CHILD CHARACTERISTICS, COPING AND STRESS IN PARENTS OF CHILDREN WITH AUTISM



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CERTIFICATE

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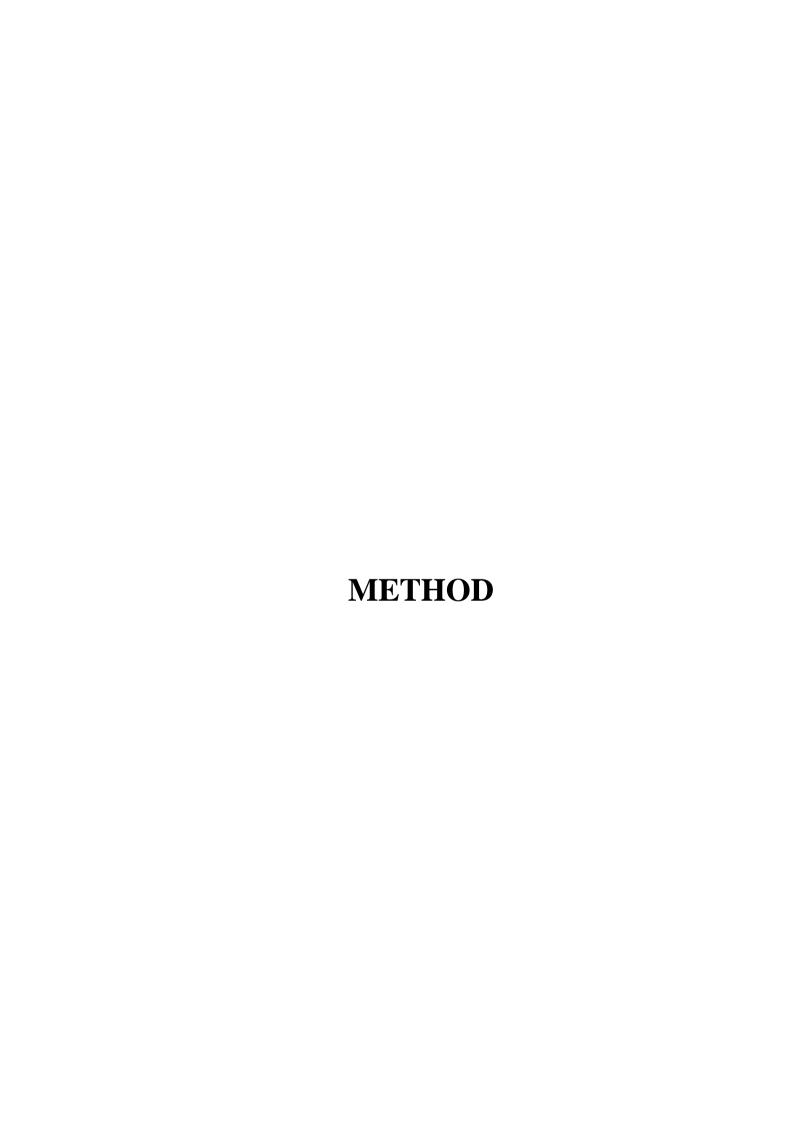
