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Living with Autism in Vietnam

Libie Motchan
SIT Study Abroad

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Living with Autism in Vietnam

SIT Study Abroad Fall 2012

Libie Motchan

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Abstract

This paper examines the many implications of living with Autism in Vietnam on both affected children and their families. The lack of information, statistics and awareness of autism in Vietnam is reflected in the limited treatment resources available. This study calls attention upon what problems parents are most affected by what they feel needs to change. It also looks at the current sentiment and understanding of autism and its perceived causes. The results of this paper come from background research, observation at clinics and special education facilities, interviews with professionals in the fields of psychology and education, interviews with parents of affected children and a survey distributed to 41 parents.

The results of this study indicate that there is a lack of awareness and understanding of Autism by both medical professionals and the general population. Parents are not satisfied by the diagnostic process and the resources they are provided with by doctors. They are also generally not satisfied by special education facilities but there are several schools in Ho Chi Minh City that indicate a potential for progress. Autism has significant implications on parents but they are willing to make extensive sacrifices to ensure the success of their children. The findings also indicate that there is a more modern perspective developing among the current generation of parents in Ho Chi Minh City. Traditional values that lead parents to feelings of shame and guilt are being replaced by a motivation to spread awareness and understanding of autism. The new generation is proactive, well-informed and determined to make sure their children are successful. These findings suggest that there is a need for standardization in the diagnostic process and a new special education curriculum that has been adapted to fit Vietnamese culture.

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fortunate to spend my semester among ten incredibly intelligent and outgoing individuals and am so grateful for the long-lasting friendships I have made and the adventures and experiences I was able to share with the people I met.

I. Introduction

Focus of Research

The purpose of this project will be to answer the question “what is it like to live with Autism in Ho Chi Minh City?” In order to fully answer this question, I will take a holistic approach to studying Autism and look at both the resources available and the current sentiment felt by families of affected children.

Justification

Why Study In Ho Chi Minh City, Vietnam?

In the past several decades, Vietnam has been rapidly developing its infrastructure and facilities. Societies are quickly modernizing and Western ideals are being intertwined with deeply rooted traditional values. I chose to study in Ho Chi Minh City specifically, because as the economic capital of the country, it is developing more rapidly than Vietnam’s rural sectors and therefore reflects progress that is not yet present nationally. Its urban population is exposed to many forms of media and education levels are higher than in most other parts of the country. People living in Ho Chi Minh City hold many contemporary values and should have a better understanding of mental illness. Furthermore, Ho Chi Minh City has many resources available for the treatment of mental illness that are intended for both locals and foreigners. Conducting a study such as this one in a more rural area would be less relevant and therefore provide less applicable results. In rural areas, people may not have as deep an understanding of Autism and also lack access to special schools, psychiatrists and other medical services.

Ho Chi Minh City was a practical choice for me in terms of the accessibility of resources and contacts. There are several schools for children with developmental disorders along with many doctors and specialists that I was able to contact. Because I was dealing with an urban population, I was able to distribute questionnaires and conduct interviews to a wider sample.

Why Study Autism?

Given Vietnam's rapid development, the field of psychology is changing quickly. The few statistics and resources that currently exist will quickly become irrelevant as the country modernizes. It is important to constantly update information in order to determine the most appropriate direction new developments should head in. I chose to study Autism rather than other psychological disorders for several reasons. Autism has a relatively early age of onset and therefore affects not only the disabled child, but also his family. Therefore, the benefits of my study are not be limited to just affected individuals. The early age of onset also meant that most of my interviews and observations were conducted with parents rather than adult patients. I anticipated that it would be significantly more difficult to interview patients directly given confidentiality laws and therefore concluded that a childhood disorder was more appropriate to study. I find Autism to be a particularly interesting childhood disability that is misunderstood and debated on not only in Vietnam but in Western nations as well.

Aim

This study aims to be the first of its kind conducted in Vietnam and to ultimately call attention to what the country is lacking and where improvements should be made. Autism creates extensive difficulties for both the affected and those around them. This study will highlight which difficulties are most significant and taxing and will therefore offer insight as to what needs to change. By improving the availability of mental health resources, future generations of individuals affected with Autism in Vietnam will have more successful lives and be more likely to overcome their disorders.

II. Background

What is Autism?

Autism is a developmental disorder characterized by an individual's inability to connect with and understand others. Symptoms begin from the beginning of life and vary from case to case. It is a pervasive developmental disorder marked by extreme unresponsiveness to others, poor communication skills and highly repetitive or rigid behaviors. The diagnostic statistical manual (DSM-IV-TR, 2000) includes the following core features in its classification of the disorder: impairment in social interaction, impairment in communication, preference for stereotyped, repetitive behavior and onset before the age of three (Comer, 2011). Autism is said to affect 1 in 88 people and affects males at significantly higher rates than females (Comer, 2011). The severity of autism and its implications on the affected person's functioning vary greatly between individuals; approximately 10-15% of individuals have average or above average intelligence, 25-35% have borderline to mild mental retardation and the remainder are moderately to severely retarded (Mesibov & Shea, 2006).

