Socio-demographic Variables and Parental Stress of Children with Autism Spectrum Disorder

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Abstract

Perceived stress among parents of children with autism spectrum disorder is a known phenomenon in recent empirical evidences. The aim of present study was to explore the role of different socio-demographic variables predicting parental stress of children with ASD. Through purposive sampling, 251 parents (fathers & mothers) were selected from different special education schools and centers located in five cities of Pakistan. Parental Perceived Stress Scale was used to measure the parental stress. Descriptive statistics indicated the frequencies and percentages of different socio-demographic variables of the parents. Neural network indicated that parental education, monthly family income, severity of disability, age of special child and gender of special child are contributing in parental perceived stress. Focusing the findings of the study, it can be concluded that working on different socio-demographic stress related factors among families having children with ASD, can manage parental stress.

Key words: Parental Perceived Stress, Autism Spectrum Disorder, Socio-demographic Variables, Neuro-developmental Disorder, Stereotyped patterns of behavior

Introduction

Parenting is the process of biological and social stress with intense feelings of belongingness from parents towards their children. Although, parenting children with normal developmental patterns is another name of a great struggle for a long period of time but still this struggle mostly has an end when the children become independent in their adulthood but parenting children with developmental disabilities is another name of continuous struggle which does not seems to have an end. Neither this struggle is life-long rather it is full of stress, anxiety and depression throughout the life. Current study targeted the parental stress of children with a neuro-developmental disability of autism spectrum disorder.[1]

From last five decades the stress has been used with increasing popularity in the behavioral and health sciences. Stress is a state in which cognitive, behavioral and emotive responses become affected and it demands a certain level of adjustment with the situation. If the individual fails to

maintain balance between the threating situation or individual resources in term of their cognitive, emotive and behavioral abilities, he/she become stressful. Many time available resources are not enough to meet the needs of environment. These situations not only hinder in their performance but also badly effect the mental health of the individuals.

Krohne, 2002 conceptualized stress in following three ways:

   i.   Stimulus is a factor for creating stress for the person. It can be disturbing events, problematic circumstances and particular events happens in one's life

   ii.   Response: it means how an individual react to the stressful factor

   iii.   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

In response of stress, a natural reaction is called a stress response. This stress response can stimulate a person's abilities or it can also become a hindrance in his or her performance when dealt improperly. Stress response to parenting a child with some disability is very much obvious as compared to parenting a normal child. Because parenting a child with disability have different levels of demands and pressures due to physical, emotional and behavioral demands of disability. In Pakistan, lack of resources, less income, lack of education, poverty and lack of awareness make the situation more problematic for parents of disabled children. Different parents react the situation differently and many times due to above mentioned factors; parents get into some psychological imbalances or disturbances.

A linear "stage theory model" describes that when a child born with some disability, parents passes through a sequential process before adjustment. First reaction usually begins with shock, moving towards denial, anger, recognition and finally reaches the acceptance. They might experience shock, denial, guilt, depression, anger, defensiveness, ambivalence, shame, rejection of child, chronic sorrow, over protectiveness, and so on until finally, in the last stage of acceptance (Bailey. et al, 2006). But following the all stages, a continuous fact, associated with parenting special children is stress.

According to Lessenberry and Rehfeldt (2004) many of the empirical evidences highlighted that parents having children with developmental disabilities reported significantly high level of stress. Similarly, Dervishaliaj (2013) also reported through literature review that parent of children with disabilities experience higher level of stress as compared to parents of children without disabilities.

