

Perceived Causes of Autism Spectrum Disorders among Taiwanese Parents of Affected Children: A Qualitative Study

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Abstract: *Background:* Autism Spectrum Disorders (ASDs) represent a complex group of neurodevelopment and mental disorders. Currently, the etiologies for ASDs are unclear. Consequently, it is important to assess the perceptions of ASDs among parents of affected children, as their perceptions can impact parent-child bonding, disease prognosis and treatment, subsequent education and living environment of the affected child, and interactions with health professionals. The majority of available research regarding parental perceptions of ASDs has been conducted in the Western countries. Given that culture plays an important role in parents' views regarding the causes of ASDs, this study aims to examine perceptions of the etiology of ASDs among parents in Taiwan – an Asian country strongly influenced by the Chinese culture.

Methods: Participants were recruitment through ASDs organizations in Taiwan. In-depth interviews were performed with 31 mothers and 8 fathers who had at least one child diagnosed with ASDs. All interviews were audio-recorded, transcribed, and subsequently analyzed via content analysis.

Results: The themes of ASDs etiologies identified by participants from the highest to the lowest frequencies were: genetics (n=30; 76.9%), problems during mother's pregnancy (n=18; 46.2%), complications/situations during delivery (n=13; 33.3%), vaccination (n=11; 28.2%), environmental pollutions (n=10; 25.6%), children's non-ASDs related health problems and unintended injuries (n=9; 23.1%), parenting style (n=7; 17.9%), parents' occupation (n=7; 17.9%), spiritual or religious factors (n=6; 15.4%), children's diet (n=2; 5.1%), maternal age at the time of pregnancy (n=1; 2.6%), and children's use of traditional Chinese medicine (n=1; 2.6%).

Discussion: Taiwanese parents held diverse views on the causes of ASDs. Overall, parental beliefs were based on culture, scientific evidence/research and uninformed non-scientific views. Our results may help health professionals and researchers identify gaps in parents' knowledge of ASDs and understand commonly held misperceptions about the causes of ASDs. Further, findings generated from this qualitative research may serve as the foundation for a research instrument to survey beliefs regarding the causes of ASDs among larger samples of Taiwanese parents who have children affected by ASDs.

Keywords: Autism spectrum disorders, Causes, Parental beliefs, Taiwan.

INTRODUCTION

Autism Spectrum Disorders (ASDs) represent a complex group of neurodevelopment and mental disorders [1, 2]. Signs and symptoms of ASD include impaired intelligence, repetitive behavior, as well as limited language, social communication and motor skills [2]. In Taiwan, ASDs are often classified by five types: Autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS) [3]. Additionally, ASDs are further classified by four levels of severity: mild, moderate, severe, and profound [4]. The overall prevalence of ASDs in Taiwan is 12.3‰, with a higher prevalence noted among males (19.2‰) than females (6‰) [5].

Although the etiologies for ASDs are unclear, genetics and environment have been identified as contributing factors [2, 6-8]. Due to the elusive etiology of this condition, the beliefs about the causes of ASDs among parents of affected children are especially important to understand and examine. Their perceptions can impact parent-child bonding, interactions between parents and health professionals, disease prognosis and treatment chosen, and the subsequent education and living environment [9-13].

Several studies have previously explored parents' views and beliefs about the causes of ASDs [9-22]. While their findings vary, the most frequently cited causes of ASDs include: genetics/ heredity, vaccination, complications during gestation and delivery period, child's illnesses, diet (for both children and pregnant women), child rearing, spiritual/religious factors, advanced parental age, and environmental/toxic exposure [9-14, 16-22]. The

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majority of these investigations, however, were conducted in Western settings (mainly in the United States). Given that culture can play an important role in parents' views of causes of ASDs, this study aims to assess the beliefs regarding the etiologies of ASDs among parents of affected children in Taiwan – an Asian country strongly influenced by the Chinese culture.

METHOD

Participants

Eligible participants were parents (mothers and fathers) of children with ASDs. These parents were members of major autism organizations in Taiwan. Organizations from which participants were drawn include: Autism Society of Taiwan R.O.C., Hsinchu Association of Autism, Changhua County Autism Association, and Taichung County Autism Association.

