

Locus of Control, Perceived Social Support and Quality of Life between Mothers of Autism Spectrum Disorder and Mainstream Children

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The present study compared locus of control perceived social support, and quality of life between mothers of Autism Spectrum Disorder (ASD) and mainstream children. Through purposive sampling, data were collected from 200 mothers of children having ASD ($n=100$) and mainstream ($n=100$) children. Children's ages ranged between 3-13 years ($M=7.4$; $SD=2.3$). Urdu Translated Multidimensional Scale of Perceived Social Support (Jibeen & Khalid, 2010), Urdu Translated Rotter's Locus of Control Scale (Khan), Urdu Translated World Health Organization Quality of Life Scale (Khalid & Kausar, 2006) and Demographic Form was administered. A comparative research design was used. One time approach to the participants was carried out. The results revealed a significant difference in the locus of control, perceived social support, and all four quality of life subscales, i.e., physical, psychological, social, and environmental between mothers of ASD and mainstream children. Moreover, mothers of Autistic children scored significantly low on perceived social support and quality of life scores whilst scoring high on locus of control as compared to the mainstream group mothers. Lastly, results revealed a significant positive relationship between perceived social support and quality of life among mothers of ASD children. Implications and suggestions of research have been discussed.

Keywords: *Locus of control, Perceived social support, Quality of life, Autism Spectrum Disorder*

"If you've met one person with autism, you've met one person with autism" (Shore as cited in Devine, 2014, p.175)

The life of a child with Autism Spectrum Disorder (ASD) is known to include many difficulties, not only due to communication, behavioral, and social difficulties but also as the child does not fit society's stipulation of 'normal' (Weastell, 2017). Child rearing brings with it great responsibilities especially if the child is disabled. Diagnosis of a child with Autism Spectrum Disorder (ASD) particularly makes the parents anxious and fearful especially about the ambivalent future of their child (Finnegan, 2014). Parents of children with ASD are more likely to experience serious psychological distress (Bromley et al., 2005). The whole family is affected by the disability of any family member (Cynic et al., 1983). ASD--- a neurodevelopmental disorder that affects social, verbal, and cognitive aspects of an individual's life. Repetitive behaviors,

difficulty in communication and restricted interests are the main features of children having ASD. Further, it is diagnosed between the ages of 2.5 to 3 years (Luiselli, 2014). There are 350,000 estimated children in Pakistan (The Nation, 2012). The prevalence rate of ASD in Lahore alone is reported to be 6.31% (Suhail & Zafar, 2008). Autism is more prevalent in males as compared to females. Baird et al. (2006) reported the ratio of boys to girls as 3:1 in ASD.

Pakistan is a developing country where parents already struggle a lot to provide their children with a safe environment for their emotional, social, and biological development. Whilst, parents who have ASD children face many more challenges like stigma, and special needs of the child as compared to parents of mainstream children (Tarabek, 2011; Imran & Azeem, 2014). Moreover, in a collectivist country like Pakistan, a mother is by and large considered a child's caregiver. Research shows that many life domains of children are affected by the mental health of mothers such as cognitive, social, emotional as well as physical health and nourishment (Manning & Gregoire, 2009).

Parenting a child with ASD involves a lot of emotional consequences, especially for mothers (Dale et al., 2006; Zhou, 2014; Davis & Carter, 2008). Demanding parenting, routinized behavior, and child-problematic behavior make parenting more intricate (Ludlow et al., 2012). One of the variables in this study is the parental locus of control, which plays an imperative role in reducing the stress of parents with a special child. Many studies signify the role of internal locus of control with positive outcomes and family adjustment (Dyson, 1991; Hastings & Brown, 2002; Miller et al., 1992; Rimmerman, 1991). Rahman et al. (2012) found that the religious beliefs of eastern people like parental sins, curses,

and karma play a central role while dealing with their autistic children. They concluded that those parents who believe in such religious beliefs are most likely to use external locus of control. Therefore, the present study aims to compare the locus of control of ASD and mainstream children mothers.

