



RESEARCH ARTICLE

EMOTIONAL FACTORS AFFECTING TAIWANESE PARENTS' DECISION-MAKING REGARDING AUTISM GENETIC TESTING

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ARTICLE INFO

Article History:

Received 5th, April, 2015
Received in revised form 12th,
April, 2015
Accepted 6th, May, 2015
Published online 28th,
May, 2015

Key words:

Autism Spectrum Disorders,
genetic testing, Taiwanese

ABSTRACT

Autism Spectrum Disorders (ASD) is one of the fastest growing disabilities in Taiwan. With the wider application and availability of the next generation sequencing, it is foreseeable that Taiwanese parents with ASD will get access to more reliable diagnostic tests for detecting the genetic component of their children's ASD. It is imperative, therefore, to investigate factors that may influence Taiwanese parents' decision-making in regard to ASD genetic testing. The purpose of this study was to investigate the influence of attitudes and emotions on Taiwanese parents' intention to allow their children with ASD to undergo autism genetic testing. Using survey instrument, we recruited 444 Taiwanese parents (N = 444) of children with ASD. A two-step Structural Equation Modeling (SEM) analysis was conducted to assess the influence of different kinds of attitudes and emotions on parents' intention to allow their children to undergo autism genetic testing. Based on our findings, parents' intention was negatively influenced by their fear and guilt while positively affected by their anxiety toward genetic testing. Moreover, parents with higher annual household income showed greater interest in testing. Parents' favorable attitudes towards testing, however, did not show significant relationship with parents' intention. Our findings provided support to the need of pre-test counseling and genetic education among the general public in Taiwan. To manage parents' concerns resulting from fear, policymakers and legislators should consider enacting genetic discrimination laws in Taiwan to facilitate alleviating the fear of genetic testing for ASD and ensure proper use of ASD genetic services.

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INTRODUCTION

With the continued advancement of genetic technologies, the next generation sequencing technology for Autism Spectrum Disorders (ASD) is further used to predict the risk of developing ASD and open avenues for timely diagnosis, treatment and medical intervention (Marchant and Robert, 2009; Shen *et al.*, 2010; Johnson *et al.*, 2011). More advanced genetic tests for patients and their families with ASD in clinical settings are increasingly available across countries (Maya *et al.*, 2010; McGrew *et al.*, 2012), and direct-to-consumer (DTC) genetic testing for genetic susceptibility to ASD is also under development – although still extensively debated (Jordan and Tsai, 2010).

ASD is one of the fastest growing disabilities in Taiwan, with a high annual growth of 16.52%. In 2013, a total of 13,366 patients were diagnosed with ASD (Foundation TACSW, 2014). The estimated prevalence of childhood ASD in Taiwan (26.6 per 10,000 people) appeared lower than that in western countries (e.g., one in 68 children in the U.S. and one in 94 in Canada). However, people with ASD in Taiwan may be under-diagnosed or under-detected because of inadequate awareness of ASD among clinicians and researchers, absence of

knowledge or acceptance of individuals with ASD, or cultural influence (Sun *et al.*, 2013).

In general, Taiwan lagged behind western countries in genetic research associated with autism (Jiang, 2008). Compared with western countries where genetic evaluation is an integral part of the diagnostic process (Schaefer *et al.*, 2013), autism genetic testing is neither incorporated into the diagnostic process nor officially recommended in Taiwan for ASD diagnosis (Shen *et al.*, 2010). Clinical evidence demonstrated that cytogenetic screening, such as Fragile X and Karyotyping, remains the primary approach to detect the chromosomal abnormalities among patients with ASD in Taiwan (Liao *et al.*, 2013).

With the wider application and availability of the next generation sequencing, it is foreseeable that Taiwanese parents with ASD will get access to more reliable diagnostic tests for detecting the genetic component of their children's ASD. Consequently, individuals and their family members affected with, or at risk for ASD, face more genetic test decisions related to ASD. It is imperative, therefore, to investigate factors that may influence Taiwanese parents' decision-making in regard to ASD genetic testing.