Autism in Vietnam

The Viet Nam Public Health Association estimates that there are approximately 160,000 individuals suffering from Autism in the country but no official statistics exist (Brown, 2009). This rate is comparable to that of developed countries, but unfortunately the availability of education and discussion of Autism in universities is severely lacking when compared to Western nations. As of 2009, there were no books printed in Vietnamese about Autism and a necessity for more research to be conducted on the

disorder (Brown, 2009). There are over one hundred educational establishments for children suffering from developmental disorders in Ho Chi Minh City that are both private and publically funded, but unfortunately, these institutions lack materials and staffing to effectively benefit their students (Ngoui Lao Dong, 2010). Furthermore, there is no health literacy data available from Vietnam, but reports indicate that levels are lower than those of Western countries (Ying K.C, Browne, Hutchinson, Cashin & Vu Binh, 2012)

Autism is a disorder that is generally not well understood by societies in Asia and therefore the diagnosis of Autism is a cause for great distress and tension to those related to the individual suffering from the disorder (Ying K.C. et al, 2012). A Western view of Autism is just developing in Vietnam, but despite this, resources for the community and children are still underdeveloped and steps are being taken to address the nation's educational needs (Ying KC et al. 2012).

Perceived Causes

Western psychologists offer many different possibilities for explaining the development of Autism. Studies examining the prevalence of the disorder among fraternal and identical twins support a genetic source of the disorder. There are also links to prenatal infections such as Rubella or chemical exposures at labor that are linked to increased likelihood of developing autism (Comer, 2011). There are several differences in brain anatomy in individuals suffering from autism such as increased brain volume, enlarged ventricles, abnormal cerebellum and a defective layering of the cortex (Comer, 2011). A study conducted in 2006 that surveyed American parents of autistic children, revealed that parents were most likely to attribute their child's disorder to immunizations,

genetic predispositions and environmental exposure, respectively (Harrington J, Patrick P., Edwards K., & Brand D., 2006).

Differences in Vietnamese cultures and values could be responsible for different perceived causes of mental disorders. Several studies show that Vietnamese parents still believe in more traditional causes of their child's autism that relate to the actions of either the child or his parents in their past life and that views of causation are often grounded in Karma (Ying et al. 2012). Lauber and Rossler (2007) explain that in traditional societies mental conditions are thought to be the result of spiritual punishment, possessions by demons, transgressions towards ancestors, or wraths of gods. A study performed by Van Der Ham L., Wright P, Thang VV, Vuong D. K. Doan, & J. E. W. Broerse (2011) revealed that Vietnamese people often mention stress, tension, studying or thinking too much as causes of mental illness.

Stigmas and Caring for a Child with Autism

Many traditional values still exist in Vietnamese societies. According to Jane Luong, Marian K Yoder and Daryl Canham (2009), Southeast Asian families live in clans and depend on each other for all family needs. Traditional societies are characterized by familial orientation and a strong sense of responsibility for the actions of all family members. Therefore, the existence of a mental disorder is not only a burden to the affected individual, but to all members of his family, as it threatens their social status. Furthermore, in an effort to ensure that their non-disabled children find spouses, parents often hide the existence of a disability in their genes by entirely denying the existence of their affected child (Lauber and Rossler, 2007). Stereotypes about people suffering from mental

disorders exist cross-culturally. Christopher Lauber and Wulf Rossler (2007) report that stereotypes that are held by the general public are that people with mental illness are dangerous, violent and unpredictable.

Vietnamese values and philosophies differ from Western ones in ways that critically deter them from seeking proper treatment. Vietnamese culture focuses on the idea of *saving face* which is defined as the avoidance of humiliation and disgrace by maintaining one's social image (Ashwill, 2004). Although children are generally too young at the onset of Autism to be affected by the concept of saving face, it is likely that their parents are affected by it. Parents of autistic children may be less likely to seek treatment for their child due to the shame it will bring upon their families. Individuals suffering from mental disorders in Vietnam are often reluctant to seek treatment because they believe it is inaccessible, or unacceptable, particularly in the treatment of less severe mental disorders (Van Der Ham L. et al. 2011).

According to K. C. Ying et al (2012) people view a disability as a punishment for the disabled person's sins in a past life or for the sins of his or her parents. These traditional beliefs are rooted in Confucian ideals and result in much guilt and shame by the families of the disabled. Many studies note that parents living in cultures with the aforementioned traditional beliefs will often deny their child's disability or delay receiving treatment due to the related stigmas (see, for example, Jin Y. Shin, Nguyen Viet Nhan, Kathleen Crittenden, S. Stavros Valenti and Hoang Thi Dieu Hong, 2008).

These stigmas result in increased stress and anxiety and K. C. Ying et al (2012) note that numerous studies indicate that caretakers of children with autism experience higher rates of depression, anxiety, diminished health and increased pressure in relationships.

These stresses are not only the result of the stigma's related to autism but also due to the anxiety parents feel because of the lack of available information and resources providing guidance and advice. Parents feel extreme levels of distress after receiving a diagnosis of autism, arising from not only the diagnosis, but also from confusion about implications the disorder will have on their child and families (Howlin & Moore, 1997).

Luong et al (2009) cite a study by Gray about coping strategies used by parents that concludes that such strategies change over time as the needs of the child change. They report that the level of support received by parents from their families declines as the child ages. The results of the study by Luong et al (2009) indicate that parents of children affected by autism in Southeast Asia need to rearrange their schedules, homes and finances in order to take care of their children. Mothers who were employed prior to learning about their child's disorder were often forced to quit their jobs, and many parents reported having limited time for leisure activities. Parents frequently use spiritual resources to help cope and reported that such resources increase their sense of hope. Two out of the nine parents interviewed in this study noted that they believe in paying debts from their previous lives and therefore felt that they owed their children something in the past and are paying for this debt by taking care of them and loving them.

The results of the aforementioned study (Luong et al, 2009) also indicate that Southeast Asian parents have a limited support network. Eight parents stated that they depended minimally on resources beyond those available from their immediate family. Six mothers stated that they were not satisfied by the support offered by their respective spouses. The stress caused by raising a child with autism creates tensions in relationships between all family members.