Autism is one of the neuro-developmental disability in which the symptoms of disorder effects the major areas of child's life. Impairment of autism interferes in three major areas of life: Communication, Social Interaction, and Restricted, Repetitive, and Stereotyped patterns of behavior. Children with autism spectrum disorder, experience impairments in i- social interaction and social communication in term of lack of social emotional reciprocity, non-verbal behavioral

deficits used in social communication, impaired ability to maintain social relationship. In behavioral patterns, children mostly have repetitive restricted behaviors, activities and interests in form of inappropriate use of objects, motor activities, repetition in speech, routine fixation, active resistance to change, rituals in verbal and non-verbal behavior and inappropriate sensory responses. The most worsen aspect of the disorder is that it impairs daily functioning of the child with the presence of symptoms in early years of childhood (APA, 2013). According to a study of Suhail and Zafar, 2008, autism prevails with the ratio of 103 out of 1633 with 6.31 % in Special Education Schools of Lahore, Pakistan.

Perception of Stress among Parents of Children with Autism Spectrum Disorder:

Due to the complexity of impairments in autism spectrum disorder, parents having children with this developmental disorder most of the time experience clinically significant level of stress.

Padden and James (2017) reported high level of depression, anxiety and distress in parents of children with autism spectrum disorder as compared to parents of children without autism. Jx, Si, Vy, and AR. (2017) studied stress among 30 parents from Malaysian who have children with autism. Findings indicated that parents having children with ASD reported extreme level of stress. Dardas (2014) reported psychological along with social effects of raising children with Autistic Disorder in a sample from Arab population. Pisula and Porębowicz-Doersmann (2017) reported high level of stress among parents of children with autism as compared to parents of children with typical development.

Stress related factors among Parents of Children with Autism Spectrum Disorder:

When parents have special children, they evaluate the situation as challenging, threatening or harmful in terms of many factors e. g. lack of awareness, dependency of the child, severity of symptoms, child's gender, need of special educational services, lack of social support, financial problems, and social stigma, which may cause stress. There are number of empirical evidences reported the exaggerated level of perceived stress among parents of children with autism spectrum disorder due to these factors which are mostly related to child's characteristics, family resources or parental characteristics.

Habib, Prendeville, Abdussabur and Kinsella (2017) investigated experiences of Pakistani mothers' raring children with Autism Spectrum Disorder (ASD) in Ireland. A long list of demographic variables of work status, marital status, educational level, school type, level of cognitive functioning of child with ASD, age of child when diagnosed, number of dependents, number of children in family, age of child with ASD, mother's years of living in Ireland was included in the study. The results revealed high level of stress among mothers. Further, it indicates a significant relationship of parental stress with severity of child's symptoms, maternal education and age of child with ASD.

Khawar and Saeed compared stressful outcomes related to parenting among mothers of children with autism and with normal development in 2016. Researchers also included child's age, gender, mothers' age, income and education in the study. Findings highlighted that mothers of autistic

children had higher level of stress as compared to normal mothers. Further, results also indicated a significant positive relationship between severity of autistic symptoms and maternal stress.

Soltanifar et al (2015) evaluated parental stress in relation to severity of symptoms among children with autism in Iran. Comparison of stress among mothers and fathers of children with autistic spectrum disorder was also done in the study. Demographic variables of education level of mother and father, age of mother, father and child, number of children, history of seizure of children, child's intellectual level and number of children were included in the study. Results suggested a positive relationship between CARS score and parent domain on Parenting Stress Index. Another positive correlation between the total stress index and CARS rating for fathers was also found. Results further highlighted significantly higher level of stress among mothers as compared to fathers in three subscales of Parenting Stress Index.

Batool and Khurshid (2015) examined factors related to stress among parents of children with autism in Lahore, Pakistan on a sample of sample of 100 parents (including 50 fathers and 50 mothers). Different demographic variables of parent's education, gender, income, age, child's age, gender, family system and number of children were selected. Findings indicated that severity of autistic symptoms had significant correlations with parenting stress.

Comparison of stress among fathers and mothers of children with autism spectrum disorder was also conducted by Foody, James, and Leader (2015). Results reported that that mothers experienced higher levels of stress, parenting accountability, anxiety, and depression as compared to fathers.

Sabih and Sajid (2008) examined parental stress in relation to some demographic factors in a sample of 60 parents (30 mothers and 30 fathers) in Pakistan. Through findings, it was reported that parents of boy child had lower level of stress than parents having girl child with ASD. Similarly, Parents of young children with ASD had high level of stress as compared to parents of older children with ASD.

