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Development of an Indigenous Parental Perceived Stress Scale for Children with Autism Spectrum Disorder

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The major aim of this study was to develop an indigenous Parental Perceived Stress Scale in Urdu for parents of children with Autism Spectrum Disorder (ASD). The research was divided into two phases: In Phase-I, indigenous Parental Perceived Stress Scale was developed and in Phase-II, psychometric properties of the scale were established. An item pool of 46 items was generated based on the Lazarus and Folkman's (1984) stress model and interviewing the parents having children with ASD. A purposive sampling technique was used to select the sample of 502 parents from different special educational institutes. Generated items were evaluated by a panel of experts and were pilot tested on 25 parents. Exploratory factor analysis fixed to seven factor structure with 42 items. Confirmatory factor analysis yielded 32 item scale revealing Cronbach alpha of .95 indicating the scale as a reliable and valid scale for the measurement of parental perceived stress for parents of children with ASD. Clinical implications of the study indicate its use for counseling and clinical services.

Keywords. Autism spectrum disorder, perceived stress, primary stress, secondary stress

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In social world humans are connected to each other in the chain of different relations. These relations have their own structural and functional mechanisms. They have their own needs and demands; in order to foster the relationship, persons and parties involved in the relationships have to perform certain roles. Among all these relations, the most demanding and intimate relation in nature is parent. Parenting is the most demanding in term of taking care of children and supporting during journey from depending infant to an independent individual. During this journey, parents experience worries, concerns, demands, stresses, excitements, happiness, and expectations. Parenting children with normal developmental patterns have an end of struggle, but this struggle becomes lifelong when a child with developmental disability is born in the family. Parenting a child with disability incurs emotional disturbance and stress, especially when the nature of disability is severe and associated to many of the unknown factors and uncertain future prospects. Resultantly, stress caused in parents may lead to different types of psychological disturbances and sometime psychological disorders in parents (Deater-Deckard, 1998).

In this regard, current study targeted the parents of children with ASD which is a neuro-developmental disability (American Psychological Association, 2013). It is also called a triad disorder as impairment exists in three major areas of life: Social interaction; communication; and restricted, repetitive, and stereotyped patterns of behavior. Autism usually gets evident before age 3 that adversely affects a child's functioning in all areas. Suhail and Zafar (2008) reported 103 out of 1633 (6.31%) children suffering from autism in special education schools of Lahore, Pakistan. Similarly, Imran and Azeem (2014) reported that 32 in 1000 to (3.2%) children are suffering from Autism in Lahore with 2:1 male to female ratio. Krohne (2002) reported that stress needs adaptation in terms of physiological, cognitive, and behavioral responses. It becomes evident when the individual feel discrepancy between his/her resources and demands of the environment. He describes stress in following three ways. Firstly, stimulus is a factor for creating stress for the person. It can be disturbing events, problematic circumstances, and particular events that happen in one's life. Secondly, response is how an individual reacts to the stressful factor. Thirdly, process refers to mechanism of individual's adjustment between environment and person by means of different interactional and adjustment patterns. Stress is a transactional process, which is directly performed according to individual's emotive, cognitive, and behavioral strategies. The events/situations or actions that provoke stress are called stressors**,** and they have a wide range from a very simple event

to a complex situation.

Perception of Stress among Parents of Children with ASD

Parents of children with ASD are highly vulnerable to experience elevated levels of stress. Dardas (2014) studied psycho-social impacts of raising children with Autism in a sample from the Arab world. His findings revealed that parents of children with Autism experience significantly high levels of parenting stress. Tripathi (2015) conducted a case study on parenting style and parental level of stress having children with ASD in Northern India on a sample of 320 parents. Results revealed that most of the parents (81%) were having high level of stress. There are some other empirical evidences which indicate that parents experience high level of stress in response to a child with disability (Batool & Khurshid, 2015; Dervishaliaj, 2013; Paden & James, 2017; Sabih & Sajid, 2008). Rauf, Haque, and Khan (2018) reported that symptoms severity of children with ASD is associated with parental stress. Qayyum, Lasi, and Rafique (2013) reported that parental distress is also because of their children's behavioral issues along with their limited physical and functional capacities. Further, limited medical resources and financial services are the factors in creating the distress in parents. Pisula and Porębowicz-Doersmann (2017) reported high level of stress among parents of children with ASD. Khawar and Saeed (2016) explored the stressful effects of autism on mothers' parenting. Their findings indicate that mothers of children with autism had child-rearing and life stress as compared to normal children. Different empirical evidences also suggested that there is difference in perception of stress among fathers and mothers of children with ASD. Rauf et al. (2017) reported that mothers of children with ASD experienced more stress in domain of family problems as compared to fathers' stress related to the lack of services. Many other empirical evidences also reported that mothers of children with ASD had significantly more stress as compared to fathers (Foody, James, & Leader, 2015; Moes, Koegel, Schreibman, & Loos, 2015; Ozturk, Riccadonna, & Venuti, 2014; Soltanifar et al., 2015).

Need of Indigenous Stress Scale

Stress in parents of children with special needs is measured by using the different standardized scales. Mayer, Davis, and Schoorman (1995) assert that a standardized, specific scale is important to identify issues which could be addressed in practice, and to explore relationship between various sources of stress and parental and child

characteristics. Kumar (2008) studied the stress among parents of mentally challenged children in India by using the Perceived Psychological Stress Life Events Scale (PSLE). PSLE Scale for parents having children with mental retardation was developed by Sheela and Kumar (2003). Family Stress and Coping Interview for mental retardation is a semi-structured interview schedule developed by Girimaji, Srinath, Seshadri, and Subbakrishna (1999). It has 4-point Likert pattern of responses and based on semi-structured interview, parents sometime may not be comfortable with format. Therefore, self-reporting would be less threatening and less embarrassing for parents as taken up in development of scale in the current study. Dardas (2014) used a self-administered questionnaire for parental stress to measure stress of raising children with autistic disorder in Arab sample.

