

Anthropological and Socio-Economic Issues Faced By Autistic Patients and Their Families

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Abstract: - Autism is a biological disorder coming from the brain that impairs people’s communication and their social skills. Main objective of this study was to determine the anthropological and attitudinal issues faced by Autism patients and their families by their social groups. Descriptive cross-sectional study was selected as the research design of this research. The descriptive cross-sectional design, data was collected using following tools, Interviews – Semi structured interviews / Observation - Participant as observer. Research was conducted using multi sites from Western and North Western Provinces. In depth interview questionnaire guideline was used to collect information from doctors and nurses. In Attitude perspective, People have started to see in a different manner than before without their religious, cultural, ethical spectacles about these kind of medical conditions. In social and economical perspective, people have started to see in a different manner than before without their religious, cultural, ethical spectacles about these kind of medical conditions.

Keywords: Physical Anthropology, Mental Disorders, Autism spectrum disorder, Cultural Anthropology

I. INTRODUCTION AND RESEARCH PROBLEM/ HYPOTHESIS

Autism is a biological disorder coming from the brain that impairs people’s communication and their social skills. It covers an exceedingly broad spectrum of disorders ranging from very mild to severe. Autistics are described to be living in their “own world” and the high functioning autistics usually have two worlds; the “outside world” and “their world”. Autism can be accompanied with having many serious sensory challenges, such as lack of verbal communication, lack of eye contact, and the inability to hear what others are saying. (Volkmar, F. R, 2007:30). This study was focused to determine the anthropological and sociological issues pertaining to Autism. Autism at present is becoming a social problem. With the increase in the patient numbers and without the proper knowledge and awareness of management techniques, the parents of these children are undergoing many problems in their families, and face economic and social problems. Therefore, this study was focused on finding the anthropological and sociological aspects of this disease to identify proper management techniques. The anthropological aspect deals with the people’s attitudes about the patients and their families, mainly of their attitudes about this disorder and the sociological aspect deals with the patient's family background, economical status and social background.

II. METHODOLOGY

Descriptive cross-sectional study was selected as the research design of this research. Descriptive Cross-sectional study was used to capture information based on data gathered at a specific point in time. The data was gathered from a pool of participants based on characteristics and demographics variables such as age, gender, income, education, geographical locations, ethnicity etc. The variables used in this study were based on the type data collected and on what the study aims to prove or validate. The research findings were helped to remove assumptions and replaced them with actual data on the specific variables studied during the time period accounted for in the cross-sectional study. In this descriptive cross-sectional design, data was collected using following tools,

Interviews - Semi-structured interviews

Observation - Participant as observer

Research was conducted using multi sites from Western Province and two hospitals in North-Western Province as follows and the breakdown of sample sizes in each data collected places, 03 Hospitals, 02 private clinics, 02 OSILMO Research Centers.

Place	Number of Informants
Dambadeniya Hospital	10
Dr. (Mrs.) Champa Rathnayake's private clinic	12
Dr. H.S. Madugalla’s private clinic	10
OSILMO Research Center - Boralasingamuwa	32
OSILMO Research Center - Kaluthara	28
Kurunegala Central Hospital	24
Kuliyapitiya General Hospital	22

Used primary and secondary data collection to conduct the research. In primary data collection, data was collected from parents of Autistic patients using structured interview method. In depth interview questionnaire guideline was used to collect information from doctors and nurses.

III. RESULTS DISCUSSION AND CONCLUSIONS

Results and discussion were arranged according to the questionnaire and questionnaire gridline. The researcher has

analyzed data one by one in questions in questionnaire and questionnaire gridline. The questionnaire was divided into four parts such as Basic Information, Behavioral data, Socio-Economic Data and Attitudes to collect most effectively.