Significance of the Study

There are very few studies conducted on parental perceived stress based on an indigenous stress scale in children with autism spectrum disorder in Pakistani culture.

It would give a reliable and valid measurement of stress among parents in Pakistani culture as its contents was developed based on most relevant stress factors of Pakistan. Findings would be helpful for social scientists, future researchers in the same field and students of social sciences to use it in meta-analysis. Through the identification of stressors for parents and caregivers of children with special needs, management program can be applied for the targeted population. Based on the findings, clinical psychologists can directly work on cognitive, emotive and behavioral aspects of disturbances in order to reduce their stress levels. Effective social welfare and mental health policies can be chalked out for the targeted families. Based on the findings, Government health department can be requested to appoint the special educationist and clinical psychologist in the community settings of most of the cities including the small cities. Current study also spotted light on Government for provision of special educational institutions and

services for such families so they can train or educate their children with special needs up to their abilities. Parental support group could be arranged for stressed parents/caregivers for improving their mental health condition and their quality of life.

Objectives of the Study

Study was designed with the objective to find the predictors of stress among parents of children with autism spectrum disorder.

Method:

In the current study cross sectional survey research design was used to measure parental perceived stress through a self-tailored indigenous Parental Perceived Stress Scale among parents of children with autism spectrum disorder. Settings for study were special educational schools and clinical settings of Lahore, Gujranwala, Gujrat, Lalamusa and Karian. Target population of the study was parents of children (boys & girls) with autism spectrum disorder (mild to severe categories) diagnosed through Childhood Autism Rating Scale(CARS). Purposive sampling technique was used to select the sample from the target population. Sample of 251 parents (fathers=127, mothers=124) from targeted settings was obtained. Parents (fathers & mothers, age ranges between 20 years to 60 years) having children (male and female, age ranges between 3years to 18 years) with autism spectrum disorder fall within the categories from mild to severe autism spectrum disorder were included in the sample. Parents of children with profound and unspecified category of autism spectrum disorder were excluded from the sample. Further, the parents whose children were having any additional physical or mental disability were excluded from the sample. Similarly, parents having any physical or mental problem were also excluded from the sample.

Instruments: The research instruments consisted of three parts. First part was related to consent form, second part was related to demographic information of parents and children while the third part was related to Parental Perceived Stress Scale.

  i- *Consent Form:* It was related to brief introduction of the study and participants' consent for inclusion in the study.

  ii. Demographic Questionnaire. First part of the demographic questionnaire was consisted of parents' age, education, occupation, family monthly income, no of children, family system, nature of house. Second part of the demographic questionnaire was consisted of child's age, gender, category of disability, duration of training and any other treatment.

  iii.Parental Perceived Stress Scale (Kausar, Akram, Dawood, & Ahmad, 2019): It was self-tailored scale for measuring the perceived stress of parents for children with Autism Spectrum Disorder. It consisted of 32 items. It has high Cronbach alpha reliability of .945 items. Response pattern was based on following five-point likert scale from strongly agree (5) to strongly disagree (1):

Pilot study was conducted on fifteen participants in the same targeted population of parents having children with autism spectrum disorder (mild to severe categories) by the researcher. The aim of

pilot study was to have clarity of instructions, identification of any ambiguity in items and to set the uniform patterns of instructions for all participants. Cronbach alpha reliability of pilot study was .950 for the targeted population. For main study, permission was taken from the head/principals of special educational schools or clinical settings. Sample was approached by the researcher in group of 5 to 10 parents from targeted cities of Pakistan. After instructions, participants were briefed about the purpose of the study. They were briefed about their right to withdraw from the research at any time. Written informed consent was also taken from parents. They were also briefed about confidentiality. Mostly parents completed the questionnaire by themselves. It almost took 15 to 20 minutes on average to complete the questionnaire. Data were entered in Statistical Package for the Social Sciences (SPSS) version 21 for windows. Cronbach's Alpha reliability of Perceived stress scale was measured. Pearson Product Movement Correlation was used to measure the relationship between the levels of parental perceived stress and different demographic variables. Neural network was used to find the different factors as predictors of parental perceived stress. Ethical issues of informed consent and confidentiality were monitored by the researcher. All information was kept confidential, used only for research purpose and constructive programme planning of mental health services for parents of children with special needs.

