2008-04-12

Validation of the Social Communication Questionnaire (SCQ) in a Hispanic Sample: Understanding the Impact of Expressed Emotion

Vanessa Gonzalez
University of Miami, vanessagonzalez2@gmail.com

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VALIDATION OF THE SOCIAL COMMUNICATION QUESTIONNAIRE (SCQ) IN A HISPANIC SAMPLE: UNDERSTANDING THE IMPACT OF EXPRESSED EMOTION

By

Vanessa Gonzalez

A DISSERTATION

Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

Coral Gables, Florida

May 2008

UNIVERSITY OF MIAMI

A dissertation submitted in partial fulfillment of
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Approved:

_____
Marygrace Yale Kaiser, Ph.D.
Research Assistant Professor of Psychology

_____
Terri A. Scandura, Ph.D.
Dean of the Graduate School

_____
Daniel S. Messinger, Ph.D.
Associate Professor of Psychology

_____
Jennifer Stella Durocher, Ph.D.
Clinical Assistant Professor of
Psychology

_____
Marjorie Montague, Ph.D.
Professor of Education

_____
Frank J. Penedo, Ph.D.
Associate Professor of Psychology

GONZALEZ, VANESSA   (Ph.D., Psychology)
Validation of the Social Communication   (May 2008)
Questionnaire (SCQ) in a Hispanic Sample:
Understanding the Impact of Expressed Emotion.

Abstract of a dissertation at the University of Miami.

Dissertation supervised by Professor Marygrace Y. Kaiser.
No. of pages in text. (65)

The SCQ is a popular screener for ASDs derived from the gold-standard diagnostic interview. This study examined the validity of the SCQ in a Hispanic sample. Additionally, the mother's expressed emotion toward her child with ASD was examined. Participants included 217 Hispanic and non-Hispanic white mothers of children with and without ASDs ages 4-10. The actual diagnostic status of all children was determined using a historical review of records. ROC curve analysis yielded much lower sensitivity and specificity than the original validation study, with very little difference found between the 15 and 22 cutoffs. A cutoff score of 12 performed the best with a sensitivity of .86 and specificity of .54 in distinguishing between ASD and Non-ASD. There were no significant findings in expressed emotion between Hispanics or Whites, nor did it predict SCQ score. Limitations included a small non-Hispanic White sample. Findings of this study corroborate recent validation results.

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Chapter 1: Introduction

Is autism a culturally relative or universal disorder? The idea that autism is universal is supported by new evidence indicating there is a biological cause for autism (Daley, 2002). Berry and colleagues (1992) contended that a psychiatric condition can be considered universal if its etiology is determined to be biological in nature. However, the dearth of information on cultural differences in the diagnosis and the perception of this disorder does not allow an easy answer to the above question. This issue also translates to the assessment of autistic symptoms for children of other cultures. There is a need for a valid and reliable method of screening that will insure the identification of all children at risk of having autism.

Therefore, the objective of the present study was to validate a common parent report screening questionnaire in a Hispanic sample. Furthermore, possible explanations for why Hispanic parents may differ from non-Hispanics in reporting on a questionnaire were also examined.

Perception of ASD Symptoms and Culture

The current criteria for Autism Spectrum Disorders (ASDs) have emerged following many years of revision and research, following the very narrow definition of "classic autism" (Kanner, 1943) to the more broad idea of a spectrum of disorders. The present criteria are thought to be widely accepted by clinicians and researchers. However, the actual translation of these criteria to other cultures has not been studied. The scarcity of research in this area could be due to a general consensus that all children with autism will manifest the same symptoms and, therefore, there is no need to redefine the criteria in other cultures (Daley, 2002). However, it is clear that children with autism or ASD form

a very heterogeneous group with respect to symptom type and severity. Furthermore, to ignore the impact of culture with respect to how the diagnosis of this disorder is made would seem problematic. A culture is defined by its customs, beliefs, values, behaviors and attitudes that make it inherently different from another group of people or culture (Mio, Barker-Hackett, & Tumambing, 2006). Being that the major deficits in autism refer to qualitative impairments in social interaction and communication, it is possible that the kinds of behaviors thought to be the very deficits that define the disorder may in fact vary from culture to culture.

In most cases, ASDs are diagnosed based on extensive parent report of their child's past and present behaviors (Lord et al. 1994). Therefore, one consideration is the differences among parental interpretations of their child's behavior, which specifically stem from the different social demands that may be placed on the child. The importance of how a child does or does not respond in specific social situations may very well be mediated by cultural factors. It is important to understand that such differences do exist and may impact perceptions of a developmental disorder when considering a population consisting of children born to parents from cultures different than traditionally seen in the United States. Applying the same criteria to every child, which may in fact be culturally insensitive, could result in misclassification of symptoms. Plainly speaking, if using parent report to screen children showing signs of an ASD, it is imperative to consider and understand how cultural differences may impact their responses.

Identification of ASDs

When establishing a screening procedure it is crucial to understand the nature of the population being studied. The discriminative power of any screening questionnaire will

be influenced by the sample on which it is administered. For example, in Miami-Dade County, Florida, the population total in 2000 was 2,253,362 where Hispanics made up 57% (United States Bureau of the Census, 2000). Hispanics are one of the fastest growing minority groups in the US. It is also currently thought that the prevalence of ASDs nationwide is on the rise as well with rates ranging from 3 to 10 per 1,000 (Centers for Disease Control and Prevention [CDC], 2007). The prevalence rates of autism have been found to be lower in Hispanics; however this finding is inconsistent across studies and contexts.

The notion of a universal autism has been challenged by some reports of lower incidence of autism in Latin American countries, such as Peru, Argentina, Brazil and Venezuela (Sanua, 1981). Similar to Latin America, low rates have also been found in developing countries, such as Kenya, India, and Hungary (Sanua, 1981). It was hypothesized that autism is more prevalent in Western countries where there is a predominance of nuclear rather than extended families (Sanua, 1981). However, this theory was solely based on the higher prevalence and threat of increase in Western civilization and Westernized individuals. Of the few prevalence studies taking cultural differences into account, most use immigrant status, studying first degree families who have recently moved from one country to another rather than comparing groups of individuals from different ethnicities. Most of these studies report a higher proportion of children with autism from immigrant families compared with the nonimmigrant population in the United States (Gillberg, Steffenburg, & Schaumann, 1991; Gillberg, Steffenburg, Borjesson, & Andersson, 1987). These studies do not study culture in

particular but do indicate that there are differences found in overall prevalence for individuals who are not originally from the United States.

At present time, many possibilities have been investigated in order to understand the overall apparent increase in prevalence. Environmental toxins, vaccines, and methodology have all been considered (Lemer, 2006; Taylor, 2006; Croen, Grether, Hoogstrate, & Selvin, 2002). However, differences among cultures have not been investigated in great detail. An effective and culturally-sensitive screening measure can greatly increase the likelihood of a child with ASD being identified as early as possible. This can then lead to early intervention, which is considered imperative for children diagnosed with an ASD and their later outcome. Identification and subsequent treatment for children with disabilities such as autism should be impartial to cultural differences among them. Hispanics in the United States are the most rapidly growing population and are estimated to continue this increase (United States Bureau of the Census, 2000). Incorporating cultural disparities and parental interpretations in the implementation of a screening measure such as the Social Communication Questionnaire (SCQ) can help assure that the diagnosis and subsequent treatment plans for all children can occur in the same manner, regardless of their individual ethnicity.

Current Prevalence of ASDs

As part of a national effort by the CDC (2007) to understand the changing epidemiology of autism, several locations throughout the US used the same methodology of reviewing historical records and released the most recent ASD estimates. Case finding procedures involved screening and abstracting records at multiple educational and clinical sources of all children suspected of having an ASD born in 1994 with a parent or

legal guardian living in the study area in 2002. The abstracted behavioral information was then scored by trained clinician reviewers and determined if it met ASD case status. Thirteen of the 14 participating states found consistently lower prevalence rates for Hispanics than for non-Hispanic white and non-Hispanic black children, 8 years of age. Data derived from 6 of these states found that the difference between Hispanics and non-Hispanic white children was statistically significant (CDC, 2007). The ASD prevalence for Hispanics ranged from 0.3 to 4.7 per 1,000 children. Conversely the prevalence for non-Hispanic whites ranged from 5.9 to 8.9 and for non-Hispanic blacks ranged from 3.7 to 6.8 per 1,000 children. The investigators of this multi-site study urge caution when interpreting the reasons for this ethnic variation, stating the need for further investigation. The article also raised the issues of variability in who gets evaluated for developmental concerns and how those concerns are documented. It is very possible that culturally insensitive screening measures were part of the factors that decided who and how Hispanic individuals were evaluated for developmental concerns. Therefore, it may have created an imbalance in the way the children were being assessed. This in turn could have translated into lower prevalence estimates for these particular Hispanic samples overall.

This being the case, in a population where the majority of individuals are of a different culture, specifically Hispanic, it is crucial to be able to accurately evaluate these individuals in the same way that all other children are assessed. Oftentimes, a screening measure is developed and validated using one particular population, generating promising and reliable results, such as the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) and the Early Screening for Autistic Traits (ESAT; Swinkels et al.,

2006). However, this does not imply that this method can then be used with any other population and assume to have the same utility.

Use of Parent Screeners for Early Identification of ASD

The most widely used and convenient method for initially evaluating young children is through the use of parent report questionnaires. Parent completed questionnaires provide systematic data collection, help detect co-morbidity, are economical and efficient, and most importantly, can be used to survey large groups (Brereton et al., 2002). A variety of questionnaires have been constructed to assess the symptoms associated with ASDs. The validity and reliability of these instruments range from fair to good (Baron-Cohen et al., 2000; Robins et al., 2001; Swinkels et al., 2006) but none of them address the issue of cultural differences that may exist in different populations. These screeners include the CHAT, M-CHAT, and ESAT, which were developed in Great Britain, Connecticut, and the Netherlands respectively. They were all created through clinical observation and review of literature on the disorder, relying on manifestations of criteria that have not been studied across cultures. Consequently, the impact of culture is ignored in the scoring and cutoffs for these screeners. It would be beneficial to take the efficiency of a valid questionnaire and adjust it to become culturally appropriate to the particular population being studied. However, this adjustment has not always been considered in the development of various screeners.

The Social Communication Questionnaire (SCQ)

The SCQ (Berument et al., 1999) is a valid, brief, easily administered, and cost effective measure that is commonly used to determine whether an individual should be referred for a complete evaluation. Formerly known as the Autism Screening

Questionnaire, it is a 40-item screening questionnaire based on questions from the original Autism Diagnostic Interview (ADI; Lord et al., 1994), which is considered one of the gold standard instruments for diagnosing ASDs. There has only been one validation study of this screener, which was conducted by the group of researchers who developed it. Berument et al. (1999) tested the SCQ on a sample of 160 individuals with Pervasive Developmental Disorders (PDD) and forty with non-PDD diagnoses. The non-PDD group included children with conduct disorder, language delay, mental retardation, and other clinical diagnoses. They found that the screener had good discriminative validity when differentiating PDD from non-PDD diagnoses at all IQ levels. The separation of autism from other types of PDD was not as strong.

In its validation study (Berument et al., 1999), the SCQ was found to be highly correlated to the ADI. The overall correlation between the SCQ total score and the ADI algorithm score was 0.712. The instrument was found to be as discriminative as the ADI in effectively screening for PDD. Bishop and Norbury (2002) also found that there was good overall agreement between the SCQ and ADI-R in diagnostic categorization. This data supports the validity of the SCQ when given to parents who are not familiar with autism diagnostic procedures. There was no difference in terms of age, IQ or language ability between those individuals who met criteria on the SCQ but not the ADI–R.

Various studies (Keller et al., 2003; Rutter et al., 1999, 2001) have used the SCQ to date, all of which use the screener to assess the presence of autistic features, and not to verify a preexisting diagnosis. There is scant and conflicting evidence on the agreement between the ADI-R and preceding SCQ (Bishop & Norbury, 2002; Howlin & Karpf,

2004). However, none of the following studies reexamined the sensitivity or specificity of the SCQ.