Existing literature indicates availability of number of stress scale, but most of these are western culture based. Parenting Stress Index-Short Form (Abidin, 1992) consisted of three domains; parenting distress, parent child dysfunctional interaction pattern, and difficult child. Dardas and Ahmad (2013) reported that difficult child and Parental Child Dysfunctional Interaction subscales did not exhibit structural stability in a psychometric study of Parenting Stress Index-Short Form with parents of children with ASD.

Questionnaire on Resources and Stress (QRS) was also used to measure the parental stress of children with ASD (Rauf et al., 2018). QRS has 51 items with five dimensions. Two dimensions of "family, parent problems" and "pessimism" are translated and adapted that were developed in foreign culture and rest of three dimensions are developed by author in Pakistani culture. QRS has 51 items, hence, it is relatively long questionnaire and further two dimensions are adapted and translated. Further, QRS is developed by using the data from Rawalpindi and Islamabad that may not be representative of culture in Punjab province. Current study aims at developing scale for measuring parental perceived stress by using 2 dimensions 'primary stress' and 'secondary stress' based on transactional model of Lazarus and Folkman (1984) through parental interview. It is very much important to incorporate the parental perspective in development of an indigenous tool to measure parental perceived stress. Parental perspective may gives a more accurate picture of perceived stress. Furthermore, Parental Stress Scale by Berry and Jones (1995) was translated and adapted by Khanzada and Bashir (2013) in Pakistan. It contains 18 items exploring positive and negative domains of parenting of children with and without clinical problems. Stress is a phenomenon which is highly based on environmental factors. Many of

the environmental factors such as availability of resources in the environment, available, social support, and awareness level about the disability may affect the stress level of family. Similarly, parental and family's own resources such as parental educational and awareness level, no of family members, severity level of disability, and parental economic status may contribute in stress level. These factors are usually different in developed countries as compared to a developing country like Pakistan. In developed countries, medical and health services are usually available and accessible of general public. On the other hand, in developing countries many of the basic needs are not generally met rather there are lack of health and medical services for general population. Similarly, in Pakistan, parents face lack of medical and health services for diagnosis and treatment of ASD. Many special educational schools are unable to cater the developmental disorder of ASD because of its individual based needs and training. Mostly parents also have financial issues because of the low monthly family income and they are unable to afford the treatment services of ASD available in big cities of Pakistan. Arshad, Iqbal, Waris, Ismail, and Naseer (2016) reported that Pakistan is spending about 0.8 % on health care even lower than Sri Lanka (1.4%) and Bangladesh (1.2%). They further reported that lack of awareness, perception about health related facilities, and financial issues are major resisting factors in provision of health care services.

Keeping in view the available literature, a Pakistani culture based scale for measuring parental stress was very much needed. Therefore, current study is designed to fill this gap. It was aimed to develop an indigenous scale for measuring parental perceived stress having children with ASD. Items of the measure are formulated on Lazarus and Folkman's (1984) theory of stress through parental interviews. Aim was to develop a reliable and valid measure to study stress among parents of children with ASD in Pakistani culture.

Theoretical Model of Perceived Stress

Scale is based on Lazarus and Folkman's (1984) "Transactional Model" of stress. They defined stress as individual's appraisal of challenging life events. *Primary appraisal* is evaluation of the challenge, threat or harm posed by a particular event. *Secondary appraisal* is assessment of individual's abilities and resources for coping with that event (Lazarus & Folkman, 1984). In the context of the present study, this theory can be best understood as the primary appraisal of the situation when parents have children with ASD, they evaluate the situation as challenging, threatening or harmful. When

they do the secondary appraisal of their insufficient resources in terms of many factors, for example, lack of awareness, dependency of the child, need of special educational services, lack of social support, and financial problems; it may cause stress to cope with these challenging situations. This primary and secondary appraisal associated with child with ASD in the family leads to overloaded stress for parents.

Objectives

The objectives of the study are to:

1. Develop an indigenous tool of Parental Perceived Stress Scale (PPSS) for parents of children with ASD in the context of Pakistani culture.
2. To determine the psychometric properties of indigenously developed Parental Perceived Stress Scale.

Method

Current study consisted of two phases. In Phase I, PPSS was developed. In Phase II, psychometric properties of scale were determined.

Phase I: Development of Parental Perceived Stress Scale (PPSS)

Phase I was consisted of three stages**.** In first stage of Phase 1, items were generated on the basis of field interview and aforementioned Lazarus and Folkman (1984) transactional model. Expert evaluation of items was conducted on second stage of Phase I. At third stage, Pilot study was conducted.

Stage I: Generation of item pool. For item generation, 10 parents/caregivers (5 mothers & 4 fathers and 1 caregiver who was member of extended family taking care of child) were interviewed. A performa based on semi-structured interview was prepared for identifying the stress related aspects of their children with autism. Commonly reported problems stated by parents of children with ASD were phrased as items. Followings are some examples of questions asked in interview from parents: State some of your feelings, emotions, and behaviors about your child with ASD?; Report some common problems you face while rearing your child with ASD; and List some of your apprehensions about your child with disability. On the other hand, Lazarus and Folkman's (1984) transactional stress model was used to develop the items for the PPSS**.** According to the

model, stress is generated by the individuals' evaluation of stressors (primary stress) and individuals' evaluation of their resources to deal with those stressors (secondary stress). In the current study, items were also formulated following these two dimensions. On the whole, items were generated by following the parental comments and transactional model of Lazarus and Folkman (1984). After compiling the generated items in PPSS, total 46 items in Urdu language were pooled up.