Teachers in Vietnam

A 2008 study conducted by Shin et al. examined the agreement on childhood disability between the teachers and parents of children affected by cognitive delays in Vietnam. Parents rated the functional levels of their child's disability higher in most domains measured but particularly in the child's intellectual functioning, social behaviors and communication skills. Shin et al. (2008) theorize that this disparity is the result of cultural beliefs that affect the parents' perceptions of the disability, or that the parents suspect the child's disability but deny it due to the related stigmas. They also theorize that the strict standards of academic performance that pervade Asian education systems result in the harsh ratings given by teachers. Shin et al. (2008) note that the discrepancies that they found are particularly troublesome in developing countries when children are qualified to receive special services and specialists must go through great lengths to convince parents to get their child treatment. If specialists are unsuccessful, parents continue sending their children to normal schools. Teachers are unlikely to be proactive about calling attention to the child's autism so it often goes unnoticed for a long time.

III Methodology

In order to gain a holistic understanding of the implications of living in Autism with Vietnam, I used several forms of secondary and primary research.

Much of my secondary research was conducted through searches performed in databases such as PsychINFO, PsychARTICLES and JSTOR, using search terms such as “autism,” “cognitive delays,” “childhood disabilities,” “Vietnam” and “Southeast Asia.” The articles collected came from predominately European and American journals. The literature review provided me with an understanding of symptoms, causes and the prevalence of Autism – as understood by Western cultures. It also gave me an overview of the current mental health care facilities in Vietnam and an understanding of how traditional Asian values relate to psychological disabilities.

Another part of my research involved interviews with professionals in the fields of psychology and education. I was able to interview psychologists, psychiatrists, early intervention therapists, doctors conducting research on autism, teachers and principals working at schools for children with disabilities and university students studying psychology. My interviews with professionals in such a wide range of positions provided me with varied perspectives and a comprehensive overview of the resources available in the country and the different techniques being practiced. I conducted most of these interviews early into my research period and was therefore able to use my findings to modify my interview questions and questionnaire.

I also used first hand observation at several sites to learn about clinical and educational facilities. I visited Santa Maria’s, a private clinic in Ho Chi Minh City where I was able to observe a psychiatrist perform diagnoses on children and provide parents with

evaluations. I witnessed the full diagnostic process and gained much insight from the parents' responses to their doctor. I visited both public and private schools for children with disabilities and attended classroom activities to see how children were treated. I was able to review the curriculum used by some of the schools that I visited to understand more about the theories and approaches currently being applied.

The second part of my research involved parents of children suffering from Autism. I created a questionnaire because it would allow me to have a large sample size of participants, which is necessary in measuring the views of parents. The questionnaire was written in English and translated into Vietnamese. It was then formatted to be available online, which gave me access to a larger pool of participants. It was posted on parent forums from schools for children with disabilities and was sent to psychiatrists and doctors to distribute to their patients. By sending it to multiple schools and doctors, I was able to diversify my participants and make more general conclusions. The questionnaire included multiple choice and open ended questions and touched upon several aspects of raising a child with Autism. It consisted of questions about demographics, the diagnostic process, forms of treatment, and perceived causes.

Data from the questionnaire were reviewed to determine any consistent trends. The responses to the open ended questions were translated from Vietnamese to English and evaluated to add depth to my data and learn anecdotes from the parents' experiences.

I was able to conduct nine interviews with parents of autistic children. These interviews were organized by the Khai Tri School and by Ms. Trinh Thi Kim Ngoc, who introduced me to parents who brought their children to her private special education center. The interviews were conducted with the help of a translator and lasted

approximately thirty minutes. The interviews gave me insight into the family's history of treating their child, their level of satisfaction with treatments available and the implications the disorder has had on various aspects of their lives.

IV Results

Participant Demographics

Of the nine parents I interviewed, seven were mothers and two were fathers of autistic children. All of them were parents of sons and lived in Ho Chi Minh City.

A total of 41 participants completed the questionnaire. Participants were predominately female; 88 % were female and 12 % were male. A majority of participants were parents of sons; 76 % of participants were parents of an autistic son, and 24 % were parents of an autistic daughter. The most common age of the participants' autistic son/daughter fell in the range of 4-6 years old (29% of participants). The majority of participants were employed full time.

Treatment

The most common forms of treatment participants used for their children were private schooling for children with disabilities, schooling for children with normal learning skills, and regular meetings with a psychologist, respectively. 44 % of participants reported bringing their child to a private school for children with learning disabilities, 28 % of participants reported bringing their child to a normal school for children without learning disabilities, and 17 % of participants reported bringing their child to regular meetings with a psychologist.

Perceptions of Autism

The majority of participants (63%) reported that they did not know what autism was prior learning about their child's diagnosis.

Participants were asked about what they believed were possible causes of their child’s disorder. They were asked how likely it is that their child’s autism was caused by either weak nerves/bad character, chemical imbalances in the brain, supernatural causes, inherited condition from parents or problems during labor. They were able to choose between “very unlikely,” “unlikely,” “likely,” “very likely” and “don’t know.” The results are displayed in the table below:

Perceived Cause	Percentage of Responses *
Weak Nerves / Bad Character	46.2%
Chemical Imbalances in the Brain	33.3%
Supernatural Causes	0.0%
Inherited Condition from Parents	53.3%
Problems During Labor	60.0%

* Percentages represent a sum of “likely” and “very likely” responses

The most common cause attributed was problems during labor and the second most common cause attributed was inherited conditions from parents. “Supernatural causes” was the least likely cause attributed and was never perceived as “likely” or “very likely.”

V Discussion

In this section of my paper I will provide an analysis of my findings using both the results of my questionnaire and the various interviews and observations I conducted.