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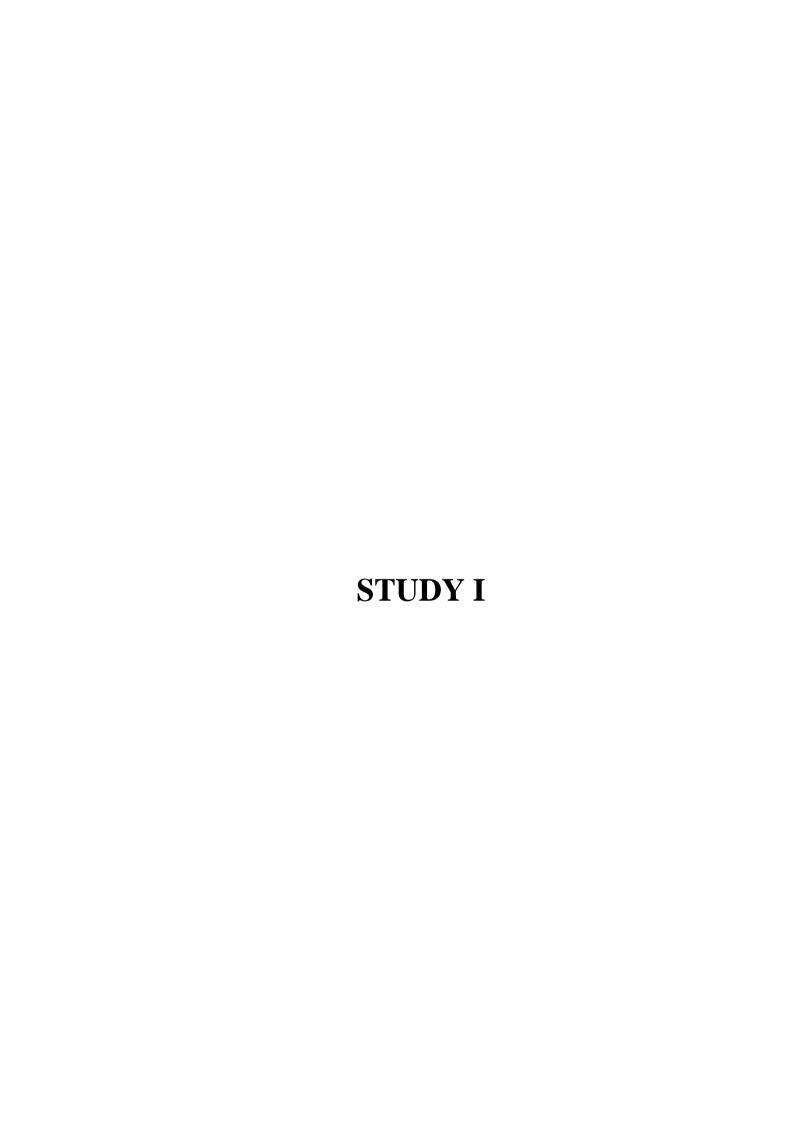
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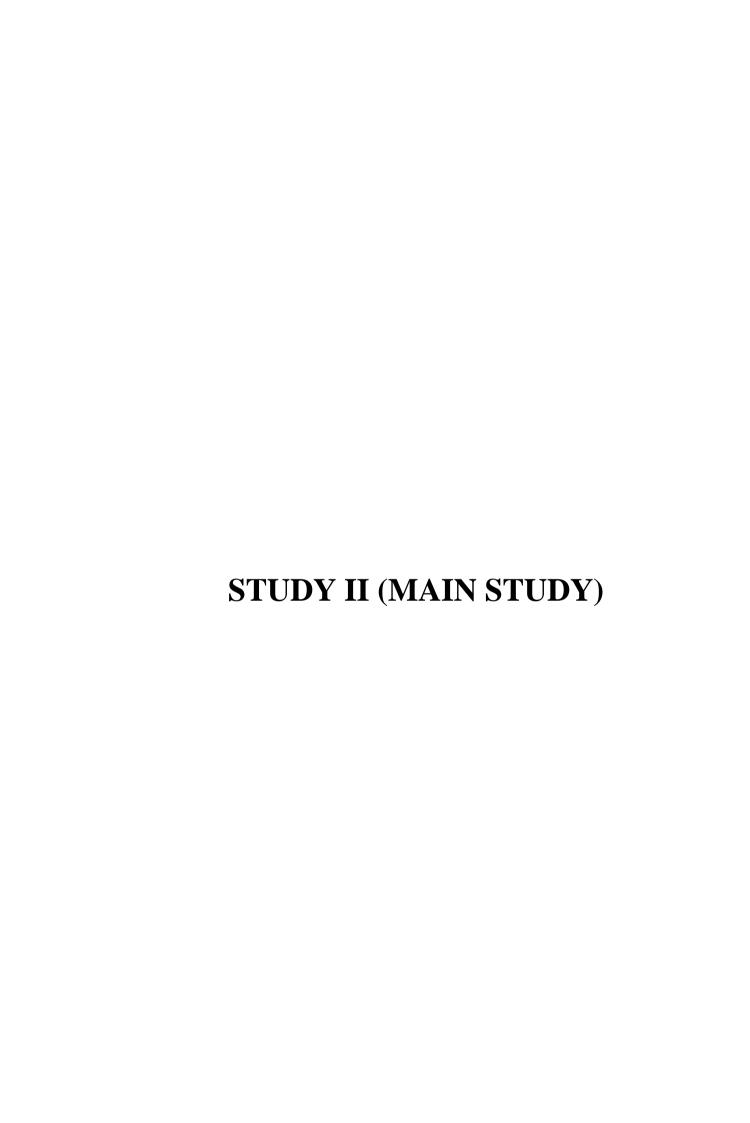
