
Autism and its Impact on Families in Three Autistic Centers in Khartoum State, Sudan

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Abstract:

Autism Spectrum Disorder (ASD) is typically diagnosed in children and has a wide range of symptoms, some being more severe than others. These symptoms consist of communication, socialization, behavioral and interest impairments as well as minimal social skills.

Objectives: *the aim of this study is to determine the impact and effect of autism on families of autistic children at 3 different autistic centers in Khartoum State, Sudan.*

Methodology and results: *it is a quantitative as well and qualitative study where (30) families of autistic children were*

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interviewed used a questionnaire at these centers. The data was collected and analyzed by using SSPS. It was obvious that autistic children have a negative impact on their families as half of the families with autistic child suffered lack of sleep, one third had family problems related to the parent relationship, one mother stopped working to care her autistic child and (4) reported no change.

Recommendations: *it is recommended to establish national awareness campaigns in all the available media about autism as well as opening autistic centers to support these needy children and their families.*

Key words: autism, impact on families, Sudan.

INTRODUCTION

Autism Spectrum Disorder (ASD) is typically diagnosed in children and has a wide range of symptoms, some being more severe than others. These symptoms consist of communication, socialization, behavioral and interest impairments as well as minimal social skills (Weiss & Lunsky, 2011). Due to these symptoms, a child with ASD may have trouble relating to peers and forming meaningful relationship. Social workers may encounter autistic children who express restricted and repetitive motor mannerisms in order to self-stimulate such as rocking, banging on objects, biting themselves and spinning (Mays, Beal Alvarez & Jolivette, 2011) . Finding from recent study indicated that ASD is affecting 1 in 110 children with growing rate of 10% to 17% per year (Meadan et al, 2010).

The precise etiological factors which predispose a child to ASDs are not fully understood. Individual with an ASD often have a positive family history with the same. In addition, there is a positive family history of autoimmune and/or psychiatric disorders. Theories purporting environmental etiologies have been raised including prenatal and perinatal factors, diet and

childhood vaccinations. However, scientific evidence has either been inconclusive or in case of the MMR vaccine, has excluded them as likely etiologies (L. Mercer et al, 2006).

The diagnosis of autism is mainly based on the presence of two major aforementioned symptoms: social-communication deficits, and restricted and repetitive interests/behaviors. These symptoms must be shown from early childhood of individuals with ASD. But autism is also associated with various comorbidities, including sensory and motor abnormalities, sleep disturbance, epilepsy, attention deficit/hyperactivity disorder (ADHD)-like hyperactivity, intellectual disability, and mood disorders such as anxiety and aggression (Hyejung Won, Won Mah and Eunjoon Kim, 2013).

Parents whose child is diagnosed with ASD experience difficulties and it changes the dynamics of the family in that everyday activities need to be modified and the child with ASD needs extra attention from the parents. Upon hearing their child's diagnosis, one study found that in parents; 52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise and 10% felt self-blame (Banach, M. et al, 2010). Stressors from an ASD diagnosis can cause a strain on parent's marital relationship, increase financial burdens and result in parents socially isolating themselves from others (Naseef, R., 1989). A study indicated siblings ages 7-20 who have brother/sister diagnosed with ASD mentioned feelings of embarrassment. Another study confirmed these results with siblings reporting the negative aspect of having a brother/sister with autism is feeling embarrassment (Orsmond, G.I. & Seltzer, M., 2007).