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Based mainly on well-established Theory of Planned Behavior (TPB) and Health Belief Model (HBM) (Gooding *et al.*, 2006), previous studies have confirmed the influence of some psychological factors, e.g., attitudes and intention, on people's uptake of genetic testing for different diseases, including Alzheimer's disease, cervical cancer, and colorectal cancer (Roberts, 2000; Bosompra, 2001; Frost *et al.*, 2001; Stein *et al.*, 2001; Gooding *et al.*, 2006). However, these attitudinal and intentional factors have not been explored in genetic testing for ASD.

Further, important emotional variables, e.g., fear, guilt, and anxiety, which might predict genetic testing decisions, have been largely neglected in the well-established health theories (Goodson, 2010). Although less frequently adopted for genetic testing research, two theories, the Common Sense Model of Regulation (CSM) and the Transactional Model of Stress and Coping (TMSC), have been validated and used to explain the influence of emotional responses on people's intentions to undergo genetic testing for various genetic conditions, including Huntington's disease, Alzheimer's and hereditary colorectal cancer (Lazarus, 1984; Leventhal and Cameron, 2001; Tibben, 1997; Broadstock *et al.*, 2000; Decruyenaere *et al.*, 2003). Again, however, the influence of these emotional factors has not yet been examined in genetic testing for ASD.

The purpose of this study, therefore, was to address these research gaps and investigate the influence of attitudes and emotions on Taiwanese parents' intention to allow their children with ASD to undergo autism genetic testing. Specifically, we hypothesized that controlling for socio-demographic characteristics, 1) parents' attitudes played a positive role on their intention to undergo genetic testing; and 2) parents' emotions, including anxiety, fear, and guilt, also influence their decision-making toward genetic testing.

METHODOLOGY

Study Design

Based on previous literature (Skinner *et al.*, 2003; Chen and Goodson, 2007; Levine *et al.*, 2010), we developed a multi-part, paper-and-pencil survey to investigate factors affecting participants' intentions to undergo genetic testing, including demographic information, the ASD-affected children and their parents' knowledge of ASD genetic testing, parents and the families' previous experience with genetic services, emotional factors that might influence parents' decisions to undergo genetic testing, parents' attitudes toward ASD genetic testing, and parents' intention to undergo ASD genetic testing. The questionnaire was developed in traditional Chinese (the official language in Taiwan) for the convenience of the participants.

Once drafted, the preliminary survey was sent to two MDs (one family doctor and one genetic pediatrician), one special education expert and one social behavioral specialist to assess content validity of the items. After appropriate revisions were made based on the experts' suggestions, the survey was pilot tested in Taiwan. We invited seven parents of children with ASD to participate in the cognitive interview, four parents to

participate in the retrospective interview, and one parent to participate in both cognitive and retrospective interviews.

Sample and Recruitment

The sampling and recruitment were carried out with the assistance of the Department of Special Education, National Hsinchu University of Education, Taiwan. Initially, the research team retrieved the list of all preschools and elementary schools with special education classes in Hsinchu area and Taoyuan County from the official website of the Department of Education. Then, phone calls were made to the special education/resource teachers working in the abovementioned schools to obtain the exact number of children with ASD in their schools. Afterwards, parents of all the children with ASD enrolled in these schools were directly contacted by their special education/resource teachers and invited to participate in this study. Subsequently, a package containing the survey and information sheet was distributed to all the potential participants in Hsinchu area and Taoyuan County by the teachers.

To enlarge the sample size, the research team extended sampling to Miaoli County and other areas in Taiwan. All participating parents were encouraged to complete the survey and return it to their children's teachers in two or three weeks to meet the deadline for entering the drawing. Each participant had the opportunity to enroll in the drawing and win gift vouchers for their participation. The first-place prize was for eight participants and each of them won a gift voucher of NT\$3,000 (\$100). The second-place prize was for 20 participants and the gift voucher was with NT\$ 2,000 (\$67). Lastly, the third-place prize was for 200 participants and each winner received a gift voucher of NT\$ 1,000 (\$33).

Altogether 243 schools responded to the study, 862 surveys were sent to participants, and 454 were returned (response rate: 52.8%). Although the approval of an Institutional Review Board (IRB) is not mandatory in Taiwan, all the research protocols for this study were approved by the IRB at Texas A&M University.

