

Mothers of Autistic Children Insisting Needs

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ABSTRACT

Objective: To identify the needs of those mothers to put the corner stone in diagnosing mothers of autistic children needs and accomplish them.

Study Design: A cross sectional descriptive study

Place and Duration of Study: This study was conducted at the different places in Nasiriyah city, Thi Qar governorate, Iraq from 1st September 2024 to 1st December 2024.

Methods: The needs questionnaire scale" it is based on previous studies and it was divided into two main parts (the first part contains socio-demographic information, and the second part included questions about the needs of mothers with autistic children). Study instrument contains eleven questions about sociodemographic information and they are, educational level of the mother, the economic status, the age of the mother, the marital status of the mother, the sex of the child, his age, his arrangement among his siblings, the number of all children in the family, The degree of autism disability, the current place of education for the child, and are there any disabilities associated with autism. Part two which is the needs of mothers contains 26 questions to assess the needs of those mothers.

Results: There are high, financial needs with mean score 4.4429, high Knowledge and training needs with mean score 4.5375, high societal needs with mean score 4.4557, and high social needs with mean score 4.2850.

Conclusion: Mothers with autistic children have high needs in order from the top are, financial needs, knowledge and training needs, societal needs, and social needs.

Key Words: Autism spectrum disorder, Needs assessment, Mothers

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INTRODUCTION

Autism Spectrum Disorders (ASD) are consistently life-long neurodevelopmental disorders characterized by impairments in behavior, communication social interaction accompanied with restricted and repetitive interest and possible sensory disturbances cases taking origin from early childhood.¹ The issue provided by current epidemiological investigations in the preceding 20 years is a rise community incidence of ASD.² This is a big group of children, because there are many subjects that suffer from chronic diseases. Forty percent of the world's children are infected by one or more diseases and therefore require special protection (statistics).

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In them, especially disorders that include children's mental and psychological area become of the first important shall be stated autism is one from a lot of these disorder.³ Children with Autism spectrum disorder (ASD) require whole-care treatment and routine therapy plan for which it is important.⁴

Families of children with ASD are up against more expensive needs, which in any case require additional financial support from their parents. But they do require help from professionals, such as therapists and psychologists to perform developmental or therapeutic examinations of their children, in case these care givers may not have the professional training needed.⁵

Identifying the significant and unmet support needs of parents is important in reducing parenting stress, and potentially improving psychological well-being. Parental Psychological well-being research has found that parental satisfaction with supports is very strongly associated with the behavior of staff working alongside parents.⁶

For mothers of children with autism symptoms studies are presented where the absence of perceived social support has been identified as above all other factors in mental health issues.⁷ It is these mothers that give everything to make the structure and process of family as average, ordinary or automatic offering all their capacity into this care business. They practice to look good and mask the pain. Several physical (insomnia, tiredness, headache, back pain and anorexia, dyspepsia

and palpitations) as well emotional problems in the lives of these mothers have been observed.^{8,9}

The higher cost of ASD-related special education and treatment that will require a general need to supplement income throughout the course of life, are all important factors in increasing parental fatigue, especially for low-income households.¹⁰ For parents of children with ASD, the five most frequently rated unmet needs were: financial support, my child having friends, help dealing with concerns about my child's future, ongoing services, and my child's other friends feeling comfortable around my child. Parents' unmet needs were also examined in a recent Canadian study of 101 parents of children with ASD aged 6-13 years.¹¹ Two of their most frequently identified unmet needs were similar to those reported by Kerns and Siklos including social inclusion for their child and services provided on an ongoing basis rather than only in times of crisis.¹²

As far as we know, there are limited studies from Iraq addressing the needs of families for children with ASD. Previous studies have found that mothers of children with ASD report high psychological distress and caregiver burden.¹³

METHODS

This cross sectional descriptive study was conducted at different places in Nasiriyah city, Thi Qar governorate, Iraq from 1st September 2024 to 1st December 2024 vide letter No. 02 dated 8-8-2024. Non-probability (accidental sampling) of 165 mothers of autistic children in Al-Nasiriyah city, Iraq was included.