The study was approved by Advance Study and Research Board of University of Gujrat.

Results:

  Table.1 indicates a sound reliability for the 32 items of Parental Perceived Stress Scale for parents of children with ASD. Table 2 describes different demographic variables of parents of children with ASD. It indicates that sample consisted of almost equal number of fathers (127, 50.6%) and mothers (124, 49.4%). Mostly participants are living in nuclear family system (155, 61.8%) as compared to joint family system (96, 38.2%). Regarding the parents' education, highest percentages of parents have education level up to masters (62, 24.7%) and bachelor (62, 24.7%) as compared to the lowest percentage of technical education (4, 1.6%). Regarding the severity level of parental stress, table 2 indicates that the majority of the parents experienced severe level of perceived stress (171, 68.1%) as compared to moderate (76, 30.3%) and mild (4, 1.6%) level of perceived stress. Table 3 describes the composition of ASD children whose parents were included in the sample. Gender ratio shows more number of boys (165, 65%) in sample as compared to 86 (34.3) girls. Loomes, Hull, and Mandy (2017) reported gender bias male to female ratio after reviewing the 54 articles on prevalence of ASD. According to the findings of the review, among 53,712 diagnosed children, boys were 43,972 as compared to 9,740 girls with the ratio of 3:1 male-to-female. Majority (147,58.6%) of the ASD children falls in the category of requiring substantial support as compared to other two categories of severity requiring support and requiring very substantial support (46, 18.3% and 58, 23.1% respectively). Table 4 indicates a relative error of training set of 70.914 as compared to relative error of testing set of 29.030.

    Table 5 and fig 1 indicates the importance of independent factors in predicting the parental perceived stress among parents of children with ASD. It further highlighted that the most important predictor of parental perceived stress was parental education .436(100%) while the second and third predictors were monthly family income .278(63.8%) and severity of disability (.198,45.5%)respectivelt. Age of special child was the fourth predictor (.047, 10.7%) and gender

of special child was the fifth predictor (.041, 9.4%) of parental perceived stress among parents of ASD.

Table 1: Reliability Analysis

Cronbach's Alpha	No of Items
.945	32

Table 2: **Frequencies and Percentages of Demographic Variable of Parents (N=251)**

Variables	f	%
Parent		
Fathers	127	50.6
Mothers	124	49.4
Family System		
Nuclear	155	61.8
Joint	96	38.2
Parent Education		
Illiterate	13	5.2
Up to primary	21	8.4
Up to middle	13	5.2
Matric	47	18.7
Intermediate	20	8.0
Bachelor	62	24.7
Masters	62	24.7
Professional	9	3.6
Technical	4	1.6
Parental Stress Levels		
Mild	4	1.6
Moderate	76	30.3
Severe	171	68.1

Table 3: Frequencies and Percentages of Demographic Variables of Children (N=251)

Variables	f	%
Child Gender		
Boy	165	65.7
Girl	86	34.3
Severity of Disability		
Requiring support	46	18.3
Requiring substantial support	147	58.6
Requiring very substantial support	58	23.1

Table 4: Model Summary

Data set	Relative Error	
	Training	Testing
Parental Perceived Stress	70.914	29.030

Table 4: Predictive Importance of Independent Factors

S.No	Independent Factors	Importance	Normalised Importance
1	Parental Education	.436	100
2	Monthly family income	.278	63.8
3	Severity of Disability	.198	45.50
4	Age of special child	.047	10.7
5	Gender of special child	.041	9.4

