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Autism Screening and MMR Vaccination in Children of Somali Refugees

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Abstract

Autism-specific screening is recommended during certain well child visits using an instrument such as the Modified Checklist for Autism in Toddlers (M-CHAT). The purpose of the study was to evaluate the use of the M-CHAT in a family medicine clinic with a large Somali patient population. This study compared the utility of the M-CHAT and a general developmental screen, the Parent's Evaluation of Developmental Status (PEDS), while examining measles-mumps-rubella (MMR) vaccination rates. Somali parents have concerns about higher rates of autism in their children caused by the MMR vaccine. A retrospective chart review of well child visits of 90 children ages 18 months through 2 years was done. There was a strong correlation between abnormal PEDS and M-CHAT screens in this population. None of the Somali children screened positive on the M-CHAT, nor did their parents report concerns on the PEDS. All five children with positive M-CHAT results also had abnormal PEDS results. The rate of Somali children not immunized for MMR was significantly higher than for non-Somali children (29% vs 6%, p=0.006). Despite increased concerns for autism in the Somali community, none of the Somali children screened positive on the M-CHAT. Although studies have shown no relation between MMR and autism, significantly fewer Somali children were immunized for MMR than non-Somali children. There was a strong correlation between abnormal PEDS and M-CHAT screens. Ideally, screening tools that work well in one language and culture should be validated before use in others

1. Introduction

Autism Spectrum Disorders (ASD) are a group of developmental disorders that include deficits in socialization and communication as well as repetitive or stereotyped behavior. Symptoms are usually present before the age of 3 years. ASDs are currently estimated to affect 1 in 68 children. [1]

Identification of children with ASD before age 3 years is crucial because early intervention with intensive, sustained special education programs and behavioral therapy yields improved outcomes and decreased stress for families. [2] However, the average age of diagnosis is between 3 and 6 years, and many children are not diagnosed until they enter kindergarten. [2] Therefore, the American Academy of Pediatrics (AAP) recommends that all children undergo ASD screening at 18 and 24 months of age, in addition to general developmental screening. [3] However, the US Preventive Services Task Force recently concluded that the current evidence is insufficient to assess the

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balance of benefits and harms of screening for ASD in young children. [4]

The Modified Checklist for Autism in Toddlers (M-CHAT) is one of the validated autism screening tools suggested for use by the AAP. [3] It is a 23-item parent report checklist developed to screen children aged 16-30 months. The reported sensitivity is 85% and specificity is 93%. [5] A child with a positive M-CHAT should be referred for further evaluation of possible ASD.

Somali parents in Minneapolis, MN have raised concerns about what appears to be a high rate of ASD in their children. [6] The prevalence of ASD in children in Minneapolis ages 7 to 9 years was recently reported in a study conducted by the University of Minnesota. [6] The prevalence was one in 32 in Somali children, which was similar to the prevalence in white children (one in 36). However this prevalence was higher than that for black (non-Somali) and Hispanic children, whose prevalence of ASD was one in 62 and one in 80 respectively.

Many Somali parents believe that measles-mumps-rubella (MMR) vaccination causes autism. [7, 8] This belief has contributed to low vaccination rates. The MMR vaccination rate in the broader community (Hennepin County) in 2011 for two-year-old non-Somali children was 85%, compared to Somali children, which was only 54%. [7] This low vaccination rate contributed to a large measles outbreak in Minnesota in 2011. [7] The purpose of this study was to compare the utility of the M-CHAT and a general developmental screening tool, the Parent's Evaluation of Developmental Status (PEDS), while examining MMR vaccination rates in a clinic population including many Somali patients.

2. Methods

A family medicine clinic that is located in a Minneapolis neighborhood with a large Somali population began screening children for autism with the M-CHAT at their 18 and 24 month well-child visits. The children at the clinic are also screened at all of their well-child visits with a general developmental screening tool, the PEDS. The PEDS is a validated 10-item questionnaire that elicits parental concerns in multiple developmental areas and takes 2 to 5 minutes to complete. The provider reviews the answers and determines the risk category, or "Path". Path A, B and C results mean that the parent reported one or more developmental or behavioral concern. Path D results indicate that the parents had difficulty communicating with the provider about their concerns.

This study examined the percentage of children age 18-35 months screening positive for ASD with M-CHAT and possible rate differences for the Somali and non-Somali populations. It also compared positive M-CHAT and abnormal PEDS results in these populations; and also compared the measles-mumps-rubella (MMR) vaccination rate among these children. A retrospective chart review of 90

consecutive well-child visits of children ages 18 months through 35 months beginning March 2011 was performed by the co-author (S. M.) to obtain this information.