The needs questionnaire scale" it is based on previous studies and it was divided into two main parts (the first part contains socio-demographic information, and the second part included questions about the needs of mothers with autistic children). Study instrument contains eleven questions about sociodemographic information and they are, educational level of the mother, the economic status, the age of the mother, the marital status of the mother, the sex of the child, his age, his arrangement among his siblings, the number of all children in the family, The degree of autism disability, the current place of education for the child, and are there any disabilities associated with autism. Part two which is the needs of mothers contains 26 questions to assess the needs of those mothers.

Scoring and rating include five points Likert scale applied for rating mother's needs (happens little, happens a lot, never happened). The data were analyzed with descriptive statistics, levels of need and psychological problems are mild (mean less than 2.333), moderate (mean from 2.34 to 3.67), and high levels (mean between 3.68 and 5). Significance was set at $p < 0.05$ and CI confidence interval estimated at the 95%

level. Study instrument was checked for its validity and reliability. Sensitivity and specificity of the instrument also checked. The data was entered analyzed through SPSS-25.

RESULTS

The demographic information of the participants is shown in Table 1. The mothers need assessment for each domain and total needs is shown in Table 2. Relationship between all the needs of mothers is shown in Table 3.

Table No. 1: Demographic data of 165 participant in the study (n=165)

Variable	No.	%
Child gender		
Male	126	76.4
Female	39	23.6
Child age		
4	37	22.4
5	58	35.2
6	39	23.6
7	17	10.3
8	14	8.5
Mothers age		
25-35	138	83.6
36-45	27	16.4
Child order among children		
1	69	41.8
2	41	24.8
3	55	33.3
Disability level		
Sever	14	8.5
Moderate	87	52.7
Mild	64	38.8
Economic status		
Rather enough	71	43.0
Enough	94	57.0
Educational place for autistic child		
Governmental center	17	10.3
Special center	92	55.8
Governmental school	14	8.5
Home	42	25.5
Number of family members		
1	13	7.9
2	18	10.9
3	51	30.9
4	56	33.9
5	27	16.4
Mother educational level		
Illiterate	10	6.1
Primary school	24	14.5
Secondary school	40	24.3
Bachelor's degree and above	91	55.1

Table No. 2: Mothers need assessment for each domain and total needs

	Mean	Std. Deviation	Assessment	Rank
Financial needs	4.4429	0.48305	High	3
Knowledge and training needs	4.5375	0.45224	High	1
Societal needs	4.4557	0.38020	High	2
Social needs	4.2850	0.47957	High	4
Total	4.4303	0.34552	High	

Mild (mean less than 2.333), Moderate (mean between 2.34 and 3.67) High (mean between 3.68 and 5)

Table No. 3: Relationship between all the needs of mothers

Domains	Statistical parameters	Financial needs	Knowledge and training needs	Societal needs	Social needs
Financial needs	Pearson Correlation	1	0.861**	0.788**	0.211
	Sig. (2-tailed)		0.000	0.000	0.540
Knowledge and training needs	Pearson Correlation	0.861**	1	0.428*	0.520**
	Sig. (2-tailed)	0.000		0.017	0.002
Societal needs	Pearson Correlation	0.788**	0.428*	1	0.611**
	Sig. (2-tailed)	0.000	0.017		0.000
Social needs	Pearson Correlation	0.211	0.520**	0.611**	1
	Sig. (2-tailed)	0.540	0.002	0.000	

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed).

DISCUSSION

In fact, all means of the needs are high and even the mean of each item alone, which indicate high needs among mothers and the general mean is (4.4303) which reflecting the high level of needs among mothers, Knowledge and training needs is the highest need among mothers with mean about (4.5375), second comes the societal needs with mean about (4.4557), third needs were financial needs with mean (4.4429), and the fourth needs are social needs with mean (4.2850) which is the last rank.

