

Importance of Early Detection of Autistic Children and their Susceptibilities in Educational Setting

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Abstract

This research was carried out to identify different problems faced by family of autistic children while trying to detect this disorder; to analyze effect of family's socio-economic setting on early detection of children and their level of satisfaction from educational sector. It was qualitative and case study was done by using in depth interview. Sample consisted on 40 parents of autistic children. Purposive sampling technique and NVIVO was used. Major findings were grouped in to 3 broad regions as diagnosis of autism, socioeconomic context of family, and satisfaction of family with educational institutes. It was concluded that there is dire need to implement different challenges faced by family in early diagnosis of their children and approaches of educational rehabilitation.

Keywords: Early detection, Autistic children, Vulnerabilities, Educational setting

INTRODUCTION

Autism is existing more than formerly predicted (Chakrabarti & Fombonne, 2005 and Baird et al., 2006). An estimation entails a high increase in students with autism in England, with figures depicting a ratio as high as 116 in every 10,000 children of age ranging between nine to ten years (Baird et al., 2006), as evaluated to a previous stat of 20 in every 10,000 children (Aitken, 2001). It has been assessed by specialists that in Pakistan 345,600 individuals out of 172.8 million falls anywhere on extreme introverted issue i.e. Autism (Actionautism.org, 2011). According to Kamal, (2010), one out of every five hundred children is suffering from autism in Pakistan. This proportion is rising through fifteen to seventeen percent per annum. Autism is a multifarious developmental-disorder that affects a person's communication, and social-interaction skills. These children have issue of repetitive behavior and bizarre-development. ASD ranges between mild to severe and usually occurs in early years of life and lasts till adulthood. Several autistics are gifted in their particular meadow (Brazier, 2016). Early identification of autism is essential in ensuring appropriate educational intervention and improving

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child's adaptableness and inclusion in community. Though, it's a complex disorder so its susceptibilities lie in heterogeneity which makes early identification tough and challenging. Detection of autism is possible in less than 18 months' time period but practically it's difficult to implement due to diverse characteristics and lack of expertise (Attwood, 1993). According to Carlos III Health Institute, (2004) Parents of autistic children turn out to be suspicious regarding their child's growth and development in 22 months of age; before this they do not pay attention to delayed development of their child. Besides, Hernandez (2005) concluded that they get ultimate detection in 2.5years after consultations (as cited in Moreno, Morales, & Seller, 2017). Another susceptibility element of autistic children can be their parents' socio economic level which may affect early diagnosis. Those parents who are economically strong can move to private sessions for early identification of autism but poor people are unable to do so (King, & Bearman, 2011). These conditions influence the children in educational system because the deficiency of agreement in detection of autism creates trouble in outlining inclusive education in institutes.

This disorder has become contemporary focus of research. Parents and even early childhood caretakers don't have enough knowledge about different developmental disorders of childhood. In developed countries, there is trend of infant education so families can get benefit but in developing countries scenario is totally changed. Consequently, children and parents both suffer. Current study will highlight the significance of timely detection of autism, different problems faced by family of autistic children while trying to detect this disorder, effect of family's socio economic setting on early detection of children and their level of satisfaction from educational sector.

Objectives

This research was carried out to achieve the following objectives

- To identify different problems faced by family of autistic children while trying to detect this disorder.
- To analyze the effect of family's socio economic setting on early detection of children
- To assess the level of parental satisfaction from educational sector.

Review of literature

Autism is a multifarious neural disorder that has impact on brain functions and characteristically gives the impression with in first three years of age. It origins deficits in numerous areas of development comprising of social interaction, communiqué and activities which is called as triad impairment and can be range from mild-severe. Certain autistics have somewhat appropriate spoken abilities and least communication deficit but considerably weakened social-skills. They don't participate in pretending play and encounter numerous problems in instigating social-interactions and keep involve in self-stimulating behavior (CDC 2007). Severe autistic children are somehow early diagnosed as compared to mild or moderate autistics (Mandell, Maytali, Novak, & Zubritsky, 2005; Siklos & Kerns, 2007). Children with autism have complex degrees of heterogeneous symptoms which make early diagnosis complicated. Consequently, they remain un-diagnosed or somehow mis-diagnosed (Siklos & Kerns, 2007; White, Oswald, Ollendick, & Scahill, 2009). Parallel findings are been reported somewhere else in Canada (Oullette-Kuntz et al., 2009), UK (Howlin & Moore, 1997) and US (Wiggins, Baio, & Rice, 2006). So it has become contemporary focus of research to explore problems faced by families of autistic children in diagnosis of this neurobehavioral condition.