Measures

Outcome: parents' intention to undergo autism genetic testing

Six items were used to measure parents' *intention* to take the test. Parents were asked about their intentions of testing the following people: 1) their children with ASD, 2) the siblings of their children with ASD, 3) themselves, 4) their spouses, 5) relatives from their biological family, and 6) relatives of their spouses. Responses were reported on a 4-point scale ranging from "very unlikely" to "very likely."

Predictors: emotional responses and attitudes toward undergoing ASD genetic testing

As described earlier, emotional responses included anxiety, fear and guilt.

Anxiety included trait anxiety and state anxiety. Trait anxiety was evaluated by six items assessing participants' enduring characteristic related to anxiety (e.g., "You easily get worried"). State anxiety refers to the state that lasts for a short period of time and was evaluated by 1) six items related to the anxiety caused by the disease of ASD (Anxiety-ASD) (e.g., "Thinking of ASD makes you feel nervous"), and 2) five items associated with the anxiety caused by ASD genetic testing (Anxiety-GT) (e.g., "Thinking about ASD makes you feel worried"). Parents were asked to respond a 4-point response format, from "strongly agree" to "strongly disagree."

Fear was assessed by five items on parents' perceptions about the possible consequences or social, legal concerns related to undergoing autism genetic testing (e.g., "You are fearful of genes discrimination caused by ASD genetic testing", and "You are fearful that the general public will not accept ASD-affected individuals". Responses ranged from "strongly disagree" to "strongly agree".

Guilt was assessed by nine items (e.g., "You feel guilty toward your child because you gave birth to him/her and he/she has ASD", and "Bringing your child with ASD to undergo ASD genetic testing can make you feel guilty." Responses ranged from "strongly disagree" to "strongly agree".

Parents' attitudes toward genetic testing in children included a) attitudes toward testing the affected children (3 items), b) attitudes toward testing biological family members (5 items), and c) attitudes toward carrier testing, prenatal testing and newborn screenings for ASD (6 items). Participants were asked to indicate their beliefs ("disagree" or "agree") and values ("not very important" or "important") on specific items. Items under each category of attitudes were summed to constitute both the belief and the value measures of attitudes.

Data Analysis

Descriptive analyses and exploratory analyses

We conducted descriptive and exploratory analyses using SPSS version 22 to examine psychometric properties of the variables determine the appropriateness of the proposed hypothesis tests.

The two-step SEM modeling

A two-step Structural Equation Modeling (SEM) analysis was conducted to assess our hypothesized relationships using Mplus7.11 (Muthen & Muthen, 2012; Peshkin et al., 2009). Model fit was evaluated based on the following indices: chi-square, Comparative Fit Index (CFI), the Root Mean Square Root Error of Approximation (RMSEA), and Standardized Root Mean Square Residual (SRMR) (Schumacker, 1996). The cutoff values for these fit indexes were not consistently recommended (Villagran et al., 2012). However, based on previous literature, we used the following cutoff criteria-values of RMSEA less than 0.06, SRMR less than 0.05, CFI more than 0.90 (Mega et al., 2014).

At step one, a series of confirmatory factor analyses (CFA) were conducted to establish measurement models for nine latent constructs, i.e. trait anxiety (six items), state anxiety caused by ASD (six items), state anxiety caused by ASD genetic testing (five items), fear (five items), guilt caused by carrying ASD genes (three items), guilt caused by undergoing ASD genetic testing (six items), attitudes toward testing the immediate family members (five items), attitudes toward carriers, prenatal genetic testing, pre-implantation genetic diagnosis (PGD), and newborn screening (six items), attitudes toward testing the affected children (3 items), and intention (six items).