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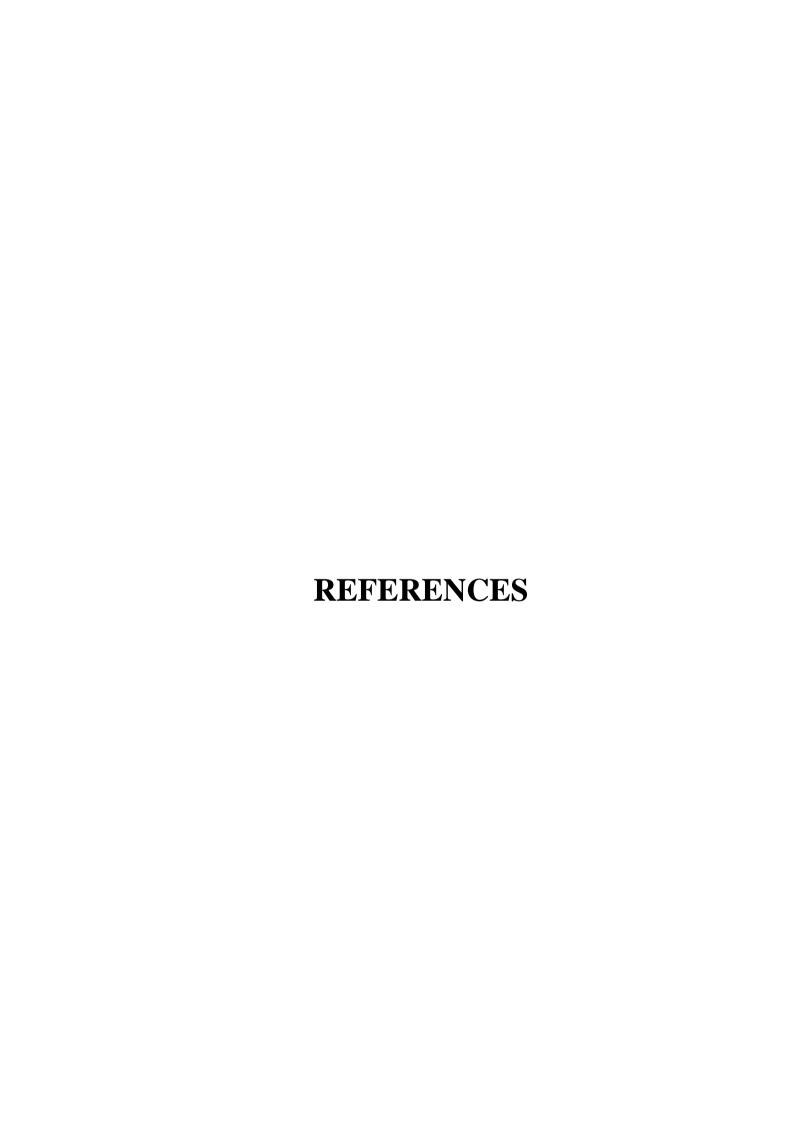
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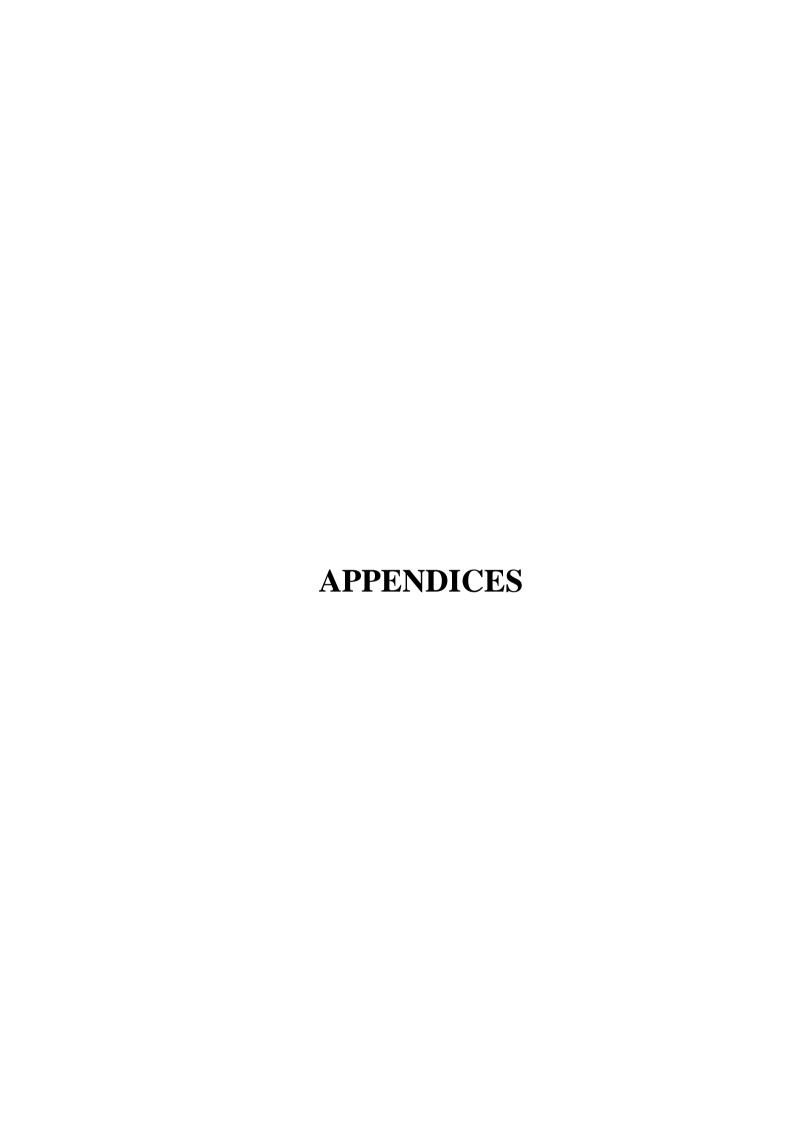