This disorder is developmental which is caused via numeral diverse familiar and unfamiliar genetic nervous dysfunctions. Ways of perception, dispensation and interpretation of info is

different among people suffering with autism (Zander 2004). Negative signs i-e fear, nervousness, uneasiness and anxiety are most common in autistic children (Bellini, 2004; White et al., 2009) which can worsen the social-problems related to ASD predominantly domestic relations and social-interactions (Reavan, et al., 2009). Procurement of an identification of autism frequently include excessive deferrals, numerous detects and some appointments to health care specialists. Subsequently, family members exhibit disappointment and frustration with their child's early detection (McMorris, Cox, Hudson, Liu, & Bebko, 2013). According to CDCP report of US autism spectrum disorder affect one in every sixty eight children in which boys are 4 times most probable to be affected than girls. Carrying an autistic child are really puzzling family members particularly when others don't realize the matters and paternities avoid moving in social events with their autistic child (Brazier, 2016). Hence this study has importance as it will highlight the gap between literatures regarding detection problems faced by families. The literature shows that autism is not only a disorder but it is collection of many others i-e epilepsy and ADHD. It's hard to early identify autism due to its diverse characteristics. Idea of ESSENCE may be beneficial in proper identification of this disorder (Fennell, Eriksson, & Gilberg, 2013). It is witnessed that autistic children's parents exhibit different mental problems stemming from pressures of parenting. These psychological pressures become visible through anxiety, depression, poor marital adjustment, hopelessness and guilt. These indicators become prominent as parents progress through five phases of emotions: sorrow refutation, annoyance, bargain, despair and accept (Morrow, 2008; Forsyth, 2011). So, it is important to find out the problems faced via family of autistic children in identification of this disorder. Autism has its unique characteristics; due to which it is complicated for family members to get early diagnosis. Delay in initial diagnosis of autism has harmful effects on educational intervention of children. So, when they are not properly intervening then parents suffer stress and remain dissatisfied (Howlin & Moore, 1997; and White et al., 2009). Hence, it's essential to investigate more regarding detection process of children with autism.

Parents of autistic children have expressed preliminary trepidations at somehow late and face thwarting with diagnostic progression. Extended deferrals among early manifestation of concern and identification were found to be related by lesser parental gratification with diagnostic procedure (Howlin & Asgharian, 1999). Experts frequently point collective topographies of worry in correct and early diagnosis which frequently increase time period to obtain identification succeeding cure for worry (Grondhuis & Aman, 2012). The demanding parental role intensifies the psychological strain on parents (Sabih & Sajid, 2008). Consequently, they undergo to loads of pressure (Gray, 2002; Sivberg, 2002; Hasting & Johnsons, 2001 and Tarahkeshwar & Pargament, 2001). Anderson, (2010) and Dixon, (2009) exposed, additionally becoming stressful, numerous parents can suffer from frustration, grief or gloominess. Prime reason as indicated by Fleischmann, (2005) originating stress is their kid's stipulation. Hence, it is important to identify the different problems faced by family of autistic children while trying to detect this disorder. Early identification of autism is essential in ensuring appropriate educational intervention and improving child's adaptableness and inclusion in community. Though, it's a complex disorder so its susceptibilities lie in heterogeneity which makes early identification tough and challenging. Detection of autism is possible in less than 18 months' time period but practically it's difficult to implement due to diverse characteristics and lack of expertise. Screening and identification of autism ought to be with collaboration of different people including family, psychologists, behavioral therapists, and social health workers but in actual fact there is no connection between these groups so parents face difficulty in diagnosis (Attwood, 1993). A study was conducted in Brazil which exhibits that heightened emotions of parents are very challenging for them. Mothers

are more prone to have stress from which predominant stress is associated to delayed diagnosis of autism and poor interaction to therapists, psychologists and relatives which caused gloominess and disappointment in their life (Gomes, Lima, Bueno, Araujo & Souza, 2015). Literature shows that parents of children with autism do over time at their workplace to full their economic needs (Zuleyha, Steven & David, 2012).

