



**Abstract:** *The study was designed with the objective to examine the perceived social support (PSS) as a moderator between parental perceived stress (PPS) and quality of life (QOL) among parents having children with special needs. A sample of 300 parents was selected through purposive sampling from special education schools and health care centres of Lalamusa, Kharian, Gujrat and Gujranwala, Pakistan. Parental Perceived Stress Scale (PPSS), Multi-Dimensional Scale of Perceived Social Support (MDSPSS) and quality of life was measured through the Urdu version of the Quality of Life Questionnaire (Parent Version of QOLA) were administered to collect the data. Findings illustrated that PPS, QOL and PSS had statistically significant relationships ( $p < .001$ ) with each other. Further, PPS is a significant moderator between PPS and QOL among targeted parents. On the basis of findings, it is concluded that there is an intense need of providing awareness and social support to empower parents for coping with stresses.*

**Key Words:** Perceived Social Support, Autism Spectrum Disorder, Intellectual Disability & Perceived Stress

## Introduction

Parenting a child with special needs is not an easy task because, as compared to children with a normal developmental pattern, a child with special needs requires individual care, supervision and attention for his upbringing. This type of needs is generally associated with his/her education, personal hygiene, social life and many everyday related tasks.

Numerous empirical pieces of evidence (Dervishalaj, 2013; Sabih & Sajid, 2008; Lessenberg & Rehfeldt, 2004) reported a high level of stress among parents having children special needs.

Parental stress is a specific type of pressure that emerges when parenting expectations exceeds their resources, and it triggers the uncertainty of circumstances. Literature suggested that parental stress and family stress are two different components resulting from various circumstances. The people who provide care for children with special needs have to face challenging circumstances. In order to meet the special needs, sometimes they have to do extra work to save money for their children with special needs. Numerous studies have focused on the stress in parents of adolescents and children with special needs (Azeem et al., 2013; Khawar & Saeed, 2016 & Minhas et al., 2015). Paden and James (2017) described that parents

have a high level of stress due to the experience of parenting a child with a disability.

Parenting responsibilities, along with the emotional stress of having children with special needs, create stress for parents. Many time they find it very difficult to manage their parental responsibilities of other children, job responsibilities and requirements of social life. In addition, they are facing continuous emotional distress and fear of the social stigma of having a child with special needs. In such cases, parental quality of life (QOL) starts impairing because of the traumatic emotional experience. Several studies have shown that parents reported higher stress levels, insufficient social support, and low standard of living (Feizi, Najmi, Salesi, Chorami, & Hoveidafar, 2014; Kuru, & Piyal, 2018; Lima, Cardoso, & de Silva, 2016; Mugno, Ruta, Arrigo, & Mazzone, 2007; Sheikh, Ashraf, Imran, Hussain, & Azeem, 2018).

With the emotional trauma of having a child with special needs, parents also face difficulties in managing the child physically and financially. Further, in many situations, they also face social criticism (Kausar, Akram, Dawood & Ahmad, 2019). Due to social, psychological, financial and physical pressure, parental quality of life having children having special

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needs become impaired. Kumar (2016) described that parents having children with intellectual disability reported poor QOL.

Various studies highlighted the role of perceived social support in managing parental stress (Lu et al., 2018; Pandey & Dubey, 2019; Zeng, Hu, Zhao & Stone-Macdonald, 2020). Lakey and Cohen (2000) reported that PSS is one's subjective feelings about his needs to get support from others individuals, including his peers, family members and others during any stressful situation.

Social support served as a mechanism in reducing perceived parental stress and contributing standard of living. Lu et al., (2018) reported that social support is a significant moderator and mediator between the relationships of childrearing stress and QOL.

