

Parents' Attitudes Towards Having Child with Autism and Related Intervention Programs: A Literature Review

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ABSTRACT

Background: Issues related to the caring process for children with autism is considered significantly challenging for their parents because of disease severity and its complications, its progressing and developmental complications and persistent comorbidities, as well as the vast difficulties of healthcare services in achieving the different needs of children and their parents. The main aim of this paper is to highlight the parents' attitudes toward having a child with autism and related Intervention programs within the context of previous studies.

Methods: Search was conducted for the studies which have been published between 2008 and 2019 in English language using different electronic databases such as PubMed, JSTOR, MEDLINE, CINAHL, Scopus, Cochrane Collaboration, EMBASE, Science Direct, ASSIA, and Web of Science. Keywords used in the search included: autism, parents, autistics disorder, attitudes, father, mother, disability.

Conclusion: Parents of children with autism have a huge caregiving burden, subjective distress, and symptoms of depression and anxiety. There should be a design of effective interventions aimed at reducing the burden among the parents of children with autism.

Keywords: Parents; Attitude; Child; Autism

Introduction

Autistic disorder is among the world's 20 most disabling childhood conditions, accounting for more than 58 Disability-Adjusted Life Years (DALYs) per 100,000 population and other Autism Spectrum Disorders (ASDs) for 53 DALYs per 100,000 [1]. Autism disorder is an

acute neurodevelopmental defect and relates to ASDs [2]. The most notable phenotypic and clinical features of autism are broad impairments in behavioral and social communication, impaired language or speech inability, and a strong tendency towards repetitive and stereotypical behavioral patterns [3].

Received: 21-Mar-2022,
Manuscript No. ijocs-22-57904;

Editor assigned: 23-Mar-2022,
PreQC No. ijocs-22-57904(PQ);

Reviewed: 02-April-2022,
QC No. ijocs-22-57904(Q);

Revised: 07-April-2022,
Manuscript No. ijocs-22-57904(R);

Published: 15-April-2022,
10.37532/1753-0431.2022.16(4).236

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Parents who have an autistic child are considered to have the same disorder, which is a pervasive and multifaceted disorder. Meeting the high care standards of affected children needs a lot of time, patience, and effort [4]. Furthermore, looking after children with autism is demanding for parents because of disease chronicity and severity, extensive developmental and somatic diseases, and health services difficulties in making the intensive and integrated interventions that people with autism need [5].

The tremendous outcomes of having an autistic child are evident in both the breadth and severity of parental domains that seem to be affected [6]. The impact of owning a child with autism disorder is susceptible to influence parents in many ways, involving increasing problems and challenges in marital relationships, high parental stress, increased levels of mental health concerns, emotions of depression and anxiety and perception of isolation at home, because they fear taking their children out in public and reducing the quality of family life [7,8].

Significance of the Problem

The prevalence of autistic disorder reaches 62/10,000 in the general population worldwide [4]. Parents of autistic children confront challenges that expose them to increased levels of depression, stress, and other negative psychological consequences. This disease demonstrates additional stress related to the child's communication challenges, social isolation, odd behaviors, self-care difficulties, and a lack of attention and understanding of society. In addition, the obstacles facing parents of children with autism may be serious and critical because their children's disability and social complications require great efforts to transact with [9].

In Saudi Arabia, previous studies revealed that 59.9% of families claimed that their autistic child negatively affected their lifestyle socially and economically, 60.4% reported that their family relationships have been affected and 53.5% reported that the siblings' quality of life was affected, while parenteral distress was 62.6% [10].

Most significantly, parental aspects that may affect the long-term consequences and the continuation of treatment are often overlooked.

Parental factors, such as mental health conditions, stress levels, and marital quality, could influence the child's responses to intervention [11]. All these factors can put the parents at social and psychological stress, which in turn they cannot achieve the normal tasks at home, and they cannot achieve other tasks for their developing children such as raising, socialization, and education and learning. There are no researches that take into account the obstacles that parents of children with autism confront in the Kingdom of Saudi Arabia, so this study was performed to fulfill this gap to shed light on these obstacles and present them as key indicators to find effective solutions for them and their families.

Aim of this Paper

The main objective of this paper is to elucidate the attitudes of parents who have children with autism against the background of preceding studies.