LIST OF ABBREVIATIONS

ASD Autism Spectrum Disorder

PDD-NOS Pervasive Developmental Disorder - Not Otherwise Specified

DSM-IV-TR Diagnostic and statistical Manual of mental disorders, 4th Edition,

Text Revision

ICD 10 International Classification of Diseases

CARS-2 Childhood Autism Rating Scale-2

ABS-S: 2 Adaptive Behavior scale-School Edition :2

SDQ Strengths and Difficulties Questionnaire

QRS-F Questionnaire on Resources and stress –Short form

F-COPES The Family Crisis Oriented Personal Evaluation Scale

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My personal interest in children with special needs with specific focus on autism set the route for this doctoral work. Beside my personal interest, the fact was that there were many researches available with respect to the individuals themselves but rarely the people around the special person were channelized or documented properly. There were many instances during my doctoral work, when I was emotionally moved and enchanted by the bravery and courageousness of parents of children with autism. These parents have to fight a multi-dimensional war with the immediate family members, the society and their inner-self to provide the child with the care and attention he/she deserves. I was mesmerized from a single mother whose husband had been working abroad and she has to travel more than fifty miles just to take her child to the school which caters the needs of special children in Rawalpindi. The tears swept through her eyes when I asked her that "how does she manage to cope with the needs of a special child, even when his father was not here"? And she replied in a determined way "I want to give him the best of opportunities, because there is one life to live".

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ABSTRACT

The purpose of this research was to study the relationship between child characteristics, coping and stress in parent of children with autism. One of the objectives was to study the impact of child characteristics on paternal and maternal stress. The factors included in child characteristics were autism symptom severity, adaptive behaviors, and problem behaviors. The study also investigated the mediating role of family coping (reframing, passive appraisal and mobilizing family to acquire and accept help) between child characteristics and paternal, maternal stress. Moreover, the relationship of different family socio-demographic variables (age, gender of the child; age, education, and work status of mothers; socio economic status and type of family system) was also examined with reference to paternal and maternal stress. The measures used to assess characteristic of children with autism were Childhood Autism Rating Scale-2 (CARS-2), Adaptive Behavior scale-School Edition (ABS: 2S, Part-1) and Strengths and Difficulties Questionnaire (SDQ). The measure used to assess parental stress and coping were Questionnaire on resources and stress (QRS-F) and The Family Crisis Oriented Personal Evaluation Scale (F-COPES). Two independent studies i.e. study I and study II were carried out to meet the objectives of the study. The objective of study I was to translate and validate the instruments of the study. Furthermore, study I, consisted of three phases, phase I was related to Urdu translation of Adaptive Behavior scale-School Edition (ABS: 2S, Part-1), Questionnaire on resources and stress (QRS-F), The Family Crisis Oriented Personal Evaluation Scale (F-COPES) and few modification were done in already existing Urdu version of Strengths and Difficulties Questionnaire (SDQ). In Phase II content validity index (CVI) of translated instruments was established and in phase III other psychometric properties were addressed. Findings of study I, found that the content validity index for the translated instruments was well above the critical value of .80. Similarly, the instruments also showed satisfactory psychometric properties for the current sample. This indicated that the instruments were valid and reliable measures to be used with the present population. The Study II (main study) consisted of hypothesis testing. A purposive sample of 103 mothers and 83 fathers (having at least one child with autism within age range of 3 to 14 years) participated in the

