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A qualitative study exploring the attitudes toward prenatal genetic testing for autism spectrum disorders among parents of affected children in Taiwan



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ABSTRACT

Background: Prenatal genetic testing (PGT) for Autism Spectrum Disorders (ASD) raises more complex ethical, legal, and social implications in Taiwan than in Western countries due to policy-related, practical, cultural, and familial reasons. This first qualitative study examines attitudes towards PGT for ASD among Taiwanese parents of children with ASD – an elevated risk group for having another affected child, and one that is mostly likely to be impacted by PGT for ASD.

Methods: We conducted in-depth, face-to-face, individual, semi-structured interviews with 39 parents of children with ASD from various ASD organizations in Taiwan.

Results: Most parents favored PGT for ASD mainly for terminating the affected pregnancy and receiving early intervention and treatment. Less than one-third of participants was against PGT for ASD due to perceived no value for this testing, contradiction with religion and/or personal beliefs, doubt of the test's accuracy, or concerns about the negative consequences of the testing.

Conclusion: The majority of Taiwanese parents of children with ASD in this study supported PGT for ASD. Guidelines and regulations should be developed to regulate the provision and quality of this testing. Genetic counseling should also be recommended to parents of children with ASD in Taiwan.

1. Introduction

Autism Spectrum Disorders (ASD), characterized by lifelong impairments in social communication and interaction (Christensen, 2016), is one of the common developmental disabilities in the world (World Health Organization, 2016). Specifically, in Taiwan, ASD has been the third leading developmental disability since 2011 (Lai, Tseng, & Guo, 2013), and its prevalence has increased drastically by 497.3% over the past decade (Lai et al., 2013). While no testing is officially named as “ASD genetic testing” in Taiwan, many hospitals and clinics offer prenatal genetic testing (PGT) via chorionic villus sampling and amniocentesis to detect a number of

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disorders such as ASD (Dianthus MFM Center, 2018a; Ko's Obstetrics & Gynecology, 2018a; neoGene Obstetric & Pediatrics Clinic, 2018). The frontline method is chromosomal microarray analysis (CMA) (Dianthus MFM Center, 2018a; Ko's Obstetrics & Gynecology, 2018a; neoGene Obstetric & Pediatrics Clinic, 2018). CMA is also known as array-based comparative genomic hybridization (aCGH), which can detect DNA copy number changes or copy number variations (CNVs) in a genome (Lichtenbelt, Knoers, & Schuring-Blom, 2011). Some CNVs may be associated with ASD. For example, chromosome 16p11.2 deletion or duplication is detected in about 1% patients with ASD (Schaefer & Mendelsohn, 2013; Weiss et al., 2008). Different resolution of CMAs, from 35 K to 180 K oligonucleotide chip, are used for PGT in Taiwan. Nearly all CMAs are conducted by commercial companies (e.g., Agilent Technologies, Inc., Affymetrix, Inc., and Phalanx Biotech Group).

In clinical practice, PGT for ASD is mostly offered by obstetricians and performed as part of the amniocentesis during 16–20 gestation weeks. Obstetricians often provide a brief explanation before testing. Because Taiwan's National Health Insurance does not cover PGT for ASD, patients need to pay about NT\$18,000 (USD \$600) (Dianthus MFM Center, 2018b; Ko's Obstetrics & Gynecology, 2018b) out of pocket for this genetic test. The amniotic fluid samples are usually sent to private laboratories and would take approximately two weeks for the results to return to the obstetricians. During that time, obstetricians would inform and briefly explain the findings to the patients.