METHODOLOGY AND RESULTS

The study was conducted in Khartoum State in 2013 where 30 caregivers of 30 autistic children (18 mothers/ 7 fathers/ 5 others) in three different autism centers in Khartoum State

(Khartoum, Khartoum North and Omdurman cities) were interviewed and answered the questionnaire prepared. The type of study was quantitative and qualitative. The data was collected and analyzed. The male: female ratio was 2:1. There was one child less than one year (3.3%), 17 children 1-3 years (56.6%) and 12 children above 3 years (40%). Three of them were the only child in the family, while the others with siblings. 16 children were diagnosed for more than 2 years ago (53%), 11 diagnosed for less than 2 years (37%) and 3 children were diagnosed for less than 1 year (10%). 60% of the parents of the autistic children (18) were aged 20 – 40 years, 36.66% were aged 41 – 60 years (11) and only 3.33% aged above 61 years (1) (**Fig. 1**). The family's reactions after the diagnosis of autism is varied where 50% of families (15) were shocked after the diagnosis, 23% (7) were normal and 27% (8) were denial (**Table 1**). The majority of families (21) had no any previous background or knowledge of autism where 30% (9) had some knowledge. Only 23% of families did not isolate the autistic child from other siblings, where 67% (20) isolate autistic child some times and 10% usually do (**Table 2**). It was found that 60% (18) of families educated their-self about autism from their doctors, 27% (8) from media and 13% (4) from relatives. The vast majority of families with autistic child suffered from the autistic child's behavior outside the house as 43% (13) usually suffer, 40% (12) sometimes suffer and 17% (5) did not suffer at all (**Table 3**). The vast majority of families with autistic child were prevented to go out by their autistic children as 60% (18) for sometimes, 13% (4) always and 27% (8) had no effect. 23% (7) of families always take their autistic children to occasions outside the house, where 50% (15) sometimes and 27% (8) never take their autistic children on occasions outside the house. All families needed more expenditure for autistic children compared to other siblings. Half of the families (15) with autistic child suffered lack of sleep, one third (10) had family

problems related to the parent relationship, one mother stopped working to care her autistic child and 4 (13%) reported no change (**Fig. 2**). The majority of children (60%) showed some improvement since they joined the autistic centers, one third showed great improvement and only 2 (7%) showed no improvement.

Fig. (1): The age of parents of autistic children.

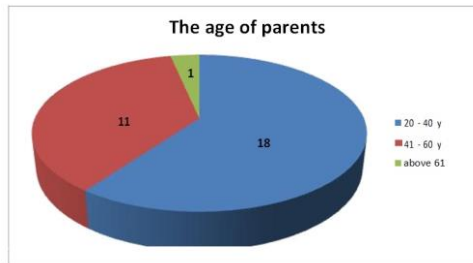


Fig. (2) Showed the impact of autistic child on his family.

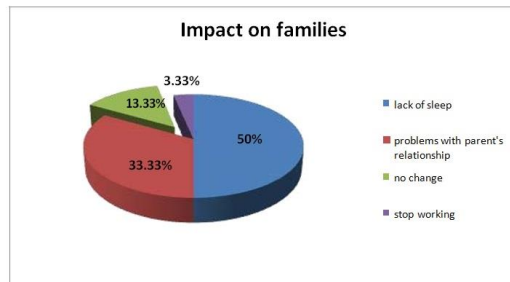


Table (1) showed the reaction of family when told the diagnosis.

| Reaction | No. | Percentage |
|--------------|-----------|-------------|
| Shock | 15 | 50% |
| Normal | 7 | 23% |
| Denial | 8 | 27% |
| Total | 30 | 100% |

Table (2) showed the Isolation of autistic child from other siblings

| Isolation | No. | Percentage |
|--------------------|-----|------------|
| Always isolated | 7 | 23% |
| Usually isolated | 3 | 10% |
| Sometimes isolated | 20 | 67% |
| Total | 30 | 100% |

Table (3) showed the reaction of family to autistic behavior.

| Reaction | No. | Percentage |
|------------------|-----|------------|
| Usually suffer | 13 | 43% |
| Sometimes suffer | 12 | 40% |
| Not suffer | 5 | 17% |
| Total | 30 | 100% |

DISCUSSION:

The purpose of this research is to examine ASD and its impacts on families. Despite the increased prevalence, awareness, and diagnostic Improvements over the last 20 years much of ASD remains a mystery. In Sudan no study showed prevalence of ASD.

