Chinese Parents’ Perception of Autism Spectrum Disorders:
An Exploration of the Influence of Culture

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ABSTRACT

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A thesis presented to the Department of Biology,  
Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences  
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Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impaired communication skills, repetitive behaviors, and restricted interests. Numerous studies have examined the underlying causes of ASD and have identified biological causes including genetic and environmental factors. Researchers have also explored parental perceptions regarding the etiology of ASD. These studies have demonstrated that parents endorse a wide variety of causes for ASD, including genetic factors, vaccinations, prenatal exposures, and other environmental factors. However, there are few studies addressing parental perceptions among minority or immigrant populations, who may be likely to hold beliefs that are heavily influenced by their own culture. The purpose of this study was to explore the impact of culture on perceptions of causality, treatment and family dynamics among parents of children with ASD who are of Chinese ancestry. To this end, we conducted semi-structured interviews with six Chinese-American mothers of children with ASD and analyzed the interview transcripts using ATLAS.ti software. We found that as a group the experiences and beliefs of the mothers we interviewed were similar to those of parents described in previous studies. For example, the mothers we interviewed believed in Western notions of causality (including genetics) and treatment (such as ABA therapy), and shared stories of guilt, shame and blame in their families
and social networks. However, our mothers also commented on experiences that were unique to their status as immigrants, such as additional grief over the loss of opportunity in the United States for their child, and further isolation caused by language barriers and geographical distance from extended family members. Our results suggest a need for additional support for Chinese immigrant parents coping with their child’s diagnosis of ASD. Future research should focus on exploring the experiences of a broader population of immigrant parents whose children have been diagnosed with ASD.

KEY WORDS: autism spectrum disorder; ASD; Chinese-American parents; immigrants; cultural beliefs; parental perception; cultural competency;
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INTRODUCTION

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders characterized by impaired social interactions and communication abilities, as well as repetitive/restricted behaviors and interests. The prevalence of ASD in the United States is estimated to be 1 in 91 among children 3 to 17 years of age, and is more common among males than females (Kogan et al., 2009). Despite considerable efforts to determine the underlying etiology of ASD and strong genetic contribution, only a small percentage of children with ASD have an identifiable genetic diagnosis. Shen at al. (2010) conducted clinical genetic testing on a cohort of 933 individuals with a diagnosis of ASD using karyotype and chromosome microarray. Abnormal karyotypes were detected in 2.23% of the cohort and 18.2% had abnormal chromosome microarray findings (Shen et al., 2010). There are many single gene disorders (e.g., fragile X syndrome, tuberous sclerosis complex, MECP2 mutations), that may also lead to an ASD phenotype, but none account for large percentages of ASD (Muhle, Trentacoste, & Rapin, 2004; Reddy, 2005; Schaefer & Mendelsohn, 2013). Among members of the autism research community, it is widely accepted that genetic factors play a large role in determining which children are likely to develop ASD, and that the specific factors are heterogeneous (Folstein & Rosen-Sheidley, 2001; Klauck, 2006; Marshall et al., 2008).

Several studies have examined parental perceptions regarding the cause of ASD (Dale, Jahoda, & Knott, 2006; Elder, 2001; Folstein & Rosen-Sheidley, 2001; Mercer, Creighton, Holden, & Lewis, 2006; Selkirk, McCarthy Veach, Lian, Schimmenti, & LeRoy, 2009). Through
both survey and interview-based research protocols, these studies have demonstrated that parents believe the major contributory factors leading to ASD are genetic and environmental. In 2006, Mercer et al. surveyed a group of parents (from the United States and Canada) with at least one child diagnosed with an ASD. The authors observed that genetic, vaccination, diets, prenatal and perinatal factors including advanced maternal age, smoking, medications, maternal vaccination, and infection were considered to be the most common contributory elements. However, recent studies examined parents from culturally diverse backgrounds and provided explanations of causality that were more rooted in cultural beliefs such as diet, parental age, illness during infancy/childhood or religious beliefs (Mickelson & Wroble, 1999; Shaked, 2005). In fact, using a web-based survey of families originated from India and currently residing in the United States, Ravindran and Myers found that in addition to genetic and environmental factors, most parents also believed destiny, karma, or parental mistakes in the present or past life played a role in causing their child’s ASD (Ravindran & Myers, 2012). Personal experience, religious practices, or cultural beliefs have also been shown to impact parental decision-making with regard to family planning and clinical management of a child with ASD (Hebert & Kouloughlioti, 2010).

To date, similar studies investigating the beliefs of Chinese parents of children with ASD have not been conducted. However, it is well known that among traditional Chinese families, disability is viewed as a punishment for sins committed in this lifetime or previous life by the disabled person’s parent (Liu, 2001). Many religious people will visit temples of worship or perform rituals to find the cause and/or remedies to cure their child’s disabilities. Dietary practices are viewed as an important factor in maintaining the body’s balance of yin (cold) and yang (hot), and many families will use traditional remedies (e.g. Chinese traditional medicine
herbs or foods) to attempt to correct for this imbalance. The belief is that once balance is achieved, the illness will be cured.