Stage II: Content validity through experts' evaluation of items. Total 46 items of initial form of PPSS were presented to a panel of 5 experts (two PhD and three M.Phil in Psychology) of relevant field for content validity. Purpose of expert evaluation was to get the experts' opinion about the contents of each item either it is measuring the stress related to children with ASD. Through experts' evaluation, suitability of items in the scale was evaluated on four-point scale of *very important* (4), *important* (3), *important but not necessary,* and (2) *unnecessary* (1). They also reported about the ambiguity and inappropriateness of words or items. Expert reported that most of the items were relevant and reasonably constructed on targeted domains under consideration. However, two items were deleted due to repetition of the concept and some minor changes were incorporated in wording and phrasing of items as per their suggestions. Few words were substituted with words easier to understand for general public. CVR was measured by using following formula: CVR = n_e-(N/2)/N/2 (Cohen, Swerdlik, & Sturman, 2013).

Table 1

Content Validity Ratio of Items

No. of Items	Items	Range (from1-4)
22	1,4,5,6,7, 14,15,16, 18, 19, 20, 21, 22,23,26,27, 31, 34, 40,41,42,44	3.8-4.0
15	2, 3, 8,9,10, 11, 17, 24,28,29, 36, 37,38, 39, 43	3.5-3.79
4	12, 13,25,32,	2.83-3.49
3	30,37,45	2.5-2.80
2	33, 35	2.0-2.40

Table 1 indicates the content validity of 46 items rated by 5 experts. When three or more experts rated items as very important to important, but not necessary were retained in item pool and items rated as unnecessary were deleted. Followings are some sample questions from PPSS: It is very difficult to physically manage my

child with ASD along with other household responsibilities; I fulfill the needs of my child with ASD alone; 3. I can never get rid of stress about my child any time; The lack of professional teachers in special educational institutions is one of the cause of my concern.

Stage III: Pilot study. Pilot study was conducted on 25 parents of children diagnosed with ASD who were diagnosed through Childhood Autism Rating Scale. Targeted parents were recruited from Gujranwala and Gujrat city through convenient sampling technique and they were instructed to fill the form according to their opinion and understanding about the stated items. Data were collected by using the initial form of PPSS. Age range of the participants (parents) was 25 years to 50 years. Initial form of PPSS was used that consisted of 44 items. The response format of PPSS was Likert type based on 5-point scale with *strongly agree* = 5, *agree* = 4, *neutral* = 3, *disagree* = 2, and *strongly disagree* = 1. High scores indicated high level of stress, and low scores indicated low level of stress. Pilot study was conducted in order to judge the items' comprehension and best items based upon response rate. Parents were approached at special educational institutes during their monthly visits. They were briefed about the purpose of conducting the pilot study. Instructions (in Urdu language) were given to the participants. Participants filled the questionnaire by themselves. During pilot study, there were some commonly asked queries, for example, meaning of professional support and examples of environmental factors. It was decided to explain the queries with uniform words in field administration. In pilot testing, the Cronbach' alpha was .90 which indicated a high internal consistency. In pilot testing, it was observed that mothers wanted to talk about their children with ASD and their level of stress in detail. Keeping in view their need, in the second phase of stress management, mothers' qualitative perspectives were also obtained through open-ended questionnaire.

Phase II: Establishing Psychometric Properties

In Phase II, pilot tested initial form of PPSS was administered to establish psychometric properties including; internal consistency; Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). Total 505 parents consented to participate in the study and 502 completed the questionnaire. Exploratory factor analysis and confirmatory factor analyses were run on different data sets of 251 parents each.

Exploratory Factor Analysis. In order to determine the basic structure of the newly phrased stress scale, EFA was tabulated.

Sample. Purposive sampling technique was used to select the sample of 251 participants (127 fathers & 124 mothers) having children (male & female) with ASD (mild to severe) from Gujrat, Gujranwala, Lahore, Kharian, Lalamusa, and Jhelum. Total 251 participants completed the questionnaire. Age range of participants was between 21 to 60 years. Parents who had children with multiple disabilities, more than one child with disability, and severity unspecified were excluded from the sample. Parents of children with ASD were approached in the special educational schools where their children were enrolled.

Table 2

Frequencies and Percentages of Demographic Variables of Participants (N = 251)

Variable Categories	*f*	%
Parent		
Fathers	127	50.6
Mothers	124	49.4
Parental Marital Status		
Married	245	97.6
Divorced	2	.80
Widow	3	1.2
Separated	1	.40
Family System		
Nuclear	155	61.8
Joint	96	38.2
Residential Area		
Urban	212	84.50
Rural	39	15.50
Gender of Special Child		
Male	165	65.70
Female	86	34.30
Severity of Child's Disability		
Mild	44	17.50
Moderate	147	58.60
Severe	60	23.90
Age of Special Child (years)		
4-8	75	29.90
9-13	98	39.00
14-18	78	31.10

Table 2 indicates that the parental category comprising of fathers and mothers. The marital status of majority of the parents is married

and very few are divorced, widow, and separated parents. Further, it indicates that majority of parents have male children with ASD as compared to female. Further, it also indicates that highest category of parents have children with moderate level of disability following by the severe and mild level of disability that is ASD. Maximum parents have children that fall in the category of 9 to 13 years of age, rest of two categories of age groups of children have almost equal number.

Measures. For field administration, measures consisted of two parts:

Demographic form. It was used to get information related to age, education, occupation, monthly family income, no of children, residential area, gender, and age of child with disability, family system, severity of illness and birth order of child with disability.

