The impact and relation of different socio-demographic variables on social support among parents of children with autism spectrum disorder

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Abstract

Background: Social support might have a strong impact on family functioning because many families of individuals with autism spectrum disorder begin by seeking social support and resources to cope with stressful situations while facing challenges and caregiver burden. **The study aimed to** examine the effect and relation of different socio-demographic variables on social support among Parents of Children with Autism at a Mental Health Hospital in Assiut City. **Subjects and method:** A descriptive, correlational research design was utilized in this study. The present study included 291parents having children with autism **Setting:** This study was carried out at a Mental Health Hospital in Assiut City. **Tools of study:** The data for this study was collected by using a self-administered questionnaire. Multidimensional Scale of Perceived Social Support, socio demographic data and socioeconomic state of parents. **Results of the study:** The current study revealed a highly statistically significant difference between social support and level of education, Occupation & socioeconomic **Conclusion:** There is a highly statistically significant positive correlation between socioeconomic status and social support among parents of children with autism spectrum disorder(ASD). (r=0.358& p=0.000**). **Recommendations:** Recognize coping strategies used by family caregiver for handling children with autism and provide suitable ways to support family to cope with stressful situations while facing challenges and caregiver burden .

Keywords: Autism Spectrum Disorder, children, Parents & Social Support

Introduction

Autism, a multifaceted developmental condition, is commonly identified or detected in children between 18 months and three years of age. It is part of a group of five conditions referred to as Pervasive Developmental Disorders (PDD), marked by significant challenges in communication, behavior, and social interaction. This condition is present across various social, racial, and ethnic demographics, as noted by **(Maenner, 2023).**

Social support, a factor widely acknowledged to be shaped by societal, economic, and cultural factors, stands as a crucial resource that individuals require. The availability of social support can foster a more optimistic view within the family life cycle. Parents might experience heightened anxiety due to their concerns about the future well-being of their adult children or apprehensions regarding the care their children with autism might receive if the parents are unable to provide necessary support **(Einav et al., 2024).**

Notably, high parental stress can, in turn, have a negative impact on the affected children's psychological well-being, and exacerbate ASD-related behaviours and symptoms, creating a vicious circle **Mauma, (2023).** The child's noncompliance,

disturbed mood or irritability, and increasingly maladaptive behaviours will leave parents frustrated and lacking confidence in their parenting abilities. The high demands placed on parents of children with autism spectrum disorder (ASD) take a toll, leading to both physiological and mental fatigue. **(Horbay, 2023).**

The traits exhibited by children with ASD can strain families with a child on the spectrum, leading to internal discord within the family structure. Referring to the commonly cited definition of social support, it is described as "the social assets that individuals believe are accessible to them or that are actively extended by non-professionals within the framework of both organized support networks and informal assistance bonds" **(Lei & Kantor, 2023).**

Social support is recognized as a crucial buffer against parental stress and its associated challenges in caring for both neuro-typical children and those with special needs like autism. Studies suggest that informal social support from sources like family and friends may be more beneficial than formal professional assistance in reducing high levels of parental stress. Given the significance of perceived social support in alleviating parental stress and its effects on child well-being, it is essential to delve

deeper into examining this connection, especially for parents of children with special needs, as emphasized by **(Romero, 2024).**

Numerous research works highlight the advantages of social support for parents of individuals with autism. For example, studies have established a connection between social support and reduced distress, parenting stress, as well as enhanced general well-being and life contentment **(Bi, et. al., 2022).**

Broadly, social support can be divided into two main categories: formal and informal. Formal social support encompasses assistance obtained from structured environments like a parent's workplace, health professionals, or social service agencies. Conversely, informal social support involves help from family, friends, and casual groups **(Ran et al., 2023).**

According to **Dunst, et al., (1986),** social support is defined as the provision of physical, emotional, informational, and practical aid that is perceived as beneficial and forms a part of an individual's social circle **(Charlton & Wallace, 2023).**

 parents of autistic children exposed to high parental stress and burden so that parents need to social support and resources to cope with stressful situations, challenges and caregiver burden. **Higgins et al., (2023).**

Significance of the study:

A major reason for studying autism is its ever-increasing prevalence, recently estimated to be approximately 10-12 per 1,000 individuals **(Baghdadli, et al., 2024).**