Furthermore, shame and stigma played an essential role in Chinese culture, especially when families encounter certain medical conditions or disabilities since “disability” is perceived as something shameful and therefore make them “lose face” in the society. Parents of the disabled child often faced self-blame or blame by others while the family often experienced disgrace and criticism from the community. This often creates conflicts and barriers within the family (Liu and Zhang 2005). The sentiment of blame and guilt among family members is common among individuals with genetic conditions in all families (Weil, 2000), and can negatively impact relationships among family members. This phenomenon may be more pronounced in individuals of cultural backgrounds with less accepting views of disability.

Acculturation has been shown to influence individual perceptions, attitudes and values that resulting from adaptation to a new culture and environment; this is particularly notable regarding the cause and treatment of illness (Mandell & Novak, 2005). Tseng (1972) examined Asian students’ attitudes toward people with disability and revealed a direct correlation between the number of years lived in the United States and a positive attitude towards disability, indicating a strong influence of acculturation in a person’s belief system (Tseng, 1972). These beliefs are typically modified or strengthened based on education, perception of disabilities, accessibility to resources, and family lifestyle in the host country (Neeraja Ravindran & Myers, 2011).

To date, the research regarding parental perceptions of ASD has focused predominantly on the general U.S. population. Similar research has not been conducted among parents of children of Chinese ancestry who may be more likely to hold strong cultural beliefs that may
contradict current medical practices in the U.S. The purpose of this study was to investigate cultural influences on Chinese parent’s perception of their child’s ASD diagnosis, as well as to discern the impact of these cultural beliefs on their treatment choices and family dynamics.
METHODS

Methodology and Informed Consent

We applied a thematic and grounded theory approach to explore Chinese parents’ experiences with respect to their child’s ASD diagnosis, their perceptions regarding the cause of ASD, and the impact of these beliefs on behavioral/medical management and family planning. The study protocol was reviewed and approved by Brandeis University Institutional Review Board, and informed consent was obtained from all study participants.

Sampling Methods and Inclusion Criteria

We recruited participants through the Center for Children with Special Needs (CCSN) at the Floating Hospital for Children - Tufts Medical Center, the Boston Autism Consortium, and the Boston Chinatown Neighborhood Center (BCNC). Study inclusion criteria included:

- Biological parents who were at least 18 years old with at least one child who received a diagnosis of ASD in the United States within the last 10 years.
- The child with ASD must not have had an identified genetic diagnosis, such as fragile X syndrome.
- Parents must have been fluent in either English or Mandarin.

A total of nine individuals expressed interest in participating in the study and six of them ultimately participated in the study. One parent was excluded from the study because the child was not diagnosed in the United States and two declined participation before study enrollment.
Interviews

We conducted semi-structured interviews (Appendix D) with the participants to explore the experiences of Chinese parents who have a child, or children, with ASD. During the interviews, we asked participants a series of questions regarding their demographic information and diagnostic journey. The following were the core questions contained within the interview guide:

- What was your child doing or not doing that made you decide to seek professional help for your child?
- How did your child come to be diagnosed with an ASD?
- Can you describe what was it like for you to learn that your child has an ASD?
- What do you think caused your child to have an ASD?
- What was it like sharing this information with other family members?
- What do your family members believe is the cause of your child’s ASD?
- Regarding the services/treatments your child has received, which do you think have been the most effective?

The interviews were conducted in person or via telephone in either Mandarin or English, depending on the parent’s preference. The interview duration ranged from 30 to 45 minutes.

Data Analysis

The interviews were digitally recorded and transcribed. The data was entered into ATLAS.ti (version 7.0). Sentences and paragraphs of the interviews were coded according to emergent themes.
RESULTS

Study Participant Demographics

The demographics of the study participants are summarized in Figure 1. We interviewed six parents, all of whom were mothers that range from early 30s to mid 40s of age. All reported having two or more children with at least one child diagnosed with ASD. Four of the affected children were boys and two were girls. Most of the mothers have been living in the U.S for over 10 years and Mandarin is their primary language. All of the study participants were recruited through BCNC and reported that they were the main caregivers for their children at the time of the interviews.

Parent 1 (P1) is a 32-year-old female originally from the Fujian Province who immigrated to the U.S. at age 21. She and her husband, who is from the same province, have two children born in the USA: a 5-year-old son diagnosed with ASD when he was 3 years old and a healthy 4-year-old daughter. P1’s mother in-law also lives with the family. P1 describes her family as intact.

Parent 2 (P2) is a 39-year-old female originally from Tianjin Province who immigrated to the U.S. with her husband at age 25. Both of them obtained a bachelors degree in China and they have two children together born in the USA: a 6-year-old son who was suspected to have an ASD at 18 months old and was confirmed to have an ASD at age 3, and a healthy 3-year-old daughter.
Parent 3 (P3) is a 46-year-old female originally from Guangdong Province. Both she and her husband, who is from the same province, immigrated to the U.S with their older daughter in 2008. They have two children together, both of whom have been diagnosed with ASD. The older daughter was diagnosed in China at approximately age 7 and is now a 14-year-old, while the younger daughter was diagnosed in the U.S. at the age of 2 and is currently a 3-year-old. For the purpose of this study, we primarily focused on the younger daughter’s diagnosis because of the eligibility criteria.

Parent 4 (P4) is a 45-year-old female originally from Hong Kong who immigrated to the U.S with her husband at age 29. They have two children together, a 7-year-old son who was diagnosed with ASD at the age of 3 years and a healthy younger son.