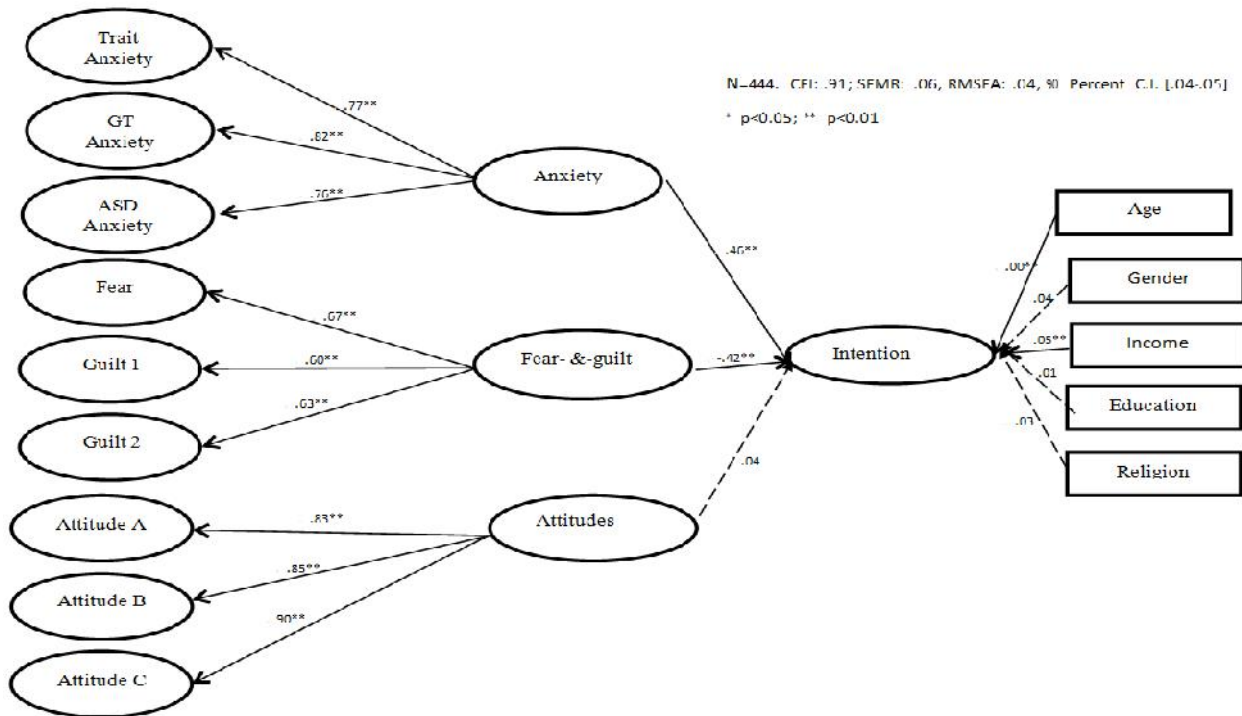


Figure 1 Final structural model of emotions, attitudes and intentions associated with undergoing autism genetic testing

At step two, a SEM model was established to assess the underlying relationship between and among the proposed variables [anxiety intention, fear & guilt intention, and attitudes intention]. To improve model fit, we re-specified the models based on modification indices. *Mplus* MLR estimator was used at both steps (Schumacker, 1996; Wade *et al.*, 2012).

RESULTS

Sample characteristics

The final sample consisted of 444 parents of children with ASD in Taiwan, representing a response rate of 52.3%. Participants were predominately females (77.5%), with an average age of 39.9 years (SD=5.4). This study involved 468 children diagnosed with ASD, among whom 88% were boys. The average age of these children with ASD was 9.5 ± 2.24 . (See Table 1 for details)

Table 1 Study sample characteristics (N=444)

Characteristics	n (%)
Gender	
Female	334 (77.5)
Male	97 (22.5)
Age of parents, mean \pm SD (range)	39 \pm 5.4 (28-63)
Age of spouses, mean \pm SD (range)	41.3 \pm 5.6 (26-63)
Birth place	
Taiwan	413 (95.2)
Non-Taiwan	21 (4.8)
Education	
Below college	292 (67.3)
Above college	141 (32.7)
Marital status	
Married	384 (88.7)
Others (divorced, single)	50 (11.3)
Current Employment Status	
Non-full time	218 (50.2)
Full time	216 (49.8)
Annual household income	
<TW\$ 600K (~US\$20K)	143 (33.6)
TW\$ 600K (~US\$20K) to < TW\$1200K (~US\$40K)	174 (40.8)
TW\$1200K (~US\$40K) to < TW\$1800K (~US\$60K)	62 (14.6)
TW\$1800K (~US\$60K) to < TW\$ 2400K (~US\$80K)	24 (5.6)
TW\$ 2400K (~US\$80K)	10 (2.3)
Others	13 (3.1)
Religion	
Buddhism	112 (25.9)
Folk religions	119 (27.5)
I-kuan Tao	7 (1.6)
Christian (catholic)	39 (9)
Atheists or Non-believers	92 (21.2)
Others	64 (14.8)

Note: The sample size (N=444) was used for the preliminary stage of the data analysis.