Design, Researchers' Biases and Procedure

The Institutional Review Board of Texas A&M University vetted and approved all procedures outlined in this study. We used a qualitative research approach to obtain rich, in-depth, narrative data on Taiwanese parents' perceptions regarding the causes of ASDs. An emergent design was adopted to allow for flexibility during data collection (e.g., refining and adding new questions during subsequent interviews that might not have been previously considered) [23]. A semi-structured interview guide comprised of several interview questions was developed by the research team, which was later reviewed by a panel of experts in special education, genetics/genomics, health promotion, and qualitative research.

Since the researchers' background, experiences, beliefs, and values can influence the qualitative data collection process, interpretations, and findings [23], it is essential to be cognizant of this bias. The current team of key investigators included a group of diverse Asians, such as males and females, working in academia and non-academia, and with various expertise (e.g., genomics, special education, and public health). One research member, who has a child with ASDs, is also the leader of one of ASDs organizations in Taiwan. Two investigators are prospective parents and care about the health of their newborns. The research team believes (1) the prevalence of ASDs is high in Asian countries, and (2) there is a lack of social and behavioral research in this area.

Before each interview, the research team introduced themselves, their respective area of expertise, and explained the purpose of the study. Participants were asked to provide demographic information (e.g. age, religious beliefs, marital status, educational level, annual household income) for their partners and themselves. In addition, we collected information on their ASDs-affected children, such as age, gender, birth order, year of diagnosis, degree of severity, and ASD-related complications. Next, we asked participants about their perceptions regarding the causes of ASDs, recurrence risk of having another affected child, genetic testing, family planning, and educational needs. Data presented herein are focused exclusively on parents' beliefs about the causes of ASDs.

All face-to-face interviews lasted, on average, two and half hours (range = 43 minutes-7 hours). With participant permission, all sessions were audio-recorded. Interviewers also took field notes during each session. All participants received TW\$500 (~US\$16.7) as compensation for their time and participation. Data saturation was reached after 39 in-depth interviews.

Data Analysis

At the conclusion of each interview, recordings were transcribed verbatim. Once transcribed, we coded the transcript through a content analysis approach using the qualitative software package *QSR Nvivo version 8* (QSR International, Victoria, Australia). The content analysis involved three steps. First, to obtain a general idea of participants' responses and ensure data accuracy, two authors (J.Y. and S.Z.) read the transcripts several times and compared transcripts with the field notes. Next, the two authors discussed the data in order to extract and code subthemes with similar context. If applicable, relevant subthemes were categorized and combined into main themes [23]. Finally, all subthemes and themes were discussed for verification and agreement with the other author (L.S.C.) who conducted interviews with several participants.

RESULTS

Sample Characteristics

The final sample (n=39) was comprised of 31 mothers (79.5%) and 8 fathers (20.5%) who had at least one child diagnosed with ASD. On average, participants were 42.0 years of age (SD=4.9, range

=34-52). The majority of interviewees were married (92.3%), had completed at least a college degree (61.5%), and were employed full-time (53.8%). Participants held a variety of religious beliefs, including Buddhism (30.8%), folk religion (17.9%), Taoism (12.8%), Christianity (12.8%), and other religions (10.3%). Some participants were self-described atheists (15.4%). As for their respective ASD-affected children, there were 34 boys and 6 girls with a mean age of 10.9 years (SD=4.4, range =2-26 years). Parents reported their degrees of severity as mild (n=24), moderate (n=13), and severe (n=3).

Parents' Perception of the Causes of ASDs

We asked participants to state the causes of ASDs based on either their own children's ASDs or general knowledge of ASDs. Among the 39 participants, two (5.1%) were unsure or did not know the etiologies of ASDs. As seen in Table 1, the remaining identified a variety of causes, such as genetics (n=30; 76.9%), problems during mother's pregnancy (n=18; 46.2%), complications/situations during delivery (n=13; 33.3%), vaccination (n=11; 28.2%), environmental pollutions (n=10; 25.6%), children's non-ASDs related health problems and unintended injuries (n=9; 23.1%), parenting style (n=7; 17.9%), parents' occupation (n=7; 17.9%), spiritual or religious factors (n=6; 15.4%), children's diet (n=2; n=5.1%), maternal age at the time of pregnancy (n=1; 2.6%), and children's use of traditional Chinese medicine (n=1; 2.6%). The following

sections describe the causes from the highest to the lowest frequencies.

Genetics

More than three-fourths of participants (n=30; 76.9%) described heredity, chromosome or genetics as the cause of ASDs. Some parents reported that family health history exist in families affected with ASDs. According to them, in many cases, there were multiple members in the same family who had some form of ASDs or mental retardation. As illustrated by one mother:

"I suspect my parents-in-law, husband, my mother, uncle...although they didn't have ASDs, I feel they have the characters of Asperger syndrome."