study. Results of the main study revealed that all three child characteristics autism symptom severity, adaptive behaviors and problem behaviors were the significant predictors of maternal stress. However, problem behaviors were impacting more on maternal stress, followed by autism symptom severity and adaptive behaviors. Whereas, autism symptoms severity was the only significant predictor for paternal stress. Further analysis into child characteristics revealed that core symptomology of autism was the significant predictor of maternal stress. In case of adaptive behaviors, poor personal self sufficiency of children with autism accounted for significant proportion of variance in both maternal and paternal stress but the impact was more for maternal stress. Similarly, sub facets of problem behaviors that were emotional symptom and conduct problems accounted for significant proportion of variance only in maternal stress. Moreover, present study also revealed that family coping (reframing, passive appraisal and mobilizing family to acquire and accept help) partially mediates the relationship between child characteristics (autism symptom severity, adaptive behaviors, problematic behaviors) and maternal stress. Whereas, in case of paternal stress no significant mediation effect was found. In addition, it was found that stress for employed mothers and those living in nuclear families was greater as compared to those who were not employed and living in joint families. With increase in mother's age and monthly income stress in mothers decreased. Moreover, with increase in the monthly income of the family, stress in mothers of children with autism decreases.. Implications of the present study are discussed under need for interventions for families with autistic children in Pakistan and need for awareness in general masses regarding autistic disorder. Limitations have been acknowledged and future research directions have been suggested accordingly.

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INTRODUCTION

Stress in parents of children with a disability can be challenging and demanding. This is because parents are expected to take care of the developmental needs of their children, along with making sure that their disability is supported as effectively as possible. This additional burden usually results in stress in parents of children with disability. The stress experienced by the parents is linked with complex care needs of their children (Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016).

Most of the developmental disabilities can easily be identified at birth or soon after birth. Physical disabilities tend to be more prominent as compared to intellectual disabilities. This means that parents can identify the needs of their physically disabled child more effectively as compared to their child with intellectual disability. Thus, when the disability is hidden behind normal appearance, like in autism, things become even more difficult. Research evidence support the notion that parents of children with autism experience more stress as compared to the parents of children with other disabilities (Dabrowska & Pisula, 2010; Estes et al., 2009; Griffith, Hastings, Nash, & Hill, 2010). The reasons for elevated stress in parents of children with autism are unknown etiology, complicated diagnosis, unique characteristics of the disorder (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004), severity of autism symptoms (Rivard, Terroux, Parent-Boursier, & Mercier, 2014), emotional and behavioral manifestation of symptoms (Huang et al., 2014).

These unique child characteristics place inimitable and possibly damaging set of responsibilities on parents of children with autism. These characteristics lead to functional limitations in variety of everyday life situations. Most of the issues are related to communication, social interaction, daily functioning, restricted behaviors, emotional problems, mood swings, sensory overload, sensory sensitivities, problems related to transitions etc. As a result, constant care and attention is required by the child. This ongoing care, support and concern provided by the parents often leads to higher stress.

The higher stress affects in both positive and negative ways. In positive manner it has the potential to be productive as it can accelerate the parents to take on their role effectively. However, stress can negatively affect the functioning of the parents. Elevated stress has been associated with poor physical and mental health problems. The health related problems resulting from stress can jeopardize daily routine tasks and responsibilities of life.

If not effectively managed, the stress experienced by the parents of the children with autism can have negative impact on both parents and the child. As mentioned earlier, elevated stress can affect a parent's mental and physical health. Knowing this, the parent's ability to manage stress is critical for the wellbeing of both the parents and the child.