Initial form of PPS. Parental perceived stress was measured by using initial form of PPSS, consisting of 44 items. Response pattern was based on five-point Likert scale.

Procedure. After taking permission from principals, heads, and directors of schools/special educational institutes, parents were called to school/institute in group of 8 to 12 parents according to the given schedule by the relevant institute. After giving a brief introduction, purpose of study was explained to parents. Written consent was taken from each parent. Data were collected through self-reported questionnaire. They were asked to respond the items according to their perception closely associated to their emotions, behaviors, and cognition. On average, each administration took 15-20 minutes in completion of Initial form of PPSS. Study was approved by Advanced Study and Research Board of University of Gujrat. Ethical principle of informed consent and confidentiality was maintained in the study. Participants were also informed about their right to withdraw from research at any stage. Risk-benefit ratio was also monitored in the study. Participants were not bound to show their identity, rather they were assigned ID numbers.

Results. Reliability of scale was obtained, frequencies, and percentages a cross different demographic variables were computed. Factors of the Scale were explored through exploratory factor analysis and further, factors were confirmed through confirmatory factor analysis. Before conducting the EFA, sampling adequacy test was run. Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy for pilot

tested items (44 items) of initial form of PPSS reveal that these set of variables was .91 falls in the range of being superb (.91>.90; Kaiser, 1970). Bartlett's test of sphericity indicated X^2 value of 8098.593 ($p <$ .001). It indicates the factorability of the R-matrix and data set of PPSS is suitable for exploratory factor analysis.

Table 3

Factor Loading on Parental Perceived Stress Scale after Varimax Rotation (N = 251)

Final Items	Factors						
	1	2	3	4	5	6	7
3	.52	.48	.12	.10	.13	.40	.35
6	.43	.41	.10	.03	.14	.40	.12
7	.30	.27	.25	.26	.13	.28	.14
8	.64	.47	.01	.14	.05	.10	.01
9	.64	.33	.04	.05	.10	.06	.04
10	.45	.30	.09	.07	.01	.41	.43
11	.64	.60	.35	.10	.14	.21	.10
12	.40	.35	.32	.40	.37	.30	.03
14	.78	.55	.24	.03	.37	.20	.10
15	.70	.58	.01	.05	.35	.04	.21
16	.76	.47	.03	.02	.33	.30	.20
13	.31	.48	.34	.13	.32	.15	.02
17	.01	.60	.15	.35	.34	.46	.37
18	.04	.67	.19	.30	.04	.11	.11
19	.02	.70	.18	.28	.01	.14	.17
20	.08	.66	.23	.31	.10	.14	.01
21	.01	.74	.23	.25	.10	.29	.03
22	.01	.74	.31	.27	.10	.31	.02
23	.30	.71	.22	.25	.26	.15	.16
24	.43	.55	.10	.38	.20	.36	.10
40	.32	.64	.80	.44	.02	.14	.01
41	.22	.67	.76	.28	.20	.16	.11
42	.25	.70	.81	.34	.14	.11	.10
43	.22	.54	.70	.30	.10	.24	.22
44	.21	.62	.81	.37	.10	.18	.02
30	.01	.27	.06	.49	.22	.33	.20
31	.65	.35	.33	.70	.15	.13	.03
32	.37	.61	.38	.80	.22	.25	.10
33	.36	.50	.43	.80	.27	.10	.20
34	.15	.44	.41	.66	.14	.04	.23
25	.37	.30	.10	.32	.42	.01	.03
26	.30	.53	.29	.38	.81	.35	.20
27	.38	.58	.24	.35	.80	.29	.20

Continued…

Final Items	Factors						
	1	2	3	4	5	6	7
28	.31	.57	.24	.37	.61	.20	.07
29	.34	.23	.27	.31	.39	.08	.27
1	.32	.44	.38	.19	.35	.79	.12
2	.28	.45	.48	.06	.43	.83	.12
4	.40	.37	.31	.01	.28	.60	.07
5	.08	.41	.40	.10	.52	.69	.13
35	.03	.41	.38	.27	.42	.75	.32
36	.23	.04	.44	.35	.02	.24	.55
37	.03	.32	.39	.25	.03	.20	.55
38	.11	.37	.37	.14	.13	.20	.53
39	.13	.33	.29	.31	.20	.21	.41
Eigen Value	3.39	16.18	2.67	2.38	1.82	1.36	1.21
Variance Percentage	11.58	13.63	11.04	9.30	7.00	4.21	3.34

Table 3 indicates that most of the items have loadings between .60 to .80. Items were retained with the criteria of equal to or greater than .30 loading. If an item has loading more than .30 in more than one factor, then criteria for content relevance of that item with other items is used for item retention in respective factor. It further indicates that all factors have a reasonable number of items.

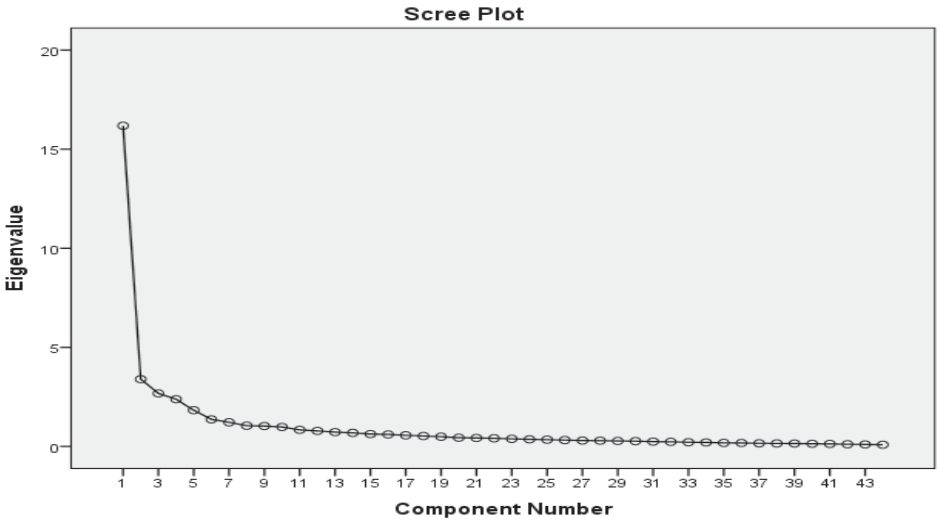

Figure 2. Scree plot indicating factor solution.