Some studies reported that parents having children with a disability had a higher level of stress, poor social support and low quality of life (Feizi, Najmi, Salehi, Chorami, & Hoveidafar, 2014; Kuru, & Piyal, 2018; Lima, Cardoso, & Silva, 2016; Mugno, Ruta, Arrigo, & Mazzone, 2007; Sheikh, Ashraf, Imran, Hussain, & Azeem, 2018). Further, perceived parental stress also had associations with perceived social support and quality of life (Pandey & Dubey, 2019; Zeng, Hu, Zhao, & Stone-Macdonald, 2020). In perceived parental stress and quality of life's relationship, perceived social support worked as moderator. Lu et al. (2018) reported that social support played the role of moderator and mediator between the relationships of perceived parental stress and quality of life among parents.

The present study aimed to examine the mediating role of social support in the relationship of PS and QOL among parents having children with special needs.

The child that requires special attention and care, which other children do not need, is a child with special need. Children with an intellectual disability are one of the targeted categories in the current study. In intellectual disability, children experience deficits in cognitive abilities and have limitations in adaptive functioning tested by some culture-based standardized tests. These conditions occur before age 18 years (APA, 2013). Children with intellectual disabilities may exhibit behavioral problems as compared to children with normal developmental pattern (Totsika, Hastings, Emerson, Berridge & Lancaster, 2011). Parents or caregivers of children with intellectual disability experience stress in term of fulfilling not only the basic needs of their children but they have to supervise them for a longer period of their life as compared to children with the normal

developmental pattern. Masulani-Mwale, Kanye, Gladston & Mathanga (2018) described that parents of children with intellectual disability reported their experiences of psychological distress. Similarly, Gupta and Kaur (2010) reported that parents having children with intellectual disability experience stress, and further, their level of mental stress is higher as compared to the level of physical stress.

The other category of disability targeted in the the current study is Autism Spectrum Disorder (ASD). According to APA, 2013, children with Autism Spectrum Disorder experience impairments in three areas. They exhibit a significant deficit in their verbal and non-verbal communication, have a prominent deficit in social interaction as well as have restricted repetitive behavioural problems. Stress experiences of parents having children with autism spectrum disorder are reported by different studies (Dardas, 2014; Gobrial, 2018; Rauf, Haque & Khan, 2018).

## Objectives of the Study

The objectives of the study are to:

- Find the relationships among PPS, PSS and QOL among the parents of children with special needs
- Examine the role of PSS as a moderator between PPS and QOL among parents who have children with special needs

## Method

In the current study, the moderating role of PSS was examined in PPS and QOL among targeted parents through a cross-sectional research design. Parents (fathers & mothers) who have children (boys & girls between age ranges of 5-18 years) diagnosed in either category of Autism Spectrum Disorder or Intellectual disability were selected through purposive sampling from the special educational institutions and health care centres of Kharian, Lalamusa, Gujrat and Gujranwala, Pakistan. Parents (146 fathers & 154 mothers) falling in age ranges from 25 to 60 years with the mean age of 41.5 years participated in the study. The exclusion criteria of the study were the parents who had more than one child with a disability, had a child with another disability, and had /herself any mental or physical disability. The instruments of the study consisted of three parts. The first part was related to the consent form for participation, the second part consisted of demographic characteristics (parental educational status, their age, profession, residence, monthly family income, child's type of disability, age and child's severity of disability) and the third part was related to

the following instruments for measuring perceived parental stress, perceived social support and quality of life of parents with special needs:

### Parental Perceived Stress Scale (Kausar, Akram, Dawood & Ahmad, 2019)

Parental Perceived Stress Scale developed by Kausar, Akram, Dawood & Ahmad (2019) was used to measure parental perceived stress. It consists of 32 items comprised of two dimensions: Primary Stress and Secondary stress. It is based on a Likert scale (5 points) ranging from strongly disagree (1) to strongly agree (5). High scores on the Parental Perceived Stress Scale indicate a high level of stress as far as low scores indicate a low level of stress. The scale has Cronbach's alpha reliability of .90 to .94 at pilot testing and field administration, respectively.

