Autism-risk screening in the first 3 years of life in Taiwan Birth Cohort Pilot Study

For-Wey Lung [a,b,c,g], Tung-Liang Chiang [d], Shio-Jean Lin [e], Bih-Ching Shu [f,*]

[a] Department of Medicine, Kaohsiung Armed Forces General Hospital, Kaohsiung, Taiwan
[b] Department of Psychiatry, National Defense Medical Center, Taipei, Taiwan
[c] Department of Neurology, Kaohsiung Medical University, Kaohsiung, Taiwan
[d] Institute of Health Policy and Management, College of Public Health, National Taiwan University, Taipei, Taiwan
[e] Department of Pediatrics, National Cheng Kung University, Tainan, Taiwan
[f] Institute of Allied Health Sciences and Department of Nursing, National Cheng Kung University, No. 1 Da-Hsueh Rd., Tainan, 701, Taiwan
[g] Calo Psychiatric Center, Pingtung County, Taiwan

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ABSTRACT

To increase public awareness and sensitity, a two-stage screening with a community-based approach is proposed, with the use of the broadband Taiwan Birth Cohort Study (TBCS) developmental instrument in the first stage and the narrowband Modified Checklist of Autism in Toddlers (M-CHAT) in the second stage. Thus, the purpose of this study was to use the M-CHAT as the lead criteria in the investigation of whether the TBCS developmental instrument can be used in first-stage detection of autism spectrum disorder (ASD) at 6, 18, and 36 months. The TBCS dataset, which included 1783 children in the first stage, 1620 in the second stage, and 1630 in the third stage was used for this study. The M-CHAT and the TBCS 6, 18 and 36 months' developmental scales were collected. Using the M-CHAT, 292 (18.0%) children were screened out as being at high risk for ASD; using this as the lead criteria, the cutoff points of 65/66 for the 6 months' scale, 42/43 for the 18 months' scale and 51/52 for the 36 months' scale, with negative predictive values of 83.44%, 84.21% and 85.35%, respectively, were established. With the cutoff points, TBCS developmental instrument can be used as a community-based first-stage screening instrument at 6, 18, and 36 months. Early diagnosis and intervention optimizes the long-term prognosis of ASD and also decreases family stress. Follow-up of these children and further evaluation using standard diagnostic assessments will help us in understanding the accuracy of the TBCS developmental instrument and M-CHAT use in the community.

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1. Introduction

Autism spectrum disorder (ASD) is defined by deficits in the three main areas of reciprocal social interaction, communication, and restricted and repetitive behaviors and interests (American Psychiatric Association, 1994). ASD used to be considered a rare event, with an estimated prevalence rate of 6.7 per 1000 (Centers for Disease Control and Prevention, 2007). However, a study in Taiwan found that 34 out of 1000 children listed in the National Health Insurance Program database were diagnosed with ASD, revealing a 14% increase in the incidence rate (Chen, Liu, Su, Huang, & Lin, 2007). In addition to Taiwan, the prevalence of ASD has increased dramatically in the United States, as well (Gurney et al., 2003). With this increase in the prevalence of ASD, screening and surveillance is of vital importance.

* Corresponding author. Tel.: +886 6 2353535x5822; fax: +886 6 273750.
E-mail addresses: forweylung@gmail.com, shubih@mail.ncku.edu.tw (B.-C. Shu).

Many studies have found that early diagnosis and intervention optimizes the long-term prognosis for ASD (Lord, 2000), and also decreases family stress (Scahil, 2005). However, gaps were found among the parent's first concern about their children's behavior, the age of first evaluation and the final diagnosis (Siegel, Pliner, Eschler, & Elliott, 1988). Therefore, autism-specific screening tools, such as the Modified Checklist of Autism in Toddlers (M-CHAT) have been developed, and have been found to be effective in identifying those at risk for ASD in clinical (Robins, Fein, Barton, & Green, 2001) and primary care settings (Robins, 2008). However, its effectiveness as a community-based screening for ASD has shown inconsistent results (Perera, Wijewardena, & Aluthwelage, 2009).