Parents can manage their stress by adopting coping behaviors in order to alleviate physical and mental burden of taking care of the children with autism (Hall & Graff, 2011). Coping in a family system is a bridging concept that consists of both behavioral and cognitive aspects. All aspects including perceptions, resources and behavioral responses all aspects play vital role in family coping. These three aspects interact as family tries to bring about a balance in the family functioning. Given this,

parents of children with autism could benefit from the use of family coping to counterbalance the stress experienced through caring for children with autism.

Autism and its management is relatively a new area of study in Pakistan. Unlike the west where services for autism are well developed and help is well placed, in Pakistan parenting a child with autism is in the early phases of development. Some of the identified causes of stress in parents of children with autism are lack of awareness in general masses (Rahbar, Ibrahim, & Assassi, 2011), lack of proper educational services, professional care and stigmas attached with the disorder (Feinstein, 2010).

Keeping in view the present condition in Pakistan the present study is focused the relationship between child characteristics, coping and stress in on examining parents of children with autism. One of the objectives is to study the impact of child's characteristics on maternal as well as paternal stress whereas, the factors included in the child's characteristics are autism symptom severity, presence of core and associated autism symptomology, poor adaptive behaviors and problematic behaviors in children with autism. The core symptoms refer to those symptoms designated in the DSM IV-TR as being diagnostic criteria of autistic disorder whereas, associated symptoms are the frequently occurring symptoms. Adaptive behaviors included tasks carried out regularly by the children with autism in different domains of daily functioning. The domains encompass skill related to daily functioning such as social interaction, communication skills, day-to-day routine activities and motor skills. While, problem behaviors include behavioral and emotional problems of children with autism. Moreover, it also aims at studying the mediating role of family coping between child characteristics (autism symptom severity, adaptive behaviors and problem behaviors) and maternal, paternal stress. Furthermore, the relationships of different family socio-demographic variables (age, gender of the child; age, education, and work status of mothers; socio economic status and type of family system) are also studied with reference to paternal and maternal stress.

Before moving further to narrate the relationship between child characteristics and stress in mothers and fathers of the children with autism, it is important to conceptually highlight the Autistic disorder. Therefore, the next section of the chapter highlights the early symptoms of autism, its etiology, prevalence and therapeutic interventions. Moreover, it also provides the information related to the characteristics of the disorder including—core and associated symptomology, adaptive behaviors and problem behaviors.

Autistic Disorder

In present study parents of the children with autistic disorder (also referred as autism) were included and the diagnostic criterion of DSM-IV-TR was applied. Children with autistic disorder show marked impairment in areas of social interaction, communication, restricted, repetitive and stereotyped patterns of behaviour (see Appendix A). The disorder can easily be identified at the age of three years and in few cases as early as eighteen months. Nadel and Poss (2007) suggested that many children can be accurately identified at the age of 1 year or even younger.

Early symptoms. During the first five years of his life, the infant does not babble, he/she has difficultly pointing towards different things and not able to produce meaningful gestures. When the infant grows up, he/she does not speak one word by sixteen months, does not combine two words by two years and, does not respond to his/her name. Some other indicators are poor eye contact; does not seem to know how to play with toys; excessively lines up toys or other objects; attached to one particular toy or object; does not smile and at times seems to be hearing impaired (Wetherby et al., 2004).

Etiology. The etiology of autistic disorder remains vague, although research continues in the fields of genetics, neurology, and metabolic disorders (Gillberg & Coleman, 2000; Kabot, Masi, & Segal, 2003). Researchers are confident that genetic research will determine a specific genetic marker for these disorders. Family heritability emerges to be another rational avenue for investigation, as twin studies depicted that siblings of children with autism are more likely than the general population to develop autism or related disorders (Bailey et al., 1995).

Abnormal brain development in infant's first few months may be the contributing factor to autism. The "growth dysregulation hypothesis" claims that abnormalities in brain growth are caused by genetic factors. Sudden rapid growth of infant's head might be an early warning signal that will lead to early detection and successful biological intervention or possible prevention for autism (Courchesne, Carper, & Akshoomoff, 2003). Post-mortem studies have also depicted that there are conflicting anatomical differences in the brains of persons with Autism (e.g., increase in neuronal mass and decrease in Purkinje cells in the cerebellum). This suggests that

there might be numerous developmental and neurological pathways to autistic disorder (Tanguay, 2000).