The worldwide occurrence of autism is documented to range from 1% to 2%. Research focusing on African Arab-speaking nations revealed that within the special needs population, the prevalence of ASD was reported to be 11% in Tunisia and 33% in Egypt. However, there is a lack of data on ASD prevalence estimates in sub-Saharan African countries, as noted by **(Oti-Boadi, et al., 2023).**

The Social Solidarity Ministry estimates that there are 800,000 autistic people in Egypt. Autism symptoms are present in one out of every 160 children, with males experiencing prevalence four times higher than that of females. **(Mohammed et al., 2024)**

Until now, only a limited number of research investigations have explored the primary impact and stress alleviation models for parents of individuals with autism. These studies have utilized diverse social support measures and have examined various outcomes such as stress, distress, physical health, and mental well-being **(Crasta et al., 2021).**

In Assiut City, there are few studies on the buffering effect of social support and parental stress on mothers of disabled children. Moreover, the mothers of children with Autism always bear higher stress levels than mothers of normal children.**(Sowmida et al., 2023).**

 Aim of the study

To examine the effect and relation of different socio demographic variables on social support among Parents of Children with Autism at a Mental Health Hospital in Assiut City.

Research questions:

Is there effect and relation of socio demographic variables on social support among Parents of Children with Children with Autism at a Mental Health Hospital in Assiut City?

Subject and Method

Research design:

A descriptive, correlational research design was utilized in this study.

Research setting:

 The current study was carried at child psychiatry outpatient clinic at Assiut mental health hospital. The mental health hospital consists of two floors , child psychiatry outpatient clinics in the ground floor which works one day\week (Tuesday) and consists of four rooms.

Subjects:

Target population:

The target population of this study involved caregivers of autistic children at assiut mental health hospital.

Inclusion criteria:

- Parents of children with ASD who agree to participate in the study.
- Parents of Children with ASD only or ASD with ADHA or mild mental retardation (IQ 50-70) (intellectual disabilities)

Exclusion criteria

- Parents of autistic children with chronic medical diseases
- Parents of autistic children with neurological disorders (epilepsy)
- Parents who refuse to participate in the study
- Parents with past history of neurological and psychiatric disorders
- Parents with history of taking psychotropic drugs or substance abuse

Sample size

Non probability (purposive) sample of 291 parents were included in the study according to admission office at Assiut mental health hospital from January 2022 to December 2022 were 515. using the software EPI/Info, (version 3,3) with a 95% confidence interval (CI). **calculated according to the following equation:**

n = [DEFF*N p (1-p)]/ [(d^2/Z$^2_{1-α/2}$*(N-1) + p*(1-p)]
DEFF (Design effect) = 1
N (population) = 515
P (Hypothesized %) = 50%+/-5
D (tolerated margin of error) = 0.05
Z (level of confidence) = 1.96
α (Alpha)= 0.05
N (parents of autistic child population)=
[1*515*50%+/-5 (1-50%+/-5)/ [(0.05)^2/ (1.96)^{2}1-
0.05*(515-1) + 50%+/-5 (1-50%+/-5)]
N (parents of autistic child population)=221
Final Sample Size =291
Study subject selected according to the following criteria
 Criteria of selection
• Parents of children with ASD who agree to participate in the study.
• Parents of Children with ASD only or ASD with attention deficit hyperactivity(ADHA) or mild mental retardation (IQ 50-70) (intellectual disabilities)
 Data collection tools: consisted of three parts:-
 Part (1): Socio demographic data of parents
This tool was developed by the researcher, it included: name, age (years), gender, residence, level of education, occupation and marital status.
Part(2): Scale for measuring socioeconomic status of parents
This scale was initially created by **Fahmy & El-Sherbini** (**1983)** and was later updated to include all the previous variables. The updated version was translated into Arabic by **El-Gilany, et al., (2012)** and subsequently back-translated into English to ensure its validity and reliability. The scale comprises seven domains, covering areas such as education and culture, occupation, family dynamics, family assets, economic status, home hygiene, and healthcare, all aimed at evaluating the family's socioeconomic standing. The correlation coefficients exhibited strong values, ranging from 0.84 to 1.00, as reported by (**El-Gilany et al. in 2012).**
This scale has a total score 84 and levels of socioeconomic status were categorized as following:
  - <42 = very low level of socioeconomic status.
  - 42< 63= low level of socioeconomic status.
  - 63<71.4= middle level of socioeconomic status.
  - 71.4-84= high level of socioeconomic status.
 Part (3): social support Assessement scale:
 Social support developed by (**Zimet et al., 1990)** measured the multidimensional scale of perceived support [MSPSS]. Modified and translated by (**Mohmmed et al., 2015)**. It is 12 item self-report scale to measure perceived adequacy of social support from family and significant others. responses are scored on a five– point Likert scale, ranging from [1] very strongly disagree to [5] very strongly agree.