Literature Search

All researches conducted between 2008 and 2020 were done in English by electronic databases: Cochrane Collaboration, MEDLINE, CINAHL, EMBASE, Science Direct, ASSIA, Web of Science, Scopus, PubMed, and JSTOR. Keywords used in the research included: autism, fathers, autistic disorder, attitudes, father, mother, and disability.

Definition

Autism includes a variety of childhood-onset and lifelong neurodevelopmental disorders with an enduring impact on multiple domains of functioning, characterized by persistent deficits in social interaction, communication, behavioral repetition [12].

Literature Review

■ Parents' attitudes toward autism

Raising a child with autism involves an increase in the number of parental responsibilities, or even leads to a change in parents' plans for their lives, which undoubtedly affects their attitude towards a child, relationships between spouses, and their physical and mental health. Tokarewicz, et al. demonstrate a study to evaluate the parents' attitudes and perception towards

children with ASD in Poland [13]. The study results revealed that some parents were diagnosed with attitudes that were not desirable in the process of childrearing, which in turn may have a negative influence on the upbringing and the development of a child. Relevant research results were made available to the parents participating in the study to help them take corrective actions because the best interest of a child should be a priority for its parents.

Additionally, Picardi, et al. demonstrate a study to determine the subjective and objective load of autism on parents, promoting understanding of the interaction among parental burden, parents' resources and strategies for coping, and child characteristics [4]. The results of the study showed that children with autistic parents revealed an increase in subjective and subjective burden, more persistent psychological distress, and less social support. Also, mothers showed a higher personal burden than fathers. The structural correlation design showed that the most positive and negative indicators of objective and subjective load were autism symptom severity and social support, respectively.

Moreover, Vohra, et al. reported that the impact of having an autistic child on parents and families, such as the disorder itself, is pervasive and multifaceted. Meeting the top care standards of ASD children takes a lot of time, patience, and effort [5]. Caring for ASD children is difficult because of the criticality and crisis of autism, their developmental and physical ailments, and the challenges of health services in making the integrated and intensive interventions widely needed by people with autism. The tremendous impact of having an autistic child is evident in both the intensity and breadth of parental domains that seem to be affected [6].

On the other hand, a meta-analysis was performed by Ooi, et al. to investigate the attitudes and perceptions of parents who have autistic children to acquire insight into parents' adaptations and beliefs regarding autism, their family experiences, in addition to their perceptions of education and health services [14]. The results of the study revealed that there are four main axes that emerged from their study related to parents' perception, feelings, and experiences expressed by parents in general, namely: The Parent, effect of autism on the family, effect of autism on the social aspect, and educational and health services.

The results concluded that parents who have a child with autism face significant challenges in the care of their child, which in turn affect the parents in terms of stress and adjustment.

In addition, Obeid (2012) performed a study to examine the parents' perception and attitude of their autistic child, meeting the initial needs of the autistic child, and to shed light on the parents' attitudes towards the autistic child [15]. The impact of autism on social acceptance, knowledge of the effect of the gender of each parent, and the educational level of the parents. The results of the study showed that the highest average for the component stating, "I take better care of my autistic child and feed him everything I train on" was the lowest average for the component stating "I don't care." For my autistic child if he gets sick. The results also revealed that the mother's attitudes were more negative than that of the father, and concerning the educational qualifications of the parents, it had no significance, and the parents' attitude towards the female was more negative, and the parents were more negative. Attitudes toward a female: The mother and father are not affected by the presence of another child with a disability.

■ Early intervention for autism

As stated by Patterson and Smith (2011), initial intervention is significant to assure that children with special requirements receive additional assistance during the adequate stages of life. Programs should be devised to conduct services and interventions to support children with disabilities and their relatives [16]. Children with disabilities, involving those with ASD, are presently having high-quality intervention and educational approaches in Saudi Arabia during a less limited environment. Although, the trials and abilities which guided towards these services in the country are prominent, more initiatives are required to raise the quality of service, to match the quality of services conducted to children in European countries [17].

The different initial intervention and treatment models may permit the provision of some suggestions that can be considered in the early intervention for autism [18]. There appears to be a high convergence of developmental and behavioral styles and study results indicate that the concentration of early interventions for ASD is directed towards skills development deemed

“central” such as shared imitation, attention, symbolic play, communication, cognitive abilities, organization, and attention [19].

