
9. Autism is caused by vaccinations. (F)	69.8%
10. Autism is more frequently diagnosed in males than females. (T)	48.5%
11. Children with autism tend to resist being held or touched. (T)	66.9%
12. Autism is primarily a genetic disorder. (T)	36.1%

*Correct True (T) or False (F) answers are in parenthesis

To determine if there were differences in responses between individuals with high acculturation and individuals with low acculturation, the questions concerning knowledge were examined using t-test analysis. Significant differences were found between the responses of those with high acculturation and those with low acculturation (see Figure 5). Individuals with low acculturation, on average demonstrated less knowledge about autism ($M = 6.60$, $SD = 2.09$) than those with high acculturation ($M = 7.98$, $SD = 2.07$), $t(157) = -4.16$, $p = .001$.
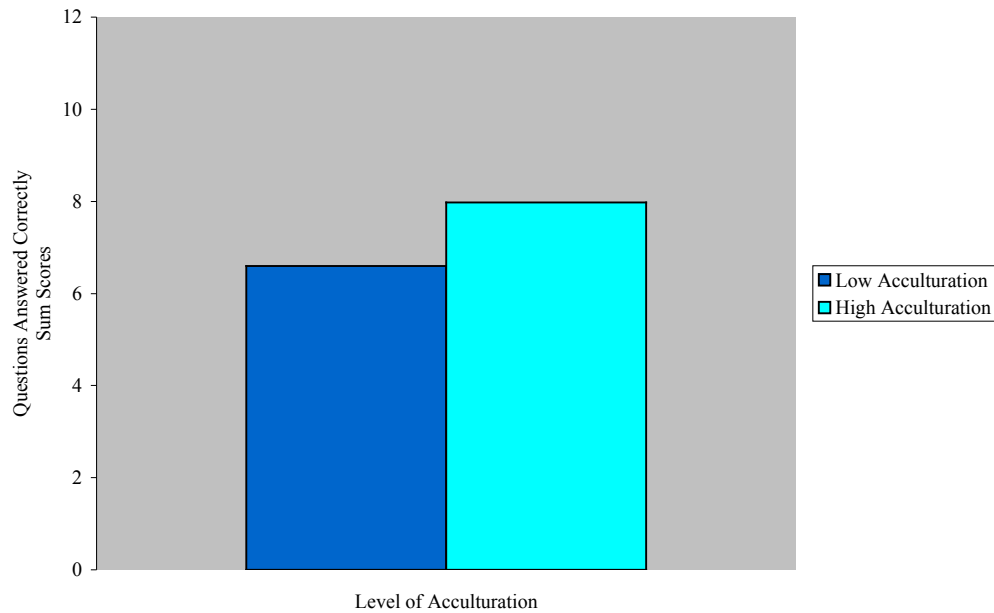
Figure 5. Comparison of Responses to Knowledge Questions

DISCUSSION

Researchers have found that Hispanics in the United States perceive more

barriers to accessing health care than their Anglo contemporaries (Alvarado,

2005; Bearman & Fountain, 2011; Durkin et al., 2010; Flores, 1984; Kraemer,

2010; Flores, Abreu, Oliver, & Kastner, 1998; Graf, Blackenship, Sanchez, &

Carlson, 2007; Guendelsberger, 1992). The results of this study build on past

research by delineating significant differences in the perceived barriers to care

between Hispanics with low acculturation and Hispanics with high acculturation.

The findings are not surprising, but this study clearly demonstrates that Hispanics

with low acculturation perceive more barriers to accessing health care than those

with high acculturation. Speculatively, it could be that Hispanics with high

acculturation perceive less barriers to care because they can communicate more

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confidently in English with health care professionals and have higher English literacy, meaning they can access publicly disseminated literature and information more easily.

This research additionally contributes information on the previously unexamined topic of Hispanic's level of exposure to autism. Hispanics with low acculturation reported significantly less exposure to autism than Hispanics with high acculturation with the questions pertaining to having met someone with autism, having read about autism and personally knowing someone with autism. Interestingly, there were no significant differences in the responses about having heard of autism. This could indicate that some information concerning the disorder has effectively circulated to the Hispanic population. On the other hand, the lack of direct contact with people with autism and the lack of exposure to written material concerning autism could indicate that Hispanics with low acculturation have only a cursory understanding of autism and that there needs to be more effort in offering education about the specifics of the disorder.