Similarly, another mother told us that her husband was quiet when he was a child. When he talked, people did not understand what he tried to say. Her ASD-affected daughter had similar difficulty in expressing herself, like her husband in the past. Thus, she believed that her daughter inherited her ASDs from her husband.

In addition, one interviewee explained that civilization leads to evolution and genetic mutations, which in turn leads to more people having ASDs than in the past.

Problems during Mother's Pregnancy

About half of the respondents (n=18; 46.2%) attributed ASDs to problems occurred during

Table 1: Parents' Perceived Causes of ASDs

Parents' Perceived Causes	Frequency	Percentage
Genetics	30	76.9%
Problems during mother's pregnancy	18	46.2%
Complications/situations during delivery	13	33.3%
Vaccination	11	28.2%
Environmental pollution	10	25.6%
Children's non-ASD related health problems and unintended injuries	9	23.1%
Parenting style	7	17.9%
Parents' occupation	7	17.9%
Spiritual or religious factors	6	15.4%
Children's diet	2	5.1%
Maternal age at the time of pregnancy	1	2.6%
Children's use of traditional Chinese medicine	1	2.6%

Note: Two participants were unsure and did not know the causes of ASDs.

pregnancy. Specifically, several participants mentioned that they took antiabortifacients (i.e., medication/drugs to stabilize the fetus) during pregnancy. They suspected that the antiabortifacient caused their children's ASDs. Parents also mentioned other medications, which might contribute to their children's ASDs, such as ovulation drugs and pills for treating inflammations and flu. Furthermore, several parents recalled they had insufficient or imbalanced nutrition, ate too much deep-fried food, and consumed alcohol and caffeine or cold drinks during pregnancy. They believed their respective dietary habits during pregnancies influenced their children's ASDs status.

Moreover, some parents identified bad mood during the pregnancy (e.g., anxiety and suicide thoughts) as the causal factor of their children's ASDs. As illustrated by one mother, whose husband was in Canada during her pregnancy:

"My work caused me lots of nervous and anxiety...I was in Taiwan by myself. I was really in bad mood and thinking about suicide during the pregnancy and even when I was about to deliver the baby."

Other causal factors identified by parents included mothers' pre-existing diabetes and immunization problems, inappropriate behavior during pregnancy (e.g., diving and going to a hot spring), individual factors impacting the likelihood of having viable pregnancies, morning sickness, fainting or illness, as well as the car accident occurred during pregnancy.

Complications/Situations during Delivery

Thirteen parents (33.3%) believed that complications or situations during delivery initiated ASDs for children. Some blamed the long and/or delayed labor as the factor. For example, one father asserted the whole process of delivery was long (12 hours), which led to his child's ASDs. Another father reported that his wife suspected her child's ASDs were associated with the delayed delivery process. His wife's delivery was delayed because the doctor came to the delivery room late so that the nurse kept the baby's head from delivering. Conversely, few participants thought the expedition of child delivery time was the reason, as one highly educated mother stated:

"I read something like ASDs are equal to an emotional problem. The oxytocin produces emotion, which should be released by the baby itself during the delivery time. When we induce the baby, he or she is not ready to be delivered so that he or she does not release any oxytocin at all. This leads to the difficulty in his/her emotional development."

Additionally, some parents mentioned that they had pre-term infants, who had jaundice, hypoxia, and/or low birth weight. They were concerned that these complications and treatment in incubators might be the causes of their own children's ASDs. Likewise, two parents reported that their baby's abnormal head shape was due to the delivery process. They thought this might cause their children's ASDs.

Vaccination

Eleven (28.2%) of the respondents acknowledged vaccination as the contributing factor to ASDs. Some parents attributed the causal mechanism to mercury and lead in the vaccines. They also explicitly stated that diphtheria-tetanus-pertussis (DTaP) and Bacillus Calmette-Guerin (BCG) vaccines lead to their children's ASDs. According to them, these vaccines caused side effects among their children (e.g., a shock, a high fever and swelling at the injection part), and their children became abnormal after being vaccinated. For example, one mother complained that her ASD-affected son was normal until having the DTaP vaccine at the month of five, as her son was screaming during the injection, and subsequently experienced a high fever and a large swelling at the injection site.