In our study the age of Autistic children less than one year was one child (3.3 %) , 17 children 1 -3 years (56.6%) and 12 above 3 years (40%).

We found that males were more predominated than females as the ratio was 2:1. In other study prevalence males were 4.5 times more affected than females (Fombonne, E. 2008). In our study 16 children were diagnosed for more than 2 years ago (53%) , 11 diagnosed for less than 2 years (37%) and 3 children were diagnosed for 1 year (10). Yet in one study parents typically encountered a delay of 3.5 years between first contacting a healthcare professional and receiving a formal diagnosis of ASD for their child (Laura Crane et al 2015).

We found that parents reacted differently as 50 % are shocked, 23% comfortable and 8% denial while Banach et al found that upon hearing their child's diagnosis, 52% of parent felt relieved, 43% felt grief and loss, 29% felt shock or surprise,

and 10% felt self-blame. This difference could be influenced by different education and culture (Banach et al., 2010). As stated by Gibson, L. "People experience the stages of grief differently because there is no sequential order in which each stage should occur and because some people may not experience some of the stages" (Gibson, L. 2004). There are few things in life scarier than having a child with any kind of special need, and autism is one of the scariest disabilities, because the diagnosis tells you nothing about a child's prognosis. No one can honestly say to you "We know exactly what your child will be like when he's twenty (Koegel, L. & La Zebnik, C., 2004).

In this study half of the families 50% (15) suffering from lack of sleep , 33% (10) of family problems related to parents relationship, one mother 3% stop working and 4 (13%) and in 4 (13%) had a normal life. Davis, C. et al found that parenting children with developmental disabilities is associated with impaired mental health, higher levels of stress, a sense of devaluation and blame, and impaired physical functioning such as tiredness or exhaustion. After the initial diagnosis of ASD parents must learn how to cope with all the changes that are occurring within their family (Davis, C. et al, 2008).

It was obvious from our study that the vast majority of families with Autistic child suffered from the autistic child behavior outside the house as 43% (13) usually suffer, 40% (12) sometimes suffer and 17% (5) did not suffer. The vast majority of families with autistic child were prevented to go out by their autistic children as 60% (18) for sometimes, 13% (4) always and 27% (8) had effect. 23% (7) of families always take their autistic children to occasion outside the house, where 50% (15) sometimes 27%(8) never take their autistic child on occasion outside the house. It was found that parents have to rearrange their daily routines to accommodate their child with autism as the child is unpredictable and often unable to regulate their behavior. Parents reported that routines were

much easier to follow in familiar spaces such as their own home, however more difficult in familiar places such as another relatives home or out in the community (Schaaf, R. C., et al., 2011).

In our study 67% of families sometimes isolate Autistic Children from others (not permanent) while in 10 % isolate them permanently. In another study by Ross & Cuskelly it was found that 40% of siblings reported by their mothers were experienced adjustment problems and major depressive disorders (Ross & Cuskelly 2006). Furthermore, all families needed more expenditure for autistic children compared to other Siblings and this is same as other studies indicated for example Naseef, R. stated that; stressors from an ASD diagnosis can cause a strain on parent's marital relationship, increase financial burdens and result in parents socially isolating themselves from others (Naseef, R. 1989).

CONCLUSION AND RECOMMENDATIONS:

Autism affects families enormously. They are challenged physically, emotionally and financially. Every day activity that most of us take for granted has to be carefully planned and executed. It was obvious that autistic children have a negative impact on their families as the families with autistic child suffered lack of sleep, had family problems related to the parent relationship, difficulty planning social occasions, siblings reporting embarrassment of having a brother/sister with autism and stopped working to care her autistic child.

It is recommended to establish national awareness campaigns in all the available media about autism as well as opening governmental and private autistic centers to take care and give enough support to these needy children and their families.

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