The collectivist culture particularly in Pakistan gives a lot of importance to the joint family system because of the closely knit family connections in the form of social support provided by family members. This support can be emotional, psychological, informational, tangible, and companionship as well (Zimet et al., 1988). Researches show that an increase in social support decreases the stress experienced by parents of an autistic child. Having social support also increases the psychological well-being of parents (Samadi & McConkey, 2014; Hartley et al., 2012; Benson & Kersh, 2011). Therefore, social support is explored in the present study. Many types of research focus on maternal quality of life because a child with special needs cannot achieve a quality of life unless the mother's quality of life is at least average (Yamada et al., 2012; Reine et al., 2003). Moreover, Allik (2002) reported low quality of life in mothers of children with Autism Spectrum Disorder. Low maternal quality of life has been significantly associated with low psychological and physical health (Yamada et al., 2012). Since rearing children with special needs is demanding, difficult, and requires additional effort, therefore parents of these children experience more challenges in all domains of life than the parents of normal children (Chetwynd, 1985).

Rationale

A child with special needs is considered a stigma in a developing country like Pakistan because it brings shame, guilt, financial burden, and social rejection for the family, parents, and especially for the mother. There is a lack of awareness regarding ASD and special schools for such children, though available only in a few main cities of Pakistan, are very expensive. Bristol et al. (1983) reported difficulties faced by the mothers of disabled children to include: Increased stress levels; botheration about child dependency; parental burnout; excessive time demands; effect on family health and future psychosocial problems. Studying a mother's locus of control, perceived social support, and quality of life in a stigmatized population is incredibly important to develop an empirical understanding of such stigma affecting the psychological health of a mother in various domains of life. Further, the joint attention of policymakers, mental health practitioners, and society is required to raise awareness regarding ASD so that early detection and structured foundation years program based on transactional analysis may be implemented during the early years for a better prognosis.

Objectives

- To check the relationship between locus of control, social support, and quality of life among mothers of Autism Spectrum Disorder.
- To compare scores of locus of control, social support, and quality of life between the mothers of Autism Spectrum Disorder and Mainstream children.

Hypotheses

- External locus of control and low social support will be significantly related to low quality of life among mothers of Autism Spectrum Disorder children.
- Mothers of children with Autism Spectrum Disorder will have a significantly high external locus of control as compared to mothers of mainstream children.

- Mothers of Autism Spectrum Disorder will significantly have low perceived social support scores as compared to mothers of mainstream children.
- Mothers of Autism Spectrum Disorder will have a significantly low quality of life scores as compared to mothers of mainstream children.

Method

Sample

Through purposive sampling (Ritchie & Lewis 2003) 200 mothers (ASD children = 100; mainstream children=100) with the ages between 24 – 53 years ($M=34$; $SD=6$) were included in the sample. G power analysis was used to determine the sample size. Moreover, research conducted in past further guided about sample size (Kuru & Piyal, 2018; Khan., et al, 2017). For children, the age range was between 3-13 years ($M=7.4$; $SD=2.3$). A sample of mothers having ASD children was collected from Amin Maktab Centre for Special Education ($n=20$), Autism School Lahore ($n=40$), Shadab institute for handicapped children($n=10$), and Rising Sun Institute for Special Children ($n=30$). All mothers were educated, 12% had done intermediate, 36% bachelors, masters 18%, and 1% have done higher studies. In the present sample, the majority of children were firstborn (54%) and males (72%). The mainstream children group was matched and blocked on the age and gender of the children. Sample for mainstream children was collected from The Punjab School and through acquaintances. In the mainstream group majority of children were firstborn (44%) and male (72%). Ethical considerations were carefully dealt with and permission to conduct the study was sought from Departmental Research Committee and ORIC Kinnaird College, Lahore.

Assessment Measures

Rotter's Locus of Control Scale. In the present study, the Urdu version of Rotter's Locus of Control Scale was used to measure the personal belief of participants whether they are external or internal. The scale consists of 23 items and six fillers. Response items include two statements. This scale provides one global score, a high score indicates the external locus of control whereas, a low global score indicates the internal locus of control. Rotter (1966) reported the test-retest reliability of this scale as 0.49 to 0.83. The scale internal consistency was between .65 and .79.