Environmental Pollution

Ten (25.6%) of the respondents recognized environmental pollutions as the likely cause of ASDs. They were concerned about the increase in various environmental pollutions on earth, their surroundings, and work place in recent years. Respondents felt those pollutants might contain heavy metals and many other toxic chemicals. When prospective parents were exposed to the toxic substances, they would be more likely to having children with ASDs. According to one father:

"I think the reason might be environmental pollution...now we have water and air pollutions. Food we intake is contaminated as well."

Moreover, several parents lived in the heavily polluted city Hsinchu, which is considered a "U.S. silicon valley in Taiwan." They identified the pollution in this city as a reason causing many children in Hsinchu to have ASDs, as stated by one mother:

"I heard that many children with ASDs are from Hsinchu. Their parents worked in semiconductor factories there." Another father echoed this sentiment:

"It seems that the Silicon Valley area have a higher population of people with ASDs in the United States compared to other areas...because the semiconductor technology is very toxic."

Children's non-ASDs Related Health Problems and Unintended Injuries

Nine (23.1%) of the interviewees reported that their children's non-ASDs related health problems and/or subsequently inappropriate medical treatments were the cause of ASDs. These include flatfoot, allergy, atopic dermatitis, and otitis media. For example, one mother told us that her child had a severe atopic dermatitis at age of one month. She suspected that since many children with ASDs had the same condition and allergies, there existed a link between atopic dermatitis/allergies and ASDs.

In addition, three parents recalled their children had unintended injuries when they were little, which were likely to be the reason of their ASDs. In particular, one father felt that the accidental burnings (from a topical hot formula spray) of his daughter's feet might attribute to ASDs. The other two mothers stated that their children fell down from a chair or stairs around the age of two, which might cause some brain damages linking to ASDs.

Parenting Style

Seven parents (17.9%) attributed the etiology of ASDs to parenting style. The majority thought the interactions and stimulations that they (and other caregivers) supplied their children were less than ideal. As explained by one mother who lived together with her parents-in-law:

"My mother-in-law took main care of my son. She had a very protective parenting style. She always took my son back to room immediately after meals. The family members already had less interactions and talks. When my mother-in-law took my son away from other members, there was even lesser interactions between him and others...my son had ever played with his elder sister until the age of three."

Furthermore, two participants had conflicts with their spouses. In particular, one father mentioned that he and his wife fought in front of their son since his birth to the age of one. He felt his son isolated himself from the entire world since then and refused to grow-up in order to avoid the adult world, which was full of fighting and arguments.

Parents' Occupation

Seven interviewees (17.9 %) labeled some occupations as a risk factor of having children with ASDs. These included teachers, researchers, computer science engineers, semiconductor workers, and those with high achieved, well-paid, but stressful jobs. In general, these occupations dealt with numbers, computers, toxic chemicals, and/or high stress tasks. For example, one mother stated that her husband studied computer science. Due to this job involving numbers and using a computer all the time, she thought this might be the factor for their children' ASDs. Another respondent claimed that many high-achieving parents ended up having children with an Asperger's disorder. Therefore, it was possible that these parents' occupation contributed to the development of ASDs for their own children.

Spiritual or Religious Factors

Six parents (15.4%) perceived spirits or other supernatural factors as the etiology of ASDs. Others claimed that destiny was a contributing factor to their children's ASDs. For example, a Buddhist mother believed that her child developed ASDs because of Karma. Likewise, another Taoist mother stated that because she did something bad to her children in her past life, she was paying her debt in this life. In other words, her children were her "karmic creditors." Furthermore, one interviewee claimed ASDs was due to the attack from ghosts. Lastly, one mother told us her son was an alien who needed to learn the many rules of survival on earth, but he wanted to be happy by keeping his alien characters, which were considered as ASDs by earth people. This mother further explained that the reason she came out would keep her from worries and suicide.

Children's Diet

Two parents (5.1%) associated ASDs to their children's dietary choices, such as milk, gluten, coke, deep-fried chicken, and pizza. As one father with a graduate level degree stated:

"Too much milk and gluten food consumption affected normal function of brain."

The other mother noted that her daughter's ASDs condition was sometimes improved after having a balance diet. Therefore, she thought there was a relationship between ASDs and diet.