The scree plot also indicates factor solution with a clear break after 9th component. Keeping in view the factor loading and theoretical relevance, only 7 well-defined factors were retained, which accounts the 64.14 of total variance.

EFA was run with varimax rotation and by using the Principle Component Analysis (PCA) in order to explore the factor structure in the scale. Initial Analysis with Eigen value > 1.00 (the Kaiser-Guttman criterion) extracted 9-factor solution accounting for 70.72% of total variance. Items selected in certain factor based on high loading. Factor no 8 had only one item no 35 with the loading of .752. Due to a single item, factor 8 was deleted. Items explored in factor 9 have relatively weak loading < .3. Due to weak loading items, factor 9 was also deleted. Following the thematic understanding of the items in each factor, researcher labeled the factors as: Factor 1 was labeled as Perceived Emotional Stress, Factor 2 as Perceived Social Stress, Factor 3 as Perceived Financial Stress, Factor 4 as Perceived Lack of Resources, Factor 5 as Perceived Lack of Social Support, Factor 6 as Perceived Physical Stress, and Factor 7 as Perceived Lack of Knowledge. Theoretically, Factor 1, 2, and Factor 6 seemed to be covering Primary Stress domain of Lazarus and Folkman's (1984) stress model, while, Factor 3, 4, 5, and factor 7 were covering Secondary Stress domain.

Confirmatory Factor Analysis. Factors retained after EFA, CFA was run on different data set of 251 participants by using the 42 items for measurement of model, factor structure, and determination of dimensionality of initial form of PPSS by using the AMOS-21.

Sample. For CFA, sample of 251 participants (117 fathers, 133 mothers & 1 caregiver) having children (male & female) with ASD (mild to severe) diagnosed through, Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1988) from Lahore, Gujranwala, Gujrat, Lalamusa, Kharian, and Jhelum was selected. Inclusion and exclusion criteria was same as for EFA data set.

Table 4 indicates that the parental category comprises of both fathers and mothers. Further, it indicates that majority of parents have male children with ASD as compared to female children. It also indicates that highest category parents have of children with moderate level of disability following the severe and mild level. Regarding the age group of children, children fall in group of 9 to 13 years with the highest frequency in the sample.

Table 4

Frequencies and Percentages of Demographic Variables of Participants (N = 251)

Variable Categories	*f*	%
Parent		
Fathers	117	46.61
Mothers	134	53.38
Gender of Child with ASD		
Male	167	66.53
Female	84	33.46
Severity of Child's Disability		
Mild	37	14.74
Moderate	151	60.15
Severe	63	25.09
Age of child with ASD(years)		
4-8	59	23.50
9-13	121	48.20
14-18	71	28.28

Same measures, procedure, and ethical principles were used in data collection for CFA as followed in EFA.

Results. CFA run through AMOS This structure did not indicate a good fit to the data (chi-square = 2257, *df* = 798, CFI = .806, RMSEA = .086, and GFI =.706) as the value of CFI was not in acceptable limit of .90. Modification indices were used to re-consider the model keeping in view the co-variance and regression weights. Items 11, 13, 23, 24 were deleted on the basis of co-variance. Item number 30 was deleted on the basis of redundancy. Item number 4, 12, 16, 25, and 29 have high regression weights, hence, these were deleted due to their problematic status in the model. Execution of 4 items were run: item no 9 executed to item number 8; item number 15 to item number 14; item number 18 to item number 17; and item number 16 to item number 15 resulting in total of 32 items out of 46. CFA was run again on these 32 items to measure the model. The model indicated a good model fit with (chi-square = 977.132, *df* = 439, CFI = .901, RMSEA = .070, and GFI = .811). In final model, 7 factors were confirmed with 32 items.

Table 5

Factor Loadings for Seven Factors of PPSS (N=251)

Item No.	Factor Loadings	Item No.	Factor Loadings
Perceived Physical Stress		**Perceived Financial Stress**	
1	.59	40	.42
2	.39	41	.57
5	.51	42	.35
Perceived Emotional Stress		43	.90
3	.57	44	.54
6	.59	**Perceived Lack of Resources**	
8	.45	31	.38
9	.51	32	.62
14	.64	33	.92
15	.52	34	.66
16	.60	**Perceived Lack of Knowledge**	
Perceived Social Stress		36	.67
17	.74	37	.43
18	.50	38	.54
19	.54	39	.55
20	.62	**Perceived Lack of Social Support**	
21	.49	26	.66
22	.47	27	.69
-	-	28	.69

Table 5 indicated the standardized regression weights or factor loadings for all 32 items of PPSS. It depicted that all of the items have factor loading > .30 in each factor. Model fit indices are also established (CFI = .90, RMSEA = .06, GFI = .81) indicating the values are in acceptable limit and indicating a good model fit.

Pearson Product Moment correlation was used to measure the correlation among seven factors. Table 6 indicates that there is significant positive correlation among all seven factors. Cronbach's alpha reliability coefficient of Parental Perceived Stress Scale of 32 items and subscales have high reliability. Further, primary and secondary stress scales also have high internal consistency (see Table 6).

