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Perceived Genetic Cause and Recurrence Risk of Autism Spectrum Disorder among Parents of Affected Children in Taiwan

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Purpose

- This qualitative study aimed to examine the perceptions of Taiwanese parents regarding the genetic component of Autism Spectrum Disorders (ASD), etiologies of their children's ASD, and their recurrence risk of having another child with ASD.

Background

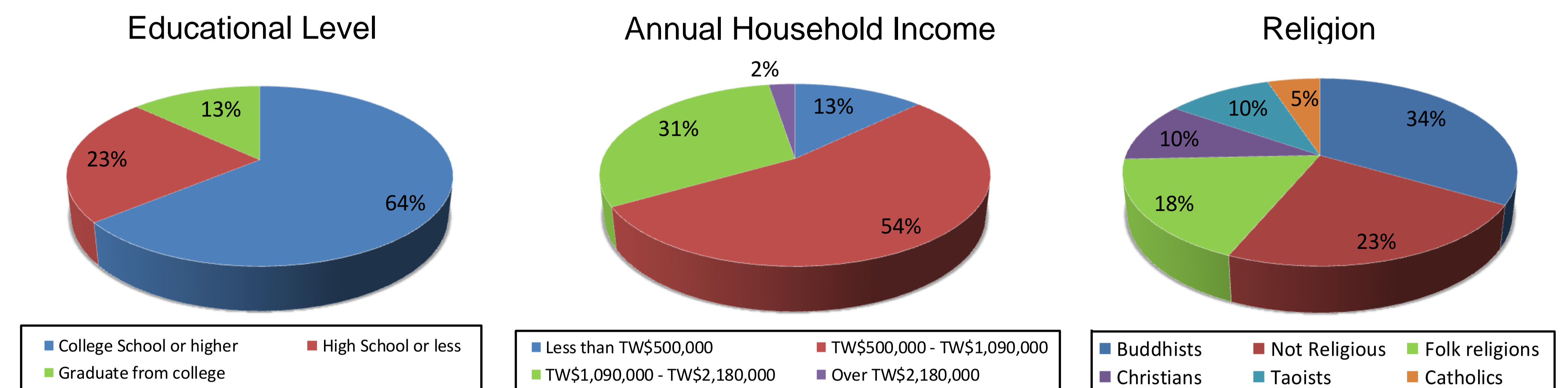
- Autism Spectrum Disorders (ASD), an urgent public health concern in Taiwan, is a type of highly heritable neurodevelopment disorder.
- Only few studies have examined parents' views regarding causes of their children's ASD and the risk of having another child with ASD.
- Although previously mentioned studies (albeit limited in number) shed light on perceived genetic causes and recurrence risk of ASD among parents of children with ASD, those studies were conducted primarily in the Western countries.
- To the best of our knowledge, this is the first study that attempts to address perceived causes and recurrence risk of ASD among Taiwanese parents of children having ASD.

Methods

- Semi-structured, in-depth interviews were conducted among 39 Taiwanese parents who have at least one child diagnosed with ASD.

Demographic Characteristics

- Sample size: 39 (31 females/8 males)
- Mean age: 42.0 ± 4.9 (Range: 30-55)



Results & Discussion

Table 1: Parents' Perceptions of the Genetic Component of ASD (N = 39)

Parents' Perception	n	Percentage %
Yes	28	71.8
No	4	10.3
Don't know	7	17.9

Table 2: Parents' Perceived Causes of Their Children's ASD (N = 39)

Cause	n	Percentage %
Genetic influence	16	41.0
Don't know	12	30.8
Complications during birth	8	20.5
Vaccination	7	17.9
Complications during pregnancy	6	15.4
Environmental factors	5	12.8
Parenting style	4	10.3
Destiny	4	10.3
Physiological problems	3	7.7
Unintended injuries or illness	2	5.1
Diet	1	2.6
Chinese alternative medicine	1	2.6

Note: Total percentage is more than 100% because participants could indicate more than one cause contributing to their children's ASD.

Table 3: Parents' Perceived Recurrence Risk of Having Another Child with ASD (N = 39)

Perceived Recurrence Risk	n	Percentage %
Don't know	12	30.8
High recurrence risk	9	23.1
Low recurrence risk	9	23.1
No recurrence risk	7	17.9
Moderate recurrence risk	2	5.1

- Findings indicated that only 71.8% of participants believed that ASD has a genetic link, and less than half (41.0%) perceived genetic influence as the cause of their children's ASD.

- Additionally, none of the participants identified the accurate recurrence risk of having another child with ASD.

❖ *Our data suggested that Taiwanese parents of children with ASD in this sample had limited knowledge regarding the genetic cause and recurrence risk of ASD.*

❖ *Health education for ASD is urgently needed to help this vulnerable group obtain correct genetic knowledge and make informed reproductive decisions.*

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