Preliminary analyses

Missing data ranged from 2% to 7.6% for the variables in this study. By default, *Mplus* employed full information maximum likelihood (FIML) to deal with missing data when MLR estimator was used. We examined frequencies for nominal/ordinal variables and distribution and normality of continuous variables; no violation of the normality assumption was detected in any continuous variable. Table 2 presents

descriptive statistics for the emotional factors – both latent and observed variables – that we used.

Measurement models

Most items loaded significantly on their respective factors, with factor loadings ranging from 0.580 to 0.929). For the construct *Intention*, however, two items did not load at an acceptable level (i.e. with loading below 0.45) and were therefore deleted from further analysis. A subsequent CFA containing all latent constructs demonstrated good fit to our data ($\chi^2=2803.9$, $df=1112$, $p<.001$; CFI=0.92; RMSEA=0.04; SRMR=0.06).

The internal consistency of items under each latent construct was also supported, with Cronbach's α for each construct as follows: trait anxiety (.85), ASD anxiety (.92), GT anxiety (0.95), fear (0.90), guilt 1 (0.88), and guilt 2 (0.86.), attitude A (0.95), attitude B (0.91.), attitude C (0.82) and intention (0.89).

Structural model

After confirming the goodness-of-fit of the measurement models, we performed SEM to verify the proposed structural relationships in this study. The values of fit indices ($\chi^2=2224.263$, $df=1109$, $p<0.001$, CFI: 0.917, SRMR:0.06, RMSEA:0.048) suggested that the hypothesized model offered a parsimonious but adequate explanation of the observed data.

As shown in Figure 1, parents' Anxiety ($\beta=0.460$, $p<0.001$) positively influence parents' intention to undergo ASD genetic testing: The greater anxiety parents have with regard to ASD genetic testing, the more likely they might undergo the test. Fear and guilt ($\beta=-0.0410$, $p<0.001$) negatively predicted parents' intentions to undergo ASD genetic testing: The more fear or guilt parents have, the less likely they might make the decision to undergo the test. Attitudes, however, did not predict behavioral intention to undergo the test.

As to socio-demographics, parent with older age appeared less likely to undergo autism genetic testing, whereas parents with higher income were more likely to undergo the test. Further, 10% of variance in parents' intention to undergo genetic testing for ASD can be explained by their emotional responses: anxiety, fear and guilt.

DISCUSSION

To our knowledge, this is the first theory-driven study examining the impact of emotion (anxiety, fear-&-guilt) and attitudes on the intentions to undergo ASD genetic testing among parents of children with ASD in Taiwan.

In line with previous findings that fear or guilt might potentially lead to a decline in genetic tests or refusal to participate in genetic research (Schumacker, 1996; Chen and Goodson, 2007), our findings confirmed the negative influence of fear and guilt on parents' intentions to undergo ASD genetic testing. The negative influence of fear and guilt might be explained by culture and societal stigmas related to having a child with genetic disabilities (Meiser and Dunn, 2001; McBride *et al.*, 2008; Yuan and Bentler, 2010; Aatre and Day, 2011).

Table 2 Emotional factors (trait anxiety, state anxiety caused by ASD, state anxiety caused by ASD genetic testing, fear and guilt) and the percentages of the individual statement