A two-stage screening method may be more suitable in a community-based setting, since it entails using a less expensive, less invasive test at the first stage, and a more expensive or more invasive, but more sensitive and specific test at the second stage (Gordis, 1996). An example of this method used in the screening of development and ASD is described in Lung et al. (2011). The first stage uses a broadband instrument which assesses all developmental domains (e.g., Parents' Evaluation of Developmental Status), then a narrowband focusing on a single domain or condition for the second stage (e.g., M-CHAT). Using this screening approach, only a portion of the children need to be further assessed at the second stage, thus the prevalence of the disease is enhanced, which would increase the positive predictive value (PPV; the proportion of true positives among individuals who tested positive) of the instrument and provide better accuracy in predicting the disease (Gordis, 1996). In addition, time, human resources and money may be saved (Chien, Huang, & Lung, 2009). These savings are essential in a community-based screening, since a large number of children will need to be screened in these settings.

The Taiwan Birth Cohort Study (TBCS) developmental instrument is a broadband screening instrument that has been found to be reliable, valid and effective in community screening for developmental delay in a national birth cohort study (Lung, Shu, Chiang, & Lin, 2008; Lung, Shu, Chiang, & Lin, 2010). However, broadband screening instruments have been criticized for their over-referral (Glascoe, Macias, Weqner, & Robertshaw, 2007) and failure to detect a portion of those with ASD (Pinto-Martin et al., 2008). These limits maybe minimized using a two-stage screening approach.

The TBCS developmental instrument has been found to be applicable in large-scale community screening in Taiwan (Lung et al., 2008, 2010), and the M-CHAT has been found to be applicable to the Chinese population (Wong et al., 2004). Hitherto, no studies have tested the use of the M-CHAT in randomized community-based screening for ASD. Therefore, this study used a randomized community-based birth cohort sample to investigate whether the TBCS can be used as a first-stage broadband screening instrument in the detection of ASD at 6, 18, and 36 months. In addition, using the M-CHAT as the lead criteria, the cutoff points for the TBCS developmental instrument in the screening of ASD were investigated.

2. Methods

2.1. Participants

This study used the dataset from the Taiwan Birth Cohort Pilot Study (TBCS-P), a national birth cohort study of a sample of infants born between November and December 2003. Two-stage stratified random sampling using the township as the primary sampling unit (PSU) was carried out. In the first-stage sampling, 29 out of 369 townships were chosen, using the systematic random sampling method. The next stage involved selecting individual cases by random sampling from the national birth report database within each selected PSU, proportionate to the number of births. The final target sample resulted in 2048 babies, with an approximate sampling rate of 12%.

Three stages of data, at 6, 18, and 36 months of age, have been collected up to now. The first stage included 1783 children (response rate of 87.1%); the second stage, 1620 (response rate of 90.6%); and the third stage, 1630 (response rate of 91.4%). Those who participated in all three stages were included in this study, yielding at total of 1618 children.

The protocol of this study was approved by the Institutional Review Board of a teaching hospital in Taiwan, and informed consent was collected at all stages of the study.

2.2. Materials

When the children were 6, 18 and 36 months, parents filled out the TBCS developmental instrument; the M-CHAT was collected at 36 months.

The M-CHAT is a 23 yes/no item parental report screening instrument for ASD. Children who failed 3 of the 23 items or 2 of the 6 critical items were suspected of having ASD. The M-CHAT is simple, easy to use, and easily comprehensible, and no parent or physician training is required. The original M-CHAT was developed by Robins et al. (2001) and translated into Chinese by Wong et al. (2004). This Chinese-language version (CHAT-23) was found to be discriminative of ASD in a Chinese cohort in Hong Kong (Wong et al., 2004). Since there are dialectic differences between Cantonese (the Chinese dialect used in Hong Kong) and Mandarin (the Chinese dialect used in Taiwan), we did not use the CHAT-23. Translation and back translation was carried out, and the criteria for failing were adopted from Robins et al.'s study (2001).

There are 26 items in the TBCS 6-month, 17 in the 18-month, and 16 in the 60-month scale, measuring the children's daily performance based on parental observations. The items are answered using a 3-point Likert scale: higher scores meant better development. The TBCS is a culturally sensitive, easily comprehensible instrument measuring children's development in the four dimensions of gross motor, fine motor, language and social. The TBCS has shown good concurrent validity with the Bayley Scales of Infant Development-Second Edition (BSID-II) (Bayley, 1993). The TBCS instrument exhibits high reliability,