Multidimensional Scale of Perceived Social Support (MSPSS). MSPSS (Dahlem et al., 1988) was developed to assess perceived social support among individuals. It consists of twelve items that are answered on a 7-point Likert scale where 1 means strongly agree and 7 means strongly disagree. The scale consists of three subscales of social perception i.e. friends, family, and significant others. Its translated Urdu version was used in the study (Jibeen & Khalid, 2010). Cronbach alpha is 0.87 in the clinical population and Cronbach α 0.91 in the students. Cronbach α for the Urdu version of this scale is 0.86 (Rizwan & Aftab, 2009).

World Health Organization - Quality of Life-BREF. The WHO-QOL instrument was developed by the WHO group (1991) to measure the quality of life. The scale consists of 26 items. It is 5 point Likert scale with varied indications according to the nature of the questions. It consists of four subscales with domains of physical, psychological, social, and environmental quality of life. The internal consistency of scale i.e. Cronbach alpha ranges from 0.82 to 0.92. Urdu-translated version (Khalid & Kausar, 2006) of this scale was used in the study. The internal consistency of the Urdu version was 0.86.

Demographic Information Sheet. The self-constructed demographic form was used to gather personal information like age, gender, socioeconomic class, total family income, education, family

system, the total number of children, age of the child, birth order of children, occupation, country, religion, type of disability, and marital status.

Procedure

Written consent was obtained from mothers to participate in the study. Participants were briefed about the purpose and nature of the research. They were informed that research is only for educational purposes. Mothers were assured that their information shall be kept confidential. Participants were told about their right to leave research at any point. Participants were administered Rotter's Locus of Control Scale, Multidimensional Scale of Perceived Social Support, WHO Quality of Life Scale, and Demographic Form, respectively. One time approach to participants was used. Administration of questionnaires took 15 to 20 minutes approximately.

Results

Table 1

Demographic characteristics of participants (N=200)

Variable	ASD (n=100)		Mainstream (n=100)	
	N	(%)	N	(%)
Child Age				
3-6	47	(47%)	47	(47%)
7-10	39	(39%)	39	(39%)
11-14	14	(14%)	14	(14%)
Child Gender				
Male	72	(72%)	72	(72%)
Female	28	(28%)	28	(28%)
Mother's Education				
Matric	29	(29%)	33	(33%)
Intermediate	12	(12%)	9	(9%)
Bachelors	36	(36%)	34	(34%)
Masters	18	(18%)	33	(33%)
Child Birth Order				
First Born	54	(54%)	44	(44%)
Second Born	20	(20%)	19	(19%)
Last Born	26	(26%)	37	(37%)

Note N=Number of participants, %=Percentage of participants

Table 2

Independent sample t-test Comparing Mothers of Children with ASD and Mainstream Children on Locus of Control (N=200)

Variable	ASD (n=100)		MC (n=100)		t(198)	p	95% CI		d
	M	SD	M	SD			L	UL	
Locus of Control	11.74	2.92	10.44	3.22	2.93	.00	.42	2.17	.41

Note. MC=Mainstream children; M = Mean, S.D= Standard Deviation, d = Cohen's , df = degree of freedom; **=p < .01

Table 2 shows a highly significant difference in the scores of Locus of Control of both groups.

Table 3

Independent sample t-test Comparing Mothers of Children with ASD and Mainstream Children on Perceived Social Support (N=200)

Var	ASD (n=100)		MC (n=100)		t(198)	p	95% CI		d
	M	SD	M	SD			LL	UL	
Perceived Social Support	38.9	10.45	59.07	12.21	-12.5	.00	-23.29	16.94	1.77

Note. MC=Mainstream children; M = Mean, S.D= Standard Deviation, d = Cohen's , df = degree of freedom; **=p < .01

Table 3 shows a significant difference in the scores of Perceived Social Support scores of Mothers of ASD and Mainstream Children.