Second, the literature suggests some guidelines for effective treatments such as:

- Initiating as early as possible;
- Reducing the gap between diagnosis and management;
- Apply at least 3 hours-4 hours of therapy per day;
- Focus on family participation;
- Choose from behavioral/developmental approaches relying on the child’s history and/or management response;
- Promoting spontaneous contact.
- Enhancing skills through playing with identical peers;
- Completion of acquiring new generalization, skills, and maintenance in natural circumstances and
- Support for positive practices rather than simply addressing difficult behavior [20]

Chaaya, et al. conducted one cross-sectional research to examine early intervention services as observed by parents’ view of autistic children in Egypt and Saudi Arabia [21]. The findings of the study indicated that there is a limited level of parents’ awareness of early intervention approaches and a deficiency of early intervention services conducted to children with autism in Egypt and Saudi Arabia and that there is an immediate requirement for additional of these services. Research has revealed that the time between birth and age of 36 months is a sensitive growth period in a baby’s life. These months present a window of chance that will not be obtainable later. Early intervention approaches reduce and, in some cases, avoid developmental delays in infants and young children with disabilities. They can reduce the requirement for special teaching and regarded services when a child enters school, and be more reliable in own. The results of the current study also reported that Saudi and Egyptian parents do not know the significance of early intervention for their autistic children.

Al-Oufi (2011) revealed in his research that early intervention is involving several disciplines

service, where more than one intervention approach can be applied to the child and family as needed, and the multidisciplinary character aims to determine the range of capabilities regarding autism through the provision of mental services, diagnosis, evaluation, transportation counseling, and training Family, speech therapy, occupational therapy, nutritional therapy, pharmacotherapy, practice modification, and play therapy [22,23].

Another study was done by Forment-Dasca to review two intervention models specifically designed for working with persons with ASD. The review first examines an early intervention model, the Early Start Denver Model, which consists of a checklist for children with ASD aged from 12 to 48 months, based on their progress. The study concluded that in the absence of further results from scientific evidence-based practice regarding the two models reviewed here, it can be concluded that there is no single standardized model and that children with difficulties in joint attention and imitation need to be referred at an early stage, as well as working together with the families. therefore, for effective intervention, it is essential to consider evidence-based practice and for the therapist to have in-depth knowledge, respect, and understanding of children with autism and their families [23].

Moreover, a qualitative mixed-method case study was conducted to raise awareness about Autism disorder in Africa and create dialogue about probable intervention strategies for Autism disorder in low-resource institutions. The study investigated that four initial interventions were discovered to be beneficial in enhancing the growth of an autistic individual. he is called; Speech therapy, creative endeavors, animals (human-animal interaction), and counseling [24].

Importantly, cross-sectional research was performed by Alotaibi and Al-Maliki (2016) in Saudi Arabia to analyze parents’ perceptions and attitudes of initial interventions and correlated services for autistic children in Saudi Arabia. Study results reported that parents have different perceptions of early interventions and regarded services. Nevertheless, they appear to accept that these services are significant in helping their children. Accordingly, parents suggested that the government require to heighten these services by conducting more centers for children with autism in the Kingdom of Saudi Arabia, applying

more specialists to handle children with autism, promoting participation in regular schools, and conducting more data about the intervention [17].

Recommendations

Suggestions for this problem based on what has been mentioned include re-design of important and effective interventions toward decreasing this burden, which produce significant diseases among parents. In addition, the parents who have children with autism can get the benefit from interventions that are designed to enhance and improve the process of their coping ability thereby cognitive-behavioral approaches. These approaches can provide good benefits in promoting the parents' acceptance of negative emotions due to their feelings and help them in pursuing and identifying goals and personal values.

Moreover, health professionals including nurses who are working with parents with children of autism should be aware and alert about different signs and symptoms among parents such as depression and anxiety, they should work to recognize these symptoms and help them in managing professionally.

Future research studies should be done by different researchers including nurses to identify more about the parents' attitudes about autism and reveal more about hidden sides in parents through conducting an in-details interview with families and parents.

Limitations

According to the available literature in the context of KSA, the parents of autism are more likely to have the same disorders (at least such tendency). Thus, the parents' health/mental condition might be partly due to their inherent mental/psychological condition. Naturally, how much are due to this inherent condition and how much are due to having children of autism disorders are difficult to discern. Please state this meaning around the last of the discussion.

Conclusion

Based on what have been mentioned in the preceded results, parents of autistic children have a big and significant burden upon them, they have major subjective distress as well as huge signs and symptoms of concern and depression.

