PARENTS PLAY A SIGNIFICANT ROLE IN THE DETECTION OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN LOW RESOURCE SETTINGS

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Introduction

The Center for Disease Control and Prevention (2014) estimated 1 in 68 children to have Autism Spectrum Disorder (ASD) in the USA in 2010. Small community studies in Sri Lanka estimated ASD prevalence to be 1 per 93 children, aged 18–24-months. Speech delay was the main reason for presentation in a similar local study. There is a worldwide increase in the prevalence of children with ASD.

The age and the reason for parental concern is an important indicator of early identification. Early identification leads to early intervention and therefore better outcomes. Therefore identifying the factors leading to concerns regarding their children For speech and language therapy interventions it is important to identify the presentations of these children in the local settings.

Objectives

General objective
To describe the parental concerns leading to seek intervention for their children with ASD aged less than 5 years attending selected special clinics in the Western Province

Specific objectives
To describe main presenting features of children with ASD
To define pathways taken by parents when seeking interventions
To describe the factors in the family that initiated them to seek intervention.

Method

Design: A descriptive cross sectional study.
Study period: March to December 2015

Study setting: Government: Clinics at the Department of Disability Studies Faculty of Medicine Ragama, Child Mental Health Clinic at Lady Ridgeway Hospital for Children
Private: 2 speech therapy clinics in the Western province.

Study population: The parents of children with ASD aged 1-5 years with a confirmed diagnosis according to the DSM - 5 criteria and no other co-morbidities.

Sampling procedure: Convenience-sampling. All eligible children with ASD we selected from three clinics to represent the public and the private sector

Sample size: 150 mothers or fathers representing parents of 150 children with ASD were selected according to the inclusion criteria.

Data collection method: a pre tested interviewer-administered questionnaire.

Data analysis: SPSS software

Results

Total population = 150
Participants: Mothers 133(88.7%) Fathers 17(11.3%) Male children: 120(80%) Female children: 30(20%)

The mean age of parental concern: 27.49 (SD 9.566) months
The mean age of diagnosis: 33.19 (SD 10.499) months
The mean duration taken to seek services after identifying the problem: 21.83 (SD 29.535) weeks.

Mothers identified the child to have a problem in 80% of children.

Families with a higher educational level in the father sought intervention earlier than the others (p = 0.003).

Conclusion

The proportions of males: females in this study matched the global patterns. Mothers being the principal caregivers identified the condition first. Unlike in previous findings from Sri Lanka this study shows communication and specifically poor eye contact as an early feature for parental concern. The cultural factors significantly contributed to the delay in seeking services.

Discussion

Eye contact and neologisms were the most frequently observed features. Majority of children were referred for services at the first contact but 10.70% were reassured. Cultural factors contributed to the delay in presentation for services.

Recommendations

Increasing awareness amongst mothers about early communication is important for early detection. More epidemiological studies should be undertaken on ASD to identify culturally specific reasons for presentations

References