Table 4

Independent sample t-test Comparing Mothers of Children with ASD and Mainstream Children on Quality of Life (N=200)

Variable	ASD (n=100)		MC (n=100)		t(198)	p	95% CI		d
	M	SD	M	SD			LL	UL	
Physical	22.12	3.79	27.80	2.85	11.96	.00	6.61	4.74	1.69
Psychological	16.40	2.97	23.88	2.66	17.92	.00	8.30	6.65	2.53
Social	8.52	1.90	12.05	1.74	13.65	.00	4.04	3.02	1.93
Environmental	22.83	5.00	30.65	4.45	11.66	.00	.42	9.14	6.49

Note. MC=Mainstream children; M = Mean, S.D= Standard Deviation, d = Cohen's , df = degree of freedom; **=p < .01

Table 4 shows a highly significant difference in the scores of the Quality of life subscales of both groups

Table 5

Point Biserial Correlation showing a relationship between Locus of Control, Perceived Social Support, and Quality of Life among Mothers with ASD Children (N=100)

Variables	1	2	3
1. RLOC	-	-.03	-.19*
2. PSS		-	.37**
3. QOL			-

Note. *p<0.05, **p < 0.01, LOC=Locus of control, PSS=Perceived social support, QOL=Quality of life

Table 5 showed that there is a significant positive relationship between perceived social support and quality of life among mothers with ASD children. Moreover, the table depicts an inverse relationship between locus of control, i.e., higher scores(external locus of control) would be related to lower quality of life.

Table 6
Psychometric properties of major study variable (N=200)

Variables	K	M	SD	α	Skew
Multidimensional Scale of Perceived Social Support	12	51.87	15.56	0.96	-.34
Significant Others	4	17.77	5.12	0.92	-.41
Family	4	17.91	5.26	0.93	-.50
Friends	4	16.51	6.13	0.95	-.16
WHO-QoL BREF	26	82.13	16.01	0.93	-.35
Physical	7	24.96	4.39	0.57	-.29
Psychological	6	20.14	4.76	0.65	-.14
Social	3	10.29	2.54	0.80	.27
Environmental	8	26.74	6.14	0.90	-.06
Rotter's Locus of Control Scale	29	11.09	3.19	0.65	-.35

Note. k =No of items, α = Cronbach's Alpha, M = Mean, SD =Standard Deviation, WHO-QoLBREF=World Health Organization Quality of Life BREF

Table 6 suggests that sample distributions are free of significant skewness values, i.e., all values fall within the acceptable range of ± 1.96 , indicating that distributions are approximately normal. Cronbach's alpha values for all scales provide evidence of acceptable reliability.

Discussion

The present study was conducted to see the locus of control, perceived social support, and quality of life differences between mothers of children with ASD and mainstream children. The results of the independent sample t -test revealed significant differences in the locus of control scores of mothers having ASD and mainstream children. In line with the present findings, Falk (2012) reported external parental locus of control and low social support as significant predictors of high maternal depression among mothers having ASD children. In line with the existing findings mothers who use internal locus of control while parenting was wise capable and self-assured (Belsky & Barends, 2002; Guralnick, 1998). The study concluded external locus of control to be found in mothers of autistic children which can be explained by the fact that instead of considering their efforts, people in eastern countries including Pakistan use religious beliefs like parental sins, curses, and karma while dealing with their autistic child (Rahman et al., 2012). Due to

cultural differences, this practice is more prevalent in Asian culture as compared to western culture which results in an external locus of control in Asian culture. Contrary to the findings Masood (2012) compared Pakistani parents with US parents and concluded that Pakistani parents used more internal locus of control while dealing with children having special needs. The relationship of Pakistani parents with their children may be more stringent due to self-blame as most of the parents were of the view that they did something wrong in their life which resulted in a disability. The similarity in findings of the present study may be explained because the parental locus of control plays a significant role in determining the maternal stress of children with special needs. Improving parental education can result in a positive parent-child relationship thus reducing self-blame (Jones & Passey, 2005). Moreover, maternal locus of control has also been significant in understanding the behavior of children with developmental disabilities (Silbly, 2004).