Test-retest reliability. Value of .79 indicates significantly reliable coefficient of Parental Perceived Stress Scale over measuring time after three weeks on a sample of 65 parents (30 fathers & 35 mothers) of children with ASD.

Table 6

Correlation Among Factors of Parental Perceived Stress Scale (N = 251)

Variables	1	2	3	4	5	6	7	8	9	10	*M*	*SD*	α
1.Perceived Social Stress	-	.56*	.53*	.39*	.52*	.34	.61*	.86*	.67*	.83*	29.08	8.89	.80
2.Perceived Emotional Stress		-	.42*	.37*	.30*	.46	.51*	.90*	.56*	.77*	36.95	8.00	.88
3.Perceived Financial Stress			-	.50*	.40*	.25	.70*	.52*	.84*	.77*	16.38	5.71	.90
4.Perceived Lack of Resources				-	.50*	.35	.54*	.50*	.80*	.72*	17.07	5.01	.88
5.Per. Lack of Social Support					-	.35*	.43*	.55*	.74*	.72*	15.12	5.16	.86
6.Perceived Physical Stress						-	.35*	.70*	.41*	.58*	14.10	3.73	.90
7.Per. Lack of Knowledge							-	.64*	.85*	.83*	13.57	4.44	.91
8.Primary Stress								-	.66*	.90*	56.66	11.93	.90
9.Secondary Stress									-	.92*	52.21	14.24	.92
10.Parental Perceived Stress Tot.										-	108.76	23.87	.94

Note. Per. = Perceived; Tot. = Total

*$p < .01$.

Convergent and discriminant validity. Convergent and divergent validity of newly developed PPSS was established on 81 (36 fathers & 45 mothers) participants. Statistically significant positive correlation (r = .29, p < .001) between scores of PPSS and Urdu translated and adapted version (Khanzada & Bashir, 2013) of original Parental Stress Scale (Berry & Jones, 1995) showed convergent validity of PPSS. It was also supplemented with the statistically significant positive correlation (r = .24, p < .05) between the scores of PPSS and Level of Frustration Tolerance of Symptom Checklist-R (Rehman, Dawood, Rehman, Ali, & Mansoor, 2009). Discriminant validity of PPSS was established by examining the correlation among scores of PPSS and scores odu Urdu versions of Subjective Happiness Scale (Lyubomirsky & Lepper, 1999) and Satisfaction with Life Scale (Pavot & Diener, 2013). Findings established discriminant validity by showing the statistically nonsignificant correlation between scores of PPSS and Subjective Happiness Scale (r = -.12, p > .05); similarly, nonsignificant correlation between scores of PPSS and Satisfaction with Life Scale (r = -.04, p > .05).

Discussion

Current study was carried out to develop an indigenous PPSS for parents/caregivers of children with ASD.

First objective of the study was to develop an indigenous PPSS to measure the stress among caregivers/parents of children with ASD. In order to have an indigenous perspective, the procedure of generating the item pool indicated that items were developed based on commonly reported parental problems along with the transactional model of Lazarus and Folkman (1984). The model explained that stress is based on two types of appraisal; first when individual appraise the stressor as challenging events, it is called primary appraisal. In current study, parents perceived the presence of child with ASD, primary appraisal causes primary stress. Second type of appraisal is based on perception of resources to meet the challenge. In current study, parents evaluate their resources to meet the needs of their child with ASD. This secondary appraisal causes secondary stress. Finally, primary and secondary stress give an overall account of parental perceived stress. Contents of items were based on commonly reported aspects from Pakistani parents. Further, content validity of items was evaluated by five experts in the cultural context of Pakistan. Newly developed PPSS is different from already existing measures of perceived stress among parents of children with ASD. It consists of 32 items as

compared to QRS with 51 items. PPSS is an indigenously developed scale in Pakistani culture.

Second objective of the study was to determine the psychometric properties of the scale. Result indicated that the PPSS had good internal reliability, test-retest reliability, and content validity. The Cronbach's Alpha for both dimensions that is Primary Stress and Secondary Stress were quite high. Similarly, test-retest reliability of PPSS was also high. In test-retest reliability, environmental factors, for example, noise, room temperature; and subjective factors, for example, participants' general health condition were controlled. Results are supported by McCrae (2014) and McCrae, Kurtz, Yamagata, and Terracciano (2011) who reported that test-retest is a better index of the reliability. Churchill (1979) reported that value above .70 reliabilities is appropriate. Table 6 indicated statistically significant positive correlation among all factors of parental perceived stress. Theoretical relevance of factors indicated that three factors are categorized as one dimension of primary perceived stress by including the factors of perceived emotional stress, perceived social stress, and perceived physical stress. Rest of the four factors of perceived financial stress, perceived lack of resources, lack of social support, and perceived lack of awareness have been categorized under the second dimension of secondary stress.

Content-wise, findings supported the structure of two domains of primary and secondary stress labeled by following the transactional stress model of Lazarus and Fokman (1984). Deeken et al. (2017) and Wu and Amtmann (2013) also reported the two factors of perceived stress scale among clinical population. One factor is related to general stress and other factor is related to the individual's abilities to cope with the stressors as similar to secondary stress of PPSS. Further, findings are also consistent with Taylor (2015) who reported two factors structure as a good description of model for psychometric evaluation of Perceived Stress Scale. Qayyum et al. (2013) supported the findings by the notion that caregivers perceived disability as functional and physical limitations of their children accompanied with their behavioral problems. Lack of financial resources and limited access to medical and rehabilitation services are the important factors in creating the distress in parents. Parenting Stress Index (Abidin, 1992) consisted of three domains. One of the dimensions is measuring parental distress as stress is measured in PPSS, but other two dimensions of dysfunctional parent child interactional pattern and difficult child are different from currently developed PPSS. Similarly, QRS has two adapted domains of pessimism and family, and parent problems differently categorized in PPSS. Some of the indicators like

lack of knowledge and financial pressures are same in both measures.