reliability test was done to modified scale by using Cronbach Alpha it was 0.89.
All items are scored as the following
 - Strongly disagree=1
 - Mildly disagree=2
 - Neutral=3
 - Mildly agree=4
 - Strongly agree=5
The total score is ranged from 5-60.
 - 12-28(Low acuity).
 - 29-44(Moderate acuity)
 - 45-60(High acuity)
Steps of the study (Method):
Tools of validity and reliability
• Validity was established by panel of five experts from faculty members in the nursing and medical field from Assiut University who reviewed the tools of data collection for clarity, relevance, comprehensiveness, understanding, applicability and easiness.
• Tools reliability : Cronbach's Alpha was used to assess the reliability of the tools. It was (0.91) for Kessler psychological distress scale & (0.89) for social support scale. socioeconomic status correlation coefficients were very strong, ranged from 0.84 to 1.00.
The pilot study
• A pilot study was conducted on 10% of the expected sample size (28 mothers accompanied their children) from the previously mentioned settings to test the applicability, clarity, efficiency of the tools and time needed. In the light of pilot study analysis, no modification was made, parents were included to the total sample of the study.
Ethical approval:
 The Research Ethics Committee of Assiut University Faculty of Nursing granted ethical approval for this study with an approved number (1120230640) on 25june /2023. The study followed common ethical principles in clinical research. the researcher clarified the aim of the study and expected outcomes to all the studied parents participated in the study. verbal approval was prerequisite to participate in the study. The studied parents were assured that all gathered data were used in research purpose only and the study was harmless. Additionally, the studied parents were allowed to withdraw from the study at any time without giving the reason. Confidentiality and anonymity of the gathered data and results were secured.
Administrative design:
  An official approval letter from the dean of nursing faculty was received before conducting the study and it was given to the vice president for student affairs at Assiut University as well as the dean of each chosen faculty.

Field work
- The data collection process lasted for three months, from the middle of October to the middle of January 2023, one day per week (Tuesday) and the number of parents were 10–13 parents per day.
- The researchers first met with the parents and their autistic children attending the selected study setting.
- The researcher obtained verbal consent from the parents who came to out-patient clinic
- The researchers then introduced themselves to the parents and simply clarified the aim of the study to the parents who accept to participate in the study, and then the parents were interviewed individually using the previously mentioned tools.
- The researchers assessed the studied parents' socio-demographic data, their socioeconomic status , and social support regarding care of autistic children using previously mentioned tools .
- The time consumed to fill in the questionnaire for each parent included in the study was 10-15 minutes