Similarly to other reproductive genetic tests (Ballantyne, Newson, Luna, & Ashcroft, 2009; García, Timmermans, & van Leeuwen, 2008; Wang & Hui, 2009), PGT for ASD raises complex ethical, legal, and social implications (ELSI). Nevertheless, the impact of PGT for ASD might be more profound in Taiwan than in Western countries due to a number of policy-related, practical, cultural, and familial reasons. As far as policy is concerned, there are neither regulations nor practical and ethical guidelines to examine and monitor the quality and provision of PGT for ASD in Taiwan. The results of PGT for ASD may also be questionable. Moreover, given that the provision of PGT for ASD in Taiwan currently becomes a commercial model for some healthcare providers, patients may undergo unnecessary testing. From a practical perspective, pre- and post-testing genetic counseling are not required, and there is a lack of genetic counselors and geneticists in Taiwan (Chen, Chang, Kim, Talwar, & Zhao, 2017; Chien, Su, & Chen, 2013). Therefore, obstetricians and their assistants/nurses are often the main providers for counseling services. Yet, they may not have adequate genomic competency to interpret testing results nor to counsel patients (Chen, Li et al., 2015). Patients may experience enormous anxiety and stress during the testing process, and subsequently make inappropriate and/or uninformed reproductive decisions.

Furthermore, Chinese culture may play an important role in Taiwanese people's attitudes regarding PGT for ASD. In traditional Chinese culture, parents care about their children's intelligence. Having children with mental disorders (i.e., ASD in this case) may be shameful to the whole family and stigmatized by Taiwanese society (Chen, Zhao, Zhou, & Xu, 2012; Chen & Tang, 1997; Lin, Orsmond, Coster, & Cohn, 2011). Furthermore, given that the Genetic Health Act (Ministry of Health & Welfare, 2009) in Taiwan allows for the easy practice of abortion (e.g., pregnant women can undergo an elective abortion if she "believes" that the pregnancy will adversely affect the health or quality of life for her or her family), Taiwanese parents may prefer to choose an abortion if the PGT results indicate that their fetus has ASD and/or other associated conditions, such as abnormal intelligence or mental retardation.

There are familial impacts of PGT for ASD as well. The majority of individuals affected by ASD cannot take care of their own daily activities in a lifetime (Anderson, Shattuck, Cooper, Roux, & Wagner, 2013; Levy & Perry, 2011). Thus, affected families are the main bearers. Although there is social, healthcare, financial, and educational support in Taiwan for families with disabilities (Chiu et al., 2013), this support is not adequate (Chou, Chiao, & Fu, 2011; Chou, Lin, Chang, & Schalock, 2007). Consequently, raising a child with ASD is a big burden for those families. Because PGT for ASD is a potential approach to prevent prospective parents from having children with ASD, it is anticipated that an increased number of parents in Taiwan may be interested in this testing.

Although social and behavioral research on genetic testing for ASD has gained more and more attention around the world (Chen, Xu, Huang, & Dhar, 2013; Jordan & Tsai, 2010; Marchant & Robert, 2008), none of this research has been conducted in Taiwan. To the best of our knowledge, this is the first qualitative study that has explored the attitudes toward PGT for ASD among Taiwanese parents of children with ASD. In particular, we sought to understand the following questions: would Taiwanese parents of children with ASD like to undergo PGT for ASD if they or their spouses were pregnant again? What were the underlying reasons that shaped their attitudes? Were their attitudes associated with socio-demographic characteristics?

We recruited Taiwanese parents of children with ASD for our study as these parents are at a higher risk of having another child with ASD (Ozonoff et al., 2011; Sandin et al., 2014) and are more likely to be affected by PGT for ASD compared to other parents in Taiwan. A qualitative method was chosen because PGT for ASD in Taiwan has previously not been studied, and we wanted to gain a deep insight regarding parents' views for this testing and capture associated underlying thoughts (Pope & Mays, 1995).

2. Methods

2.1. Study sample

Participants were recruited from several ASD groups and organizations in Taiwan. These organizations included the Autism Society Taiwan, the Hsinchu Association of Autism, the Changhua County Autism Association, and the Taichung County Autism Association. Eligible participants were parents of children with at least one child diagnosed with ASD. Our final sample consisted of 39 parents with children affected by ASD.

2.2. Procedures

This study is part of a large qualitative research project examining parents' views regarding the (1) causes of ASD, (2) genetic

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