Parent 5 (P5) is a 46-year-old female originally from Taiwan whose husband is from Hong Kong. They both immigrated to the U.S in 2003. Most of her family members remained in Taiwan whereas the majority of her husband’s family resides in the U.S. According to P5, her husband’s family is more educated than her own. They have three children together: a 13-year-old son with a slight intellectual disability, an 11-year-old daughter diagnosed with ASD at the age of 7 years, and a healthy younger son.

Parent 6 (P6) is a 38-year-old female originally from Anhui Province who immigrated to the U.S in 1998. She stated that she was a physician in China while her husband is a chemist working in the U.S. They have two children together, a healthy 13-year-old daughter and an 11-year-old son diagnosed with ASD at age 3.
Six themes emerged from the analysis of the data regarding Chinese parents’ experience receiving and coping with their child/children diagnosis of ASD:

(1) Parental lack of awareness of ASD may contribute to delay in diagnosis.

(2) Parental beliefs about causation reflect influence of Western thought.

(3) Parents’ utilization of treatment options focuses primarily on Western therapies.

(4) Family member reactions to the diagnosis varied from hopelessness to denial.

(5) Parents express intense shame, blame and guilt associated with the diagnosis.

(6) Parents report their immigrant status leads to increased challenges and isolation.
Theme #1: Parental lack of awareness of ASD may contribute to delay in diagnosis

All of the mothers that we interviewed reported that they first became concerned with their child’s language and social development around 18th months, with the exception of one mother who was informed by the teacher from her child’s daycare center that her child did not like to interact with other classmates. They all approached their pediatrician first and the children were subsequently evaluated by developmental specialists or neurologist. On average, the waiting period for parents to see developmental specialists or neurologist for an autism evaluation was approximately a year or longer. The children usually obtained an official diagnosis of ASD around age three. Five mothers reported that their husbands were with them at the time of the diagnosis and most of them stated that they had never heard of ASD before their child’s diagnosis. Therefore, they felt overwhelmed by the unexpected and unfamiliar news. Furthermore, their unawareness of the condition may also result a delay in seeking for a diagnosis. One mother remarked:

*I have never heard about ASD or encounter families with children diagnosed with ASD when I was in China. There are not many autism-related cases documented in China 10 years ago hence we did not had a good understanding or knowledge regarding autism. Traditionally, people perceived autism as something like mental-related disorders. After coming to the USA, I began to hear about autism, and China started to emphasize more on this topic as well. Therefore, it was unexpected, upsetting and concerned the moment I heard about the diagnosis.*

The mother of a 7-year-old boy similarly noted:

*I don’t feel good, I also don’t know what is Autism, I feel fear and anxious because I don’t know how to handle the problem. I don’t know how to handle my kids. I don’t know what is going on, what is development for my kids, when I got the diagnosis.*

Theme #2: Parental beliefs about causation reflect influence of Western thought

When we asked mothers what they thought was the cause of ASD in their child, two mothers reported genetic factors, two mothers reported multifactorial etiologies that including
both genetic and environmental factors, and two reported uncertainty about the cause. Interestingly, none of our mothers attributed the cause of autism to cultural beliefs or supernatural forces other than the mother who lived with her mother-in-law and who reported that her in-law believed her child’s ASD could be attributed to a spiritual cause.

The mother of two daughters affected with ASD held a strong belief that it was genetic said:

*I think it is genetic because both of them had it.*

Furthermore, she felt that her chance of having another child with ASD would be 100% while two mothers thought their chance was greater than the general population’s chance, but less than 50%.

Two mothers who thought that the cause was a combination of both genetic and hormonal imbalance said:

*I would think somehow that each one gets the most [simultaneous conversation] maybe somewhere the bad part he got it. The bad part we carry in our body, but it didn’t show up, but it somehow meets together on him, stronger to show up, something like that. So, in my, when I’m carrying like a pregnant with my son my emotion or the hormones changing probably do something. I strongly believe that. I mean there is no medical, no science to show, but I would think something wrong or something happen changing on me due to the hormones, and then he growing up in my body and gathers something from my body and maybe something is stronger than the normal people and he growing up with that. And now he just shows up. So I do believe these two things, even though I don’t know what kind of food I’m eating makes me to changing the hormones.*

Another mother commented:

*I think it is a combination of factors, I think genetic is the fundamental cause, then comes physical healthy. I think the physical health plays an important role, such as food allergy, sleep problems, or hearing concern. All of those factors would hinder them to learn in the optimal states, since if children are physically suffering from something, then they would have hard time focus on the other things. Third, physical and emotional stresses, when I was pregnant with son, it was a tough period in my life. I was working on my thesis like you, taking care of my daughter who was 2 years old at the time, and facing pressures from both sides of the family; it was a very stressful period for me.*
Two mothers responded that they did not know the cause of their child’s ASD. For example, the mother of an 11-year-old daughter noted:

*I never thought about the causes. I am not a spiritual person as well; hence, I don’t know what causes ASD.*

These sentiments were reflected by another mother:

*Personally, I think it is very hard to say what causes this, because our family does not have a history of autism. Also, my son was developing very well earlier; his developmental milestones are typical, he started walking around 9 months and was able to walk well independently by 10 months. Around 8-9 months, he was saying “baba” and around 16 months, he said “nainai” and that was his last word. All the sudden he stopped talking, so I felt confused and really don’t know why or what causes it.*