In fact, to explain these results, it is conveyance that mothers of autistic children have high level of needs because when the child is diagnosed with autism many difficulties will arise, like behavioral problems, the difficult of care as the child needs special care, community acceptance which put more burden on both parents, and high level of stress, especially the mothers as they are the first source of care for the children.¹⁴ Knowledge and training needs come in the first rank is reasonable, as the mothers of the autistic children sees that with autism the biggest problem with their children is learning and development, and it is very difficult to deal with them, unless by the help of special specialist or special center, as the autistic child have problems with communication, learning, eating and even how other family could deal with him in right way, as it is clear from the table 3, highest needs were the needs of mother to learn how to deal with child tantrums, need to learn the child clothing eating and drinking, and the need to learn him social and communication skills, all these needs are fall in knowledge and training needs.¹⁵ Second rank is societal needs, in fact, societal needs can be linked to knowledge and training needs as the mother in

this domain needs the community and governmental support to provide and help her in the special needs of her autistic child with training programs and special centers, as the three highest needs in this domain respectively are, the need of advisory centers or programs to help in decrease stress, the need for special centers and programs to provide entertainment for mothers, and the third need is the need of special centers and programs for educate rehabilitates the autistic child. These needs are high in nature as the mothers need the support from any available services, which it was governmental or special, because of the high burden of raising autistic child.¹⁶ Third ranked need is the financial needs, these needs came in the third place may be because the enough economic status of the participants in table 1, despite this the financial needs were high and they come in the third place, as the medical needs of the autistic child are high and there are a lot of other needs, they all put high burden on mothers especially, needs for special centers with programs, training, and special care they all of high cost.¹⁷ Fourth ranked need is the need for social support which it is high need too, mothers of autistic children need highest available support specially form family, relatives, and neighborhoods as the highest two needs, this domain rank were the fourth may be because mothers need specialist to not only care for their children but also to treat them and made them better.¹⁸ In fact, the order of the needs order is not agreed with¹⁹ which he has societal needs in the first order, knowledge and training needs in the second order, social in the third order and financial needs in the fourth order, may that belong to the differences in culture, social structure and the big differences is in the demographic variables, which created differences in needs. The study of Al-

Kafash is agree which have mentioned that knowledge and training needs are in the first rank.²⁰ Second question to answer is the relationship between those needs, there is a strong relationship between financial needs and knowledge and training needs, as the knowledge and training need money and financial support to achieve knowledge and training needs.²¹ Also, there is a highly relationship between financial and social needs, there are many aspects could link financial needs to social needs, like social inclusion aspects, the higher financial state the easier forming relationships and more friends as they be able to go to special centers and more entertainment places, or even worse which it is the suffering of mothers from abandonment as they have autistic child, first one to leave is the father which made more social and financial burden on mothers in, furthermore, researches have mentioned that women who are alone tend to leave their work, change their work, or modify their work to meet care needs of their autistic children which create more financial needs because of the social needs.^{21,22}

In addition, there is significant relationship between knowledge and training and societal needs, knowledge and training are highly linked theoretically as the societal include special centers with special programs and training for the children and their mothers to care for the children and rehabilitates them.¹⁶

Furthermore, another relationship is between knowledge and training needs and social needs. Actually, these needs are closely connected, as the knowledge and training are for enhance social interaction and social interaction would make better knowledge and successful training.²³

Final relationship is between social and societal needs, there is high significant relationship between both of them. In fact, societal needs term is interchangeable word to social needs term also mean community needs as it include pointed sheared with knowledge and training needs, in other words societal needs are the basic needs of the mothers and children, if these needs wont met, mothers and children will be socially disabled and inactive.^{24,25}

This study recommends offer better and more training and educational programs designed in carful and scientific way to accomplish best available health promotion to the autistic children.

CONCLUSION

Mothers of autistic children have high level of needs and are divided from highest to lowest; knowledge and training needs in the first place followed by societal needs in the second place, in the third-place financial needs, and lastly in the fourth place the social needs. Also, study has found a strong relationship between financial needs and knowledge and training needs, also there is a highly relationship between financial and social needs, in addition, there is significant relationship

between knowledge and training and societal needs, and another relationship with social needs. According social and societal needs there is high significant relationship between both of them.