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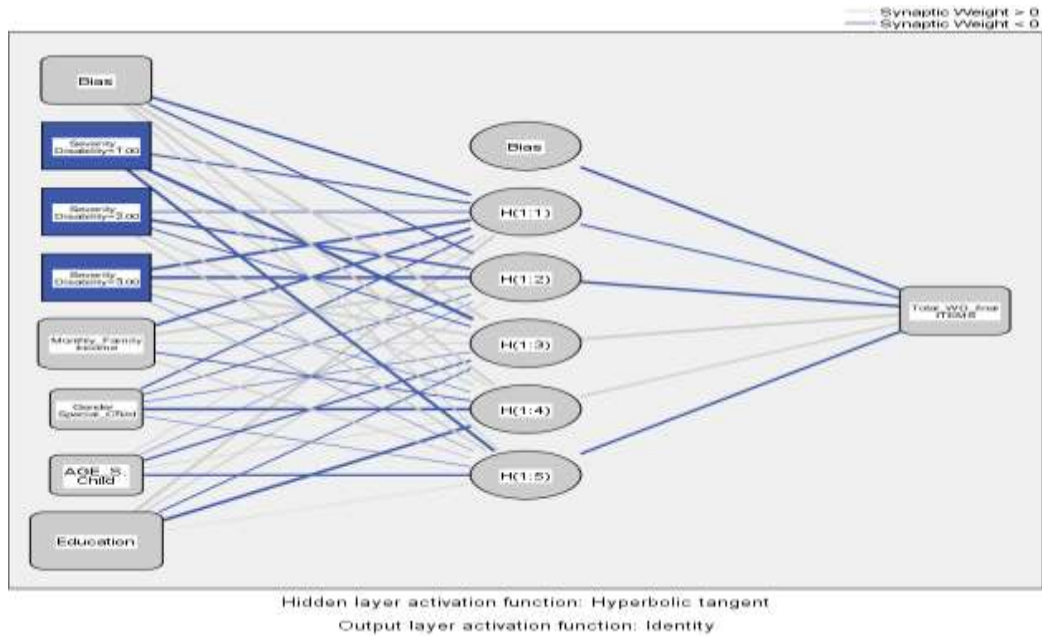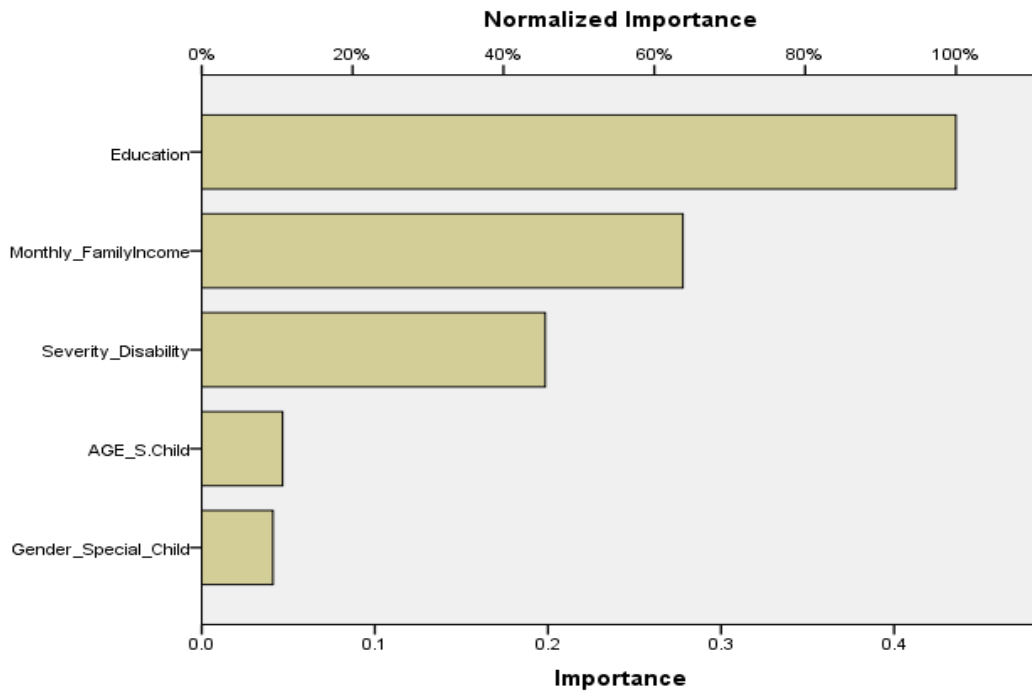Output layer activation function: Identity