Michelotti and colleagues (2002) used the SCQ to assess current diagnosis in conjunction with other standard follow-up assessments of children with severe developmental language delay/disorder demonstrating some autistic features in a major teaching hospital in London, United Kingdom. Four years after the original diagnoses, a majority of children scored above the 22 autism cutoff (11/18), or above the 15 PDD cutoff (3/18), whereas only four children scored below the threshold. The mean score for this group on the SCQ was 22.8 giving support to the clinical diagnosis given to the children as well, which was determined by a pediatrician and speech therapist using similar questions covered by the ADI. The group mean was also similar to that found in the SCQ's validation study (Berument et al., 1999). The SCQ adequately identified autistic features in the majority of these children who were showing autistic features at age 4 and later received a clinical diagnosis at age 8.

A more recent study conducted in Australia (Barret, Prior, & Manjiviona, 2004) also used the SCQ to compare children diagnosed with autism or language delay, focusing on the social interactions scale of the measure. Group differences in social interactions were in the expected direction, with autistic children showing more impairment than language-delayed children. However, these results were not statistically significant.

Another study (Charman et al., 2004) used the SCQ to determine symptom severity for children with ASD entering school with the purpose of tracking their developmental progress in the United Kingdom. At age 4, of 125 children with ASD as indicated by their educational placement and parental report, 108 were above the 15 cutoff for ASD and 49

of those were above the 22 autism cutoff, confirming the children's' diagnoses. Also, these scores did not change over time, from the first time point at age four to the second at age five. This indicates that there was stability in symptom severity as measured by the SCQ. Again, the SCQ appropriately identified children with a previous diagnosis of autism.

In an earlier study, children from Romania were assessed using a variety of instruments including the ADI and SCQ. Rutter and colleagues (1999) administered the ADI and discovered that autistic-like behaviors could be found in some children adopted into U.K. families from Romanian orphanages. However, the data derived from the SCQ would suggest that this was not the case. Therefore, most of the children only qualified as having autistic features on the ADI, but not on the SCQ. This discrepancy could have been due to the kinds of behaviors identified in the ADI, such as repetitive behaviors and circumscribed interests. The SCQ provides a much stronger measure of social and communicative abnormalities. Therefore, repetitive and stereotyped behaviors and interests were specifically identified and indicated in the ADI, yet overlooked in the SCQ. Using the information obtained from the SCQ alone would have lead to an underestimation of autistic features for this sample.

An explanation for the discrepancy found between ADI and SCQ identification for the Romanian study mentioned above was the result of a loss of discriminant power. The previously set cutoff points proved to be less sensitive, yet they were not altered. Because it was derived from the gold standard in diagnosing ASDs (ADI), the SCQ has incredible potential to be a powerful screener in different cultures if tailored to fit the differences. Being a parent report questionnaire indicates that the criteria are actually set by the

parents themselves. Therefore, the degree to which the manifestation of ASDs varies with their interpretation of the questions and their child's behavior, which may be a function of their culture, was ignored.

More recently, a variety of studies have re-examined the validity of the SCQ. Eaves, Wingert, and Ho (2006) examined how well the SCQ agreed with clinical diagnosis in a group of children ages 2-6 already identified as needing further assessment. Using the predetermined 15 cutoff, the SCQ provided a positive predictive value of .65. This cutoff also resulted in 26% of the 35 children diagnosed as having an ASD being missed by the screener. On the other hand, using a cutoff of 12 resulted in only 9% being screened out. However, as a consequence of this increased sensitivity, 70% of children found to be non-autistic were unnecessarily assessed. Surprisingly, the SCQ was found to have a higher positive predictive value, sensitivity, and specificity for families who spoke English as a second language, mostly of European/Canadian decent.

Eaves, Wingert, Ho, and Michelson (2006) examined the SCQ again in a slightly younger sample of children ages 36-82 months, where 70% of the parents spoke English only. Positive predictive value was 65% for this sample. The SCQ had the highest sensitivity for nonverbal children. However it demonstrated lower specificity, meaning that these children were more likely to be incorrectly identified as autistic, or false positives. However, no differences were found in mean SCQ scores between verbal and nonverbal children. Overall, it was also found that autistic children with higher IQ scores and milder symptoms according to the CARS were more likely to screen as false negative on the SCQ. This study provides significant insight into the various factors that can impact SCQ scores.

Wiggins, Bakeman, Adamson, and Robins (2007) examined the SCQ's effectiveness in distinguishing ASD from other developmental delays in very young children ages 17-45 months referred to early intervention. This study found that an 11 cutoff performed the best with a sensitivity of .89 and specificity of .89, as compared to the previously set 15 cutoff that yielded a sensitivity of .47 and specificity of .89. In particular, they found that eight SCQ items distinguished children between ASD and general developmental delays. However, 18 of the items found on the SCQ did not distinguish these children. Overall, the findings are supporting the use of the 11 cutoff when distinguishing between children referred for early intervention.

Similarly, Allen, Silove, Williams, and Hutchins (2007) also found that the 11 cutoff performed best in a sample of children ages 2-6 years old in Australia. In this study, the sensitivity of the questionnaire using this new cutoff rose to .93 with a specificity of .58. The SCQ again performed poorly when using the predetermined 15 cutoff with a sensitivity of .60 and specificity of .70. This study also found an age difference where the SCQ worked best with the older 3-5 year old children, achieving 100% sensitivity, as compared to the younger 2-3 year olds. Once again, the previously determined cutoff scores seem to fall short of identifying children correctly.

Another study conducted in the United Kingdom (Charman et al., 2007) with children ages 9-13 compared the SCQ to the Social Responsiveness Scale (SRS) and the Childhood Communication Checklist (CCC) in identifying individuals with ASD. The SCQ performed the best with a sensitivity of .86 and specificity of .78 using the original 15 cutoff. Behavior problems reduced the specificity for all three instruments including the SCQ. The ADI-R, where the SCQ was derived from, was used to achieve a clinical

diagnosis for the sample which may explain the high sensitivity as compared to the other questionnaires.

Lee and colleagues (2006) assessed the performance of the SCQ as a screening tool in a population of 268 young children ages 3-5 identified as receiving special education services, where 72% were White. In this study only part of the sample was administered and ADI and ADOS. The entire sample had parental self report of an ASD diagnosis or a special education documentation of an Autism classification. A cutoff of 12 yielded an average sensitivity and specificity of 80% as compared to a lower sensitivity (24-70%) for the higher 15 cutoff. They concluded that the SCQ would be useful for research studies seeking to identify ASD cases from the population of children receiving special education services. However, it was recommended that a different cutoff should be used when attempting to use the instrument clinically.

The largest validation study (Corsello et al., 2007) included 590 clinic and research referred children ages 2-16, where the majority were Caucasian. This study investigated how well the SCQ functioned as a clinical screening instrument. Once again, a lower sensitivity (.71) and specificity (.71) were found using the original 15 cutoff score. The SCQ was found to correlate with the ADI-R although the ADI-R captured more children with ASD than the screener. They also found an age difference in that children older than 8 years of age had higher SCQ scores than younger children. Furthermore, lowering the cutoff to 11 or 12 resulted in better sensitivity for the children younger than 8, but with poorer specificity. The best results were obtained when combining the SCQ with ADOS classifications. It is suggested to take the characteristics of the families and children when

considering which measure to select. See Table 1 for a review of all SCQ validation studies.

As evidenced by these various studies, the SCQ is widely used in clinical and research contexts and has reliably confirmed a clinical diagnosis of autism (Michelotti et al., 2002). This questionnaire has been used in multiple studies examining different syndromes such as Fragile X, Cohen, Prader-Willi and other genetic syndromes, as well as the presence of mood disorders (Farzin et al., 2006; Veltman et al., 2004; Howlin & Karpf, 2004; Towbin et al., 2005). This measure has also been translated into different languages such as Spanish and German (Bolte & Poustka, 2005) and has been published internationally in various countries such as Australia, Canada, Denmark, Belgium, Switzerland, France, Hungary, Italy, Spain, and the United Kingdom. However, validation studies in these various countries have not been conducted which raises questions about whether the cutoffs determined in the original validation study are appropriate.

Preliminary Findings

The SCQ was recently examined in a study comparing the questionnaire to a review of historical records. Gonzalez and Kaiser (2006) set out to determine how well the SCQ identified children already labeled as having autism via parental report. Participants included 89 families who had a child between the ages of 4 and 9 years of age who had been previously diagnosed with Autistic Disorder. Sixty-two percent of the sample was Hispanic, 25% was white, 10% was black, and 3% was of another ethnic origin. The previously set cutoffs were tested including a 15 cutoff identifying children as PDD from non-PDD and a 22 cutoff for autism versus other PDD. The sensitivity of the SCQ to

identify children in the autism range was 26%, using the most stringent 22 cutoff. This was strikingly lower than the 75% sensitivity previously reported (Berument et al., 1999). The lower ASD range cutoff of 15 was also examined, achieving a sensitivity of 78%. This was also lower than the expected 85% previously reported (Berument et al., 1999).

These findings indicate that the SCQ was not an acceptable measure to be used for these particular parents. This may have been due to the fact that the majority of this sample was Hispanic. The SCQ has not been validated with culturally diverse populations and consequently may not be sensitive to potential differences found within them. Therefore, if the SCQ were to be used as the sole method for a prevalence estimate, the number of children accurately identified with ASD would have been much lower in this sample than is actually the case. If this occurs, the erroneous information is then passed along to government agencies which would ultimately lead to inadequate service allocation for these children. Public schools in particular will not be prepared to accommodate an unexpected number of children with special needs. The effectiveness of any screening instrument is directly affected by the population being screened. Therefore, being that the SCQ was validated on a non-Hispanic sample, using it with an entirely different set of parents obviously brings about numerous problems. This paper speculated on some possible explanations as to how and why Hispanics may differ from non-Hispanics when responding to such a questionnaire.

Cross-Cultural Implications

One particular reason the SCQ should be validated in a Hispanic sample is the possible need for an adjustment to the previously set cutoff scores. This adjustment may be a result of the way Hispanic parents tend to express emotions about their children.

This can affect the way they report behaviors on a screening instrument, particularly when asked about problematic behaviors. Parents may have a tendency to perceive their children's behavior in a particular way, interpreting their actions from a positive point of view or fixating solely on the negative aspects. A measure of Expressed Emotion could aid in capturing those tendencies and shed light on variations in parental report.

Expressed Emotion

Expressed Emotion (EE) is a measure of the extent to which an individual family member talks about another family member in a critical or hostile manner, or in a way that indicates marked emotional overinvolvement (EOI) as well as positive comments and warmth (Barrowclough & Hooley, 2003). It is most commonly assessed via interview in which the dimensions of criticism, hostility, and EOI are measured and used to determine high and low levels of Expressed Emotion. Critical comments are remarks that express negative attitudes about specific and discrete patient behaviors, whereas hostility involves generalization of criticism to remarks about the person as a whole or an explicit rejection of the person. EOI is a measure of factors such as an exaggerated emotional response, overintrusive or self-sacrificing behavior, and over-identification with the patient. Associations have been found between high Expressed Emotion and relapse in schizophrenia, depression, childhood psychological disorders, and other chronic medical conditions (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). How and why these associations exist is still a topic of debate. Currently, differences between high and low Expressed Emotion relatives have been a focus of much research in this area. One possible differentiation could be the beliefs the relatives hold about the illness.

Across thirteen studies reviewed by Barrowclough and Hooley (2003), relatives of patients who were rated as high Expressed Emotion because they are consistently critical attribute more control to patients for their symptoms and problems than do relatives who are low in criticism. Also in this review, it was reported that relatives labeled as hostile also attributed problems to factors that were more internal to the patient, making the most attributions of patient responsibility. Therefore, these studies suggest that the beliefs of hostile relatives are more blaming of the patient than those of critical relatives.