- The researcher concluded by thanking the parents and medical and nursing staff for their participation.
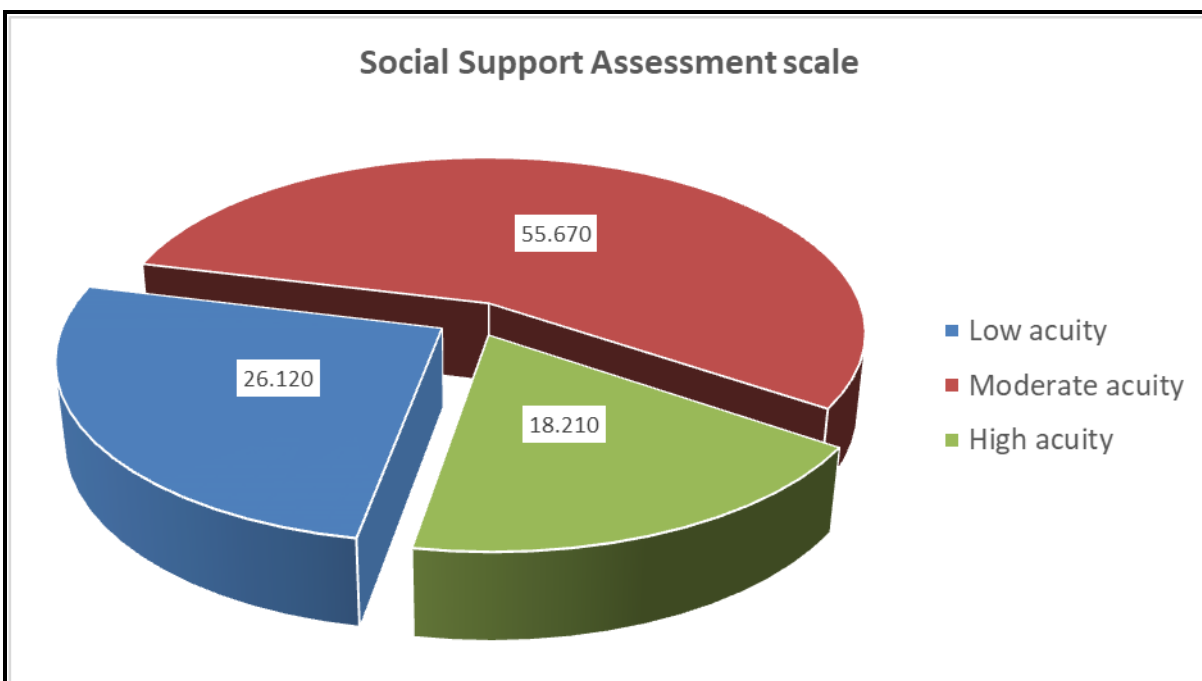
Statistical analysis

The data were assessed for normality and variance homogeneity before proceeding with additional statistical analysis. Categorical variables were presented using counts and percentages (N, %), while continuous variables were represented by their mean and standard deviation (Mean, SD). Statistical comparisons between categorical variables were conducted using the Chi-square test and Fisher's exact test, whereas t-tests and ANOVA were employed for comparing continuous variables. Pearson correlation was utilized to examine relationships between scores. A significance level of $p < 0.05$ (two-tailed) was considered statistically significant. All statistical analyses were carried out using IBM SPSS 20.0 software

Results:

Table (1): Distribution of the studied parents according to socio demographic characteristics (N=291)

Socio demographic data	No. (n=291)	%
Age		
Min. - Max.	19-55	
Mean ±SD	37.42±6.32	
Age levels		
<30 years	44	15.1
30-40 years	161	**55.3**
>40 years	86	29.6
Gender		
Male	89	30.6
Female	202	**69.4**
Residence		
Rural	194	**66.7**
Urban	97	33.3
Type of family		
Nuclear family	12	4.1
Extended family	279	95.9
Level of education		
Illiterate	49	16.8
Read and write	7	2.4
Primary	3	1.0
Preparatory	28	9.6
Secondary	128	**44.0**
University	57	19.6
Postgraduate	19	6.5
Marital status		
Married	275	94.5
Divorced	10	3.4
Widow	6	2.1
Occupation of father		
Not working	2	0.7
Working	289	**99.3**
Occupation of mother		
Housewife	225	**77.3**
Working	66	22.7
Number of children with autism		
One child	255	**87.6**
Two children	26	8.9
Three children	10	3.4

Table (2): Distribution of social support assessment Scale levels of the studied group(N=291)

Social Support Assessment scale	Score range	No.	%
Low acuity	12-28	76	**26.12%**
Moderate acuity	29-44	162	**55.67%**
High acuity	45-60	53	**18.21%**
Mean± SD(range)			35.01±10.15(12 − 58)
Total	**60**		

Figure (1): Distribution of the social support level of parents (N=291)

Table (3): Distribution according to socio demographic data of parents of the studied group with social support assessment scale (N=291)

	Social support Assessment scale		F/t	P. value
	Min. - Max.	Mean ±SD		
Age				
<30 years (n=44)	12 - 56	35.57±10.98		
30-40 years (n=161)	12 - 58	35.35±11.05	0.497	0.609
>40 years (n=86)	19 - 56	34.1±7.69		
Gender				
Male (n=89)	25 - 52	36.47±6.78		
Female (202)	12 - 58	34.37±11.27	1.632	0.104
Residence				
Rural (n=194)	12 - 58	34.37±10.66		
Urban (n=97)	19 - 56	36.31±8.93	-1.544	0.124
Type of family				
Nuclear family (n=12)	12 - 45	27.67±11.23		
extended Family (n=279)	12 - 58	35.33±10	-2.587	**0.010***
Level of education				
Illiterate (n=49)	12 - 43	30.98±7.99		
Read and write (n=7)	20 - 34	29.14±6.31		
Primary (n=3)	29 - 35	31±3.46		
preparatory (n=28)	12 - 55	30±9.96	7.162	**<0.001****
Secondary (n=128)	12 - 55	36.07±10.46		
University (n=57)	12 - 56	36.16±9.12		
Postgraduate (n=19)	32 - 58	45.05±8.74		