Fig 1: Total WD final Items=Parental Perceived Stress
Education=Parental education

Fig 2: indicates importance of independent factors

Discussion:

Findings revealed that parents of children with ASD experienced high level of stress as reported in table 2 as compared to mild level of stress reported only by 4 (1.6%) parents. Findings are in line of the previous studies which concluded that parents of children with autism have extreme level of stress. Rauf, Haque and Aftab (2017) reported high level of parental stress due to their children with autism and other related factors. Same findings were also reported by Tripathi (2015) which showed 71.9 % of the parents with ASD children had severe level of stress as compared to 81.3 % parents had high level of stress. Qayyum, Lasi, and Rafique(2013) reported that caregivers have the perception of functional and physical limitation about the disability of their children in two communities of Sindh and Baluchistan, Pakistan. Further, difficulties in financial resources and access to medical and rehabilitation services are also important in creating distress among parents.

Findings of the neural network indicated the importance of different factors in parental perceived stress. It indicates that parental education is most important predictor of parental perceived stress through table no 5 and fig 2. Parental education has (.436, 100%) importance in predicting the parental stress. Findings are consistent with the review of Al-Oran and Al-Sagarat (2016). The aim of the review was to investigate the parental stress level having children with ASD and further it also explored the other predicting factors of parental stress. They reported that many socio-demographic variables have impact on parental stress. Mothers with low education level have reported a high level of stress. In Pakistan due to lack of education, parents have low level of awareness and understanding about the ASD as neuro-developmental disability. Hence, they are unable to understand the nature of their symptoms and relative management for their children.

According to the findings of neural network the second important predicting factor of parental perceived stress is family income with (.27) 63.8% importance showed by table 5 and fig 2. Results are in line with the systematic review of Llias, Cornish, Kummar, Park, and Golden (2018) which reported financial issues as a predicting factor for parental stress. Review was conducted with the aim to explore the associated factors of parental stress and parental resilience having children with ASD in South East Asia. This review also reported that financial difficulty is frequently reported associated factor with parental stress from different empirical evidences from 1989 to 2013. Grasu (2015) also reported the financial challenges of parents in Romania faced due to their children with ASD. Low family income leads financial difficulties for the families having children with ASD. This phenomena of monthly family income as predictor of parental stress is truly understandable in the scenario of Pakistani culture. A child with special needs especially with a neuro-developmental disability of ASD needs certain type of physical, educational, social and environmental demands/adjustments. On the other hand, these children have sensory, communicative and behavioral deficits. For management they need multidisciplinary management program by involving special educationist, clinical psychologist, speech therapist and medical doctor. Every child with ASD has its unique combinations of strengths and weaknesses. Depending on the nature of disorder, most of the time, these children need educational training or behavioral management on one to one basis. Based on their individualized teaching, intervention become very costly for parents especially when there is lack of qualified professionals and lack of special educational setting intervention services become inaccessible for most of the parents with low

family income or financial difficulties. Mostly parents find it very difficult to spend a heavy amount of their family income on one child by ignoring the other expenses and children present in the family. So, they fail to provide a qualified and regular training to a child with ASD present in the family which in turns become more stressful with the feelings of helplessness and deprivation.