According to Autism Society of America (2005) families of children with autism face economic burdens on them in different means as they expend treasures on treatments of their children. Parents face financial strains throughout their life because it seems difficult to them to start their journey with lifetime demanding issue. Dealing with autistic children seems expensive to them from diagnosis to intervention (Sharpe & Baker 2007). So, there is dire need to analyze the effect of family's socio economic setting on early detection of children. Wide range of literature has already been explored about parental stress of autistic children. Parents of these children encounter extreme challenges in identifying and dealing with behavioral issues of these children. Presence of children with autism adversely affects the socioeconomic status of the family. Identification of this disorder place hassles on economic resources of the family (Bashir, Bashir, Lone & Ahmad, 2014). Those parents who are economically strong can move to private sessions for early identification of autism but poor people are unable to do so (King & Bearman, 2011). These conditions influence the children in educational system because the deficiency of agreement in detection of autism creates trouble in outlining inclusive education in institutes. In developing countries like Pakistan, autism has come in consideration merely in contemporary time. Families do not have sufficient knowledge about diverse developmental disorders of childhood while in developed nations, there is practice of infancy education so parents can obtain advantage and assistance but in developing nations situation is completely opposite. Subsequently, autistic children, their parents and siblings suffer a lot. There is dire need to explore the worth of early diagnosis of autism, different problems faced by family members while struggling with detection of this disorder, effect of family's socio economic setting on early detection of children and their level of satisfaction from educational sector.

MATERIALS AND METHODS

The approach of this research was qualitative and self-constructed instrument was used to fully achieve the objectives of the study.

Research design

It was qualitative and case study was done.

Target population

Parents of autistic children were target population.

Accessible population

Parents of autistic children residing in Lahore city were accessible population.

Sample

A sample of 40 parents (both mothers and fathers) of children with autism was purposively chosen from 4 institutes for special children in Lahore.

Place of work

The study was carried out at 4 institutes of Lahore i.e.

Amin Maktab, Centre for Special Education and Training (Firdous Market, Lahore)

- Rising Angels Centre for Special Children (Gulberg2, Lahore)
- Rising Sun Institute for Special Children (DHA, Lahore)
- Darul Mussarat (Waris Road, Lahore)

The reason for selecting these institutions was availability of autistic children in these institutions and the researcher's feasibility to approach.

Instrument of data collection

In depth interview technique was used which let parents to freely tell their life stories. A group of items was produced by taking help from literature to construct interview schedule which was comprised up of two sections. In first section biographic information of subjects were queried while second section was consisted on questions related to problems faced by parents of autistics in diagnosis; effect of their socioeconomic status on diagnosis and satisfaction from educational institutes. The instrument was distributed among the panel of experts. They thoroughly examined it and provide their opinion about each item. They declared that the interview schedule had content validity. There was consensus among them that the interview schedule was valid for the research study.

Pilot testing

Prior to finalize the research instrument, it was pilot tested with 5 parents of autistic children at Rising Sun Institute for Special Children. By this pilot testing; some shortcomings were found in interview schedule. Hence, the researcher made appropriate changes in the interview schedule to get more precise responses of the parents.

Method of data collection

Data was collected in 3 phases:

In the first phase, researcher downloaded the list of the institutions dealing with autistic children in Lahore city. Then phone calls were done to every institute to get information regarding autistic children. Subsequently the list of 4 institutions was short listed according to researcher's feasibility to approach and administration concern. Then the researcher went to those 4 institutions one by one to get permission to conduct research on parents having autistic children regarding their stress. Purpose of study was explained to the administration and permission was granted by the Directors. The administrative staff and teachers provided support at every step of the data collection. In the second phase, researcher approached to the respondents. With the help of administration, researcher planned the time table for interviews of parents having children with autism according to their convenience. Parents were informed about purpose of the study and were requested to visit their child's institute on given time and date for the interview.

In third phase, researcher conducted the interviews. Interviews were conducted in a separate room of every institute to interact better with the parents and to avoid the outside interruptions. The interviews were done in relaxed environment thus parents might easily retort. First five minutes of interview were used for rapport building with the parents. It approximately took 20-25 minutes for each interview but in few cases it prolonged to 25-30 minutes due to trailed off the track responses which were directed appropriately by the researcher. Researcher explained the questions whenever needed by the respondents and gave them appropriate time to reply. Three to four parents were interviewed in a day for the convenience of the administration and management.