	Social support Assessment scale		F/t	P. value
	Min. - Max.	Mean ±SD		
Marital status				
Married (n=275)	12 - 58	34.93±9.68	1.188	0.306
Divorced (n=10)	12 - 51	39.2±15.05		
Widow (n=6)	12 - 55	31.67±19.44		
Occupation of father				
Not working (n=2)	24 - 31	27.5±4.95	1.105	0.294
Working (n=289)	12 - 58	35.07±10.16		
Occupation of mother				
Housewife (n=255)	12 - 55	33.38±9.86	28.048	**<0.001****
Working (n=66)	24 - 58	40.58±9.13		
Socioeconomic Status of parents				
Very low level (n=149)	12 - 55	32.66±10.23	12.286	**<0.001****
Low level (n=119)	16 - 56	35.97±9.19		
Middle level (n=21)	37 - 58	45.19±6.98		
High level (n=2)	47 - 47	47±0		
Number of children				
One child (n=255)	12 - 58	35.65±9.9	4.606	**0.011***
Two child (n=26)	14 - 55	31.38±10.73		
Three child (n=10)	12 - 43	28.1±11.34		

Table (4): Multivariate linear regression to determine the effects of socio demographic data on social support Assessment Scale.

	Standardized Coefficients of Beta	P. value	95.0% Confidence Interval for B	
			Lower Bound	Upper Bound
Age	-0.063	0.340	-0.308	0.107
Gender	0.015	0.824	-2.521	3.162
Residence	-0.072	0.255	-4.223	1.125
Type of family	0.137	**0.023***	0.946	12.961
Level of education	0.049	0.624	-0.825	1.374
Marital status	-0.042	0.472	-3.446	1.601
Occupation of father	0.019	0.734	-11.116	15.754
Occupation of mother	0.123	0.134	-0.920	6.868
Socioeconomic Status of parents	0.265	**0.035***	0.017	0.457
Number of children	-0.073	0.240	-4.366	1.096

Table (1): Illustrates that distribution of socio-demographic characteristics of parents. The results reveal that, **(55.3%)** of parents were in the age group ranged from (30-40 years old) and **(69.4%)** of parents are females. Regarding to level of education, it is found that less than half **(44.0%)** of them are at secondary. Regarding the occupation of mother found that, more than three quarter **(77.3%)** of mothers are housewife and majority of fathers (**99.3%**) working. In accordance to residence, more than two quarter of parents **(66.7%)** are found to reside in rural areas. regarding number of autistic children with the family, it found that(**87.6%**) had one child with autism.

Table (2): Illustrates that **(55.7%)** of parents are moderate acuity of social support**, (26.12%)** of parents are low acuity of social support scale and **(18.21%)** of them are high acuity of social support and this difference was statistcally ,significant Mean±SD 35.01±10.15(12 – 58)

Figure (1): Shows that, (55.7%) of parents are moderate acuity of social support and (26.12%) of parents are low acuity of social support.

Table (3): Illustrates that there are highly statistically significant differences among type of family , level of education ,occupation of mother ,socio economic status and number of children with autism (p= 0.010*&<0.001**&0.011*),

Table (4): Reveals that the main contributing factors that affect social support are type of family and socio-economic status of parents (**p value 0.023*& 0.035*).**

Discussion:

The influence of social support on family functioning could be substantial, particularly as families of individuals with ASD commonly initially seek assistance and resources to manage stress and caregiver responsibilities. Social support is widely recognized as a crucial factor in enhancing overall

well-being. Scholars suggest that social support should be viewed as a multifaceted concept, comprising various measurable facets that represent distinct ideas (**Liu & To, 2022).**

So, the current study aimed to explore the effect and relation of different socio-demographic variables on social support among Parents of Children with autism spectrum disorder.