Diagnosing Autism

Many of the issues with the way that Autism is treated in Vietnam are rooted in the ways psychologists are taught. From my interview with researcher Dr. Nguyen Van Hung, I learned that until 2000, autism was not an available concentration in university studies, so even experts in the field have limited knowledge about the disorder. According to Dr. Giang Phan, students studying psychology are taught theories rather than practical forms of treatment. They have few opportunities to practice what they are taught and therefore are quick to draw conclusions (Brown, 2009). According to Tony Louw, an early intervention therapist, “local practitioners have a minimal understanding of autism” and there are no standardized measures for establishing a diagnosis. Ms. Trinh Thi Kim Ngoc relayed a long list of different diagnostic tools – M-CHAT, DSM-IV-TR, ICD-9-CM, PDM, ADOS, ADI-R – and explained that none are agreed upon or fully understood.

Another psychologist I met explained to me that autism is very often misdiagnosed in Vietnam; it is often confused with other childhood disorders. Dr. Ta Ngoc Bich at the TuNa clinic explained to me that children often come to her clinic having been diagnosed with autism but discover that they are actually suffering from ADHD or language delays and had been diagnosed at too early an age. Seven of the parents interviewed reported that their child was initially misdiagnosed or that their doctor was unsure what condition their child was suffering from. One father I interviewed explained to me that when he initially

brought his son to a doctor for evaluation, the doctor diagnosed him as being deaf. The father was immediately skeptical and a month later brought his son to another doctor who diagnosed him as severely autistic. Another mother I interviewed had a similar experience; the doctor she brought her son to was confused by his symptoms and unable to provide a proper diagnosis.

During my many observations of the diagnostic procedure, I noticed that the process took a matter of minutes. Psychologists were hasty when answering questions and reviewing information. I witnessed several appointments that lasted under twenty minutes and watched many parents leave clinics with confused expressions on their faces. My interviews with both Tony Louw and Marianne Simpson confirmed this pattern; both professionals explained to me that doctors in Vietnam work as quickly as possible to ensure that they can see a maximum number of patients. Simpson explained to me that doctors are “just trying to make money off of the drugs they prescribe,” and Louw elaborated that because of this, parents often do not trust doctors; they believe doctors are selling a service, so they are skeptical of any diagnosis that they receive.

Louw explained to me that another problem in the diagnostic process is that parents will see a family doctor rather than a specialized psychologist; this is a problem because doctors often want to humor these families so that they can keep them as clients, and therefore will tell the families “what they want to hear.” All but one of the parents that I interviewed brought their children to a doctor rather than a psychologist for their initial diagnosis. They justified this decision due to their lack of access to a psychologist, their lack of knowledge about the mental health sector, and the high prices of a specialized evaluation session. One father mother explained “I decided to have my son diagnosed by a doctor

[rather than a psychologist] because I didn't know of any psychologists." The one mother who did bring her son to a specialist explained that the psychologist was unable to attain her son's cooperation so she quickly stopped his therapy sessions.

From my interviews, I received several consistent responses related to parents' lack of satisfaction with their doctors, psychologists and the entire diagnostic process. None of the parents reviewed their experience receiving a diagnosis positively. They often left their doctors with little resolution and more unanswered questions. One mother who I interviewed told me that from parents' perspective, doctors in Vietnam are "hard to understand." Another explained, "my doctor gave me some information about the disorder but I didn't understand it because it was general and theoretical." Parents often were forced to conduct research on their by own using the internet, libraries and speaking to friends from foreign countries. From interviews, I learned that most parents did not know what autism was prior to their child's diagnosis and had little background on mental health. My questionnaire also reflected this insight; 63 percent of participants reported that they did not know what autism until their child was diagnosed. These findings are consistent with those of Van Der Ham et al (2011) that indicate that there is a general lack of knowledge and awareness in Vietnam about mental illness. Nonetheless, the parents I interviewed all felt confident with their current understanding of Autism but attributed none of it to information given to them by Vietnamese specialists. One father explained, "when my son was diagnosed my family felt helpless; we were shocked and confused and our doctor did not offer any advice." Throughout my interviews I consistently learned that doctors and psychologists were unlikely to refer parents to special schools or early intervention programs – more often they advised parents to keep their child in normal

schools. Although parents often initially followed this advice, they were eventually unsatisfied and displeased with their physician's guidance.

My findings about the diagnostic process in Vietnam are consistent with many previous studies. A newsletter from 2010 (CLAN, 2010) revealed that upon learning about a diagnosis of autism, parents in Vietnam were surprised and unsure of what to do but had minimal resources available in their communities. K. C. Ying et al (2012) explain that studies have shown that parents value written information provided after a diagnosis of autism, but unfortunately in Vietnam, such resources are lacking.

Special Education in Ho Chi Minh City

In Ho Chi Minh City, there are significantly more private institutions than public ones, and even the public schools charge a tuition fee. Of the many institutions that I visited, all but one received no funding from the government; in fact, Mr. Huyen Tan Mam of the Khai Tri school explained to me that outdated government regulations limit the school's curriculum. Ms. Ngoc of the Ban Mai school explained to me that if the school had increased sources of funding, it would lower tuition rates and offer scholarships to make the school more accessible. Similarly, Mr. Huyen Tan Mam of the Khai Tri school explained that with increased funding, he would not only decrease tuition but also expand the school so that more students would be able to enroll. He explained that the school has a lengthy waitlist and many parents who are on the waitlist have no other option but to enroll their children in normal schools. When I asked one father what he felt needed to change about the way autism is treated in Vietnam, he replied, "the government needs to support families with autistic children financially." One questionnaire respondent explained, "the special

education system doesn't receive enough attention from the government, especially the facilities.”