Length of work

Data were collected in two months, starting from getting permission by the directors of the institutions and ending with the interviews of parents having children with autism conducted by the researcher.

Delimitations

- This research was delimited to only biological parents of children with autism.
- Those children were selected who were enrolled in educational centers.

Data Analysis

Data was analyzed by using Nvivo.

Results and discussion

Major findings of this study were grouped in to 3 broad regions as diagnosis of autism, socioeconomic context of family, and satisfaction of family with educational institutes.

Diagnosis of autism

It was found from this study that parents of children with autism didn't know about this disorder before their child was diagnosed with it. Only in one case parents were aware of their child's disorder and the reason behind their knowledge was presence of their elder child with the same disorder. Parents were actually confused concerning their child's inappropriate development. They did not know that where should they go and to whom they ought to consult regarding their child's behavioral issues. Resultantly, they undergone stress and got delayed diagnosis of their child. These results are consistent with the findings of studies conducted by Morales & Sellerb (2017) in Spain and by Murphy & Tierney (2009) in Dublin and Kildare. An important finding of this study which supports the previous findings by MDH (2014) was that family was the first who noticed that something is different in their child's behavior so they move to the pediatricians and it took too long to identify that their child is suffering from a disability and this time was very frustrating for them.

Interestingly, it was noticed that among family members, mothers were the first ones who became suspicious about the different traits of their children's development. These findings were consistent with a study conducted by (Stamoltzis & Michailidi, 2016). It was found in this study that in most cases it happened during nine to thirty months and average at eighteen months of a child's age. Only in two cases children were detected at early age; among them one was diagnosed at the time of birth by experts because he was suffering with other prominent disabilities; and the second child was early diagnosed because his twin brother had different behavior and mother become conscious about it. A notable result was that no importance was given to family when they expressed their concern to their immediate environment regarding their child's developmental issue. Mothers reported that when they discussed their uncertainties to health professionals/ pediatricians; they were often said that their child is appropriately developing and his/her behavior is apt to children of his/her age group. These findings are consistent with the results by Minnesota Department of Health (2014). It was noteworthy that parents of children with autism faced many problems while trying to detect their child's disorder. When mothers showed their suspiciousness to the pediatricians; they were recommended to visit specialists of different professions i.e. psychologists, audiologists and neurologists. Parents become frustrated and discouraged because of multiple tests for getting right diagnosis of their children. It was reported in this study that parents found diagnosis process very elongated and

described that they were very upset when health professionals were not giving them the same statement about their child's condition. Each professional was showing his/her different perspective to the parents regarding their child's condition and diagnosed them with different terms. Parents exhibited their frustration that how could they thought to move to early intervention for their children unless they got the correct diagnosis. A remarkable result of this study was that parents got the first diagnosis at 19 to 35 months of their child's age which contradict with the results of Stampoltzis & Michailidi (2016) as in their study children were diagnosed at 4 years of age.

Socioeconomic context of family

An important finding of this study was that having a child with autism cause extraordinary burden on the family members. Concerning the socioeconomic status of families, parents were different ranged from working to non-working. Their monthly income were Rs. 20,000/- to 60,000/-. Parents reported that having a child with autism require extra financial resources to confirm that child is receiving best possible care and economic burden of a family increase due to existence of a child with autism. Majority of the parents felt that their socio economic status effected the detection of autism as sometime their financial resources does not allow them to acquire entire probable special educational facilities for their child with autism. These results are constant with the findings of Jarbrink, Fombonne & Knapp (2003) and Broach, Potter, Heather, Prior & Mustapha (2003).

Parental satisfaction level with educational centers

In this study more than half of the parents showed their higher level of satisfaction from educational centers while others reported their lower level of satisfaction from their child's school. These findings are constant with the findings of Dillenburger, Keenan, Doherty, Byrne & Gallagher (2007).

Conclusion

It was concluded that numerous variations in processes of early detection are essential and there is dire need to implement different challenges faced by family in early diagnosis of their children and approaches of educational rehabilitation/ intervention programs. It was concluded that experts should be better specialized in prognosis of distinguish range of disabilities; they must firmly follow a standardized detection criteria and explain the procedure clearly to the families by considering their affordability.

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