In terms of EOI, Hooley (1987) suggested that relatives high in EOI would be unlikely to blame patients for their disturbed behavior, instead making the patient a victim of the illness. Barrowclough, Johnston, and Tarrier (1994) also found that EOI relatives make sense of the illness in terms of factors that are outside of the patient's control. Therefore, these relatives attempt to ameliorate events by using themselves as a buffer between the patient and the outside world through their use of self-sacrificing and intrusive behaviors, trying to put the factors under their own control, unlike critical and hostile relatives. In three studies included in the Barrowclough & Hooley (2003) review, high Emotional Over-Involvement (EOI) only relatives, without criticism, was very similar to low Expressed Emotion relatives. These relatives tended to make fewer attributions of control by the patient, and the least amount of blaming attributions, blaming the illness instead. Positive warmth was found to be associated with relatives making more universal and fewer controllable attributions. The more a relative finds an illness to be under the patient's control, the less positive and warm they are toward that patient.

The manner in which an individual will react to a family member with an illness varies greatly from one person to the next. The level of Expressed Emotion may vary greatly depending on the situation. It may also vary according to the beliefs one has of the illness and the stigma it carries within a particular culture. Therefore, it is important to examine whether the levels of Expressed Emotion are similar for all groups or if they vary by cultural context.

Relatives with high Expressed Emotion can be found in all countries and cultures; however, it is generally true that high Expressed Emotion attitudes are less prevalent in traditional cultures than they are in more industrialized countries (Barrowclough & Hooley, 2003). These differences have not been extensively measured in this regard; however, it would be interesting to find possible distinctions between various cultures. For example, Rosales (2005) found that Latinos were rated as having high Expressed Emotion less frequently than were white and black family members of patients with schizophrenia using the Five Minute Speech Sample (FMSS).

Other studies have further investigated affect and Expressed Emotion in the Mexican culture. Jenkins and Karno (1992) examined the cross cultural validity of Expressed Emotion among families of Mexican descent residing in southern California. The CFI was adapted within a pilot study in order to incorporate the families' cultural context. For the Spanish language, criticism was defined as "verbal behavior that is observed through tone of voice or context of speech which clearly conveys dislike, resentment, or disapproval." It was found that the previously established operational definition of criticism needed to be altered to include both content and vocal characteristics of speech which may communicate criticism, and therefore be considered appropriate. EOI was

also altered for this purpose, where a common feature of individuals high in EOI included suffering from what they termed "nervios". This term is used broadly to describe everyday distress, as well as severe illness conditions, often being used to destigmatize those conditions. In this culture, "nervios" are considered curable and not blameworthy or under the individual's control, where the person inflicted with this condition should be offered sympathy, support and special treatment. Therefore, incorporating the inherent cultural difference, this study found a significantly lower rate of high levels of Expressed Emotion among Mexican-descent relatives than among Anglo-Americans.

Weisman and Lopez (1997) examined 88 Mexican and 88 Anglo American undergraduate psychology students. Participants were presented with two vignettes of a hypothetical family member with schizophrenia, one displaying predominantly positive symptoms and the other negative symptoms. As they expected, Mexicans were found to perceive the negative behavioral symptoms of schizophrenia as less controllable than Anglos. This means that Mexicans viewed the patient as having less responsibility and personal control over the negative symptoms than did Anglos. Mexicans were also found to report less intense unfavorable emotions towards the hypothetical family member. This occurred regardless of the presenting symptoms, whether positive or negative. In contrast to the Anglo participants, there were no differences in attributions of cause of behavior between male and female Mexican participants. In general, Mexicans tend to be less blaming than Anglos in this investigation.

In summary, Expressed Emotion theory relates to the experience of an individual reacting to another individual. When dealing with family members, there are variations in the reasons, explanations, criticisms, and involvement an individual demonstrates. This

theory focuses on the involvement of a dyadic interaction. In this study, that would include the parent and the child with a developmental disability, specifically autism.

Expressed Emotion and Autism

The concept of expressed emotion has been extensively studied in the schizophrenia population; however some researchers are beginning to examine its utilization for individuals with ASDs. For instance, Orsmond and colleagues (2006) examined expressed emotion as an indicator of mother-child relationship quality among adolescents and adults with ASDs, diagnosed by the ADI-R. Expressed emotion in this study was measured using the FMSS, whereas language and social impairment was measured using the ADI-R. They found that greater maternal emotional over-involvement was predicted by more severe language impairment, but less severe social impairment. Therefore, mothers were found to be more emotionally over-involved with their son or daughter who had greater difficulties communicating, but not interacting socially. These findings lead to the idea that maternal expressed emotion can have effects on the child's behavior and vice versa. However, the sample for this study was limited with less than 10% being from an ethnic minority. In addition, mother-child relationship was only measured from the mother's perspective. Additional studies examining EE and autism in ethnic minorities using both maternal and objective or child report are warranted.

Greenberg and colleagues (2006) also examined overall maternal expressed emotion, criticism, and emotional over-involvement and whether it was predicted by the severity of adolescent or adult's symptoms of autism over an 19 month period of time. The FMSS was again used to measure expressed emotion and the ADI-R was used to measure autistic symptoms. They found that a high level of expressed emotion was associated

with later increasing impairments in reciprocal social interaction. In addition, level of

criticism was significantly related to later worsening repetitive behaviors. However, no

effects were found between maternal criticism and either reciprocal social interaction or

non-verbal communication impairment domains on the ADI-R. Furthermore, the stability

of levels of expressed emotion in this sample over time supported the conceptualization

of EE as a personality rather than a state trait. This study provides interesting insight into

the interaction between expressed emotion and autism symptom severity. However, the

assessment of both expressed emotion and symptoms were via maternal report. This

likely led to the increased associations found for the two constructs in this sample.

Furthermore, the sample was limited to volunteers who were predominately White,

making the generalizability of these results unknown.

Expressed Emotion of Hispanic Parents

It has been found that Hispanics tend to demonstrate lower rates of high Expressed

Emotion than non-Hispanics (Jenkins & Karno, 1992; Weisman & Lopez, 1997; Rosales,

2005). This means that Hispanics are less likely to perceive negative behaviors as under

the individual's control and also feel less intense unfavorable feelings towards that

person. Therefore, it may be the case that when Hispanic parents are asked to describe

their child with a disability, that they will describe them in a very positive manner,

displaying positive affect. If this occurs, then their responses to a questionnaire or

interview asking about negative behavior can be affected as well.

By using Expressed Emotion theory, the possible cultural implications when

administering screening instruments can be examined. The Five Minute Speech Sample

(FMSS) can be used to determine whether a parent has high or low Expressed Emotion

and whether there are other emotions involved, such as positive affect. It is hypothesized that Hispanic parents will have lower rates of high Expressed Emotion than non-Hispanics. Hispanics will also tend to demonstrate lower levels of criticism, and possibly more EOI, then non-Hispanic white parents. Also, this may be related to lower scores on the screener indicating less severity. This would be due to the attributions made by the parent as to the cause of their child's negative or deficit behaviors. This can then result in that parent endorsing less negative behaviors overall on a screening questionnaire, such as the SCQ.

Chapter 2: The Present Study

It has been stated (Daley, 2002) that the most accurate view of autism is as a biological condition that is culturally shaped in symptom and course. However, research on ASDs within a cultural context has received limited attention (Daley, 2002). The present study re-validated a reliable screening instrument, the SCQ, with a Hispanic sample. An aim of the study was to establish a new cutoff level, thereby making the screening tool more culturally appropriate for this group of individuals.

In order to understand the force driving possible cultural differences, the parents' Expressed Emotion was also examined to determine its relation to scores on the SCQ. A parent's communicative style about their child provides insight into how they perceive their child's disability and development in general. Parents are the first and main source of information when determining a child's diagnosis in the early years. Therefore, in having this insight into how they perceive their child, detection of the deficits associated with the autism spectrum can be greatly improved across cultures.

A number of studies have looked at race or ethnicity differences and its effect on autism or developmental disabilities in general. These studies include differences in age at autism diagnosis between white and black children (Mandell et al., 2002) and the tendency for minority parents to under-report behavior problems as compared to their adolescent's self report (Lau et al., 2004). More speculative papers have been published on the relationship between culture and ASD treatment decisions (Mandell & Novak, 2005), and the impact culture may have on parent's beliefs on the nature and cause of their child's disability and its subsequent effect on their beliefs about treatment and intervention (Danseco, 1997). Most of these investigations postulate or even discover

racial or ethnic differences, yet leave many more questions unanswered. The present study will contribute to the current gap in this literature by establishing a more sensitive instrument for Hispanic parents, as well as an explanation behind the need for such a measure. It can potentially enhance the ability to assess and serve an ethnically diverse population as well as the accuracy of prevalence estimates.

Research Questions and Hypotheses:

The purpose of the present study was to validate the SCQ for Hispanic children ages 4 to 10. This study included a group of children with ASDs, children with other developmental disabilities without ASD, and children who are typically developing. The sample also included non-Hispanic children with ASD as a comparison. In addition, the mechanism underlying possible differences between Hispanic and non-Hispanic white scores on the SCQ were examined using a measure of Expressed Emotion.

<u>1) What is the sensitivity and specificity of the SCQ in a Hispanic sample?</u>

In its validation, Berument and colleagues (1999) stated that a score of 15 or more was the most effective cutoff for differentiating PDD from other diagnoses with a specificity of .75 and sensitivity of .85. A cutoff of 22 or more for autism yielded a specificity of .60 and a sensitivity of .75. The sample used in the validation study was ethnically different from the sample proposed to be used in the current study. Even though the ethnic breakdown of the original study was not reported, the study was conducted in the United Kingdom, making it very different from the present sample. Therefore, Hypothesis #1 is that the sensitivity and specificity found using the previously set cutoffs with the Hispanic sample will be lower than reported in the validation study. Furthermore, the rate of false negatives is predicted to be higher for Hispanics suggesting

lower sensitivity. Therefore, it is expected that there will be a high number of Hispanic children that will not be identified as having ASD by the SCQ, even when classified as a case of ASD by the review of historical records.

2) What are more appropriate SCQ cutoffs for the Hispanic sample?

The SCQ is intended to be used as a screening measure and should therefore have high sensitivity estimates as well as predictive rates. In other words, the SCQ should capture the vast majority of children who actually have the disorder, and conversely the vast majority of the children identified by the SCQ should actually have the disorder. Hypothesis #2 is that the cutoff scores deemed most appropriate for the Hispanic sample will be lower than the previous 15 and 22 cutoffs. By lowering the cutoff points, the questionnaire will yield higher sensitivity and specificity for the Hispanics. It is expected that with the new cutoffs, the number of false negatives will also diminish, resulting in fewer children misidentified as not having an ASD when in fact they do have the disorder.

3) How do levels of Expressed Emotion (EE) impact scores on the SCQ?

As previously reported by Weisman and colleagues (1994), Hispanics tend to show lower levels of Expressed Emotion compared to non-Hispanics. Therefore, Hypothesis #3 is that Hispanics will have lower levels of Expressed Emotion than non-Hispanic whites. Furthermore, this difference is predicted to be a result of lower levels of criticism in Hispanic mothers. In addition, it is expected that lower levels of Expressed Emotion will lead to lower scores on the SCQ. The behaviors identified and questioned on the SCQ can be perceived and characterized as mostly problematic and negative. Therefore, if Hispanic mothers tend to have lower rates of expressed criticism toward their children,

then they may be less likely to endorse these negative behaviors. This predicted

association is what may create the need for adjusted cutoff scores.