References

1. Baxter AJ, Brugha TS, Erskine HE, et al. The epidemiology and global burden of autism spectrum disorders. *Psychol Med* 45(3), 601-613 (2015).
2. Paris P. Autism Spectrum Disorders: Phenotypes, Mechanisms and Treatments. Switzerland: 2015.
3. P, Kamali E, Mousavi SM, et al. Environmental factors influencing the risk of autism. *Journal of research in medical sciences. J Isfahan Uni Med Sci* 22, (2017).
4. Picardi A, Gigantesco A, Tarolla E, et al. Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison Groups. *Clin Prac Epidemiol Mental Health* 14, 143-176 (2018).
5. Vohra R, Madhavan S, Sambamoorthi U, et al. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 18(7), 815-826 (2014).
6. Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clin Child Fam Psychol Rev* 15(3), 247-277 (2012).
7. Factor RS, Swain DM, Scarpa A. Child autism spectrum disorder traits and parenting stress: The utility of using a physiological measure of parental stress. *J Autism Dev Disord* 48(4), 1081-1091 (2018).
8. Broady TR, Stoyles GJ, Morse C. Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health Soc Care Community* 25, 224-233 (2017).
9. Alshaigi K, Albraheem R, Alsaleem K, et al. Stigmatization among Parents of Autism Spectrum Disorder Children in Riyadh, Saudi Arabia. *J Pediatr Adolesc Med* 7(3), 140-146 (2019).
10. Al-Zaalab MA, Alasmari AH, Al malki HH, et al. Characteristics of Autism Spectrum Disorder among Saudi Children and its Impact on their Families. *Neurologist* 31, 13-16 (2015).
11. Chu SY, Mohd Normal SN, McConnell GE, et al. Challenges faced by parents of children with autism spectrum disorder in Malaysia. *Speech, Lang Hear* 23(4), 221-231 (2020).
12. MJ, Grossman D, Christensen LW. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. Arlington, VA: American Psychiatric Publishing. 2013.
13. Tokarewicz E, Nazarukl S, Klim Klimaszewska A. Parents' attitudes towards children with autism spectrum disorder. Their awareness and impact on child development. practical aspects of research results. 10th Annual Int Confer Edu, Res Innovat, Seville, Spain, 4061-4069 (2017).
14. Ooi K, Ong YS, Jacob SA, et al. A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment* Dovepress 745-762 (2016).
15. Obaid MS. Parental attitudes towards autistic child. *Euro J Soc Sci* 31, 103-114 (2012).
16. Patterson SY and Smith V. The experience of parents of toddlers diagnosed with autism spectrum disorder in the more than words parent education program. *Infants Young Child* 24(4), 329-343 (2011).
17. Alotaibi F and Almalki N. Saudi Teachers' Perceptions of ICT Implementation for Student with Autism Spectrum Disorder at Mainstream Schools. *J Edu Pract* 7(5), 116-124 (2016).
18. Baduel S, Guillon Q, Afzali MH et al. The French version of the Modified-Checklist for Autism in Toddlers (M-CHAT): a validation study on a French sample of 24 month-old children. *J Autism Develop Disor* 47(2), 297-304 (2017).
19. Matta SM, Hill Yardin EL and Crack PJ. The influence of neuroinflammation in Autism Spectrum Disorder. *Brain, Behav, Immun* 79, 75-90 (2019).
20. Magán Maganto M, Bejarano Martín Á, Fernández Alvarez C. Early detection and intervention of ASD: A European overview. *Brain Sci* 7(12), 159 (2017).
21. Chaaya M, Saab D, Maalouf FT, et al. Prevalence of autism spectrum disorder in nurseries in Lebanon: a cross sectional study. *J Autism Develop Disor* 46(2), 514-522 (2016).
22. Al Awfi FMS. Styles of Communication inside Family and its Relation with the Self-Affirmation of the Sixth Grade Primary School in Jeddah. *J Edu Psychol Sci* 3(2), 123-195 (2019).
23. Forment Dasca C. Models for intervention in autism spectrum disorders: Denver and SCERTS. *Revista de Neurologia* 64 (s01), S33-S37 (2017).
24. Wannenburg N and Van Niekerk R. Early diagnosis and intervention for autism spectrum disorder in Africa: insights from a case study. *Afr Health Sci* 18(1), 137-146 (2018).