### Multi-Dimensional Scale of Perceived Social Support (MDSPSS)

MDSPSS was translated by Jabeen (2018) in Urdu language used to measure perceived social support. It is a brief tool for measurement of perceived social supports by 3 sources which are friends, family and significant others. It consists of 12 items. The scores range from 1-7, starting from 1 being the strongly disagreed to 7 being the strongly agreed. Internal consistency is also good with Cronbach's Alpha of 0.91. If the mean score ranges from 1-2.9, it indicates low support, and if it ranges from 3-5, it is an indication of moderate support exists and if it ranges from 5.1-7 indicating strong support.

### Quality of Life in Autism Questionnaire (Eapen, Crncec, Walter & Tay, 2014)

Urdu version (Kausar, Akram, Dawood & Ahmad, 2019) of QoL in Autism Questionnaire (QoLA) Part-

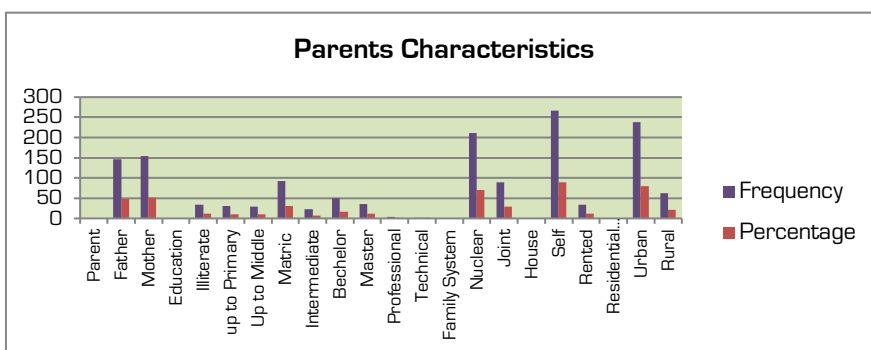
A originally developed by Eapen, Crncec, Walter and Tay, (2014) was used to measure parental perception about their own quality of life. It has 28 items. The Cronbach Alpha reliability of QoL-A Urdu version is .940.

### Procedure

The meeting was scheduled with parents of children with targeted disabilities from both government and private institutes after taking permission from their respective heads. The targeted parents were called in group settings (15-20 parents) at schools and institutes by the researcher. The researcher briefed the respondents about the study and its objectives. In order to get their willingness before the administration of standardized tools, their verbal and written consent was taken. The instructions about the scales were given to the participants, and they were asked to answer each question carefully. It took 30 minutes on average to complete all questionnaires. During the research, ethical principles of informed consent and confidentiality were monitored by the researcher. SPSS (21 version) and process Hayes (3.4 version) were used to analyze the data.

### Results

Data were analyzed by using descriptive and inferential statistics. Frequencies and percentages were run to explore the description of parents and their children's characteristics. The results depicted that there was an almost equal ratio of both parents with 51.4 (mothers) and 48.6 (fathers) percentages. Most parents (31%) were those who passed matric, had a nuclear family system (70.3%), had their own house (88.7%) and belonged to urban areas with 79.3%.