**Theme #3: Parents utilization of treatment options focuses primarily on Western therapies**

All of the mothers we interviewed reported used conventional autism therapies including speech therapy, occupational therapy and applied behavior analysis for their child. Some mothers reported that they also supplement with complementary and alternative therapies such as vitamins, special diets, and exercises. When we asked the study participants whether they have used or would consider using traditional Chinese treatments such as acupuncture or Chinese herbal medicine, most responded they have not yet tried them but expressed inclination to try traditional Chinese remedies in the future, particularly when there is evidence that these therapies can be useful. Only one mother stated that she has tried everything she could to improve her child’s condition, including chelation therapy, vitamins, herbals, essential oils from around the world and various specialized autism tests (allergy test, hair analysis, chemical imbalance test and blood test). She emphasized that it is essential for her child to remain healthy physical in order to have the full potential to learn and communicate with others.

*We tried everything we could to improve our child’s condition. Unlike many Chinese parents with a high expectation for their child to succeed; we do not have a definitive goal, my biggest hope is to have my son live happily, healthy, and make a little progress*
everyday. In order to do that, it is essential for him to maintain a healthy body, only then, he will learn and try to communicate with others.

Theme #4: Family member reactions to the diagnosis varied from hopelessness to denial.

When we asked about their initial reactions towards their child’s diagnosis, almost all mothers described their initial reactions toward their children’s diagnosis as: shock, sadness, fear, denial, and hopelessness. One mother was extremely devastated when she received her daughter’s diagnosis of ASD, because she had high hopes that her child’s early developmental delay was only temporary. She felt hopeful that someday her child would eventually catch up to her peers. Her initial reactions, therefore were disbelief, denial, and hopelessness. She remarked:

My initial reaction was disbelief; I refused to accept it, felt depressed all the time, I cried continuously for a week. I just could not accept the truth because I thought she was developmentally delayed the whole time, and with time, she would catch up to an average level. But with ASD diagnosis, it is like a death sentence; there is no longer hope for her.

Another mother felt shock, sadness, and hopelessness because she had high expectations and hope for her child’s life in the United States free of barriers that she and her husband had encountered as immigrants. Her child’s diagnosis of an ASD placed barriers on her son that she and her husband had assumed would be absent for a child born in the United States. She described her initial reaction as:

It’s kind of like a shock and how I can say this, kind of like a scare, fear, and hopeless and helpless and everything, because I wasn’t really too shocked, because like I said, by the growing up I always had the things question me, but still it’s very, very shocked and very, very sad. How I can tell this? I mean we are both Chinese culture. You understand we care about the next generation, it’s like the whole life, and my husband and me, we immigrate here a long time ago and kind of like life is a test in everything, but because the language area, the barrier, and also everything, the culture, language, and even your status, everything, I would think, “Okay, this is because I’m here, not growing up.” But for my son, he’s born here, he’ll go to the school here, he’ll adopt the culture, language, everything, it’s just like his nature, so we’ll educate him well. Hopefully he’ll be someone.

Conversely, many of the mothers described their family members as having a more
subdued reaction. In fact, two mothers stated that their spouses and in-laws felt their child’s behavior was typical and would eventually be outgrown as the child matured. One mother who said that her husband thought their child’s behaviors were temporary commented:

*His brother has a child with ADHD; he noted that as the child grew older, he became more typical. My husband also thinks that [our child] will eventually get better as she grows older.*

Another mother discussed how her in-law also thought her child’s behaviors were normal stated:

*My in-law felt its typical behavior, because some children do not speak around the age of 5 or 6 but suddenly start speaking around 7 or 8 years old with a normal development. She is disbelieving and not accepting the diagnosis.*

**Theme #5: Parents express intense shame, blame and guilt associated with the diagnosis.**

All of the mothers responded that they only shared the diagnosis with selected family members. Most received limited supports from the family members because either they did not understand the condition or they felt stigma at having an autistic child in the family. The mother of the 11-year-old daughter experience both blame and lack of support said:

*Yes, my own family members are in Taiwan. They are more neutral toward it because they do not know much about Autism. Hence, they could not provide much of supports. On the other hand, my in-laws are living in the U.S. and are highly educated as well; they think it’s a shameful thing to have a child with ASD. They blame this on my side of the family. They don’t want to tell or let other people know about the condition.*

One mother described that even though her family members accepted the diagnosis, they just could not understand the condition and what it was like to raise a child with autism:

*Well, they don’t understand this, because they always ask me why. The question is they ask me and every time I’m just calling them when I cannot take anymore. It’s just too much to take and just calling them to talk about this, and they ask me why I’m telling them. They don’t really know. I mean, because most of the family, we don’t see this kind of kid.*
Several mothers expressed challenges taking their child out in public due to their child’s behaviors that resulted certain family members distanced themselves slowly from the family with Autism. Additionally, mothers felt the public also had a lack of understanding of autism. One mother discussed the difficulty of having her child “meltdown” in public and perceived that the public believed her child’s behavior was a result of poor parenting since there are no physical manifestations of her child’s disability. These situations often made them feel frustrated.