	Strongly Disagree (%)	Somewhat disagree (%)	Somewhat Agree (%)	Strongly Agree (%)
<i>Trait anxiety</i>				
You easily get worried	5.1	33.1	54.3	9.7
You are easily inclined to feel anxious (e.g., do not sleep well, irregular diet, irritable, etc.)	6.7	40.4	42.3	10.6
You tend to be pessimistic	11.5	61.2	24.5	3.8
You easily get worried	5.1	33.1	54.2	7.6
You cannot handle emergencies calmly	9.1	61.9	25.2	3.7
You felt nervous or worried during the past year	8.9	42.1	40.0	8.9
<i>State anxiety caused by ASD</i>				
Thinking of ASD makes you feel nervous	5.3	40.6	43.5	10.6
ASD causes you to feel anxious (e.g. do not sleep well, irregular diet, irritable, etc.)	6.5	45.9	38.0	9.7
ASD makes you feel pessimistic about life	7.4	51.4	33.9	7.4
Thinking about ASD makes you feel worried	3.7	20.5	63.2	12.6
Thinking about ASD can make you feel uneasy	6.2	52.7	34.2	6.9
Thinking about ASD made you feel stressed and worried during the past year	5.8	39.4	46.1	8.8
<i>State anxiety caused by ASD genetic testing</i>				
Suppose ASD genetic testing is available in the hospitals of Taiwan. Thinking about the possible problems caused by ASD genetic testing				
Makes you easily feel nervous	7.2	49.7	38.1	5.1
Makes you feel anxious	7.2	57.4	30.1	5.3
Makes you feel pessimistic about life	9.0	63.8	22.3	4.9
Make you feel stressed and worried during the past year	6.7	42.9	44.3	6.0
Makes you feel uneasy in your daily life	7.9	63.4	25.2	3.5

Table 2. Continued

	6.9	44.0	41.5	7.6
<i>Fear</i>				
You are fearful of the negative consequences caused by ASD genetic testing (e.g., family disputes from knowing who has the ASD-associated genes, and future marriage problems for children with ASD)				
You are fearful of the violation of your privacy caused by the ASD genetic testing (e.g. ASD genetic testing, others might know my test results)	4.1	42.4	45.6	8.0
You are fearful of genetic discrimination caused by ASD genetic testing	3.7	40.9	45.3	10.2
You are fearful of stigmatization caused by ASD genetic testing	3.7	34.3	50.8	11.2
You are fearful that the general public in Taiwan will not accept individuals with ASD	2.8	26.8	54.8	15.6
<i>Guilt</i>				
You feel guilty toward your child with ASD, because you brought this child to the world	6.2	28.8	51.6	13.5
You feel guilty toward your child with ASD, because he or she has ASD, but you are healthy	8.7	37.0	44.7	9.6
You feel guilty toward your child with ASD, because the biological father/mother or yourself might carry ASD-associated genes, which causes your child's ASD	9.8	47.1	35.7	7.3
Taking your child with ASD to undergo ASD genetic testing makes you feel guilty	11.7	68.3	18.6	1.4
Taking the siblings of your child with ASD to undergo ASD genetic testing makes you feel guilty	11.1	66.8	20.0	2.1
Taking the biological father of your child with ASD to undergo ASD genetic testing can make you feel guilty	11.3	66.9	18.6	3.2
If you undergo ASD genetic testing, you feel guilty	13.8	69.3	15.6	1.4
Taking your biological family members to undergo ASD genetic testing makes you feel guilty	10.8	60.8	25.2	3.2

Unlike Western culture, Taiwanese culture is traditionally embedded within Confucianism and influenced by the centrality of “face” (Eisenbruch *et al.*, 2004). Parents of children with genetic disorders might consider having a child with disability a family stigma. Consequently, they might be inclined to forgo genetic testing because testing might verify they gave birth to “an abnormal child” (Yang *et al.*, 2013). Our findings were consistent with previous studies showing that Asian cultures might significantly influence the decision whether to undergo genetic testing or utilize genetic services (Eisenbruch *et al.*, 2004). Moreover, as autism genetic testing is still not available and officially recommended in

Taiwan, the feeling of fear and guilt might also be caused by parents’ insufficient knowledge of these yet-unknown tests. Our finding that anxiety positively influenced parents’ intention to undergo ASD genetic testing was consistent with another study by Narcisa *et al.*, which revealed that the potential for reduced anxiety was one primary reason for parents’ interest to be tested for ASD (Narcisa *et al.*, 2013). According to stress and coping theories (Baum *et al.*, 1997), parents might consider undergoing ASD genetic testing as a coping mechanism to anxiety (Baum *et al.*, 1997). Based on our findings, anxiety may predict parents’ test intention once ASD

genetic testing becomes available in Taiwan, and future studies are warranted in this direction.