Maternal Age at the Time of Pregnancy

One father (2.6%) asserted his child's ASDs was due to the mother's age at the time of pregnancy. According to him:

"Was it because my wife was 35 years-old when the baby was born? Other parents told me that mother's age might play a role in the cause of ASDs"

Children's Use of Traditional Chinese Medicine

One mother (2.6%) alleged the use of traditional Chinese medicine for her son at very young age lead to the ASD. To treat her son's atopic dermatitis, she visited and received medicine from a pharmacy which provides Chinese (non-Western) medicine only. The owner of the pharmacy instructed her to feed her son some pearl powder and bezoar for treatment from the age of four months to one year. While atopic dermatitis was cured, her son has not spoken since initiating the treatment. Consequently, she would not exclude taking the Chinese medicine at a very young age as one of the possible causes of his son's ASDs.

DISCUSSION

This qualitative study examined the perceived causes of the ASDs among Taiwanese parents who have affected children. Although several studies have been conducted in Western countries on this topic, this research targeted parents in Taiwan – an Asian country affected by the Chinese culture. Our results provide insight into cultural beliefs regarding causes of ASDs. Specifically, respondents attributed parents' occupations as a contributing factor to their children's ASDs, which have not been reported by previous literature. Nevertheless, this finding is in line with Shyu and the colleague's Taiwanese study [11], which indicated that Taiwanese parents might attribute a high stress job as a causal factor of ASDs. Additionally, one interviewee claimed that administering traditional Chinese medicine to an infant was a potential cause of ASDs. Although this finding has not been outlined in prior research, it is understandable given Chinese medicine is a very common alternative medicine in Taiwan, and it is likely that children growing up in Taiwan might take Chinese medicine [24].

Participants also highlighted genetics, problems during mother's pregnancy, complications/situations during delivery, environmental pollutions, and maternal age at the time of pregnancy as the etiology of ASDs. These factors are generally supported by the authoritative agencies [2, 6-8] and other studies

examining parents' subjective views of causes of ASDs [9, 16, 17, 19]. Yet, some associated sub-categories/themes stemming from those main factors have not been specifically reported in scientific/empirical research. These sub-themes include mother's taking specific medicine (e.g., antiabortifacients, ovulation drugs, and pills for treating inflammations and flu) and consuming certain food and drink (e.g., deep-fried food and caffeine or cold drink) during pregnancy.

Furthermore, in conjunction with other studies [10-14, 18, 20-22], our participants believed that ASDs are caused by vaccination, parenting style, spiritual or religious factors, children's diet, and non-ASD related health problems. Although none of these factors are currently supported by the scientific evidence, parents might feel guilty and use these reasons to self-blame [10, 14, 25]. Parents might also be condemned by the lay public for doing something wrong to cause their children' ASDs [14, 25]. Moreover, studies have showed that parents' beliefs affect their communications with health professionals [12, 13] and decisions regarding family planning and medical treatment selections for the children [12, 13, 17]. As such, health professionals in Taiwan need to be aware of these common-held misperceptions. Counselling and educating parents on the evidence-based causative factors of ASDs is needed to help parents make informed decisions in family planning and treatment plan for their affected children.

There are several limitations in this study, which should be noted. First, participants were recruited from ASDs organizations in Taiwan. The claim of having children with ASDs was self-reported and types of ASDs were not stated. We did not validate this information by examining their respective medical charts. Second, although we attempted to recruit a diverse sample, the majority of the participants' children had mild or moderate severity levels of ASDs. These parents might have different causation perspectives compared to parents with children having more severe ASDs levels. Third, while our qualitative data were saturated in a large sample of 39 participants, findings from this study are not generalizable to all parents of children with ASDs in Taiwan. Finally, parents' beliefs regarding the causes of ASDs are mixture of the reasons for their own children and general knowledge of ASDs. Parents might hold different attitudes toward the causes for their own children and other affected children [26]. Due to the complexity of their responses, we could not

separate the causes. Future research needs to explore this important issue.

In spite of the above limitations, we found that our sample had diverse views regarding the causes of ASDs, such as culture, scientific evidence/research and uninformed non-scientific views. The information collected from the study may help health professionals and researchers identify gaps in parents' knowledge and understand their misperceptions about the causes of ASDs, which will facilitate better health care services for this population. Further, findings generated from this qualitative research may be used to develop a quantitative instrument to assess beliefs regarding the causes of ASDs among a large sample of Taiwanese parents with children affected by ASDs. A survey such as this could also help understand the views of ASDs among Taiwan and other Asian countries (e.g., China, Japan, and South Korea) which are influenced by the Chinese culture.

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