*When it comes to Autistic children, their physical appearances are similar to healthy children. Hence, when my daughter screams in public, most parents think that I am a bad parent, do not educate my daughter well. They do not understand those are typical autistic behaviors.*

Another mother reported said that her in-laws stopped taking her child out in public due to the public’s perception and attitude:

*They couldn’t accept my daughter’s behaviors, particularly when my daughter’s tantrum meltdown in public. Eventually they stopped taking her into public places because they think it is shameful to have many gawked at by others.*

Some of the reasons mothers provided for not sharing the diagnosis were because either they did not want to give unnecessary worries to extended family members, especially those in China, or they felt that extended relatives would not able to comprehend the condition.

**Theme #6: Parents report their immigrant status leads to increased challenges and isolation**

A few mothers shared their personal experiences of coping with their child’s diagnosis in the United States. These included overcoming cultural and language barriers, which created tremendous hurdles for some parents to obtain appropriate services and reach out to available resources. Furthermore, they also faced financial burdens to obtain optimal therapies and received limited support systems since many of their family members reside in their native
country. Family and friends that reside in the U.S sometimes hesitated to support a family with an autistic child due to either family pride or a lack of awareness about ASDs. Therefore, mothers reported experiencing an intense sense of isolation. The mother of the 11-year-old daughter expressed incredible frustration and difficulty in obtaining services for her child:

*I am also disappointed and upset with myself because I don’t speak fluent English and don’t know much about school structure. When school provides me a document to sign, I just signed it. Later on, I learned that I could refuse the inadequate services provided by the school and have the power to ask for more services that are tailor towards my daughter’s need. I also had to fight constantly with school in order to obtain the services. In addition, I feel by the time I learned about new services or resources, it is usually too late because we did not have the first hand information. For example, horse riding, I heard that it might be helpful for my daughter to try it, but I don’t know where to begin or how to begin, as well as to find financial supports since everything cost a lot of money.*

Another mother expressed sentiment of isolation:

*No one is there to help us; everyone has their own life. He is my child and it is my responsibility to take care of him. No one can help or will be able help us.*

The mother of the 11-year old son expressed challenges and frustrations more so because she was not able to help her son alleviating some of his discomfort due to her son’s inability to communicate and the complexity of the condition, she said:

*We went through tremendous tough time; it is not something that a normal family could imagine what we went through. I feel my biggest frustrations and challenges are when I see my son suffering, such as banning his head on the wall. I know his body must be experiencing some level of discomfort, but I don’t know what is making him feeling this way because he cannot communicate with us. I don’t know how to help or alleviate his pain; seeing him suffering makes me feel extremely hurtful because I wanted to help him but I felt so helpless. As a mother, I would do anything and everything for him. I would not eat, drink, or sleep, anything I would do for my child. But what can I do?*
DISCUSSION

Given increasing ASD prevalence and the complexity of its etiology, it is essential for health care professionals to recognize the social and cultural impact on parents coping with a child’s diagnosis of ASD. The purpose of interviewing Chinese parents with at least one child diagnosed with ASD in the United States was to explore their experiences in receiving their child’s ASD diagnosis. Specifically, we hoped to learn how parents reacted to the diagnosis, how they perceived the causality of ASD, and the impact of cultural beliefs on family relationships and treatment choices. Mothers in our study exhibited perspectives that were consistent with experiences of parents from previous reported studies; however, there were unique issues raised by our study participants that appeared to be directly related to their cultural background and immigrant experience.

Receiving and coping with a child’s autism diagnosis is extremely challenging for parents of all cultural backgrounds. Some of the challenging factors include limited personal or family life activities, increased economic burden, concern for the child’s future, emotional frustration and physical exhaustion, social pressures of shame and stigma, as well as misunderstanding from family members and public. Therefore, it was not surprising that the mothers in our study expressed shock, fear, sadness, and denial as their initial reactions to the diagnosis. Furthermore, many reported similar responses to their children’ diagnosis as the parents from other published studies, expressing that their marital and family relationships were altered as a result of the diagnosis (Schall, 2000; Woodgate, Ateah, & Secco, 2008).
Many of the mothers who participated in our study endorsed genetic or environmental factors as the major cause that led to their child’s disorder (Herbert and Koulouglioti, 2010). In previous studies, parents cited a broader range of causal factors, including vaccination, birth trauma, diets, and cultural beliefs such as karma or sin as the cause of autism (Dale et al., 2006; Elder, 2001; Mercer et al., 2006; Neeraja Ravindran & Myers, 2011; Selkirk et al., 2009). Interestingly, none of the mothers we interviewed referenced traditional cultural beliefs in discussing the cause of their children’s condition. Instead, their assumptions of the cause may be influenced by their education level, knowledge of the disorder, personal experiences, and degree of acculturation to the Western culture. Indeed that none of the mothers in our study were recent immigrants suggests that they may have been assimilated to the Western culture. It has been shown that adaptation to a new culture impacts and shapes how we perceive, experience, and manage health and illness (Mandell & Novak, 2005). Accordingly, this seems to have been a significant influence on parents’ attitude and treatment choice.