The results of my observations and interviews indicate that there is a wide range in the quality of special education available in Ho Chi Minh City. The level of satisfaction of parents with their child’s education varied drastically depending on what institution their child was enrolled in. For the most part, parents were not satisfied with the special education system and looked for ways to supplement it. Many Vietnamese schools still use a traditional curriculum that emphasizes the role of the teacher rather than the creativity of the students. Marianne Simpson, a British special education teacher who works in Vietnam explained to me that Vietnamese teachers do not see the value of play and free interaction and that this is particularly a problem for Autistic children who need to develop their social skills. Tony Louw, a consultant for the Vietnamese organization, Learning Strategies, confirmed this idea, and explained to me that in Vietnamese schools, everything is “teacher-led.” On one visit to a special school in Ho Chi Minh City, I watched as teachers distributed sheets of paper with colored boxes and instructed the students to fill in the boxes with the corresponding colored crayon. Students were reprimanded when they chose to use the wrong color or when they got up from their desks to share their work with their peers.

Contrary to my background research, this traditional mindset was not held by parents – “learning through playing and playing through learning” was the philosophy of one mother I met. Parents are developing a more Westernized mentality that supports creativity and socializing. Unfortunately, this mentality is not in line with most special education curriculums used in Vietnam.

Vietnamese parents value both private sessions with special education teachers and class room activities. Parents acknowledged the importance of having their children interact with other children in order to develop social skills and make progress in overcoming their disorder. Nevertheless, eight parents explained that they hire a private teacher for one-on-one sessions to supplement their child's time at school. They recognized that this was not the most effective way for their child to overcome his social impairment but feel that progress made at school is not sufficient.

Every parent that I interviewed had withdrawn their child from at least one school due to their lack of satisfaction with its curriculum. Doctors generally recommended that parents kept their child enrolled in normal schools even in cases of severe autism. However, the parents I interviewed knew that this was not the best solution for their children; one mother explained "I took him to a normal preschool, but he did not make any progress so I did research and decided it was important to intervene as soon as possible. I enrolled him in a special school – it was much better but the classes were too big." She eventually founded her own private special school for her son and several other children that she is very satisfied with. After enrolling her son in several special schools, another mother withdrew her son and now brings him to normal school in the mornings, teaches him herself in the afternoon and provides him with private therapy in the evenings.

Another problem with the special education system in Vietnam is the lack of communication between teachers and psychologists. "Therapists and schools do not connect well. Therapists provide a diagnosis but that is the extent of their relationship," said Ms. Ngoc of the Ban Mai school. Another mother explained to me that "education is getting better but there is a lack of connection between teachers and psychologists" and

said that although she has complaints about the special education system, she believes it is much stronger than the mental health system in Vietnam.

After trying several schools, parents were generally able to find a school that they were satisfied with. Parents were more motivated than my background research had led me to expect; they displayed a great deal of determination to find their child the most effective school. Two schools that I visited – Ban Mai and Khai Tri – received consistently positive reviews by parents. They were happy with their level of communication with teachers and anticipated that their child would make progress. Every morning at the Ban Mai School when teachers receive students from their families, parents tell teachers how their child behaved the previous evening to help teachers predict how the child will be feeling throughout the day. Ms. Ngoc explained that “parents must be involved because learning takes place outside of school and in order for improvements to be made, treatment must be comprehensive.” A mother at the Khai Tri school told me “I think this school has better treatment for my son than normal school; I talk to my son’s teachers everyday to learn about his progress.” Ban Mai and Khai Tri reflect progressive and Westernized ideas but unfortunately are still exceptions when it comes to the special education system in Ho Chi Minh City.

Implications of Autism

The results of every interview I conducted consistently revealed that parents make great sacrifices to take care of their children. Many aspects of their lives are affected in their effort to find their child the best care and help him or her improve as quickly as possible.

The high demand for special schools in Ho Chi Minh City is enlarged due to the entire absence of such institutions in rural areas in Vietnam. Families do not have access to psychologists or schools for children with disabilities in the areas around Ho Chi Minh City and will often commute to find care for their children. During my observations at psychology clinics, I encountered several families that had traveled many hours to diagnose their children, and some who were in the process of permanently moving their families to the city to receive care. On one of my visits to the Ban Mai School, I witnessed a young boy crying as his classmates sang a song about a farmer in rural Vietnam. His teacher later explained to me that he and his mother had moved to Ho Chi Minh City from the countryside to attend Ban Mai and this song reminded him of his father who was still working as a farmer. Four of the parents interviewed had moved to HCMC to seek treatment for their children and another father reported that he considered moving as far as the United States or Canada. The implications are extensive and affect every aspect of a family's structure; from daily routine to their location of residence.

The results of my interviews are consistent with a 2002 study by Tunali and Power that concluded that mothers of children with autism believed that taking care of their child was more important than their career. All but one parent I interviewed reported either having quit their job or taking fewer hours. Parents reported feeling distressed by the financial burden of seeking care for their child that is caused by a combination of the high prices of special education treatment and the time sacrificed for care-giving.

The implications of raising a child with autism are not only financial but affect parents' levels of stress and happiness. Several parents reported feeling stressed, fatigued, experiencing weight loss, and one father disclosed that he developed insomnia. These

findings are consistent with my background research that indicated that relatives of individuals suffering from mental disorders in Vietnam encounter financial and emotional burdens (Van Der Ham et al., 2011). My results are also consistent with the aforementioned study by Luong et al (2009) on Southeast Asian families and their coping methods. When I asked one mother in what ways her life had been effected by her child's autism, she replied "every." My conversations also indicate that despite these burdens, parents are unwilling to give up on their child and still feel a great deal of love.