Regarding Socio-demographic data of the studied parents , The current study clarified that, highest percentage of parents were that the majority of parents were mothers aged 30-40 years, primarily housewives from rural areas, with secondary education, and most families had only one child diagnosed with Autism Spectrum Disorder. This result is similar to **Apoorva et al., (2022)** who reported that majority of parents were aged 30-40 years, predominantly mothers who were housewives, from rural areas, and had secondary education ; in a study conducted to understand the socio-demographic background of the children being diagnosed with autism and find out if there is any correlation between antenatal physical and mental stressors in mothers and their children developing autism .

Also congruent with **Oneib et al., (2022)** who found that the majority of parents were aged 30-40 years, with mothers primarily being housewives from rural areas. Most had secondary education and typically had only one child diagnosed with autism spectrum disorder; in a study carried to assess the socio-demographic and clinical profile of children with an autism spectrum disorder in the oriental region of Morocco. the findings in current result due to culture of soceity, responsibility of mothers with caring autistic child and takes a lot of time, effort, and patience to meet the extra care needs of child.

Regarding social support, the current study revealed that more than half of parents have moderate acuity of social support. This result is in the same line with **Rimmer, (2022)** who reported that about half of parents have moderate acuity of social support while studied Phonological awareness skills children on the autism spectrum in Canada.

But, in contrast to **Liu et al., (2024) & Wang & Zhang (2022)** Who reported that highest percentage of parents had a low acuity of social support .This difference can be explained in study of **Liu et al., (2024) & Wang & Zhang (2022)** most parents were living in nuclear family and did not have special person help them but in our study most parents had friends and family shared them caring of child and their feelings.

Regarding Comparison of social support among different socio-demographic data in parents with autistic child, the current study revealed a highly statistically significant difference between social

support and level of education, Occupation & socioeconomic status with higher mean score of social support in working women with higher education and high socioeconomic status. This result similar to **Kavaliotis, (2018)** who investigated the family resilience of parents with a child with autism spectrum disorders, parenting stress and social support and found that socio-demographic characteristics, such as education level and family income, directly influence parents' stress levels and their access to social support, impacting their overall resilience while caring for a child with autism spectrum disorders.

But in contrary to **Athbah, (2024)** who explore the issue of strengthening the family in supporting the social interaction and well-being of children with autism in Jeddah, Saudi Arabia using a descriptive approach and revealed no significant differences in social support among parents of children with autism based on occupation or education level. These results can be explained as in study of **Athbah, (2024)** these results could be because the sample comes from a similar cultural context and the level of education plays an insignificant role for the parent when the issue is related to the health of their children. Parental instinct is stronger than the type of education the parent has, as it is clear that they all agreed on the problems of having a child with ASD and the challenges they face when seeking help and support from responsible institutions , but in our study Parents with higher education levels often have better access to information about autism, enabling them to navigate support systems effectively and build networks within professional and social circles.

Study strengths & limitations

Strengths

The main strengths are the prospective way of the study research, This study provides specific insights into the unique challenges faced by this group that can guide interventions tailored to their needs, the study was carried on Probable sample size and use validated tools and helping caregivers to express their feelings and how deal with challenges.

Limitations

The generalizability of the present research is limited due to its limited sample size and population characteristics, sadness and depressed mood of caregivers during data collection , there was unequal distribution of men and women population in the current study, Further longitudinal studies and control group are needed to follow up of parents group with control group , there was an noise and other individuals' interruption during data collections and Psychatric interview is needed for comperhensive assessment of psychological distress of caregivers.

Conclusion

The current study concluded that, there is a highly statistically significant correlation between socioeconomic status and social support among parents of children with ASD. Also, there is a highly statistically significant difference of social support regarding the level of education, Occupation & socioeconomic status with higher mean score of social support in working women with higher education and high socioeconomic status.

Recommendations:

1. Comperhensive psychatric interview &screeing test are needed to assessement health of caregivers.
2. Stress reduction programs & targeted social support interventions for parents with autistic child to promote parental psychological well-being & their quality of life .
3. Parent-focused interventions as mindfulness-based interventions for improving the mental health of parents and their children with autism spectrum disorder
4. Continuing health education programs for parents of children with autism to learn stress-reduction practices and improvement of social support.
5. Develop further research as the effectiveness of tailored interventions, such as stress management programs and community support initiatives, to alleviate psychological distress and improve quality of life among parents with autistic child.

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