Keeping in view the above mentioned studies, findings of the current study are in line with the perspective of Pakistani culture as in Pakistan; children are considered the direct responsibility of the parents in term of their physical and behavioral management. Emotional stress, physical stress, lack of resources, lack of professional treatment services, and low income are the main factors faced by parents of children with ASD in Pakistan. These results are also in line with the past researches (see Hallahan & Kauffman, 1997). They reported that one stressor for parents who have children with special needs are that they may continue to care their children for extended period of time, which can be physically and emotionally draining. Lack of resources such as low income and lack of awareness have great effect in increasing the level of stress in parents of children with special needs. Research evidences of Padden and James (2017) and Mekki (2012) suggest that parents of children with autism experience significantly high level of stress because of different factors.

PPSS had statistically positive significant correlation with already developed similar measures that is Urdu version of Perceived Stress Scale and Symptom Checklist of Level of Frustration Tolerance. Findings established the evidence of convergent validity. It can be concluded that parents who scored high on PPSS, also experienced high scores on Parental Perceived Stress and had low level of frustration tolerance. Findings are consistent with the reporting of Anastasi and Urbina (1997) who reported that the convergent validity is set to be established if there is a significant positive relationship exist among similar constructs/scales. Discriminate validity of PPSS has been established by having the nonsignificant correlation among scores of PPSS with Subjective Happiness Scale and Satisfaction with Life Scale. Anastasi and Urbina (1997) also confirmed that the discriminant validity is said to be recognized if the dissimilar construct showed nonsignificant relationship. It can be concluded that parents who have high level of perceived stress, they tend to experience low subjective feelings of happiness as well as low level of satisfaction with life.

Limitations and Suggestions

Regarding the limitations of the study, one of the limitations is that the targeted population was not available in all of the special educational institutes/schools. Due to the requirements of this specific

type of neuro-developmental disability, every special educational school does not cater this category. Further, parents/caregivers were called to special schools, so data collection took time more than the stipulated timeline. One of the limitation of the study is to label the factors by researchers following the theoretical perspectives of items on their own. It is recommended to get subject matter experts' opinion in this regard. Primary and secondary dimensions were declared on the basis of content only, otherwise, it is recommended to do second-order factor analysis to validate the theoretical foundation of the PPSS. Many items were discarded after CFA that were retained at the first place in EFA. Had the data be large enough than existing in EFA, much stable factors would have been achieved with more stable factor loadings at any one factor.

Future scale development studies can also add domain of siblings related to perceived stress, so the perceived stress of family members of children with ASD can be measured by indigenous scale with in the Pakistan's perspective. For future researches, it is recommended to include other cities of Pakistan in order to increase the sample size. Future researches could follow the mixed method approaches for scale development, for example, in-depth or focused group parental interviews can give more accurate and close picture of stress related factors in Pakistan.

Clinical Implications

Present study is designed to develop an instrument which can be used to measure the stress level of parents/caregivers of children with ASD. Identifying parents with high level of stress can help to recommend them for counseling sessions.

Conclusion

It can be concluded that there was an intense need of an indigenous tool to measure parental perceived stress among parents of children with ASD. Current study provided the reliable and valid instrument of measuring perceived stress among parents of children with ASD in clinical settings. Study also highlighted the need of special educational institutions, professional services, and training workshops for parents as these are the factors, which aggravate parental stress.

References

Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of Clinical Child Psychology, 21*, 407-412.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Anastasi, A., & Urbina, S. (1997). *Psychological testing* (7th ed.). Upper Saddle River, NJ: Prentice Hall.

Arshad, S., Iqbal, J., Waris, H., Ismail, M., & Naseer, A. (2016). Health care system in Pakistan: A review. *Research in Pharmacy and Health Sciences, 2*(3), 211-216.

Batool, S. S., & Khurshid, S. (2015). Factors associated with stress among parents of children with autism. *Journal of the College of Physicians and Surgeons Pakistan, 25*(10), 752-756.

Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*(3), 463-472.

Churchill, G. A. (1979). A paradigm for developing better measures of marketing constructs. *Journal of Marketing Research, 16*(1), 64-73.

Cohen, R. J., Swerdlik, M. E., & Sturman, E. D. (2013). *Psychological testing and assessment: An introduction to tests and measurement* (8th ed.). New York, NY: McGraw Hill.

Dardas, L. A. (2014). Psychosocial impacts of raising children with autistic disorder. *Journal of Nursing Research, 22*(3), 183-191. doi:10.1097/jnr.0000000000000023

Dardas, L. A., & Ahmad, M. M. (2013) Coping strategies as mediators and moderators between stress and quality of life among parents of children with autistic disorder. *Stress and Health, 31*(1), 5-12.

Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical psychology: Science and practice, 5,* 314-332.

Deeken, F., Hausler, A., Nordheim, J., Rapp, M., Knoll, N., & Rieckmann, N. (2017). Psychometric properties of the Perceived Stress Scale in a sample of German dementia patients and their caregivers. *International Psychogeriatric Association, 30*(1), 39-47.

Dervishaliaj, E. (2013). Parental stress in families of children with disabilities: A literature review. *Journal of Educational and Social Research, 3*(7), 579-584. doi:10.5901/jesr.v3n7p579

Foody, C., James, J. E., & Leader, G. (2015). Parenting stress, salivary biomarkers, and ambulatory blood pressure: A comparison between mothers and fathers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(4), 1084-1095.