The clinic used the Allscripts electronic health record. Well-child visits are documented in templates specific for the different ages. All M-CHAT forms are scanned into the record. Abnormal PEDS forms are also scanned into the record. The following information was collected: age at visit, gender, primary language of parents, M-CHAT result, PEDS result, and MMR vaccination status.

Descriptive statistics were used to summarize baseline characteristics and outcomes. Fisher's exact tests were used to compare the M-CHAT and vaccine rates between the Somali and non-Somali children as well as the association between M-CHAT and PEDS results. P-values less than 0.05 were considered statistically significant. The study was approved by the University of Minnesota Institutional Review Board.

3. Results

The records of 90 children were reviewed, 38 (42%) of whom were Somali. The mean age was 24 months, and 55% were male. The parent's primary language was Somali for 40% of children, English for 50%, Oromo for 4%, and Spanish and Chinese for 1%.

None of the 38 Somali children had a positive M-CHAT test, while 5 (9.6%) of the non-Somali children had a positive M-CHAT test result (p=0.07). None of the Somali parents reported concerns about their child's development on the PEDS test. However, providers rated four of the Somali children as Path D, indicating difficulty assessing the child's development because of problems communicating with the parents. As shown in table 1, the 5 non-Somali children with positive M-CHAT tests also had abnormal PEDS results. There was a significant association between M-CHAT and PEDS results (p < 0.0001).

Table 1. M-CHAT results versus PEDS results.

PEDS	M-CHAT Negative	M-CHAT Positive	Total
Path	n=85 (%)	n=5 (%)	n=90 (%)
E	73 (85.6)	0	73 (81.1)
A	2 (2.4)	0	2 (2.2)
В	3 (3.5)	2 (40.0)	5 (5.6)
C	3 (3.5)	3 (60.0)	6 (6.7)
D	4 (4.7)	0	4 (4.4)

Fisher's exact test p-value ≤ 0.0001

Path A: Two or more concerns predictive of developmental problems

Path B: One concern predictive of developmental problems

Path C: Concern not predictive of developmental problems

Path D: Parental difficulties in communication

Path E: No concern

The MMR vaccine is routinely recommended at the 12-month well-child visit. At the well-child visit when the child was 24 to 35 months old, only 71% of the Somali children had received this vaccine, compared with 94% of the non-Somali children. (p = 0.006).

4. Discussion

It was surprising that none of the Somali children screened positive on the M-CHAT, given the widespread concern for ASD in the community. Approximately 9% of the non-Somali children screened positive on the M-CHAT, which is the number expected to screen positive based on the medical literature.[9] In addition, the Somali parents did not report concerns about their children's development on the PEDS form. A recent systematic review of 37 studies with a total of 210,242 subjects found that 33.6% of parents had concerns indicating developmental risk identified by the PEDS questionnaire. [10] It appears that the Somali parents did not wish to inform the provider of developmental or behavioral problems, possibly due to stigma and taboo in the Somali community [6] Screening tools that rely on parental report will not be valid in such situations. When the provider suspects but is unable to confirm a developmental or behavioral problem, the provider may label the child as Path D on the PEDS form, as did four providers in this study.

The significant association between the M-CHAT and PEDS results in this study reflects this unusual situation where none of the Somali parents reported concerns on the PEDS form and none of their children screened positive on the M-CHAT. One previous study of 152 children ages 18 to 30 months screened with both of these tools found that the two tools tested different domains of developmental concerns. [2] The PEDS missed the majority of children who screened positive for ASD on the M-CHAT, thereby supporting the recommendation for using an ASD-specific tool in addition to regular developmental screening at the appropriate ages. [3]

The Somali community's concern about ASD is reflected in the significantly lower MMR immunization rate of 71% for their children. Somali parents would rather not vaccinate and risk a rare disease (measles) than choose vaccination, which they believe could cause autism. In a previous survey of clinic parents, Somali parents were significantly more likely than non-Somali parents to believe that vaccines cause autism. All of the Somali parents reporting this belief said they knew a child who received the MMR vaccine and then got autism. [11] In 2011, this undervaccination contributed to the largest measles outbreak in Minnesota in twenty years. [7] The source was an unvaccinated 30-month-old US born infant of Somali descent who was infected while visiting Kenya. Ultimately, 3000 people were exposed, 21 measles cases were identified, 16 of whom were unvaccinated, and 6 of whom were of Somali descent.

5. Conclusion

Somali parents appeared to under report developmental and behavioral concerns about their children on the M-CHAT and PEDS tests. Implementation of screening for ASD is a challenge in patient populations from different cultures. Tools that have been validated in one language and culture may not work at all well in another. Ideally, these screening tools should be validated before being used in other languages and cultures.

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