Contrary to our hypothesis, favorable attitudes towards testing did not show significant relationship with the parents' intention to take the test in our study. This finding differed from numerous previous studies that identified strong linkage between people's attitudes and their intentions to undergo genetic testing for different diseases (Armitage and Conner, 2001; Sutton, 2006; Peshkin *et al.*, 2009). Considering our study is the first to investigate the influence of attitudes on genetic testing for ASD, future studies with larger sample size are needed to confirm the non-significant relationship between attitudes and intention in different settings and among diverse populations.

Moreover, parents with higher annual household income in this study showed greater interest in testing, which was consistent with previous finding that families with higher SES were more likely to use genetic services (Bunn *et al.*, 2002; Sutton, 2006). Our findings implied a need to address health inequities before implementing autism genetic services in Taiwan. We need to provide more resources to families with poor access to the genetic services and be aware of offering more affordable genetic services to patients of low socio-economic status.

Our study suffered from limitations. First, this is a cross-sectional study conducted among a convenience sample, which limited the generalization of our results. More empirical research is needed to recruit children from a wider range of geographical locations. Second, we only assessed pre-test emotional and attitudinal factors related to undergoing autism genetic testing; future studies should measure both pre- and post-test emotional responses when the test is available in Taiwan. Future studies are also needed to examine other predictors of intention, e.g., perceived benefits, perceived barriers and social norms. Third, although we identified most parents hold positive attitudes toward genetic testing for ASD, the underlying reasons for parents' optimistic attitudes need to be investigated.

Despite the limitations, our findings greatly extended existing literature on decision making about undergoing genetic testing for ASD. For the first time, we confirmed the predictive power of emotional factors on ASD genetic testing decision-making, which have been largely overlooked in previous studies using theoretical frameworks (Buih *et al.*, 2011). Our study notably answers the call from the National Health Genomics Research Institute to expand beyond the existing conceptual models for exploring stronger predictors of genetic test decisions (Wade *et al.*, 2012).

Our findings also have direct implications for public health genomics education and practice. First, our findings provided support to the need of pre-test counseling and genetic education among the general public in Taiwan. In order to provide better genetic services for families affected with ASD, the multi-disciplinary team composed of pediatricians and psychologists should proactively consider the possible emotional distress among parents of children with ASD in the diagnostic process.

To effectively address parents' fear, guilt and anxiety associated with the test, pre-test counseling is also needed through different kinds of education (e.g., website, DVD, lectures, and brochures).

Considering the critical role healthcare providers can play in shaping people's decision to undergo genetic testing, it is also important to educate health care providers so that they can explain the tests to the parents of children with ASD. Health care providers' insufficient knowledge regarding genetic testing has been well documented in previous literature (Baum *et al.*, 1997; Suther and Goodson, 2003; Baars *et al.*, 2005; Chen and Goodson, 2009). Less research, however, has been conducted to explore health care providers' ability to manage patients' emotions surrounding testing.

Finally, although laws and regulations that prevent the genetic discrimination have been in effect in the U.S. since 2008 (Hudson *et al.*, 2008), similar regulations or laws are still lacking in Taiwan to protect people from being genetically discriminated. To manage parents' concerns resulting from fear, policymakers and legislators should consider enacting genetic discrimination laws in Taiwan to facilitate alleviating the fear of genetic testing for ASD and ensure proper use of ASD genetic services.

Acknowledgements

This work was funded by the Chiang Ching-kuo Foundation for International Scholarly Exchange. This study was a secondary data analysis of a large research project directed by Dr. Lei-Shih Chen (PI) in the Department of Health and Kinesiology at Texas A&M University, USA and co-directed by Dr. Tse-yang Huang (Co-I) in the Department of Special Education, National Hsinchu University of Education, Taiwan.

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How to cite this article:

Lei Xu and Wenhua Lu., Emotional Factors Affecting Taiwanese Parents' Decision-Making Regarding Autism Genetic Testing. *International Journal of Recent Scientific Research* Vol. 6, Issue, 5, pp.4141-4148, May, 2015