Stigmas, Shame and Friendships

The results of both my background research and my conversations with specialists led me to anticipate that parents would be ashamed of their child and unwilling to talk openly with me. Ms. Simpson explained to me that Vietnamese parents often withdraw their children from school because of feelings of shame and guilt. Mr. Louw mentioned the concept of "saving face" and explained that it is still an issue in HCMC; he said "so much of Vietnamese culture revolves around family and arranged marriages so parents are determined not to taint their genetic blood lines with 'special needs.'" The information relayed by Simpson and Louw is consistent with the findings mentioned in the introduction by Van Der Ham et al. (2011) and Lauber and Rossler (2007) indicating that families in Southeast Asia feel very ashamed of their relatives suffering from mental illness.

Contrary to the information detailed above, the results of my interviews indicated that parents were not ashamed of their autistic children. None of my respondents mentioned that they feel pressure to keep their child or his disorder hidden and when asked if they ever felt embarrassed by their child, none of the parents answered in the

affirmative. Participants responded that they feel comfortable talking to their friends about their children and find their friends to be compassionate, especially after learning more about autism. One mother explained “My friends are completely sympathetic of all the changes I have made on my life. I have never felt that I need to keep my son hidden because I think people are becoming more aware of autism and more understanding.” Many parents mentioned that they hope to spread awareness of autism across Vietnam so that the population becomes more understanding so that resources develop. One questionnaire respondent explained, “I am willing to discuss my child's situation with people around so that they know more about autism and are more understanding.” Like many parents I interviewed, this mother believes that there is a general lack of knowledge about autism and explained to me that if this were changed, her child would be more successful in integrating into the community.

My findings indicate that a comprehension of autism is responsible for this decreased sense of shame. One mother explained, “the concept of ‘saving face’ still remains but it is not very common in big cities like Hanoi or HCMC; people know that early intervention really helps and want to help their children.” Two parents explained that when they first learned about their child’s diagnosis they were both shocked and embarrassed, but after conducting research and learning about the disorder, these sentiments were eliminated. They understood that their child’s “weird” behavior was not his fault and recognized that his symptoms were typical of an autistic child. A comprehension of autism eliminates feelings of shame and replaces them with motivation to find proper treatment. One questionnaire participant responded “community understanding would make people more accepting and allow my child be more confident to

integrate in the society.” An awareness of autism minimizes any embarrassment, because parents learn that their child’s symptoms are not his fault, and therefore believe that spreading awareness across the general population is important so that others share this view.

Although respondents consistently felt that their friends were understanding, several participants mentioned dissatisfaction with the way their extended family treated their child. One mother explained that after learning about her son’s diagnosis, his paternal grandparents cut off contact with her family and has refused to visit her son. These findings indicate that stigmas about autism are only held by an older generation of Vietnamese people who still maintain traditional values. One mother rationalized the phenomenon, saying “saving face just affects grandparents. The younger generation of parents like us doesn’t care much about maintaining our image.”

Perceived Causes

Another section of my findings that contradicts my secondary research falls in the area of the perceived causes of autism. As mentioned in the introduction, Southeast Asian traditional values promote a view of mental disorders that is tied in with Karma, ancestor worship, and sins of the past life (Lauber & Rossler, 2007). I expected that parents would attribute their child’s disorder to spiritual or religious causes. This expectation was confirmed by my interview with Marianne Simpson, who explained to me that because many people in Vietnam practice Buddhism or believe in traditional philosophies, they attribute their child’s disability to the sins of their ancestors. She provided an anecdote

about a mother she met who changed her son's name after being told by a fortune teller that his autism was a result of his unlucky name.

My interviews and questionnaire results indicate that parents do not apply traditional philosophies to their perception of the cause of Autism – or perhaps that they are unwilling to reveal such a belief if it is actually held. When asked how likely they are to believe that supernatural causes are responsible for their child's autism, a large majority of parents responded “very unlikely” or “unlikely” (86.7%) and none of the participants responded “likely” or “very likely.” Throughout interviews, when I asked parents what they believe caused their child's disorder they were either unsure or attributed it to a specific cause but none made any mention of their ancestors, actions in a past life, spirits or other traditional concepts. The only mention of religion came from two mothers who told me that since their child developed autism, they began praying more.

The results of the questionnaire indicate that Vietnamese parents are likely to attribute their child's disorder to more biological causes; the causes that received the most “likely” or “very likely” responses were problems during child labor and inherited conditions from parents. The causes that the parents interviewed mentioned were also biological but more varied. Two parents attributed the development of autism to problems during labor, one father attributed it to premature birth and one mother attributed it to her old age when bearing her son. One mother believed it was the result of a vaccine her son received for the whooping cough and one mother postulated that her son's brain development was limited because he fell down several times as a child and hit his head. All of the aforementioned perceived causes were also mentioned by American parents in the 2006 study by Harrington et al. discussed in the introduction. My results related to the

perception of cause reflect a pattern of Westernized thinking among parents and support the conjecture that a more modern view is developing among the new generation of parents in Vietnam.

Vietnamese special education teachers offered several other theories for the causes of autism. Mr. Huyen Tan Mam of the Khai Tri school attributed Autism to the rapid industrialization in Vietnam and the pollution that has resulted from it. Dr. Ta Ngoc Bich of the TuNa clinic credited the increasing prevalence of autism in Vietnam to the food hygiene — there are more chemicals in food and this affects children’s development. Although these causes are different than the ones mentioned by parents, they still reflect modern ideas and display the implications of Vietnam’s rapid urbanization.