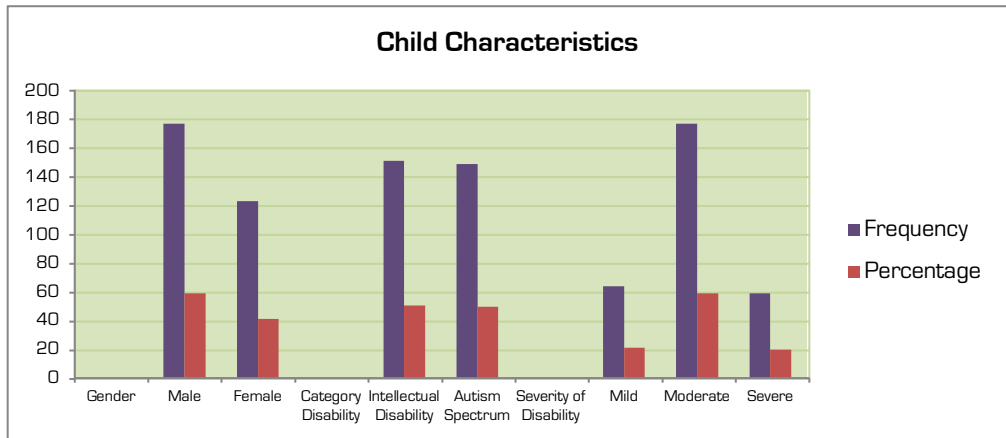


**Graph 1:** Parents Demographic Characteristics

The characteristics of the children depicted that there were 59% boys and 41 % girls with targeted

disabilities. Further, 50.3 % of children had an intellectual disability, and 49.7% of children had

autism spectrum disorder. Most children (59 %) had a moderate level of disability.



Graph 2: Child Characteristics

Pearson correlation statistical test was applied to see the relationships among PPS, PSS and QOL after checking the normality of the data. The result showed the statistically significant relationships among PPS,

PSS and QOL ( $p \leq .001$ ) among targeted parents. Further, PPS has negative relationships with PSS ( $r = -.512$ ) and QOL ( $r = -.536$ ), while PSS and QOL have positive relation ( $r = .680$ ) with each other.

Table 1. Correlation among Parent Perceived Stress, Parent Social Support and Quality of Life (N=300)

Variables	PPS	PSS	QOL
PPS	1		
PSS	-.512**	1	
QOL	-.536**	.680**	1

Note: \*\*  $p \leq .01$ , PPS= Parent Perceived Stress, PSS= Parent Social Support, QOL= Quality of Life

Moreover, moderator analysis was also run to examine the PSS as the moderator between PPS and QOL experienced among parents with special needs. Results indicated the statistically significant model ( $F(3, 296) = 111.91, p \leq .001$ ) with 72 % variance. Similarly, the interaction model brought a 21% variance in QOL.

Further, this moderation analysis indicated that PSS is a significant predictor of QOL ( $1.83, p \leq .001$ )

among parents, which represented that low PSS lead to low QOL among targeted parents. While the interaction of the parental perceived stress and perceived social support negatively and significantly predicted ( $-.009, p \leq .001$ ) the QOL among parents of special needs children. Similarly, the  $\beta$  value of the moderator ( $-.14, p \leq .001$ ) and higher ( $-.20, p \leq .001$ ) level of the interaction also showed that PPS and PSS interaction negatively predicted the QOL of the understudy sample.

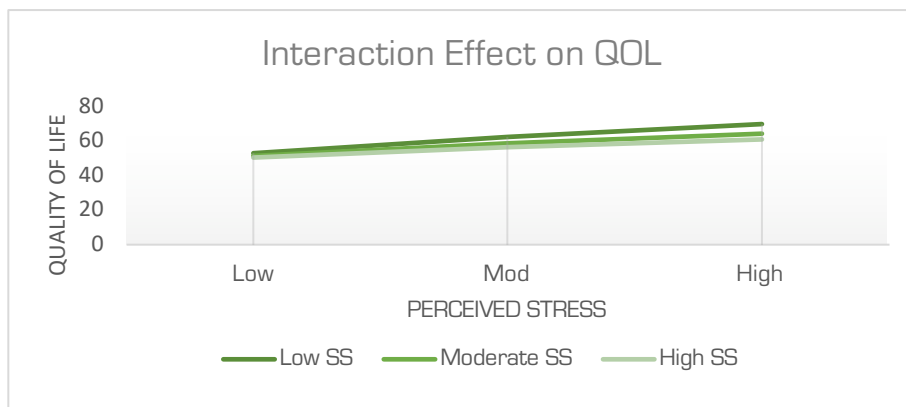
Table 2. Moderation Analysis for Quality of Life

