



Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Perceived recurrence risk of having another affected child: A survey on parents of children with autism spectrum disorders in Taiwan

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ARTICLE INFO

Article history:

Received 17 September 2017

Received in revised form 15 December 2017

Accepted 17 December 2017

Keywords:

Autism spectrum disorders

Risk perceptions

Genetics

Family history

ABSTRACT

Objective: Autism Spectrum Disorders (ASD) have a significant genetic predisposition. The recurrence risk of ASD ranges from 3% to 18.7% for parents having one affected child. As recurrence risk perceptions have important implications for family planning, prenatal preparation, and future children managements, absolute and relative recurrence risk perceptions of having another affected child among Taiwanese parents of children with ASD were assessed.

Methods: This study collected quantitative survey data from 415 Taiwanese parents who had one child with ASD.

Results: Participants reported their absolute recurrence risk of having another child with ASD was 33.4%. Compared to other parents with normally-developing children, merely 49.8% of participants perceived higher relative recurrence risk. By controlling for the sociodemographic characteristics, participants' absolute recurrence risk perceptions were significantly predicted by their perceived genetic causes of ASD and family history of ASD. Yet, participants' relative recurrence risk perceptions were significantly associated with only the perceived genetic etiology.

Conclusion: Taiwanese parents of children diagnosed with ASD had an incorrect understanding of their absolute and relative recurrence risks.

Practice implications: To facilitate informed decision-making in family planning, healthcare providers should discuss absolute and relative recurrence risks as well as genetic causes of ASD with this particular group.

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1. Introduction

Autism spectrum disorders (ASD) is a group of neurodevelopmental disabilities, which may lead to substantial challenges in social interaction, communication, and behavior [1–3]. Strong medical and epidemiologic evidence has indicated that genes play an important role in the cause of ASD [4–7]. According to recent studies and the American College of Medical Genetics and Genomics [3,8–10], the recurrence risk for the families who have one child with ASD ranges from 3% to 18.7%. For families with more than one child diagnosed with ASD, the recurrence risk increases to as high as 33% to 50%.

Risk perceptions play an important role in health behaviors [11–13]. As risk perceptions are complex constructs, using one index for measurement is insufficient. Past research recommends the

utilization of more than one approach to measure risk perceptions [14] because multiple measures represent various dimensions regarding the concept of risk perceptions, which may later affect health risk-related behavior. Two common methods have been used to examine individuals' risk perceptions [11,15–18]. In the case of assessing risk perceptions of having another child with ASD among parents of affected children with ASD, the first measure is *absolute* recurrence risk perceptions, in which a numeric value or percentage is utilized. It represents the absolute magnitude of a recurrence risk perception, which is meaningful in clinical decision-making, as such estimation of perceived recurrence risk is comparable with the objective scientific data of actual recurrence risk. The second measure is *relative* or *comparative* recurrence risk perceptions, which asks parents of children with ASD to compare their risk of having another affected child to that of parents with normally-developing children. Compare to *absolute* recurrence risk, *relative* recurrence risk perception is more likely to be associated with health behavior, cognitive knowledge of health information, and personal psychological factors, such as worry and personal experience with a health event [19–21]. Employing both

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absolute and *relative* recurrence risk perception measurements help researchers and healthcare providers comprehensively understand recurrence risk perceptions among parents of children with ASD [14,19].

Obtaining accurate perceptions of recurrence risk of having another affected child is important for families with children diagnosed with ASD, as it can affect decision-making regarding family planning, prenatal preparation, and management of the future children [13,22]. Specifically, overestimated recurrence risk could increase parents' stress and anxiety, which would in turn affect their family planning [23]. On the contrary, underestimated recurrence risk would place parents in an unexpected situation. They may not be psychologically prepared to face their child's ASD and miss the window of opportunity for early diagnosis and intervention for another child with ASD.

There has been a limited number of research in recurrence risk perceptions among parents of children diagnosed with ASD. Among those limited articles, two studies [13,24] adopted a qualitative approach to interview 39 Taiwanese and 21 Australian parents of children with ASD, respectively. The other three survey studies [22,25,26] were conducted in North America with 41–255 parents or families of children with ASD. All of these studies targeted *absolute* recurrence risk and reported that parents with existing children with ASD in their sample had incorrect recurrence risk perceptions of having another affected child [13,22,24–26]. While these studies shed a light on the parents' perception of ASD recurrence risk, their findings are limited due to the sample size, sole focus on *absolute* risk perceptions, and/or the nature of the qualitative research (i.e., lack of generalizability).