Chapter 3: Methods

Participants

Participants included a total of 178 mothers of children between 4 and 10 years of age. Validation of the SCQ was established examining 150 Hispanic mothers with 115 having a child with a case definition of Autism or ASD and 35 with Non-ASD, having other developmental disabilities or typically developing. The ASD diagnoses included Autistic disorder, PDD-NOS, and Asperger syndrome. The other developmental disabilities included children with mental retardation without autism, learning disabilities, and other clinical diagnoses. For the Autism and ASD groups, target cases included more boys (96) than girls (19) due to the much higher prevalence of ASD in boys, with a ratio of about 5:1, which is similar to the literature on the disorder. In the Non-ASD group, there were also more males (26) than females (9), with a ratio of about 3 to 1. There was no significant difference found for gender between the diagnostic groups, χ^2 (2, $N = 150$) $= 1.70$, $p = .43$. For the purposes of this study, historical review of records was used to determine case status due to previous findings of excellent sensitivity in a sub-sample from the same population (Gonzalez, 2006). Furthermore, the record review is widely accepted and utilized as part of the CDC funded ADDM surveillance studies (Rice et al., 2007). After all children's records were reviewed and scored, the sample consisted of 150 Hispanic mothers; 115 with ASD (including 67 with Autism) and 35 with Non-ASD.

The majority of the Hispanic mothers spoke English as the primary language at home (75%), were married (67%), had some college or a college degree (51%), and earned a household income of $25,000 to $74,000 per year (45%). The mean age of the Hispanic mothers was 39. Most of the mothers were born in the US (43%), while Cuba was the

most common outside country of origin (17%). The rest of the mothers were born in various other Central and South American countries. For those mothers not born in the US, the mean number of years residing in the US was 26. Additionally, the majority of the mothers were educated in the US (55%). There were no significant differences between diagnostic groups (ASD vs. Non-ASD) on any of the previously mentioned demographic variables.

In order to examine expressed emotion, an additional sample of 28 Non-Hispanic white mothers of children with ASD was also included. There were no significant differences between Hispanic and Whites in mother's age, education, employment status, household income, or diagnostic group of their children. There was a significant difference found for marital status in that more Hispanic mothers were divorced ($\chi^2 =$ 8.31, $p = .04$) as compared to White mothers. Furthermore, acculturation, as measured by the Short Acculturation Scale for Hispanics (SASH), did not have an impact on SCQ scores for Hispanics in this subsample (F = .13, $p = .72$). Most of these families were part of a larger ongoing study intended to monitor the prevalence of ASDs in Miami-Dade County, Florida. See Figure 1 for further sample description and Table 2 for descriptive statistics regarding the two samples.

Procedure

Mothers of children with ASD were recruited from the University of Miami/Nova Southeastern University Center for Autism and Related Disabilities (UM/NSU-CARD), the University of Miami-Autism Spectrum Assessment Clinic (UM-ASAC), as well as from special education classrooms in the Miami-Dade County Public School system.

Additional mothers of children without ASD were recruited from the community.

Interested families were provided a brief description of the project via phone or by mail.

Once UM-IRB approved informed consent was obtained, mothers were contacted

over the phone to obtain demographic information, SCQ questionnaire, the Five Minute

Speech Sample (FMSS), and to provide consent for records to be released for review. The

FMSS asks the mother to speak about their child and how they get along for five minutes.

The demographic questions included SES and acculturation information. The FMSS was

audiotaped, transcribed, and stored electronically.

Mothers had the choice of answering the instruments in either English or Spanish,

based on their personal preference. However, only the English administrations were used

for this investigation. This was done to eliminate potential translation and general

language comprehension issues. All SCQ items were read verbatim and questions about

the items were answered by repeating parts or the complete item again. In addition, the

Short Acculturation Scale for Hispanics (SASH; Marin et al., 1987) was administered to

the 39 Hispanic mothers of ASD children who participated in the FMSS to specifically

assess whether they were high or low in acculturation. The rationale for assessing

acculturation was to ascertain that SCQ score was not affected by the mother's

understanding of language used in the questionnaire.

On the consent and release of information form, mothers indicated all clinics,

hospitals, doctors, and other diagnostic, evaluation, or therapy centers the child has

visited. Once this form was completed and signed, each location was contacted via

telephone or mail and asked to send a copy of the child's file. When all sources were

contacted and the child's comprehensive file was complete, a record review was

completed (see section below).

Review of Historical Records

The corresponding professionals were contacted and all evaluations (including

diagnostic reports, evaluations, Individual Education Plans, and so forth) were obtained

and kept in a hardcopy file for each child. Each record was reviewed separately, and

behavioral descriptions were abstracted describing each of the following domains: social,

communication, repetitive behaviors and/or interests, associated features, developmental

delays, past and present diagnoses, as well as tests administered. The social,

communication, repetitive behaviors and/or interests, associated features, and

developmental delays included all behaviors corresponding to their respective domains as

delineated by the DSM IV (1994). Tests included all IQ, adaptive, and developmental

evaluations, interviews, scales, or questionnaires that had been administered to the child,

parent, teacher, professional or any other individual that has the opportunity to observe

and describe the child in question. Information was collected pertaining to each test

including their corresponding scores, percentiles, age equivalences and conclusions.

Also noted from each record in general was the date the evaluation was completed,

the location of where it was completed, the professional who dictated the report, and the

age of child at the time of the evaluation. Record reviews were then scored using the

DSM IV (1994) criteria and determined as a Case of Autism, Case of ASD, or Not a Case

using rules defined by the CDC. All information abstracted was entered into a database

for each child. The information pertaining to SCQ scores and categorization, and the

corresponding record review information, scoring, and categorization was also entered

into a database. See Appendix A for the Clinician review DSM-IV coding form and Appendix B for the summary form.

This method of screening and abstracting records from multiple medical and educational sources has been used in a variety of studies to identify cases of ASDs in prevalence research (Bertrand et al., 2001). It has been found to be an effective way of ascertaining an accurate measure of a specific child's possible ASD symptom presentation (CDC, 2000). Furthermore, inter-rater reliability for this methodology has achieved 92% agreement (Rice et al, 2007). In addition, Gonzalez and Kaiser (in preparation) found the record review methodology to have 97% sensitivity with a sample from the same population as the current study in identifying children whose parents reported an ASD diagnosis. Therefore, as can be seen in these studies, this case definition method of using historical records has a high sensitivity in identifying possible cases of ASD.

Social Communication Questionnaire

The SCQ was completed by mothers to obtain information about core diagnostic features of autism. The questionnaire is made up of 25 questions pertaining to deficits in social skills, 13 questions on communication, nine questions referring to repetitive behaviors, and two on associated features, all of these are preceded by the opening question, which refers to the child's current language level. The answer to this initial language functioning question determines whether or not the subsequent questions pertaining to communication need to be addressed. Half of the questions are based on whether or not the behaviors ever occurred in the child's lifetime, and the other half is focused on the 4- to 5- year age range in order to take developmental impairment into

account. A score of 1 is given for the presence of an abnormal behavior and a score of 0

is given for its absence. Therefore, higher scores reflect higher severity.

Berument and colleagues (1999) stated that a score of 15 or more was the most

effective cutoff for differentiating PDD from other diagnoses with a specificity of .75 and

sensitivity of .85. The separation of Autism from other types of PDD was not as strong. A

cutoff of 22 or more for Autism yielded a specificity of .60 and a sensitivity of .75.

Therefore, for this study, the previously set cutoff scores will be 15 identifying children

as PDD and 22 identifying Autism.

Short Acculturation Scale for Hispanics (SASH)

The SASH is a short 12 item acculturation questionnaire for Hispanics. It asks

questions about language use, media, and ethnic social relations. This measure is reliable

and valid, found to correlate highly with characteristics like respondent's generation,

length of residence in the US, age at arrival, ethnic self-identification, and an

acculturation index (Marin, Otero-Sabogal, & Perez-Stable, 1987). Furthermore, validity

between Mexican Americans and Central Americans showed similar results.

Five Minute Speech Sample (FMSS)

Expressed Emotion is generally measured using the Camberwell Family Interview

(CFI; Leff & Vaughn, 1985) which is a one to one and a half hour audiotaped interview

that is later rated on three dimensions (criticism, hostility, and EOI) using established

operationalized guidelines developed through the instruments' validation, based on

Expressed Emotion theory.

In an attempt to shorten the assessment of Expressed Emotion and make it more

clinically applicable, the Five Minute Speech Sample (Magana-Amato, 1993) was created

where the patient's family member is asked to talk freely about the patient for five minutes and judgments are made on the basis of the information obtained. The mother was read this excerpt verbatim:

"I'd like to hear your thoughts and feelings about (child's name), in your own words and without my interrupting you with any questions or comments. When I ask you to begin I'd like you to speak for five minutes, telling me what kind of person (child's name) is and how the two of you get along. After you begin I'd prefer not to answer any questions until after the five minutes." (Magana-Amato, 1993)

Ratings consist of four categories of initial statement, relationship, critical comments, and dissatisfaction rated on the basis of criticism and EOI. The criticism rating is based on the presence of a negative initial statement or description of the child, a negative relationship or evaluation, or greater than one critical or dissatisfied statement. An EOI rating includes self-sacrificing or overprotective behavior, the parent breaking down emotionally during the interview, excessive detail about the past, one or more statements of attitude, defined as expressing feelings of love, or evidence of excessive praise and excessive overall positive statements. This measure has proven to be valid, corresponding with the CFI and showing acceptable sensitivity and specificity in clinical samples (Shimodera et al., 2002).

Chapter 4: Results

Descriptive Statistics

Sixty-seven of the Hispanic children met case definition of Autism by the historical review of records, 48 met criteria for ASD-NOS, and 35 for Non-ASD. The mean SCQ score for children identified as an Autism case was 19.39. The mean for the ASD-NOS cases was almost the same at 19.73. The mean score for the Non-ASD cases was lower at 13.29. However, the range of scores for this group was very broad at 2-31. See Table 3 for complete descriptive statistics on the SCQ scores between the three groups.

1) What is the sensitivity and specificity of the SCQ in a Hispanic sample?

A Receiver Operating Characteristic (ROC) curve was used to determine the validity of two cutoffs delineated by Berument (1999): 1) a cutoff of 15 to distinguish children with PDD from those without PDD and, 2) a cutoff of 22 which is thought to distinguish children with Autism from those with PDD or without PDD. Sensitivity refers to the proportion of children identified as Cases of ASD or Autism by the record review who also met criteria for PDD or Autism on the SCQ. Specificity refers to the proportion of children that were identified as Non-ASD cases via record review who did not meet criteria for PDD or Autism on the SCQ (refer to Figure 2). The 15 cutoff yielded a sensitivity of .69 and a specificity of .54 for ASD (or PDD) for this sample of Hispanic children. Additionally, the 22 cutoff yielded a sensitivity of .33 and specificity of .86 for Autism for this sample of Hispanic children (see Table 4).