This supposition is supported by the data addressing knowledge about autism. Hispanics with low acculturation knew significantly less about autism than those with high acculturation. Although all the respondents had fairly accurate understandings about the symptoms associated with autism, they had low knowledge about the etiology and course of the disorder. More specifically, close to sixty percent of the survey participants inaccurately believed that those with autism would eventually outgrow the malady, only 36.1% percent knew that autism is a primarily genetic disorder, and 46.2% believed that trauma plays a

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large role in causing autism. This lack of knowledge concerning the etiology of autism could be indicative of a larger problem concerning the issue of culpability associated with autism. In other words, people feel like the parents of a child who has autism must have done something wrong in their parenting to somehow cause the disorder. This perception of culpability is problematic, not only because it is incorrect, but also because connects feelings of shame and guilt to autism- such that families could be less likely to seek help because they feel like society will blame them for the problem.

The findings of this research correspond with and affirm the assertions of Alvarado, Mandell and Novak, and others that language is the number one barrier that keeps Hispanics from accessing health care services. Even though this study was conducted in a city close to the Mexican/American border where one would assume high levels of multicultural awareness and outreach, there remain great disparities in the accessibility of resources between people who have fluency in the English language and those who do not. Moreover, this study again confirms the findings of Jacobson and Mulick, Mundell and Novak, and Newschaffer and Curran that the cost of health care is one of the primary barriers keeping people from accessing the health services they need.

LIMITATIONS AND IMPLICATIONS

Although previous studies have examined perceived barriers that keep Hispanics from accessing health care, the strength of this research is that while confirming the findings from prior studies, it also addresses previously unexamined topics such as Hispanics' exposure to autism, knowledge about the

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symptoms and etiology of autism, and it delineates between Hispanics of high and low levels of acculturation. This exploratory study can act as a foundation for further research and highlights the importance of continued investigation concerning autism in Southern Arizona.

Despite this strength, the study is limited by a variety of factors. First, the researchers used a sample of convenience, which is a non-probability approach and therefore the responses may not be truly representative of the target population. Additionally, the small number of participants limits the external validity and generalizablity of the study. Another limitation of the study is that the survey instrument was newly developed and therefore could be lacking validity. The acculturation scale used in the survey, however, has good reliability ($\alpha = .96$) and is a standard measure used with this population. Unfortunately, one question from the original acculturation scale was inadvertently left off of the final version of the *Autism Awareness Survey*, which renders the scale used in this survey inconsistent with the standardized measure. Finally, another limitation of the research is that the Spanish translation of the survey may not be the best dialect of the language for the population surveyed, which could impact the participants' understanding of the questions and therefore influence the responses. To minimize this limitation the researchers did forwards and backwards translations of the survey and several native Spanish speakers collaborated together to ensure the best possible word choice.

The implications of this research for social work and health care practitioners are far-reaching. Once again it has been demonstrated that the

primary barriers keeping Hispanic families from accessing health care services are language and finances- the same barriers that researchers have identified for this population for the last twenty years (Alvarado, 2005; Bearman & Fountain, 2011; Durkin et al., 2010; Flores, 1984; Kraemer, 2010; Flores, Abreu, Oliver, & Kastner, 1998; Graf, Blackenship, Sanchez, & Carlson, 2007; Guendelsberger, 1992). It seems that there has been little progress in the development of culturally appropriate and cost efficient services. The cost of health care has been the topic of national debate, yet there has been no tangible movement to reduce the cost of health services, particularly for the uninsured and underinsured. Additionally, with the upcoming, highly politicized changes to the diagnostic criteria for autism spectrum disorders within the *Diagnostic and Statistical Manual for Mental Disorders* (2000), many families who currently receive support through the Department of Developmental Disabilities may cease to qualify for assistance, leaving the financial burden of care entirely on the family. This research again highlights the uncertainty felt by the general public- and the need for social workers to engage in national dialogue and advocacy for the marginalized populations in our communities.

The other primary barrier to care pertains to language- lack of Spanish-speaking health care professionals and lack of Spanish information and literature concerning autism. The implications for mezzo level change was obvious- health care programs need to broaden services that address the specific cultural needs within their community. In the Southwest, this means making health care services equally accessible for English and Spanish-speaking populations. Although it

seems this community is generally aware of autism as a concept, education about

autism, specifically about issues concerning culpability, is clearly necessary.

Without addressing the stigma of the disorder, vast numbers of those with autism

spectrum disorders are unlikely to receive the care they need during the prime

treatment years, and will reach adulthood without the skills to effectively engage

with the world around them. This research should remind health and education

professions of the unique needs of the diverse populations within this country,

which must be met with equitable and appropriate care.

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