Despite the overwhelming array of treatments available for autism, including behavioral, cognitive, pharmaceutical, sensory, relational, vitamin, and diet therapy, most mothers in our study selected conventional autism behavior treatments with complementary and alternative therapies, such as restricted diets or vitamins, similar to previous reported studies from individuals in Western Culture (Hanson et al., 2007). Only one mother reported using traditional treatment, suggesting that decisions regarding the treatment were not generally influenced by parent’s traditional cultural beliefs. This may be explained by the fact that mothers have more trust in their healthcare professional regarding Western managements and interventions since ASD has been recognized for a longer period of time in the U.S than China. Furthermore, mothers may also be concerned with possible side affects due to limited documented case
examples of using traditional remedies. The fact that several mothers expressed an inclination to try Chinese remedies someday indicates that their use of Western treatments is due to a lack of accessibility and affordability to additional alternative treatment options.

Despite the similarities between our mothers’ reaction to the diagnosis, impact on family dynamics, believed cause of ASD, and treatment options and those from the reported literature, there were significant differences that may have been related to their immigration status and cultural background. First, our mothers demonstrated a lack of awareness and understanding of ASD despite varying degrees of education, suggesting that cultural and language barriers played a role, which may ultimately contributed to a delay in seeking professional help or educational services. Particularly in China, ASD is typically perceived as a mental illness disorder and it was not until recently that clinicians began to recognize it as a developmental disorder and diagnose children with ASD. Furthermore, medical terminology and concepts are quite different between different cultures. Thus, even with the help of an interpreter, many parents have difficulty understanding the diagnosis of ASD.

The issue of stigma may also play a role in the delay between first parental concern about a child’s development and the child’s diagnosis. Particularly among Chinese culture, disability is often perceived as something shameful, and families with disability often experience disgrace and criticism from the community. Therefore, parents may be hesitant to seek an official diagnosis due to concerns about losing face that would affect the entire family’s reputation. In fact, many mothers shared the perspective of their spouses regarding the delays in their child as only temporary, indicating that fathers either did not fully understood the condition or were in denial and embarrassed by their child’s diagnosis.
Furthermore, many Chinese immigrants came to the United States to work hard in hopes of providing a solid foundation for their child/children to succeed. They often have high hopes and expectations for their child/children to achieve high levels of education; they felt that children born in the U.S would not face similar hurdles as they did, such as overcoming cultural and language barriers. Therefore, receiving an ASD diagnosis for their child is very devastating. It is difficult for parents to accept because they view the diagnosis as a loss of opportunity for their child/children to succeed in their new country, resulting in changes in parental perspective and expectations for their children. Furthermore, Chinese culture highly values collectivism, having a child or children with ASD has a significant impact not only on the individual level but also affects entire family’s pride and reputation. As result, mothers often encounter a strong feeling of guilt and blame since the whole family is being stigmatized by the disability.

Immigrant parents often experience tremendous challenges and a sense of isolation because they not only had to conquer the language barrier, but also faced challenges coping with the diagnosis, including financial burdens, identifying available resources and supports for their child, as well as living with blame and guilt from family members and public. Many extended family members also had difficulty conceptualizing the condition, resulting in not being able to help parents of a child with ASD, while others distanced themselves due to shame. In fact, most mothers reported that they were the primary caregivers for their child, which may be influenced by traditional gender roles, however, it may also be due to the fact that the fathers were avoiding the reality of coping with their child’s condition. The level of stress on mothers was also compounded by their physical distance from extended families and close networks due to immigration.
Another frustration reported by our mothers was the difficulty in taking their child into public due to stigma. In addition, autistic children are often isolated because some parents fear that their healthy children will be negatively influenced. These attitudes added another element of oppression in the lives of the parents and children, indicating a need for advocacy and outreach to enhance public understanding and awareness of the challenges parents of children with ASD cope with. In spite of all the challenges, many mothers demonstrated resilience and learned to cope with their stresses. They believe that it is their responsibility to take care of their children regardless of how others perceive them, even if no one can or will be able to help them.

Overall, the study provided insight into the experiences of Chinese parents who have a child with ASD. Despite the cultural disparity, the experiences of the mothers we interviewed were consistent with those of parents from the reported literature, but there were several unique aspects among our study mothers, including their lack of knowledge about ASDs, limited support/availability of family members, language barriers, and immigrant status. This study demonstrated a need of further research studies to investigate the experience of immigrant parents coping with their children’s diagnosis in a broader population in order to help clinicians gain a better understanding regarding the efficacy of the services they are providing to these immigrant families having children with ASD.

Study limitations
There are a number of limitations that may influence interpretation of the findings. First, we had a small sample size and a non-homogenous group. All of the parents participated in this study were from different provinced in China that may hold different cultural beliefs; they had varying levels of education and degrees of assimilation to the Western culture; none were very
recent immigrants. All of these factors may skew the findings and limited the generalization of the general Chinese population. Second, of six interviews we conducted, two of them were done in English where parents sometime had difficulty expressing certain thoughts; four interviews that were conducted in Mandarin were manually translated and transcribed by the student researcher that may affect the quality and accuracy of the interpretation. Third, our study parents were all mothers, although it was informative to learn about their perspectives, but it is also important to gain experience from the fathers directly. Four, our study parents were recruited from the same organization suggesting that people in this support group were more likely to seek for acceptance elsewhere due to lack of support systems from the family.