To fill this gap, the purpose of this first-of-its-kind survey study is to examine the perceived *absolute* and *relative* recurrence risk of having another child with ASD among parents of children with ASD in Taiwan. Moreover, given that genetics is an imperative risk factor of ASD [4–7], we hypothesized that parents' beliefs regarding their children having the genetic predisposition for ASD and the family histories of ASD would influence their recurrence risk perceptions. As such, we further assessed the association of perceived genetic causes and family history of ASD with parents' *absolute* and *relative* recurrent risk perceptions of having another child with ASD.

2. Methods

2.1. Sample and study design

This study was approved by the Institutional Review Board at Texas A&M University as well as the Research and Development Office at the National Tsing Hua University (former National Hsinchu University of Education) in Taiwan. The eligibility criterion was parents who have at least one child diagnosed with ASD in Taiwan. During the recruitment process, the research team first retrieved a list of all public elementary schools with special education classes in Hsinchu City and County, Taoyuan County, and Miaoli County from the official website of the Department of Education in Taiwan. These counties were selected because the collaborative university, the National Tsing Hua University (former National Hsinchu University of Education), had extensively networks and long-term trust relationships with public elementary schools with special education classes in these geographical areas. We then contacted special education teachers working in these schools, informing them of the purpose of this study, study design, and eligibility of prospective participants. These special education teachers were asked to recruit eligible parents who might be willing to participate in our study. The paper-and-pencil survey was utilized as it was a preferred method for both special education teachers and parents. Furthermore, to increase the sample size, we extended the recruitment to other areas in Taiwan,

including Taipei City, New Taipei City, Taichung City, Tainan City, Kaohsiung City, Yilan County, Chiayi City, Chiayi County, and Yunlin County. As incentives, parents who completed the survey were eligible to enter the drawing for eight gift vouchers of 3000 NT\$ (\$100), 20 gift vouchers of 2000 NT\$ (\$67), and 200 gift vouchers of 1000 NT\$ (\$33).

Out of 862 surveys that were sent out, 451 were returned (response rate: 52.3%). After removing the duplicated surveys and those filled out by ineligible respondents (e.g., family members who were not parents and parents without any children diagnosed with ASD), 443 surveys were valid. Among these, parents who had more than one child diagnosed with ASD ($n = 28$) were excluded in this study as their objective recurrence risks of having another child affected by ASD differ from those of the parents with only one affected child. Moreover, parents with two or more children diagnosed with ASD might have different characteristics (e.g., perceived cause of ASD and family history of ASD) compared to parents having only one affected child. Thus, the final sample comprised 415 participants who had only one child with ASD.

2.2. Survey design

Survey questions written in Mandarin were developed based on the previous literature [22,25,27–32] and the findings from the qualitative data we collected previously [13,33–36]. To ensure content validity, experts from multiple related fields, including family medicine, pediatrics, special education, and social and behavioral sciences, reviewed the survey. Subsequently, cognitive interviews with eight parents of children with ASD and retrospective interviews with additional five parents were conducted in Taiwan. Multiple revisions of the survey were made based on the feedback from both the experts and parents. The survey was then pilot tested using four parents of children with ASD in Hsinchu City and County, Taiwan. The final version of the survey included 33 pages, 15 sections, and 375 items. For the purpose of this manuscript, we extracted the following sections: (1) parents' perceived etiologies of ASD for their own children, (2) family history of ASD, (3) parents' demographic information, (4) parents' emotional factors (i.e., anxiety, fear, and guilt), and (5) perceptions of *absolute* and *relative* recurrence risk of having another child affected by ASD.

2.3. Measurement

2.3.1. Parents' perceived genetic etiology of ASD

Parents' perceived genetic etiology of ASD was assessed by asking participants to choose the factors that might cause ASD for their own child. Twenty-one factors (e.g., genetics, vaccination, and environmental factors) with "others" and "I don't know" options were provided. Parents could choose more than one options. If participants choose "genetics" as a factor, their responses would be classified as perceiving genetics as a cause of ASD.

2.3.2. Family history of ASD

Four questions were used to collect the family history of ASD. Participants were asked whether any of their own family member or their spouse's family members (including themselves) have ASD or have certain symptoms or traits of ASD, except for their child with ASD. Having any "yes" response to these questions was coded as a positive family history of ASD.

2.3.3. Recurrence risk perceptions

Two types of recurrence risk perceptions were obtained: *absolute* and *relative*. The question regarding the *absolute* recurrence risk perception was presented as, "Suppose you plan to have another child, your chance of having another child with ASD is ____

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