Looking Forward

The parents I interviewed relayed stories ranging from frustration to complete satisfaction with special education facilities in Vietnam. Unfortunately, only two institutions were mentioned positively – the Khai Tri School, and the Ban Mai School. These schools are using progressive programs that do not reflect the standard curriculums used by typical special education schools in Vietnam. The Khai Tri school and Ban Mai school both bring in foreign specialists to train teachers and provide teaching materials. Mr. Phi, from the Ban Mai school often travels to California to bring back new Western ideas about treating Autism. The Khai Tri school invites foreign specialists to host seminars for teachers and parents about raising and treating an autistic child. Both schools follow the TEACCH autism program developed in North Carolina. Ban Mai and Khai Tri represent

progressive and successful facilities – both were founded within the last decade and are constantly adapting their curriculum based on foreign influence and trying new techniques.

There are limitations to a curriculum that comes entirely from Western cultures. Ms. Trinh Thi Kim Ngoc, a special education teacher, explained to me that there are extensive cultural differences between Western and Southeast Asian cultures and therefore teaching materials from foreign countries cannot be used in Vietnam without adapting them. Curriculums used in Vietnamese schools must reflect Vietnamese culture in order for them to be effective. Instead of taking materials from foreign specialists, it would be ideal to have Vietnamese doctors and educators go abroad and apply foreign principals to creating entirely new autism treatments specifically for Vietnam.

Despite the deficiencies of the Vietnamese mental health system, parents I interviewed felt a great deal of hope for the future of their child. All of the participants anticipated that their child's autism would eventually improve, regardless of their level of satisfaction with the education their child was receiving. They were generally uncertain about what would happen in the distant future but were hopeful about the short-term.

VI Limitations:

This study has several limitations. In regards to the questionnaire participant pool, there was a relatively small sample size and a lack of random sampling. Participants were all parents who are either part of an online forum for HCMC parents of autistic children, or parents who send their children to a special school in HCMC. Therefore, participants all had some level of awareness of the treatment facilities available for their children. Random selection would have allowed for a sample that included participants that did not know what special education resources are available in HCMC.

The participants interviewed were not randomly sampled either. All participants either brought their child to Khai Tri school, or Ms. Trinh Thi Kim Ngoc's special education center. It would have been interesting to diversify the sample by including parents whose children attended normal school in HCMC or whose children were not receiving any treatment at all.

I would have liked to make changes to the questionnaire. Because I did not anticipate that I would be able to interview as many parents as I did, I included several open ended questions; I believe these questions were superfluous and I learned more when I asked them during interviews. I would have liked to replace them with more multiple-choice questions related to satisfaction of treatment facilities and about the effects of autism on participants' lives. I would also add in a fill-in for the question that asked participants about perceived causes, because based on the results of my interview, there seems to be much variation in parents' views on this subject.

My interviews with parents were limited by a language barrier. Unfortunately, during all but two interviews I had to use a translator. This hindered my ability to

communicate with interviewees and I was unable to fully interpret emotion and tone of voice. I also felt that parent's were not always sure whether their responses should be addressed to the translator or to me, but I made an effort to maintain eye-contact with participants at all times throughout our conversations.

VII Suggestions for Future Study:

Given the lack of information and statistics about autism in Vietnam, there are many opportunities for conducting more research on the subject. I feel that it is imperative to conduct research on the prevalence of Autism in Vietnam; these statistics are lacking and it is difficult to make progress on developing treatments and spreading awareness without such information. It would be interesting to conduct a study similar to the one I conducted but in more rural areas where many traditional values are still maintained and resources are significantly more limited.

It would also be interesting to conduct studies on the effectiveness of various treatments in Vietnam. Although statistics and research about the success of certain treatments already exist, this information was collected in Western countries, and it is very possible that treatments have different levels of efficacy when conducted in Vietnam due to the cultural differences.

Another approach to studying autism in Vietnam would involve looking at the stigma held by the general population. Given the current lack of awareness on mental health conditions in Vietnam, it would be beneficial to learn about current beliefs held by the people who are not directly related to an individual suffering from Autism. My findings imply that a majority of this population does not know what Autism is at all, so it would be interesting to see how they interpret symptoms of the disorder.

VIII Conclusion:

Based on the results of my research I have come to several conclusions about the many implications of living with autism in Vietnam. Firstly, there is a clear lack of both awareness and understanding of the disorder by the general population and professionals in the field. Psychologists and doctors are taught theories rather than practice and their ability to provide an accurate diagnosis is hindered by their education, lack of standardized measurement tools and hastiness. They are not helpful in providing parents with information about their child's disorder or available treatment options so parents often feel confused and shocked. They often do not trust their doctors and are not satisfied by the advice they are given. Parents' determination compels them to take matters into their own hands and conduct research and find a suitable institution to bring their child to. There is a strong disconnect between the special education system and the medical field; doctors are not in communication with teachers and therefore improvements that are made are generally only evaluated by teachers and not by medical specialists.

The special education facilities in Ho Chi Minh City are relatively few, and for the most part, offer poor qualities of education. Parents often bring their children to multiple institutions before eventually either finding a suitable one, or giving up and withdrawing their children from special schools and providing them with personal treatment. The curriculums used by special schools in Vietnam are generally not effective but there are some schools that create a sense of hope for the future of special education in Ho Chi Minh City. Schools like Khai Tri and Ban Mai apply foreign research to their treatment approaches, but there is still a need for a curriculum that has been created uniquely for Vietnamese culture. Hopefully in the future, Vietnamese professionals will apply

information from abroad to create teaching and diagnostic tools that are customized for Vietnamese culture.