Future study

Future studies include expanding current study with a more homogenous sample. We would also like to explore paternal perspective regarding their child’s ASD diagnosis. Lastly, it would be interesting to compare experiences of parents with a child or children diagnosed with ASD across different cultures.
CONCLUSION

This investigation of the perspectives on the Chinese-American parents’ experience of having a child with ASD diagnosis has provided information about family reactions to the diagnosis and perception on the causality of ASD, as well as the impacts of the cultural beliefs on family relationships and treatment choices. Overall, our results illustrated that despite cultural disparities and immigrant experience; there were aspects of similarities and differences in terms of how Chinese-American parents respond to disability verses the experiences of parents across culture based on reported existing literatures. This study is an initial step towards increasing awareness of the experience of Chinese immigrant who have children with ASD. By understanding the perspective of Chinese parents, we would be cognizant of these similarity and differences in order to provide the most effective care, and identify helpful resources and support systems to Chinese families who have a child or children with ASD. Additionally, our study exhibited the need for further research studies to examine the impact of cultural beliefs on the perspective of parents across different cultures.
REFERENCES


APPENDIX A. Informed Consent

BRANDEIS UNIVERSITY
DEPARTMENT OF BIOLOGY
GENETIC COUNSELING GRADUATE PROGRAM

Informed Consent to Participate in Research

Title: Cultural Influences on Chinese Parents’ Perceptions on the Etiology of Autism Spectrum Disorders

Principal Investigator: Beth Rosen Sheidley
Student Researcher: Jin Yun Chen

INTRODUCTION
The Principal Investigator is a faculty member in the Brandeis University Genetic Counseling Graduate Program where she oversees Master's thesis training. She has over 20 years of experience in clinical genetic counseling, clinical research and teaching. Her areas of expertise include ASD, epilepsy, psychiatric illness and both prenatal and pediatric genetic counseling.

The Student Researcher, Jin Yun Chen, is a graduate student in the Brandeis University Genetic Counseling Program. She is conducting a research study to understand how cultural influences Chinese parents’ perception regarding the cause of autism spectrum disorder, and impact of cultural beliefs on their decisions in treatment and family planning.

You are being invited to participate in this study because you are the parent or guardian of a child with an autism spectrum disorder. This study is completely voluntary. You should not feel any pressure to participate. You can decide to stop participation in this research study at any time for any reason.

Please read all of the following information carefully. Ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

PURPOSE OF STUDY
The purpose of this study is to investigate how cultural beliefs influence Chinese parents’ perceptions of autism spectrum disorders (ASD). Specifically we plan to assess parental beliefs regarding the underlying cause of ASD, as well as the impact of these beliefs on choices with respect to medical/behavioral management and family planning.

PROCEDURES TO BE FOLLOWED
You are being asked to participate in an audiotaped in-person or telephone interview that will last approximately 30 minutes. The interview will be in either English or Mandarin, depending on your preference. During the interview, we will be asking questions about your beliefs regarding the cause of ASD, your experiences with your child’s diagnosis of ASD, and the impact of cultural beliefs on decision-making with respect to medical intervention and family planning.

RISKS
The only risk to you is that you may experience thoughts or feel anxious or upset when you are discussing this information. Should that occur, you may choose not to answer a question or to stop the interview. Alternatively, we can refer you to a genetic counselor or mental health professional to speak about these feelings.

BENEFITS
There will be no direct benefit to you for your participation in this study. We hope that information obtained from this study will help us gain a better understanding of the cultural beliefs that influence parental perception about the cause of autism spectrum disorders. This will help genetic counselors and health professionals improve their cultural awareness while interacting with Chinese families in the future.

ALTERNATIVES
An alternative is to not participate in this research study.

PRIVACY AND CONFIDENTIALITY
Each study participant enrolled in the study will be assigned a coded ID number. Transcripts, interview notes, and audiotapes will be labeled with this code. All records containing identifying information, such as names, email addresses and telephone numbers will be kept strictly confidential during the study. All study related documents and materials (including consent forms, interview transcripts, and audiotapes) will be kept in a secure location accessible only to the Student Researcher, and any databases containing identifiable information will be stored temporarily on a password protected laptop. Hardcopy forms will be stored in a secure file cabinet in the Brandeis University Genetic Counseling office. All study identifying information will be destroyed once the study is completed.

PAYMENT
You will not be paid to participate in this study. You will receive a $25 gift certificate to Amazon.com upon completion of your research interview as a gesture of appreciation for your time.

COST
There will be no cost to you to participate in the study, other than the time it takes to do the interview.

WHOM TO CONTACT
If you encounter any problems related to study participation or have questions about the study, you may contact the Student Researcher, Jin Yun Chen, at jyc14@brandeis.edu.

You may also contact the Principal Investigator for this project, Beth Rosen Sheidley, at sheidley@brandeis.edu.

If you have questions about your rights as a research study subject, contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.

PARTICIPANT’S STATEMENT

I have read this consent form and have discussed with Jin Yun Chen the procedures described above. I have been given the opportunity to ask questions, which have been answered to my satisfaction. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.

I understand that my participation is voluntary. I understand that I may refuse to participate in this study. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.

If I have any questions concerning my rights as a research subject in this study, I may contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above.

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

By placing my initials here, I agree to the audio-recording of this interview. ______

_____________  ________________________________
Date            Participant’s Signature

_____________  ________________________________
Date            Student Researcher Signature
APPENDIX B. Recruitment Notice

Are you of Chinese ancestry? Do you have a child diagnosed with an autism spectrum disorder (ASD)? If so, I would like to invite you to participate in a research study about your experience.