Girimaji, S. C., Srinath, S., Seshadri, S., & Krishna, D. K. S. (1999). Family interview for stress and coping in mental retardation: A tool to study stress and coping in families of children with mental retardation. *Indian Journal of Psychiatry, 41*(4), 341-349.

Hallahan, D. P., & Kauffman, J. M. (1997). *Introduction to learning disabilities*. Boston: Allyn & Bacon.

Imran, N., & Azeem, M. W. (2014). Autism spectrum disorders: Perspective from Pakistan. *Comprehensive Guide to Autism*, *7*(152), 2483-2496. doi:10.1007/978-1-4614-4788

Kaiser, H. (1970). A second generation little jiffy. *Psychometrika, 35*, 401-415.

Khanzada, M. H., & Bashir, N. (2013). *Parental stress and marital adjustment among the parents of mentally challenged children*. Published manuscript, Center for Clinical Psychology, University of Punjab, Lahore, Pakistan.

Khawar, R., & Saeed, S. (2016). Autism: Stressful parenting outcomes for mothers. *Journal of Pakistan Psychiatric Society, 13*(1) 8-11.

Krohne, H W. (2002). Stress and coping theories. In N. J. Smelser & P. B. Baltes (Eds.). *International encyclopedia of social and behavioral sciences.* Oxford, England: Elsevier.

Kumar, V. G. (2008). Psychological stress and coping strategies of the parents of mentally challenged children. *Journal of the Indian Academy of Applied Psychology, 34*(2), 227-231.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lyubomirsky, S., & Lepper, H. S. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. *Social Indicators Research, 46*(2), 137-155.

Mayer, R. C., Davis, J. H., & Schoorman, F. D. (1995). An integrative model of organizational trust. *Academy of Management Review, 20*, 709-734.

McCrae, R. R. (2014). A more nuanced view of reliability: Specificity in the trait hierarchy. *Personality and Social Psychology Review, 19*(2), 97-112. doi:10.1177/1088868314541857.

McCrae, R. R., Kurtz, J. E., Yamagata, S., & Terracciano, A. (2011). Internal consistency, retest reliability, and their implications for personality scale validity. *Personality and Social Psychology Review, 15*(1), 28-50. doi:10.1177/1088868310366253.

Mekki, K. (2012). *Stress and coping in mothers of children with autism spectrum disorders,* (Unpublished manuscript), University of Ottawa, Montreal, Canada.

Moes, D., Koegel, R., Schreibman, L., & Loos, L. M. (2015). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71*(3), 1272-1274. doi:10.2466/pr0.1992.71.3f.1272.

Ozturk, Y., Riccadona, S., & Venuti, P. (2014). Parenting dimensions in mothers and fathers of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8,* 1295-1306.

Padden, C., & James, J. E. (2017). Stress among parents of children with and without autism spectrum disorder: A comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities, 29*(4), 567-586.

Pavot, W., & Diener, E. (2013). Review of the Satisfaction with Life Scale. *Social Indicators Research Series, 39.* doi:10.1007/978-90-481-2354-45.

Pisula, E., & Porebowicz-Doersmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLoS ONE 12*(10), e0186536.

Qayyum. A., Lasi, S. Z., & Rafique, G. (2013). Perception of primary caregivers of children with disabilities in two communities from Sindh and Baluchistan, Pakistan. *Disability CBR & Inclusive Development, 24*(1), 89-101. doi:10.5463/dcid.v24i1.193

Rauf, N. K., Haque, A. U., & Aftab, R. (2017). Parental stress and autism: Differences in perceived stress and coping behavior. *Journal of Pakistan Psychiatric Society, 14*(2), 8-11.

Rauf, N. K., Haque, A. U., & Khan, A. (2018). Association of autism child characteristics with maternal and paternal stress. *Rawal Medical Journal, 43*(2), 263-266.

Rehman, N. K., Dawood, S., Rehman, N., Mansoor, W., & Ali, S. (2009). Standardization of Symptom Checklist-R on psychiatric and non psychiatric sample of Lahore city. *Pakistan Journal of Clinical Psychology, 8,* 21-32.

Sabih, F., & Sajid W. B. (2008). There is significant stress among parents having children with autism. *Rawal Medical Journal, 33*(2), 214-216.

Sajjad, S. (2010). *Stress faced by mothers of children with intellectual disability and its impact on their family life,* (Unpublished manuscript), University of Karachi, Pakistan.

Schopler, E., Reichler, R.J., & Renner, B.R. (1988). *The Childhood Autism Rating Scale.* Los Angeles, CA: Western Psychological Services.

Sheela, V., & Kumar, V. G. (2003). *Single child parents,* (Unpublished thesis), University of Mysore, India.

Soltanifar, A., Akbarzadeh, F., Moharren. F, Soltanifar, A., Ebrahimi, A., Mokhber, N., & Nagvi, S. S. A. (2015). Comparison of parental stress among mothers and fathers of children with autism spectrum disorder in Iran. *Iranian Journal of Nursing and Midwifery Research, 20*(1), 93-98.

Suhail, K., & Zafar, F. (2008). Prevalence of autism in special education schools of Lahore. *Pakistan Journal of Psychological Research, 23*(4), 45-64.

Taylor, J. M. (2015). Psychometric analysis of the ten-item Perceived Stress Scale. *American Psychological Association, 27*(1), 90-101.

Tripathi, N. (2015). Parenting style and parents' level of stress having children with autistic spectrum disorder: A study based on Northern India. *Neuropsychiatry, 5*(1), 42-40.

Wu, S. M., & Amtmann, D. (2013). Psychometric evaluation of the Perceived Stress Scale in Multiple Sclerosis. *International Scholarly Research Notices Rehabilitation, 2013*, 1-9.

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