Positive and negative predictive values were also calculated for both cutoffs scores of 15 and 22. Positive predictive power is the probability that a child identified by the SCQ

actually has an ASD according to record review, and negative predictive power is the probability that a child not identified by the SCQ actually does not have an ASD according to record review. The positive predictive value is calculated by gathering the total number of true positives divided by all true and false positives (please see Figure 2). In other words, that would be the number of children correctly identified by the questionnaire divided by all of the children identified by the questionnaire, correctly and incorrectly. In this investigation, a true positive occurred in two ways: (1) a child that scores as Autistic on the SCQ and is identified as a Case of Autism by the record review, and (2) a child that scores as PDD on the SCQ and is identified as a Case of ASD by the record review. A false positive occurred in three ways in this study: (1) a child that scores as Autistic on the SCQ, but is identified as a Non-ASD case by the record review, (2) a child that scores as at risk for Autism on the SCQ, but is considered a Case of ASD by the record review, and (3) a child that scores as at risk for ASD on the SCQ, but is but is identified as a Non-ASD case by the record review. In summary, positive predictive power is the likelihood that a child identified as at risk for the disorder by the questionnaire was actually correctly identified. The positive predictive value for the 15 cutoff was .83 and for the 22 cutoff was .82 for this Hispanic sample (See Table 4)

Negative predictive value is calculated by collecting the total number of true negatives divided by all true and false negatives, or divided by the total number of children not identified by the questionnaire. In this calculation, the number of children correctly identified as a Non-ASD case by the questionnaire is divided by the total number of children not identified by the questionnaire, correctly and incorrectly. For the purpose of this study, a true negative occurred in two ways: (1) a child who scores below

cutoff for PDD on the SCQ and is Not a Case of ASD according to the record review, and

(2) a child who scores below cutoff for PDD on the SCQ and is Not a Case of Autism by

the record review. A false negative also occurred in two ways: (1) a child who scores

below cutoff for PDD on the SCQ, but is considered a Case of ASD by the record review,

and (2) a child that scores below cutoff for PDD on the SCQ, but is considered a Case of

Autism by the record review. In summary, negative predictive power is the likelihood

that a child that did not meet cutoff on the questionnaire actually should not have been

identified. The negative predictive power of the 15 cutoff was .35 and of the 22 cutoff

was .40 for this Hispanic sample (see Table 4). The area under the ROC curve (AUC)

measures the ability of the SCQ to correctly classify those with and without ASD. The

AUC can range from 1 (perfect) to .5 (worthless). The AUC does not vary by cutoff, but

instead varies by the diagnostic groups being examined by the ROC. The AUC in this

Hispanic sample discriminating between both ASD vs. Non-ASD and Autism vs. Non-

ASD was .72, which is considered fair. The AUC for Autism vs. Non-Autism (including

ASD) was .59, considered poor. These validation results for both cutoff scores are much

lower than the original validation study but comparable to more recent studies (Corsello

et al., 2007; Wiggins, Bakeman, Adamson, & Robins, 2007)

2) What are more appropriate SCQ cutoffs for the Hispanic sample?

A Receiver Operating Characteristic (ROC) curve was again used to establish an

optimal cutoff score for this Hispanic sample. This method is used to determine the best

cutoff point from which optimal sensitivity and specificity can be acquired. The ROC

curve demonstrated how raising or lowering the cutoff point for defining a case of ASD

affects tradeoffs between correctly identifying these children with ASD (true positives)

and incorrectly labeling them as having an ASD when they do not (false positives). In order to obtain the most efficient screening outcome, this also yielded the positive and negative predictive values of the measure that demonstrates the rate of true positives and negatives.

The ROC analysis works best when the sample under consideration includes different kinds of individuals, which is why this sample included children with all kinds of ASDs, including Autistic Disorder, Asperger Syndrome, and PDD-NOS. The non-ASD sample included children with other developmental disabilities (24) as well as children who are typically developing (11). The cutoff score found to perform best for distinguishing ASD (including Autism) from Non-ASD in this Hispanic sample was 12, with a sensitivity of .86 and specificity of .54. By lowering the cutoff, the sensitivity increased, yet the specificity remained the same. Therefore, this new cutoff will correctly screen more Hispanic individuals who may present with ASD without including Hispanic children that do not have ASD. This new cutoff score yielded a positive predictive value of .86 and negative predictive value of .54. The NPV also increased from the 15 cutoff indicating a higher likelihood that the Hispanic children that were not identified by the 12 cutoff, actually should not have been.

Similarly, the best cutoff for distinguishing between Autism and Non-ASDs in this Hispanic sample was also 12. This score yielded very similar results with a sensitivity of .85 and specificity of .54. By lowering the cutoff to 12 for this group, the sensitivity increased, however the specificity decreased. While using this 12 cutoff correctly identified more Hispanic children with Autism, it also mis-identified many more Hispanic children as Autistic that did not actually have Autism. The positive predictive

value was .78 and negative predictive value .65 (see Table 4 for the validation results for the 12 cutoff score). These results demonstrate the SCQ's lack of ability to distinguish between those likely to present with Autism and those not in the spectrum for this Hispanic sample. Another ROC was run including the ASD children, comparing them to those with strictly Autism. The optimal cutoff distinguishing between Autism and those without autism (including ASD) was 15, with a sensitivity of .73, specificity of .45, PPV of .52 and NPV .67. The AUC for these cutoffs are the same as mentioned in research question #1. They do not change as a result of cutoff but rather by diagnostic groups being analyzed. Not surprisingly, the SCQ had performed worse distinguishing between Hispanic children within the spectrum (Autism vs. Non-Autism) than between the most and least severe (Autism vs. Non-ASD). An ROC analysis could not be performed looking at children with Autism only versus those with ASD only, or those higher functioning versus lower functioning children. This was due to the lack of variability in SCQ scores between these two groups.

3) How do levels of Expressed Emotion (EE) impact scores on the SCQ?

Pearson chi-squares were used to determine if the levels of high and low Expressed Emotion differed between Hispanic and non-Hispanic white mothers of children with ASD. There was no significant difference found between these two groups on the overall EE rating or the EE subgroup ratings. Pearson Chi-Squares and one-way ANOVAS were used for all scoring categories that determine high and low Expressed Emotion. No significant differences were found between Hispanics and White for criticism, positive remarks, initial statement, emotional display, and excess detail. There was a significant difference found between the groups in relationship. Hispanics described their

relationship with their child as positive more often than non-Hispanic Whites (χ^2 (1, $N =$ 67) = 3.76, p = .052). Trends were found for statements of attitude (e.g. "I love him dearly") in that Hispanics had slightly higher statements than Whites (F (1, 65) = 3.15, p = .08). Hispanics also showed a trend to display more borderline self sacrificing, overprotection, and lack of objectivity as compared to Whites (χ^2 (1, N= 67) = 3.05, p = .08) Finally, regression analyses were used to determine whether overall EE ratings, subgroups ratings, and scoring categories predicted SCQ scores. Overall, no significant results were found in these analyses. None of the EE categories were found to predict SCQ score or meeting the 15 SCQ cutoff. See Table 5 for a summary of EE analyses.

Qualitative Analysis of Expressed Emotion Data. Information obtained from mothers via the FMSS was transcribed and imputed into ATLAS.ti (Muhr, 1994), which is a computer program that is used for qualitative analysis of large bodies of textural data. Exploratory analysis of Expressed Emotion data was analyzed using ATLAS.ti.

The most common words used by the mother in the FMSS were determined. One-way ANOVAS were used to determine if Hispanics and non-Hispanic Whites differed in the words they used to talk about their children with ASD. No significant differences were found. However a trend was found for Hispanics to use the word "affectionate", F (1, 65) = 3.37, p = .07, more often than Whites and for Whites to use the word "diagnosed" more often, F (1, 65) = 3.48, p = .07.

Furthermore, visual inspection of the quotations scored as positive relationship, statements of attitude, and self sacrificing/overprotective behavior between the two groups was carried out to establish comparisons. Quotations are the actual words used by the mother that were scored in the FMSS. Generally, Hispanics tended to describe their

positive relationship with their child by describing them as their "best friend" (5 out of 46 quotations) and by stating there is a special communication between them (4 out of 46 quotations). Whereas Whites tended to describe their positive relationship in terms of spending time together, this difference in proportion was statistically significant, χ^2 (1, N = 63) = 13.92, p < .01. In statements of attitude, Hispanics displayed a willingness to do anything (e.g. "I would do anything for him"; 7 out of 15 quotations) and statements of love (e.g. "I love him with all my heart"), whereas non-Hispanic Whites only displayed statements of love, χ^2 (1, N = 18) = 24.44, p < .01. Borderline self-sacrificing/overprotective behavior was only evident in the Hispanic group (total 5 quotations), where the mothers expressed borderline personal sacrifice, dedication, life changes, and self-restriction, which was also statistically significant, χ^2 (1, N = 5) = 6.40, p = .01. The age of the child at the time of the interview did not impact any of the FMSS variables examined. See Table 6 for a summary of the qualitative information obtained from the FMSS.

Chapter 5: Discussion

Validation Results

The sensitivity and specificity of the SCQ in a Hispanic sample was much lower than the original validation study (Berument, 1999). This is not surprising considering more recent validation studies finding similar results. In fact, the findings of this study closely resemble those found by Corsello and colleagues (2007). A cutoff of 12 was found to work best in both studies with a high sensitivity, but a lower specificity.

It was interesting to find that the present results matched so closely with the Corsello and colleagues (2007) study, even though that sample was comprised of mostly Caucasian participants, ages 2-16 years. While it was hypothesized that the best cutoff for a Hispanic sample would be different from a Caucasian sample, the current sample and the Corsello sample actually shared some other similarities despite differences in ethnicity. In this study, most children had a previous diagnosis of ASD and were enrolled with a university-based service program (e.g. UM-CARD). These parents are very familiar with most ASD evaluation measures and know the kinds of shortcomings their children display very well. Similarly, the Corsello et al. (2007) study had a sample comprised of consecutive referrals to two university based clinics specializing in children with possible ASDs or children that were already participants in research within the autism centers. Perhaps the validation results in both studies would be very different if taken from the general population or even from clinics or centers that do not specialize in autism, really investigating the screener's true ability in the "real world." It could be said that when the parent is already aware and educated on the disorder, Hispanics do not

differ than non-Hispanic Whites in their reporting on the SCQ. However, the potential cultural differences that can affect unsuspecting parents are still largely unanswered.

Surprisingly, the mean SCQ score for children with Autism and those with ASD was practically the same, which lead to the almost equal sensitivity and specificity found for the 15 cutoff. The SCQ has been consistently found to correlate with the ADI-R (Berument et al., 1999; Corsello et al., 2007). This means that children that are found be more severe according to the ADI-R, also have higher SCQ scores. However, in the current study, children considered a case of Autism scored the same as children with ASD-NOS on the SCQ. This highlights the SCQ's limitations in screening out the most severe Hispanic children. As a screening instrument, it would be expected that the children with the most delays and adverse behaviors would be easily captured by the measure. Consequently, it would also be expected that children that are more high-functioning would be harder to detect. In the case of the SCQ in this Hispanic sample, it was found to function equally for both cases of children. This might be problematic if one wants to use the SCQ as a first screen or to measure prevalence of ASDs. There are instances in which service delivery is heavily reliant on where the child lies within the spectrum, where a child considered Autistic will get different services than one with Asperger's disorder. Therefore, the SCQ would not be the proper instrument to use for this kind of differentiation.

Defining Cases of ASD

There was great variability in the way cases of ASD were defined by the various validation studies reviewed in the introduction (see Table 1). As aforementioned, the SCQ has been consistently found to correlate highly with the ADI-R, therefore it comes

as no surprise that studies using this measure found the highest sensitivity and specificity rates for the SCQ (Corsello et al., 2007; Charman et al., 2007). Lee and colleagues (2007) compared various criterion measures for defining ASD in children ages 3-5 (predominately White) in examining the validity of the 15 SCQ cutoff. The highest sensitivity (.70) was found when using the autism classification on the ADOS. This is a very stringent criterion in comparison to an autism or developmental delay special education classification which yielded the lowest sensitivity (.24).

While the record review methodology in defining cases has been found to be valid in prevalence studies (Rice et al., 2007), there are some limitations to making case decisions purely on historical records. At times, the availability of records became an issue for some children, making it difficult to obtain comprehensive evaluations to abstract. At other times, records did not have sufficient details to meet criteria for ASD via the record review but the records still indicated a qualified diagnostician made an ASD diagnosis. Therefore, children that may in fact be ASD can be classified as a case of Non-ASD according to the DSM-IV due to the dearth of information. Future studies should include direct observations of the children, such as with the ADOS, to supplement the information found within historical records. This clinical judgment in combination with the multi-disciplinary information obtained in the various files could provide consistent standard for determining the children's actual status.

Choosing a Cutoff Score

This study highlights the importance of adjusting cutoff scores based on the population, the purpose of screening and the way cases are defined. The importance placed on sensitivity over specificity may vary by situation. For epidemiological

research, a representative sample is most important. Therefore, higher sensitivity is considered optimal leading to a preference for lower cutoff scores. On the other hand, in a clinical setting this may not be the case. Higher cutoff scores may be preferred in order to maximize specificity. False positives or negatives may still need further evaluation for other developmental issues. If a child is missed by the questionnaire, it is likely they will still be referred for additional testing. However, if the SCQ is the sole source of information being obtained for a particular child, low sensitivity and specificity can create serious problems. Children could lose valuable time for intervention due to the lack of early detection.