Moreover, significant differences in perceived social support scores were found among mothers having ASD and mainstream children. In accordance with our findings, the study of Sarwar et al., (2022) and Weis et al., (2013) concluded that social support plays a significant role in maternal distress of Autism Spectrum Disorder children. Moreover, high social support was found related to low depressive symptoms (Bradley & Corwyn, 2002; Diviney, 2001; Bin, et al., 2022). When mothers receive support from their spouses and family members, it buffers stress and results in better mental well-being. In line with the present study, Bromley (2004) reported challenging behavior of children and poor economic condition to be linked with psychological distress and low level of social support. The similarity in findings of the present study and the existing literature may be explained in a way that due to social support, a load of responsibility and parental stress gets divided, which may result in the positive mental health of mothers. Social support plays an essential role in the lives of families who have special children as it leads to a positive outcome (Dunst et al., 2002; Ekas & Lickenbrock, 2010; Rouf et al., 2017). In contrast, a study reported high stress by parents who seek professional help, which impinges on their mental health. Unless professional support is considered helpfulness then only elevates the quality of life (Moh & Miagiati, 2012). The difference in the quality of life scores of mothers from both groups is also supported by the findings of Allik (2002) who concluded that mothers of children with ASD reported low quality of life as compared to mothers of normal children. Whilst, results showed lower scores on physical health-related quality of life. Valsamma (2023) reported high quality of life among mothers having ASD children, this difference may be explained in the light of the quality of healthcare services available. In accordance with our present study, Yamada et al. (2012) reported that mothers of children with Pervasive Development Disorders reported lower quality of life scores as compared to the normal population. Personality tendencies of mothers and relationships with their spouses are cardinal to quality of life. Impairment of the maternal quality of life was significantly associated with psychological and physical domains (Al Nabi & Sachet, 2022). Further, DeGrace and Imms (2006) reported low quality of life in parents of ASD children. In a comparative study by Mungo et al. (2007), very low overall quality of life was reported by parents of children with pervasive developmental disorder as compared to normally developing children due to higher burdens and factors related to the

environment. The symptoms and severity of autism have been well-linked with the poor parental quality of life (Wachtel & Carter, 2008; Eapen & Guan, 2016). In a Malaysian study, Aun et al. (2022) reported high physical and psychological quality of life in mothers of autistic children. This may be explained in the light of differently aged samples, different cultures, geographical locations, and high perceived social support between the couples.

Conclusion

The study concludes that mothers of children with ASD have low perceived social support, external locus of control, and low quality of life as compared to mothers of mainstream children. Also, locus of control has a negative and perceived social support has a positive relationship with the quality of life among mothers with ASD children.

Limitations & Future Implications

The sample was collected only from Lahore thus limiting generalizability of results. It comprised mothers only who were literate and well above the level of poverty.

For future studies, the sample should be collected from different cities in Pakistan keeping a cross-sectional design. The sample should also include participants from different educational backgrounds. All socioeconomic classes must be catered to. Fathers should be included. Moreover, ASD needs to be explored with other variables such as parental practices and coping strategies.

Furthermore, easily accessible institutes and participants should be included which helps in convincing the target population to participate in the study more willingly. In the long run, psychoeducational programs can be designed for improving the mental health of mothers with developmentally delayed children. It will help in creating awareness at local and national levels. Future efforts should include a guide considering present research results in providing support and help to such families with special children. A special quota for mainstreaming ASD children should be provided. Stress management programs for parents especially for mothers and burden-sharing programs which may also help mothers to achieve subjective well-being thus enabling them to cope with life stressors more effectively should be started all over the country. All these steps will help out in dealing with the stigma of having a child with special needs in Pakistani society because this stigma brings shame, guilt, financial burden, and social rejection for parents. Furthermore, at the micro level, these steps will help in the early diagnosis of an autistic child while removing elements of denial in making the case complicated whereas at the macro level government should provide support to these families thus reducing financial and psychological burden. In accordance with our findings, an inverse relationship between external locus of control and quality of life was reported by Wah (2011) revealing that parents who exhibit external locus of control reported low quality of life.

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