	B	Confidence Interval	
		Lower Limit	Upper Limit
Constant	21.24*	3.25	39.24
PPSS	0.12	-.03	0.28
PSS	1.83***	1.31	2.35
PPSS*PSS	-.009**	-.01	-.004
Low	-.05	-.133	0.01
Medium	-.14***	-.197	-.087
High	-.20***	-.269	-.145

R	0.72
F	111.91***
$\Delta R$	0.53
F	13.55***

Note: \* $p \leq .05$ , \*\* $p \leq .01$ , \*\*\* $p \leq .001$ , PPSS= Parental Perceived Stress Scale, PSS= Perceived Social Support

Furthermore, the slopes of the interaction effects levels on quality of life were also showed in graph 3.



**Graph 3:** Interaction effect of Perceived Parental Stress and Perceived Social Support on Quality of Life

## Discussion

The main objectives of the current research were to find the relationship among the PPS, PSS and QOL. The results given in Table 1 indicated that PPS was negatively correlated with quality of life and perceived social supports, whereas perceived social supports appeared to have a positive association with quality of life. The results are consistent with the findings of the previous research of Pandey and Dubey (2019), which reported the negative correlation between parental stress and social support among parents having children with special needs. Similarly, Zeng, Hu, Zhao, and Stone-Macdonald (2020) found a negative association among family support, QOL and parental stress among the parents having children with special needs.

In short, having a good social network helps parents to manage their stress. This is well known that the process of raising up a child with special needs is very challenging for both parents, and this experience may become a reason for stress and other psychological problems. The caregivers have to look after their homes financially and socially also. They have to earn; thus, they go through different social and economic pressures. In addition to the fore mentioned responsibility, they have to fulfil the special requirements of the children with disabilities. They have to put extra effort, time, money and other resources while raising up their children with special needs, which exaggerate their stress. Therefore, the

present study also explored the relationship between QOL and PS among the parents of special children. Gupta and Kaur (2010) found physical and psychological distress, which may lead to poor QOL among the caregivers having children with intellectual disabilities. A further positive relationship has also been observed among the parents of special children. The results of recent researches indicated the association between quality of life and good interpersonal relationships. One cannot have healthy interpersonal relationships without social support. Huiracocha et al. (2017) reported that PSS is very important for families having children with special needs; otherwise, the physical and psychological health of both of the caregivers and children with special needs are at risk.

The second objective of the present study was to examine the moderating role of the PSS between the QOL and PPS among parents having children with special needs. The results of regression analysis reported that PSS plays a significant moderating role between PPS and QOL. The results are in line with the previous study conducted by Lu et al. in 2018. They found that parenting stress and social support are the significant elements of the QOL among caregivers of children with special needs. Moreover, social support played a vital moderating and mediating role in the levels of parenting stress and satisfaction of life. In other words, the parental stress may be minimized or overcome as well as QOL can

be improved by enhancing the social support to the caregivers or parents of children with disabilities.

### **Limitations**

The present study did not focus on the factors of parental stress and QOL in depth through the qualitative method. Moreover, the parent of children with special needs other than autism and intellectually disabled could not be included in the present study.

### **Clinical Implications of the Study**

- Following the findings of the current study, parental stress can be reduced by providing them healthy social support.
- Special educational institutes should also focus on parental counseling and training sessions.

- Awareness based seminars and training workshops could be beneficial for parents in understanding the nature of their children's disabilities. Hence, they would be in a position to manage their children more effectively.

### **Conclusion**

Present research findings highlighted that parents experienced a high level of stress when they have children with special needs. It was also found that social support improves QOL and reduces the stress level of parents of children with special needs. It can be concluded that the upbringing and care demands of a child with special needs is taunting. Extra social support and provision of needed services will not only be helpful in the stress reduction of parents but also facilitates in improving QOL of the parents of children with special needs.

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