The lower cutoff of 12 was found to work best for this Hispanic sample. It increased the sensitivity, making the measure more able to detect the children that actually have the disorder. On the other hand, the specificity is still very low, where many Non-ASD children are being falsely screened as ASD. This kind of error would not be cost effective in the case of a prevalence study, where the objective is to screen a large amount of individuals in the most efficient way possible. This would create an unnecessary amount of testing and evaluation, wasting time and resources. On the other hand, if the aim is to screen out all children that present with any kind of ASD-like behavior, than the 12 cutoff would be more suitable. In this case, casting a larger net would be preferable.

Expressed Emotion in Parents with a Child with ASD

Expressed emotion was compared between Hispanics and non-Hispanic Whites. While no statistically significant findings were yielded, some trends were noted. Hispanics tended to describe their relationship with their child as positive more often than

Whites, which is consistent with previous findings (Weisman & Lopez, 1997). Also, Hispanics tended to make more statements of attitude, specifically expressing a willingness to do anything for their child. Furthermore, Hispanics were the only group to express self sacrificing or overprotective behavior. Although not all of these mothers were found to be Emotionally Over Involved (EOI), these two subcategories (1: statements of attitude and 2: self sacrificing/overprotective behavior) lead to that classification. These findings are actually contrary to previous studies on EE in Hispanics, which found that Hispanic parents were less likely to be emotionally over-involved compared to whites (Jenkins & Karno, 1992). One reason for this could be due to differences between the Hispanic groups. The studies aforementioned tend to look at Mexican-American Hispanics where as this study included many acculturated Hispanics born in the US or in Cuba, as reported on the SASH.

These differences in expressed emotion could have many implications for a screening instrument such as the SCQ. If Hispanics tend to feel overprotective of their child, they may be reluctant to fully disclose the deficient behaviors their child may exhibit. Barrowclough, Johnston, and Tarrier (1994) found that EOI relatives have made sense of the illness in terms of factors that are outside of the patient's control. Therefore, these relatives attempt to ameliorate events by using themselves as a buffer between the patient and the outside world through their use of self-sacrificing and intrusive behaviors, trying to put the factors under their own control. These mothers may be trying to "protect" their children in some way by not completely disclosing of their child's behaviors. Furthermore, nearly all studies examining cultural differences in expressed emotion of mothers are toward their adolescent or adult children (Barrowclough &

Hooley, 2003; Rosales, 2005; Jenkins & Karno, 1992). This sample consisted of young children, therefore the mother's expressed emotion may vary by the age of the child.

Limitations of Current Study

Initially, this study intended to include more participants than were actually involved. The Hispanic validation sample was originally set out to include 150 mothers of children with ASD and 50 mothers with children who were considered Non-ASD. The sample to investigate expressed emotion was to include 100 mothers of children with ASD, 50 Hispanic and 50 Whites. These numbers were thought possible due to the larger prevalence study from which these mothers were being recruited. However, since many of these mothers had not been contacted for a few years, issues with relocation and loss of contact information arose, making it difficult to include these families. Furthermore, the availability of non-ASD and White mothers was also a challenge. Mothers of children without ASD were more difficult to locate and recruit. Additionally, in Miami-Dade county, it can also be difficult to find a large number of White non-Hispanic mothers of children with ASD, so these mothers were mostly recruited via mass emails from UM-CARD. Due to these limitations, the number of Non-Hispanic White mothers of children with ASD was significantly lower than anticipated.

Another barrier to the inclusion of participants was the mothers' response latency as well as the response from various diagnostic resources and schools. Some mothers took more time than others to return the various consent and release forms required to conduct a historical review of records. Once those forms were received it then depended on the cooperation and timeliness of the various record sources involved. In most cases,

record requests needed to be made at least 2-3 times before getting a response. All these issues together resulted in fewer participants included than anticipated.

An additional limitation was the relatively small sample size for the non-Hispanic Whites. Perhaps if a larger comparison group would have been included, there would have been more differences found in the various components of EE. Future studies should include a larger White sample of children with and without ASD to provide further comparisons between these ethnic groups.

Lastly, the FMSS is typically administered in person to parents of adult children with various disorders. In this study, the FMSS was administered over the phone to mothers of children ages 4 to 10. The rapport that is established in person versus over the phone may vary, causing parents to divulge less or different information between the two circumstances.

Future Directions

Future studies can investigate possible differences in cutoff scores for younger versus older children in a Hispanic sample. Some studies (Corsello et al., 2007; Lee et al., 2007) have found that the SCQ does not perform as well with younger children (less than 5 years old) than with the older ones. In addition, future studies can investigate possible gender differences in SCQ performance. Gender roles tend to be very clearly defined and enforced in more traditional cultures such as Hispanics (Mio et al., 2006) therefore it would be interesting to see if parent report could vary between the genders in this respect.

The Hispanic sample used in this study were mothers mostly born in the US, highly educated, and acculturated according the SASH. It would be informative to revalidate the SCQ in a different Hispanic sample, one that is more typical to other parts

of the US. Specifically, validating the Spanish version of the SCQ is crucial. Many

Hispanic parents that are immigrants to this country may not have the financial means or

education to be able to seek out proper evaluation of their child's development.

Additionally, differences in maternal and paternal report should also be investigated.

These kinds of investigation could prove beneficial in generalizing to other Hispanics.

Furthermore, the FMSS provides a great deal of qualitative as well as quantitative

information that may be missed when analyzing the scoring categories solely. For

instance, in this sample, some mothers spoke for just a few moments at the beginning of

the sample and stopped speaking. On the other hand, other mothers spoke for much

longer than the 5 minutes required. In addition, some mothers would speak about other

issues concerning their child, such as their status at school, instead of speaking about

their relationship and how they get along. Therefore, many of the statements these

mothers would make were unable to be scored according the expressed emotion

guidelines. These differences between the mothers could also provide valuable

information outside of what is typically scored in the FMSS. Future studies could tap into

the wealth of information that the FMSS provides by establishing new scoring strategies

to detect these apparent differences between mothers.

Conclusion

The present study examined the validity the SCQ in a Hispanic sample, which has

not been done previously (Corsello et al., 2007). Results yielded low sensitivity and

specificity in this sample, nevertheless matching more recent validation studies on the

screener. Future studies examining the performance of questionnaires in larger more

representative samples are needed in order to directly compare and contrast between

ethnic groups. The differences in expressed emotion offer some insight into the variability in the ways mothers express themselves about their children with ASD.

Overall cultural differences remain an area that needs to be examined, especially within the realm of ASDs. There may be many factors influencing whether particular children are correctly identified as having the disorder. These factors include the first signs seen by the pediatrician or parent, the participation and cooperation of the family with the report of behaviors and development, and subsequent treatment. These areas are yet to be examined, yet the present study offers some insight into the subtle cultural differences that can arise in these two particular ethnic groups.

References

Allen, C. W., Silove, N., Williams, K., and Hutchins, P. (2007). Validity of the social communication questionnaire in assessing risk of autism in preschool children with developmental problems. *Journal of Autism and Developmental Disorders, 37*, 1272-1278.

American Psychiatric Association (1994). *The diagnostic and statistical manual of mental disorders: Fourth Edition*. Washington, D.C.: APA Division of Publications.

Baron-Cohen, S., Wheelwright, S., Cox, A., Baird, G., Charman, T., Swettenham, J., Drew, A., & Doehring, P. (2000). The early identification of autism: The checklist for autism in toddlers (CHAT). *Journal of the Royal Society of Medicine, 93*, 521-525.

Barrett, S., Prior, M. Manjiviona, J. (2004). Children on the borderlands of autism. *Autism, 8(*1), 61-87.

Barrowclough, C. & Hooley, J. M. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review, 23*(6), 849-880.

Berry, J. W., Poortinga, Y. H., Se all, H. H., & Dasen, P. R. (1992). *Cross cultural psychology: Research and applications.* Cambridge: Cambridge University Press.

Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001). Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Pediatrics, 108*(5), 1155-1161.

Berument, S., Rutter, M., Lord, C., Pickels, A., & Bailey, A. (1999). Autism screening questionnaire: Diagnostic validity. *British Journal of Psychiatry, 175*, 444-451.

Bishop, D. V. M., & Norbury, C. F. (2002). Exploring the borderlands of autistic disorder and specific language impairment: A study using standardized diagnostic instruments. *Journal of Child Psychology and Psychiatry, 43*(7), 917-929.

Bolte, S. & Poustka, F. (2005). Psychodiagnostic instruments for the assessment of autism spectrum disorders. *Zeitschrift fur Kinder und Jugendpsychiatrie und Psychotherapie, 33*(1), 5-14.

Brereton, A. V., Tonge, B. J., Mackinnon, A. J., & Einfeld, S. L. (2002). Screening young people for autism using the developmental behaviour checklist. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(11), 1369-1375.

Centers for Disease Control and Prevention (2000). *Prevalence of autism in Brick Township, New Jersey, 1998: Community Report.* www.cdc.gov/ncbddd/dd/reprt.htm.

Centers for Disease Control and Prevention (2007). Prevalence of autism spectrum disorders- autism and developmental disabilities monitoring network, 14 sites, United States, 2002. Surveillance Summaries, 2007. MMWR 2007; 56(No-SS-1).

Charman, T., Baird, G., Simonoff, E., Loucas, T., Chandler, S., Meldrum, D., and Pickles, A. (2007). Efficacy of three screening instruments in the identification of autistic-spectrum disorders. *British Journal of Psychiatry, 191*, 554-559.

Charman, T., Howlin, P., Berry, B., & Prince, E. (2004). Measuring developmental progress of children with autism spectrum disorder on school entry using parent report. *Autism, 8*(1), 89-100.

Corsello, C., Hus, V., Pickles, A., Risi, S., Cook, E. H., Leventhal, B. L., and Lord, C. (2007). Between a ROC and a hard place: Decision making and making decisions about using the SCQ. *Journal of Child Psychology and Psychiatry, 48*(9), 932-940.

Croen, L. A., Grether, J. K., Hoogstrate, J. & Selvin, S. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders, 32*(3), 207-215.

Daley, T. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry, 39*(4), 531-550.

Danseco, E. R. (1997). Parental beliefs on childhood disability: Insights on culture, child development and intervention. *International Journal of Disability and Development, 44*, 41-52.

Eaves, L. C., Wingert, H., and Ho, H. H. (2006). Screening for autism: Agreement with diagnosis. *Autism, 10*(3), 229-242.

Eaves, L. C., Wingert, H. D., Ho, H. H., and Michelson, E. C. R. (2006). Screening for autism spectrum disorders with the social communication questionnaire. *Developmental and Behavioral Pediatrics, 27*(2), 95-103.

Farzin, F., Perry, H., Hessl, D., Loesch, D., Cohen, J., Bacalman, S., Gane, L., Tassone, F., Hagerman, P., & Hagerman, R. (2006). Autism spectrum disorders and attention-deficit/hyperactivity disorder in boys with the fragile x permutation. *Journal of Developmental and Behavioral Pediatrics, 27*(2), 137-144.

Gillberg, C., Steffenburg, S., & Schaumann, H. (1991). Is autism more common now than 10 years ago? *British Journal of Psychiatry, 158*, 403-409.

Gillberg, C., Steffenburg, S., Borjesson, B. & Andersson, L. (1987). Infantile autism in children of immigrant parents: A population-based study from Goteborg, Sweden. *British Journal of Psychiatry, 150*, 856-858.

Gonzalez, V. & Kaiser, M. (2006). *A comparison of common methods used in identifying children with autism.* Manuscript submitted for publication, University of Miami, Miami, FL.