Author's Contribution:

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REFERENCES

1. von Gontard A, Hussong J, Yang SS, Chase J, Franco I, Wright A. Neurodevelopmental disorders and incontinence in children and adolescents: Attention-deficit/hyperactivity disorder, autism spectrum disorder, and intellectual disability-A consensus document of the International Children's Continence Society. *Neurourol Urodyn* 2022;41(1):102-14.
2. Maenner MJ, Warren Z, Williams AR, Amoakohene E, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(2):1-14.
3. Halfon N, Houtrow A, Larson K, children PNT. The changing landscape of disability in childhood. *JSTORN* 2012; 22.
4. Gowda GS, Komal S, Sanjay TN, Mishra S, Kumar CN, Math SB. Sociodemographic, legal, and clinical profiles of female forensic inpatients in karnataka: a retrospective study. *Indian J Psychol Med* 2019;41(2):138-43.
5. Leung CYS, Li-Tsang CWP. Quality of life of parents who have children with disabilities. *Hong Kong J Occupa Therapy* 2003; 13: 19-24.
6. Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism* 2004;8(4): 409-23.
7. Boyd BA. Examining the Relationship between stress and lack of social support in mothers of children with autism. *Focus Autism Other Dev Disabl* 2002; 17: 208-15.

8. Duchene MS, Harden BJ. Maternal experiences of parenting children with autism spectrum disorder: a qualitative analysis. Dissertation 2015; 15-9.
9. Sahida K. The relationship between characteristics of parent-child and level fatigue of parents with autism spectrum disorder. Int Confer Nurs Symposium 2017; 210: 155.
10. Papadopoulos D. Mothers' experiences and challenges raising a child with autism spectrum disorder: a qualitative study. Brain Sci 2021; 11: 30911.
11. Brown HK, Ouellette-Kuntz H, Hunter D, Kelley E, Cobigo V. Unmet needs of families of school. J Appl Res Intellectual Disabil 2012; 25: 497-508.
12. Siklos S, Disorders KK. Assessing need for social support in parents of children with autism and Down syndrome. J Autism Develop Disord 2006; 6: 6755.
13. Estes A, Olson E, Sullivan K, Greenson J, Winter J, Dawson G, Munson J. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. Brain Dev 2013; 35(2):133-8.
14. hattnawi KK, Bani Saeed WM, Al-Natour A, Al-Hammouri MM, et al. Parenting a child with autism spectrum disorder: perspective of jordanian mothers. J Transcult Nurs 2021;32(5):474-83.
15. Tork HMM, Bassam A, Mohamed H, Tork M. Education program for mothers of children with autism spectrum disorder: mothers and child outcomes. Am J Nurs Res 2019; 7: 1046-56.
16. Papadopoulos D. Mothers' experiences and challenges raising a child with autism spectrum disorder: a qualitative study. Brain Sci 2021; 11: 30911.
17. Liao X, Li Y. Economic burdens on parents of children with autism: a literature review. CNS Spectr 2020;25:468-74.
18. Bi X, He HZ, Lin HY, Fan XZ. Influence of Social Support Network and Perceived Social Support on the Subjective Wellbeing of Mothers of Children With Autism Spectrum Disorder. Front Psychol 2022; 13: 835110..
19. Dib AA. Psychological Stresses and the Needs of Mothers Of Children with Autism Spectrum Disorder, And The Relationship between Them in the United Arab Emirates. Theses 2016; 314.
20. Al-Khafash S, Suham R. The degree of needs of mothers of children with autism disorder in the southern region of Jordan in light of some variables. Educ Sci Egypt 2014;22:159-94.
21. Ntre V, et al. Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD). Int J Caring Sci 2018; 11: 985-95.
22. Mbamba CR, Ndemole IK. "I Paused My Life": Experiences of Single Mothers Caring for Their Autistic Children in Ghana. J Soc Serv Res 2021; 47: 659-69.
23. Buchholz AA. Correlation between resilience and social support in mothers of young children with autism. Polish perspective. Health Psychol Rep 2023; 11: 10.
24. Psaltis C, Gillespie A, Perret-Clermont AN. The importance of social relations for human and societal development. Social Relations Human Societal Development 2015; 215-42
25. Cleary M, West S, Mclean L. From 'refrigerator mothers' to empowered advocates: the evolution of the autism parent. Issues Ment Health Nurs 2023; 44: 64-70.