Thirty six patients were included in the study and most of patients were under six years of age. They have not started schooling yet. However, few patients go to school and they were in grade 1, 2 (3 patients), 3, 4 (2 patients) and 5. Out of thirty-six patients, eight patients go to school. However, they show poor attendance. They mainly stayed at home during sports meet days and examination periods. Some patients stay in the same class for two years (as 2017 in 2018). They did not engage in learning much but they are interacting with other students. For this reason and to make those children to be socialized doctors recommended that it was necessary to attend school daily. There were two patients who were admitted to school but refused to attend to school due to their hyper activeness. Some patients do not like to play with others because they get angry very easily and they were hyperactive patients too. These patients' mothers tried so hard to associate these children with other normal children and to undergo treatments Further these patients have tried to hurt others when they are out of control. Except schooling children and few patients, others Autistic patients had problems with responding to people. Most of the patients keep eye contact when someone is talking to them even if it is not a family member. However, they very rarely respond to them. All the patients had no eye contact when the disorder was first diagnosed by the doctor. Even the schooling patients are looking at the person but do not respond. However, they responded to family members during the activity period.

Friends and families invite the families of Autistic patients for parties, gatherings and other occasions. Most of the time they decline the invitations and even if they accept, they participate without the patient. The reason they provide was the behavior of the patient. The child become uncontrollable when he/she was with many people especially when people stare at them. Some patients had hurt people who were sitting or standing near him/her. According to the parents, some neighbors and relatives (not much close) have noticed this child as an abnormal child and has advised the child to be sent to mental hospitals. Parents with disable children or with chronic health problems suffer great deal of stress. There is evidence, however, that parents of Autistic children suffer the stress most of all. Parents of children with Autism Spectrum Disorder face some additional stressors. First, they often live with uncertainty about what caused their child's Autism , as

well as possible guilt over whether they did or failed to do something that led to their child's Disorder . Second, the core disability associated with the disorder is a social one. Most parents hope for a warm and loving relationship with their child. It is bewildering to find you have a baby who does not like to be held, or a child who will not look into your eyes. Parents adapt, learning to love their child, but usually not without having passed through some confusion and pain. Third, whatever their specific Disorder diagnosed or IQ, children of the Autism spectrum often have behavioral problems, from refusal to sleep to intense and frequent tantrums to extreme rigidity.

Most of the participants have a negative impression about the disorder. However some of the doctors and nurses who participated as informants are having a positive attitude about the disorder and they are hoping to overcome the disorder with scheduled and continuous treatments and proper management plans.

REFERENCES

- [1]. American Psychiatric Association (ed.) (2007). Diagnostic and Statistical Manual of Mental Disorders. American Psychiatric Association publisher.
- [2]. Bauman, M.D.(1985). Histoanatomic observations of the brain in early infantile autism: Canada: pp.173.
- [3]. Bearss, K., Johnson, C., & Smith, T. (2015). 5 Effect of parent training vs. parent education on behavioral problems in children with autism spectrum disorder, USA: pp154-153
- [4]. Amaral, D. G. (2017). Autism Research. Journal of Neuroscience, 10 (5): pp.10-15.
- [5]. American Psychiatric Association(ed.) (2013).Diagnostic and Statistical Manual of Mental Disorders, Jurnal of sage, 50(10):pp.20.
- [6]. Carol, C.(2015). Researchers urge greater attention to autism-related food issues, Center for Excellence in Developmental Disabilities at the University of Massachusetts Medical School. Journal of Editorials, 289 (1): pp.45-69. Available from: <https://www.autismspeaks.org/science/science-news/researchers-urge-greater-attention-autism-related-food-issues> (13/June/2017).
- [7]. King, B. (2015). Lower vaccination rates among families affected by autism, Seattle Children's Autism Center. Journal of Neuroscience, 10 (5): pp.10-15. Available from: <https://www.autismspeaks.org/science/science-news/no-mmr-autism-link-large-study-vaccinated-vs-unvaccinated-kids>. (Accessed 14 June 2017).
- [8]. Sandin. (2015). Large study on parent age & autism finds increased risk with teen moms, Icahn School of Medicine at Mount Sinai, New York, & Sweden's Karolinska Institute. Journal of Neuroscience, 10 (5): pp.36. Available from: <https://www.autismspeaks.org/science/science-news/large-study-parent-age-autism-finds-increased-risk-teen-moms>. (13 June 2017).
- [9]. Volkmar, F. R. (2007). Autism and Developmental Disorders. Journal of Child & School Psychology, 18 (3): pp. 30.