Greenberg, J. S., Seltzer, M. M., Hong, J., and Orsmond, G. I. (2006). Bidirectional effects of expressed emotion and behavior problems and symptoms in adolscents and adults with autism. *American Association on Mental Retardation, 111*(4), 229-249.

Hooley, J. M. (1987). *The nature and origins of expressed emotion. Understanding major mental disorder: The contribution of family interaction research.* New York, NY, US: Family Process Press.

Howlin, P. & Karpf, J. (2004). Using the Social Communication Questionnaire to identify 'autistic spectrum' disorders associated with other genetic conditions: Findings from a study of individuals with Cohen syndrome. *Autism, 8*(2), 175-182.

Jenkins, J. H. & Karno, M. (1992). The meaning of expressed emotion: Theoretical issues raised by cross-cultural research. *American Journal of Psychiatry, 149*(1), 9-21.

Kadesjo, B., Gillberg, C., & Hagberg, B. (1999). Brief report: Autism and asperger syndrome in seven-year-old children: A total population study. *Journal of Autism and Related Disorders, 29*, 327-331.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.

Keller, A., Castellanos, F. X., Vaituzis, A. C., Jeffries, N. O., Giedd, J. N., & Raoport, J. L. (2003). Progressive loss of cerebellar volume in childhood-onset schizophrenia. *American Journal of Psychiatry, 160*, 128-133.

Lau, A. S., Garland, A. F., Yeh, M., McCabe, K. M., Wood, P. A., & Hough, R. L. (2004). Race/ethnicity and inter-informant agreement in assessing adolescent psychopathology. *Journal of Emotional and Behavioral Disorders, 12*(3), 145-156.

Le Couteur, A., Rutter, M., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J.D. (1989). Autism Diagnostic Interview: A semi-structured interview for parents and caregivers of autistic persons. *Journal of Autism and Developmental Disorders, 19*, 363-387.

Lee, L., David, A. B., Rusyniak, J., Landa, R., & Newschaffer, C. J. (2007). Performance of the social communication questionnaire in children receiving preschool special education services. *Research in Autism Spectrum Disorders, 1*, 126-138.

Leff, J. & Vaughn, C. (1985). *Expressed emotion in families*. London: Guilford Press.

Lemer, P. (2006). How recent changes have contributed to an epidemic of autism spectrum disorders. *Journal of Behavioral Optometry, 17*(3), 72-77.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24*, 659-685.

Magana-Amato, A. (1993). *Manual for coding expressed emotion from the 5 minute speech sample.* Unpublished manuscript, University of California at Los Angeles.

Mandell, D. S. & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*, 110-115.

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(12), 1447-1453.

Marín, G., Sabogal, F., VanOss Marín, B., Otero-Sabogal, F., Pérez-Stable, E. J. (1987). Development of a short acculturation scale for hispanics. *Hispanic Journal of Behavioral Sciences, 9*, 183-205.

Michelotti, J., Charman, T., Slonims, V., & Baird, G. (2002). Follow-up of children with language delay and features of autism from preschool years to middle childhood. *Developmental Medicine & Child Neurology, 44*, 812-819.

Mio, J. S., Barker-Hackett, L., & Tumambing. J. (2006). What is multicultural psychology? In *Multicultural psychology: Understanding our diverse communities* (pp. 1-32). Boston: McGraw-Hill.

Muhr, T. (1994). Atlas.ti: *Computer aided text interpretation and theory building: User's manual* (2nd ed.). Berlin: Author.

Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., and Krauss, M. W. (2006). Mother-child relationship quality among adolescents and adults with autism. *American Association on Mental Retardation, 111*(2), 121-137.

Rice, C. E., Baio, J., Van Naarden Braun, K., Doernberg, N., Meaney, F. J., & Kirby, R. S. (2007). A public health collaboration for the surveillance of autism spectrum disorders. *Paediatric and Perinatal Epidemiology, 21*, 179-190.

Robins, D. L., Fein, D., Barton, M. L., & Green, J. A. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31*(2), 131-144.

Rosales, G. A. (2005). Self-construal and expressed emotion in black, latino, and white family members of patients with schizophrenia. *Dissertation Abstracts-International: Section B: The Sciences and Engineering, 66*(1-B), 573.

Rutter, M., Anderson-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., Kreppner, J., Keaveney, L., Lord, C., O'Conner, T. G., and the English and Romanian Adoptees Study Team. (1999). Quasi-autistic patterns following severe early global privation. *Journal of Child Psychology and Psychiatry, 40*(4), 537-549.

Rutter, M. L., Kreppner, J. M., & O'Conner, T. G. (2001). Specificity and heterogeneity in children's responses to profound institutional privation. *British Journal of Psychiatry, 179*, 97-103.

Sanua, V. D. (1981). Autism, childhood schizophrenia and culture: A critical review of the literature. *Transcultural Psychiatric Research Review, 18*, 165-181.

Shimodera, S., Mino, Y., Fujita, H., Izumoto, Y., Kamimura, N., & Inoue, S. (2002). Validity of a five-minute speech sample for the measurement of expressed emotion in the families of Japanese patients with mood disorders. *Psychiatry Research, 112*(3), 231-237.

Swinkels, S. H. N., Dietz, C., Van Daalen, E., Kerkhof, I. H. G. M., Van Egeland, H., & Buitelaar, J. K. (2006). Screening for autistic spectrum in children aged 14 to 15 Months. I: The development of the early screening of autistic traits questionnaire (ESAT). *Journal of Autism and Developmental Disorders, 36,* 723-732.

Taylor, B. (2006). Vaccines and the changing epidemiology of autism. *Child: Care, Health and Development, 32*(5), 511-519.

Towbin, K., Pradella, A., Gorrido, T., Pine, D. S., & Leibenluft, E. (2005). Autism spectrum traits in children with mood and anxiety disorders. *Journal of Child and Adolescent Psychopharmacology, 15*(3), 452-464.

United States Bureau of the Census (2000). *2000 Census of Population and Housing* (Data User Services Division). Washington, DC: Author

Veltman, M. W. M., Thompson, R. J., Roberts, S. E., Thomas, N. S., Whittington, J., & Bolton, P. F. (2004). Prader-willi syndrome: A study comparing deletion and uniparental disomy cases with reference to autism spectrum disorders. *European Child and Adolescent Psychiatry, 13*(1), 42-50.

Wearden, A. J., Tarrier, N., Barrowclough, C., Zastowny, T. R., & Rahill, A. A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review, 20*(5), 633-666.

Weiner, B. (1980). A cognitive (attribution)-emotion-action model of motivated behavior: An analysis of judgments of help-giving. *Journal of Personality and Social Psychology, 39*(2), 186-200.

Weisman, A., Lopez, S. R., Karno, M., & Jenkins, J. (1993). An attributional analysis of expressed emotion in Mexican-American families with schizophrenia. *Journal of Abnormal Psychology, 102*(4), 601-606.

Wiggins, L. (2005, April). *Parental screening for autism spectrum disorders in early intervention programs: The utility of the social communication questionnaire.* Poster session presented at the biennial meeting of the Society for Research in Child Development, Atlanta, GA.

Wiggins, L. D., Bakeman, R., Adamson, L. B., and Robins, D. L. (2007). The utility of the social communication questionnaire in screening for autism in children referred for early intervention. *Focus on Autism and Other Developmental Disabilities, 22*(1), 33-38.

Yeargin-Allsopp, M., Rice C., Karapukar T, Doernberd N., Boyle C., Murphy C. (2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association, 289*(1), 49-55.

Yeargin-Allsopp, M., Drews, C D., Decoufle, P., & Murphy, C. C. (1995). Mild mental retardation in black and white children in metropolitan Atlanta: A case-control study. *American Journal of Public Health, 85*(3), 324-328.

Clinician Review DSM-IV TR Coding Form

Date				
Chron. Age (yrs;mos)				
Specialty				
Source Type				
SOCIAL INTERACTION:				
1a Nonverbal behavior				
1b Peer relationships				
1c Spontaneous seeking				
1d Emotional reciprocity				
1e Soc int impairment NOS				
COMMUNICATION:				
2a Spoken language				
2b Conversational deficit				
2c Repetitive language				
2d Imaginative Play				
2e Com impairment NOS				
UNUSUAL BEHAVIOR:				
3a Restricted interests				
3b Routine and rituals				
3c Stereotyped mannerisms				
3d Preoccupation w/ parts				
3e Unusual behavior NOS				
DEVELOPMENTAL HISTORY:				
Gen dev concerns <3 yrs				
Specify age				
Soc int delay/abn dev <3 yrs				
Specify age				
Lang delay/abn dev <3yrs				
Specify age				
I/S play delay/abn dev <3 yrs				
Specify age				
Loss of skills				
Specify age				
Developmental Plateau				
Specify age				
ANY AUT DISCRIMINATOR?				
ASD EVAL DIAGNOSIS				
NON-ASD EVAL DIAGNOSIS				
OTHER NON-ASD EVAL DX				

Appendix B

ASD Clinician Review: Reviewer Summary Coding Form

Study ID:

Reviewer: _____   Review date: _____/_____/_____

_____ Reviewer 1   _____ Reviewer 2   _____ Consensus (1 and 2)   _____ Reviewer 3

Earlier PDD Diagnosis (historical report in record):   _____ None Stated

Earliest Date: _____ /_____ /_____   Age: _____   Facility: _____
Examiner and Degree: _____   Specialty: _____
PDD Diagnosis: _____ASD/PDD _____ Asperger's Disorder ____Atypical Autism ____ Autistic Disorder

                 _____ CDD   _____ PDD-NOS   ____ Rett's Disorder

Does the child have:

Any previous definitive Dx of CDD or Rett's by a qualified diagnostician? ____ Yes *(DNQ)*   ____No

Any previous Dx of Autistic Disorder?   ____ Yes *(mark AD 1.6)* ____No

Any previous ASD-NOS Dx?   ____ Yes *(mark AD 1.6)* ____No

Based on review, does child have # and pattern for Autistic Disorder?   ____ Yes ^   ____ No *

 * If not, based on review, does child have # and pattern for PDD- NOS?   ____ Yes   ____ No ____N/A

Based on review, does child have Autism Discriminators?   ____ Yes   ____ No

Reviewer rating of quality of record: 1   2   3   4   5
                                                  Poor   Adequate   Excellent

 Is there a need for a Second or Third Review?   _____ **Yes ***   _____ **No**

Final ASD Case Definition:

_____   **Confirmed ASD Case +:**   *ASD Review Classification:*   _____ *Autism*   _____ *ASD-NOS*

+ Reviewer Degree of Certainty that child is an ASD Case: 1*   2*   3*   4   5
                                                          Not Sure Somewhat Sure   Very Sure

+ Reviewer Degree of Impairment Associated with ASD: 1   2   3   4   5
                                                      Mild   Moderate   Severe

_____   **Suspected Case +:**   _____ *Probable ASD Case ^*   _____ *Possible ASD Case**

+ Reviewer Degree of Certainty that child is an ASD Case: 1*   2*   3*   4^   5^
                                                          Not Sure Somewhat Sure   Very Sure

_____   **DNQ After Review ***

* Specify most applicable reason if: A Secondary or Tertiary Review requested; Case with Certainty (1-3); Suspected Case or DNQ After Review

_____   Insufficient information

_____   Conflicting information

_____ *Could* be accounted for by other disorder(s) (specify): _____

_____ *Clearly* accounted for by other disorder(s) (specify): _____

_____ Sufficient information to rule out an ASD (specify): _____

_____ Other (specify): _____

Comments:

ASD Clinician Review: Autism Discriminators and Associated Features
StudyID:

Autism Discriminators

AD1.1 Oblivious to children

AD1.2 Oblivious to adults or

AD1.3 Rarely responds to familiar social

AD1.4 Language primarily echolalia or

AD1.5 Regression / loss of social or language

AD1.6 Previous ASD diagnosis

AD2.1 Lack of showing, bringing,

AD2.2 Little or no interest in

AD2.3 Uses others as

AD2.4 Repeats extensive

AD2.5 Absent or impaired imaginative

AD2.6 Markedly restricted

AD2.7 Unusual

AD2.8 Insists on

AD2.9 Nonfunctional routines

AD2.10 Excessive focus on parts

AD2.11 Visual inspection

AD2.12 Movement preoccupation

AD2.13 Sensory preoccupation

AD9.99 Other, specify:

Associated Features

AF1a Abnormalities in eating/drinking

AF1b Abnormalities in sleeping

AF2 Abnormalities in mood or affect

AF3 Abnormalities in the development of cognitive skills

AF4 Aggression

AF5 Argumentative, oppositional, defiant, destructive

AF6 Delayed motor milestones/motor clumsiness

AF7 Hyperactivity, short attention span, impulsivity

AF8 Lack of fear in response to real dangers, or excessive fearfulness in response to harmless

AF9 Odd responses to sensory stimuli

AF10 Self-injurious behavior

AF11 Staring spells / seizure-like activity

AF12 Temper tantrums

Tables

Table 1

Review of SCQ Validation Studies

Study	N	Age	Ethnicity	Case Definition	Cutoff	Sens	Spec	PPV	NPV
1	590: 439 ASD, 151 Non-ASD	2-16	84% Caucasian	ADOS, ADI-R, IQ, Teacher Interview Clinical Judgment	15	.71	.71	.88	.45
2	268: 54 ASD, 214 Non-ASD	3-5	72% Caucasian	ASD Parent Report	12	.82	.56	.84	.51
					15	.54	.92	.62	.89
3	119: 70 ASD, 49 Non-ASD	9-13	Not stated; conducted in UK	ADOS, ADI-R, IQ, Vineland ICD-10 Criteria	12	.80	.82	.53	.94
					15	.86	.78	.74	.88
4	81: 23 ASD, 53 Non-ASD	2-6	Not stated; conducted in Australia	CARS, DSM-IV Criteria	15	.60	.70	.63	.62
5	37: 19 ASD, 18 Non-ASD	2-3	Not stated; conducted in Georgia	ADOS, Batelle, Semi-Structured Interview, Clinical Judgment	11	.93	.58	.68	.89
					15	.50	.89	.82	.62
6	151: 49 ASD, 102 Non-ASD	3-6	Not stated; conducted in Canada	ADOS, CARS, DSM-IV Criteria, Clinical Judgment	11	.89	.89	.90	.89
					15	.71	.79	.63	.85
7	178: 89 ASD, 89 Non-ASD	2-6	65% Canadian European	Multidisciplinary Team Evaluation	11	.91	.35	.41	.90
					15	.74	.54	.49	.78

Note: Study 1: Corsello et al., 2007; Study 2: Lee et al., 2007; Study 3: Charman et al., 2007; Study 4: Allen, Silove, Williams, & Hutchins, 2007; Study 5: Wiggins, Bakeman, Adamson, & Robins, 2007; Study 6: Eaves, Wingert, & Ho, 2006; Study 7: Eaves, Wingert, Ho, & Michelson, 2006.

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Table 2

Descriptive Statistics for Hispanic and Non-Hispanic Samples.

	Hispanics	Non-Hispanic Whites
Maternal Age	38.92	40.11
Maternal Education	High School Graduate: 2 (5%) Some College: 13 (33%) College Degree: 12 (31%) Some Graduate School: 3 (8%) Advanced Degree: 8 (21%)	High School Graduate: 1 (4%) Some College: 4 (14%) College Degree: 12 (43%) Some Graduate School: 2 (7%) Advanced Degree: 9 (32%)
Maternal Employment Status	Full Time: 19 (49%) Part Time: 10 (26%) Unemployed: 10 (26%)	Full Time: 12 (43%) Part Time: 6 (21%) Unemployed: 10 (36%)
Annual Household Income	< 10K: 1 (3%) 10-24K: 6 (15%) 25-49K: 4 (10%) 50-74K: 9 (23%) 75-99K: 8 (21%) > 100K: 11 (28%)	< 10K: 0 (0%) 10-24K: 2 (7%) 25-49K: 2 (7%) 50-74K: 4 (14%) 75-99K: 8 (29%) > 100K: 12 (43%)
Child's Diagnostic Group	Autism: 27 (69%) ASD-NOS: 12 (31%)	Autism: 18 (64%) ASD-NOS: 10 (36%)
Marital Status	Married: 24 (62%) Divorced: 9* (23%) Separated: 4 (10%) Single: 2 (5%)	Married: 23 (82%) Divorced: 0* (0%) Separated: 2 (7%) Single: 3 (11%)

*Significant difference (χ^2 = 8.31, p = .04).

Table 3

Descriptive Statistics for the SCQ.

	N	Mean	SD	Range
Autism	67	19.39	5.81	10-30
ASD-NOS	48	19.73	6.73	7-32
Non-ASD	35	13.29	7.91	2-31

Table 4

Validation Results for 12, 15, and 22 Cutoff Scores.

	Sensitivity	Specificity	PPV	NPV
22 Cutoff Autism vs. Non-ASD	.33	.86	.82	.40
15 Cutoff ASD vs. Non-ASD	.69	.54	.83	.35
15 Cutoff Autism vs. Non-Autism	.73	.45	.52	.67
12 Cutoff ASD vs. Non-ASD	.86	.54	.86	.54
12 Cutoff Autism vs. Non-ASD	.85	.54	.78	.65

Table 5

Summary of Expressed Emotion Findings.

	Hispanics	Non-Hispanic Whites
Criticism	.03	.00
Statements of Attitude	.38	.11
Positive Remarks	4.36	4.04
Initial Statement	Positive: 18 Neutral: 21	Positive: 12 Neutral: 16
Relationship	Positive: 26 Neutral/Negative: 1	Positive: 12* Neutral/Negative: 16
Dissatisfaction	Present: 3 Absent: 36	Present: 3 Absent: 25
Emotional Display	Present: 2 Absent: 37	Present: 1 Absent: 27
Self-Sacrificing, Overprotection, Lack of Objectivity	Present: 4 Absent: 35	Present: 0 Absent: 28
Excess Detail	Present: 1 Absent: 38	Present: 2 Absent: 26
EE Subgroup	Low: 15 Borderline Crit: 3 Borderline EOI: 11 Borderline Crit & EOI: 0 Critical: 1 EOI: 9	Low: 8 Borderline Crit: 2 Borderline EOI: 14 Borderline Crit & EOI: 1 Critical: 1 EOI: 2
EE Rating	High: 9 Low: 30	High: 3 Low: 25

*Significant difference (χ^2 = 3.76, p = .05).

Table 6

Frequencies of Quotations and Statements in FMSS.

	Hispanics	Non-Hispanic Whites
Quotation: "affectionate"	17/21	4/21
Quotation: "diagnosed"	7/20	13/20
Positive Relationship: "best friend"	5/46	0/17
Positive Relationship: "special communication"	4/46	0/17
Positive Relationship: "spend time with me"	3/46	6/17
Statements of Attitude: Willingness to do anything	7/15	0/3
Statements of Attitude: Statements of love	8/15	3/3
Borderline self-sacrificing/overprotective behavior: Borderline self sacrifice	5/5	0/0

Figures

Figure 1

Sample description.

Overall: Record Review & SCQ
178 Mothers

Validation: SCQ
150 Hispanic Mothers =
115 ASD
35 Non-ASD

Expressed Emotion: SASH & FMSS
67 Mothers of ASD Children =
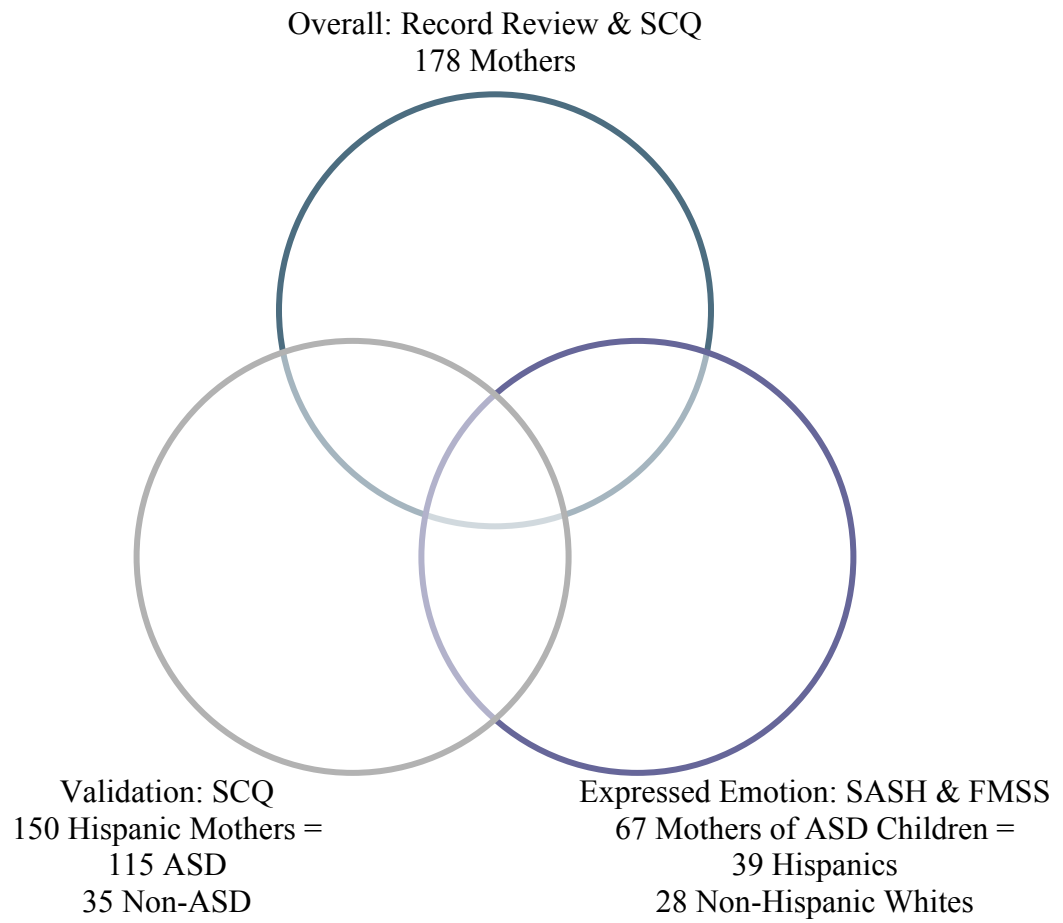39 Hispanics
28 Non-Hispanic Whites

Figure 2

Relationships among validation terms for SCQ cutoff scores.

	Actual: Record Review Case of ASD or Autism	**Actual: Record Review Not a Case of ASD or Autism**	
Predictive: Above SCQ Cutoff	*True Positives*	*False Positives*	*Positive Predictive Value =* True Positives ———— True Positives + False Positives
Predictive: Below SCQ Cutoff	*False Negatives*	*True Negatives*	*Negative Predictive Value =* True Negatives ———— True Negatives + False Negatives
	Sensitivity = True Positives ———— True Positives + False Negatives	*Specificity =* True Negatives ———— False Positives + True Negatives	

VITA

Vanessa Gonzalez was born in Miami, Florida, on June 26, 1981. Her parents are
Alberto Gonzalez and Leyda Gonzalez. She received her elementary education at Saint
Brendan Elementary School and her secondary education at Saint Brendan High School.
In August 1999 she entered the Florida International University from which she was
graduated with the B.A. degree in December 2002. During the spring of 2003, she was
employed as a research associate in the child division of the department of psychology at
the University of Miami. In August 2003 she was admitted to the Graduate School of the
University of Miami, where she is working to be granted a Ph.D. in Psychology in May
2008.

Permanent Address: 9155 Southwest 227 Street Unit 7, Cutler Bay, Florida 33190