Table 5 and fig 2 indicated the third factor of severity of disability as predicting parental perceived stress with the importance of 45.5%. Children with ASD were categorized as mild, moderate and severe category of disorder depending on their severity of symptoms by administration of Childhood Autism Rating Scale-II. Findings of Pastor-Cerezuela, Fernandez-Andres, Tarraga-Minguez and Navarro-Pena (2015) supported the results of neural network and showed that severity of child's autistic symptoms is significantly predicting parental stress. Findings of Soltanifer et al. (2015) are also in line of the current findings. They reported that fathers experienced more stress when they had children with more severe developmental disorders. Similarly, Llias, Cornish, Kummar, Park, Golden (2018); Batool and Khurshid (2015) also reported a significant correlation among severity of autistic symptoms with parenting stress. As much the severity of disorder increases based on severe sensory deficits, communicative problems and behavioral impairments it leads towards long-term, consistent, intense and rigorous intervention at different developmental stages of children. Hence, it become a long-term stress for parents with a severe case of disability as compared to a mild case with a very less hope for future.

Age of child with ASD also identified as a predictor of parental perceived stress through findings of neural network. Although, it is not as much important as parental education, family income or severity of child's symptoms but still it predicts parental stress. Findings are also consistent with the study of Al-oran and Al-Sagarat (2016) which highlighted that parents reported higher stress having children younger than 6 years as compared to parents having children above age of 6 years. However, Zamora, Harley, Green, Smith and Kipke (2014) reported somehow different results by indicating one of the findings of their study in which they reported that parents having older children experienced more child dysfunctional interactional stress as compared to parents of younger children. When parents have children younger than 6 years with autism, they may experience more stress as compared to older children because relatively they have a recent diagnosis and they are going through the process of denial, rejection, anger and acceptance. Most of the time they are at the stage of searching out the causes and nature of disorder. They are still exploring the ways to deal with their special child. With the passage of time, not only they stared to somehow understand the disorder but also find their own way of dealing a child with special needs within their family mechanism. But according to the study of Zamora et al. (2014) high stress with older parents is related to dysfunctional interactional patterns. At older ages children with autism may also have some other behavioral issues due to changes developmental stages.

Gender of special child also predicts parental perceived stress through the results of neural network. Results are confirmed by the study of Sabih and Sajid (2008) which also reported that parents having autistic girl child experienced more stress as compared to a boy child with ASD. Similarly, Zamora et al. (2014) also reported that parents having female children with autism experienced significantly higher distress as compared to parents of male autistic children. The phenomena of gender of special child as predictor of stress is understandable with the perspective of Pakistani culture. Parents who have female children with autism tend to have greater stress

because of the security issues, society's attitude toward female special child and future worries of a female child.

The strength of the study is that it is the first study to measure the importance of different demographic factors in Parental Perceived Stress by using an indigenous developed parental perceived stress scale in Pakistani culture. Findings of the current study suggest to have an action research for countering the role of demographic variables in parental perceived stress having children with ASD. Further, it also highlighted the needs of stress management programs for parents having children with ASD.

There were certain limitations in the study. Due to non-availability of targeted groups of children in many of the special educational centers/schools, sample size is relatively small. Many of the children with ASD excluded from the sample due to the mixed type of other physical or mental problems, further, the parents who also have some sort of physical or mental ailment were also excluded from the sample.

Clinical Implications and Impact of Findings:

Current study findings can be used to identify parental stress related factors. Further, it can be used by different special educational institutions for designing the self-help support groups of parents. In clinical settings, findings of current study can be used to differentiate the parents experiencing different levels of perceived stress.

 Impact of findings indicate that recommendations can be given to the health department and social agencies to work for the noble cause of parents having children with ASD and provide them the services at manageable cost with qualified professionals and other sources for improving their quality of life.

Conclusion:

 Keeping in view the findings of the study, it can be concluded that due to the present of special child in the family, parents experience high level of stress. Other than the complex picture of symptoms in children with ASD, there are many other factors such as age and gender of special child, family income, parental education, and severity of symptoms which not only contribute rather exaggerate the parental stress. These factors need to be monitored or managed by the contribution of professionals, parents and relevant agencies of the society.

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