A new generation of values is developing among Vietnamese parents and many traditional beliefs are discarded when parents conduct research about autism. Their perceptions of cause are not related to supernatural or spiritual forces and are instead attributed it to a wide variety of specific biological causes that are reflective of Western thoughts. After conducting research about autism, parents also do not feel ashamed of their child's disorder and instead believe that it is important to spread awareness so that others understand the disorder and respect their child. They are very willing to adapt their lives in any way necessary in order to ensure that their children receive the best available care. Their lives are implicated extensively but parents are willing to make a range of sacrifices to ensure the success of their child. These aforementioned findings reveal that parent's traditional values are easily replaced and indicate that the new generation of Vietnamese people living in Ho Chi Minh City is much more progressive and values the well-being of their children above many other elements of their lives.

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Mr. Nguyen Van Hung, researcher. Translated by Hai Nguyen. The Vietnam Institute of Educational Sciences, Hanoi, Vietnam. November 9, 2012

Mr. Nguyen Thi Thanh, researcher. Translated by Hai Nguyen. The Vietnam Institute of Educational Sciences, Hanoi, Vietnam. November 9, 2012

Ms. Nhu Quynh, teacher. Translated by Hai Nguyen. School for children with disabilities, Hanoi, Vietnam. November 9, 2012

Dr. Ta Ngoc Bich, teacher, translated by Hai Nguyen, Tu Na clinic, Hanoi, Vietnam. November 12, 2012

Dr. Giang Phan Xuan, psychiatrist. Santa Maria Clinic, Ho Chi Minh City, Vietnam, November 14, 2012.

Dr. Tony Louw, early intervention therapist, Learning Strategies, Ho Chi Minh City, Vietnam, November, 15, 2012

Marianne Simpson, special; education teacher, Ho Chi Minh City, Vietnam, November, 16, 2012

Dr. Giang Phan Xuan, psychiatrist. Santa Maria Clinic, Ho Chi Minh City, Vietnam, November 16, 2012.

Interview with parent #1, Ho Chi Minh City, Vietnam, November 17, 2012

Ms. Ngoc, teacher, translated by Vy Dinh, Ban Mai School, Ho Chi Minh City, Vietnam. November 19, 2012.

Dr. Huynh Tan Mam, principal, translated by Tien Nguyen, Khai Tri School, Ho Chi Minh City, Vietnam November 20, 2012

Ms. Thuy Tien Nguyen Ngoc, teacher, translated by Tien Nguyen, Khai Tri School, Ho Chi Minh City, Vietnam November 20, 2012

Ms. Trinh Thi Kim Ngoc, Dean, faculty of special education, national college of special education, Ho Chi Minh City, Vietnam, November 21, 2012

Interview with parent #2, translated by Ms. Trinh Thi Kim Ngoc, Ho Chi Minh City, Vietnam, November 21, 2012

Interview with parent #3, translated by Ms. Trinh Thi Kim Ngoc, Ho Chi Minh City, Vietnam, November 21, 2012

Interview with parent #4, translated by Ms. Trinh Thi Kim Ngoc, Ho Chi Minh City, Vietnam, November 21, 2012

Interview with parent #5, translated by Tien Nguyen, Ho Chi Minh City, Vietnam, November 22, 2012

Interview with parent #6, translated by Tien Nguyen, Ho Chi Minh City, Vietnam, November 22, 2012

Interview with parent #7, translated by Tien Nguyen, Ho Chi Minh City, Vietnam, November 23, 2012

Interview with parent #8, translated by Tien Nguyen, Ho Chi Minh City, Vietnam, November 23, 2012

Interview with parent #9, Ho Chi Minh City, Vietnam, November 24, 2012

Appendix A

Questionnaire for parents of children suffering from Autism
PLEASE CIRCLE YOUR ANSWERS. DO NOT WRITE YOUR NAME
FEEL FREE TO LEAVE QUESTIONS BLANK

How old is your son / daughter:

(1-3) (4-6) (7-9) (10-13) (14-18) (over 18)

What is your gender:

(male) (female)

What gender is your child:

(male) (female)

What is your employment status?

(employed full time) (employed part time) (unemployed – seeking employment)
(unemployed – not seeking employment)

How long ago was your son/daughter diagnosed with Autism?

(3 month ago or less) (3 months– 1 year) (1 year– 3 years) (3 years – 6 years) (6 years – 12 years)
(more than 12 years ago)

Did you know what Autism was prior to your child’s diagnosis?

(yes) (no)

Has your perception of Autism changed in any ways since your child’s diagnosis? Please explain below:

Approximately how many hours a week do you spend taking care of your child _____

Which of the following treatments/facilities does your child currently use? (please circle all that apply):

- Full time student at PRIVATE school for children with disabilities
- Full time student at PUBLIC school for children with disabilities
- Full time student at school for children with normal learning skills
- Regular meetings with psychologist
- Regular meetings with social worker
- Regular meetings with a speech therapist
- Usage of prescription medication to treat autism
- Usage of homeopathic medication to treat autism

Have you found any of these treatments / resources to be particularly effective? Please explain:

Have you found any of these treatments / resources to be particularly ineffective? How could they be improved:

How likely is it that your child's autism was caused by the following:

- a. Weak nerves, bad character:** (very unlikely) (unlikely) (likely) (very likely)
- b. Chemical imbalances in the brain:** (very unlikely) (unlikely) (likely) (very likely)
- c. Supernatural causes:** (very unlikely) (unlikely) (likely) (very likely)
- d. Inherited condition from parents:** (very unlikely) (unlikely) (likely) (very likely)
- e. Problems during child labor:** (very unlikely) (unlikely) (likely) (very likely)

Are you willing to discuss your child's condition with friends/ extended family? Why or why not?