I am a graduate student in the Brandeis University genetic counseling program and I am conducting this research study for my Master's thesis. My research protocol has been approved by the Brandeis University Institutional Review Board (IRB).

The purpose of this study is to understand Chinese parents’ beliefs about the cause of autism spectrum disorders and the impact of these beliefs on decisions with regard to medical care for their child as well as family planning.

To be able to participate in this study, you must be:

- The biological parent of at least one child diagnosed with ASD within the last 10 years in the United States
- Of Chinese ancestry (this may include individuals born in China or the United States who have at least one Chinese parent)
- Between 18 and 65 years old
- Fluent in either English or Mandarin

Following a brief phone questionnaire to assess eligibility, participants will be asked to take part in an audiotaped in-person or telephone interview, conducted in either English or Mandarin, that will last approximately 30 minutes.

Participation in this study is voluntary and confidential. Participants will receive a $25 gift certificate as a gesture of appreciation for their time and participation.

If are interested in participating in this study, please contact me by phone at (917)-660-7393 or email at jyc14@brandeis.edu

Thank you for your consideration!

Sincerely,

Jin Yun Chen (Helen)
Genetic Counseling Program
Brandeis University
Waltham, MA
APPENDIX C. Eligibility Questionnaire

Name:

Phone Number:

Email Address:

1. How old are you?

2. Are you the biological father or mother of a child with an autism spectrum disorder (ASD)?

3. Where did your family come from before the United States?

4. Where did your child’s other parent (or his/her family) come from before the United States?

5. How long have you been living in the United States?

6. How many children do you have?

7. How old is your child with ASD? (If more than one child with ASD is reported, we will focus on the oldest child with ASD for the purpose of this study)

8. What is your child’s specific diagnosis currently?

9. How long ago was your child diagnosed with ASD?

10. Was your child diagnosed in the United States?

11. Has your child seen a geneticist or had genetic testing?
   If yes, continue Q12, if no, skip to Q13

12. What have you been told by the geneticist or the test results?

13. What therapies/treatments has your child received since the diagnosis of ASD was made?

14. Would you prefer to conduct the interview in-person or by telephone?

15. Would you prefer to conduct the interview in Mandarin or English?

16. How did you find out about this study?
APPENDIX D. Interview Guide

Introduction:

Thank you for agreeing to participate in this study. It is our hope that your participation will help us learn more about the experiences of Chinese parents of children with autism spectrum disorder (ASD). By learning more about your experience we hope to provide better services for Chinese families.

I will be asking you a series of questions related to your experience with your child who has ASD, your understanding on the cause of his or her condition, your perception of the treatment your child is receiving, and the impact of your child’s diagnosis on family planning. There are no right or wrong answers. Your participation is voluntary. You may refuse to answer questions or stop the interview at any point. You will receive a $25 gift card as a token of our appreciation at the end of the interview.

I wanted to remind you that all identifying information will be kept confidential and will be destroyed after completion of the study. I would like to record this interview so that I will not miss any important information. Your name or any personal identifying information will not be used in our final report.

Thank you. Let’s begin!

Tell me about your child’s diagnosis:

• What was your child doing or not doing that made you decide to seek professional help for your child?
  o Prompt: Who was the 1st person notice a delay or have concern about your child?
    ▪ Yourself? Family member? Teacher? Healthcare provider?

• How did your child come to be diagnosed with an ASD?
  o Prompt: Who did you approached first with your concerns?
  o Prompt: How long did it take to see a specialist?
  o Prompt: Were you referred for a genetic evaluation or genetic testing?
    ▪ If yes, what have you been told about the test results?
  o Prompt: Who officially diagnosed your child with ASD?
  o Prompt: How was the diagnosis presented to you?
  o Prompt: Who was present at the time when they learned the diagnosis?

• Can you describe what was it like for you to learn that your child has an ASD?
  o Prompt: What was your initial reaction to the diagnosis?
  o Prompt: How did the diagnosis impact you emotionally?
Tell me about your understanding on the cause of ASD:

- What do you think caused your child to have an ASD?
  - Prompt: Genetics? Environmental? Spiritual/religious factors?
  - If you were to have another child, what do you think would be the likelihood of that child having ASD?

- What was it like sharing this information with other family members?
  - Prompt: Who did you tell? Were there any family members you chose not to tell?
  - If yes, how have your family members reacted to the diagnosis?
    - Prompt for: were they surprised/supportive/disbelieving?
  - If no, why have you not shared it?

- What do your family members believe is the cause of your child’s ASD?

Impact on clinical management:

- Regarding the services/treatments your child has received, which do you think have been the most effective?
  - Prompt: Western medication, Traditional medication or therapy, (acupuncture, dietary, herb, massage), Spiritual/religious practices?
  - Prompt: In what ways do you think your child has improved?

Closing Comments

- Thank you for participating in this interview.
- Is there anything that your think it might be important for me to know that I didn't ask?
- Would it be all right if I contact you be email or telephone if any questions come up when I review our conversation?
- Would you be interested in knowing the results of this study when it is complete? I would be happy to share them with you.
- Again, I want to reassure you about the confidentiality of your responses.

Thank you for your participation!