Thus, factors related to the causes of autism are the focus of an ongoing debate. Review of research from Western, Middle East and Asian countries depicted a sudden increase in the reported cases of the disorder. Presently, major emphasizes around the world is to look for the reasons of this sudden uplift in the number of such cases.

Prevalence. Numerous researchers have found out large increases in the prevalence of Autistic Disorder in defined populations and geographic areas. Croen, Grether, Hoogstrate, and Selvin (2002) reported nearly three-fold increase in the prevalence of Autistic children born between 1987 and 1994 in California. Similarly, Gurney et al. (2003) found out that among school-aged children in Minnesota the prevalence rose from 2 per 10,000 in 1991/92 to 27 per 10,000 in 2001/02. One of the reasons for the drastic increase in autism might be advancing diagnostic tools and awareness in general population about Autism.

Charman and Baird (2002) confirmed that ASDs are more common than previously thought, with a rate of approximately 6 to 7 per 1,000 children reported in the literature in year 2002. Estimates of year 2003 were as high as 10.6 per 1,000 overall and range between 5.0 to 16.8 per 1,000 male children and 1.4 to 4.0 per 1,000 female children. Yeargin-Allsopp et al. (2003) also reported the prevalence of Autism to be approximately 3 in every 1000 for the broader spectrum. Overall, there remains a higher ratio of boys to girls (4:1) overall, but this decreases to an almost 1:1 ratio when profound cognitive impairments are present.

In South Carolina prevalence of autistic disorder was 6.2 per 1000, boys were more commonly affected than girls (3.1:1). In 85% cases developmental concerns

were reported before reaching three years of age, 87.2% had language concerns, 37.2% social concerns, and 19.2% had concerns regarding lack of imaginative play (Nicholas et al., 2008).

In the United Kingdom the prevalence of childhood autism was 38.9 per 10,000 (Baird et al., 2006), in Australia the reported prevalence of autistic disorder was 39.2 per 10,000 (Fombonne, 2009) and in Canada it was 64.9 per 10,000 (Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006). In Sweden the estimated prevalence rates of children with autism spectrum disorder, diagnosed in a cohort of 6-year old children, was 6.2/1000. Out of which 51% had autistic disorder, 10% had Asperger syndrome, 36% had atypical autism (Fernell & Gillberg, 2010).

In Oman the prevalence estimates of Autistic disorder in 0–14 year old children was 1.4 per 10,000 children. The prevalence was highest among 5–9 years old children, followed by age range of 10–14 year. The ratio was 2.5 times higher in male children as compared to female children (Al-Farsi et al., 2011). In Shiraz (Iran) the prevalence of autistic disorder was 1.9% among 7 to 12 years school children. Boys were more effected than girls (Ghanizadeh, 2008).

Even though research is demonstrating an increase in overall incidence of autism, it has become more visible that a broader definition of autistic disorder, increased awareness, and more efficient assessment practices may be accountable for the apparent increase in prevalence (Wing & Potter, 2002). Due to the lack of published research such estimates are unavailable for underdeveloped and developing countries.

Therapeutic interventions. Pharmacotherapy is frequently used for managing children with autism in order to improve their behavioral symptoms that hinder their ability to participate in educational, social, work, and family systems. However, no single therapeutic agent is appropriate for the treatment of children with autism (Kohler, Strain, Goldstein, Hibbs, & Jenson, 2005). Beside pharmacotherapy different theoretical frameworks and intervention paradigms are also applied. That ranges from providing a planned educational environment, behavioral modification approaches and developmental interactive procedures. This helps in developing social and communicative skills in children with autism.

Characteristics of children with autism. The factors included in the child's characteristics are core and associated autism symptomology, adaptive behaviors and problematic behaviors of children with autism.

Core symptomology. The core symptoms usually form a triad of impairment in areas related to social interaction, communication and restricted and repetitive behaviors.

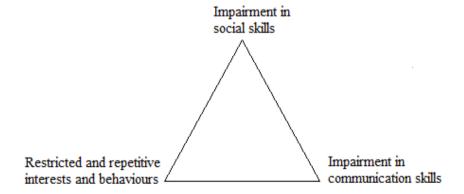


Figure 1. The triad of impairment in Autistic disorder

The core symptoms refer to those symptoms designated in DSM IV-TR as being diagnostic criteria of autistic disorder. The symptoms included in core symptomology are given below:

Social interaction. A typical developing infant usually stares at people, can turn towards sounds, give social smile and can grab a finger. However, Autistic children have difficulty in learning to engage in, the give and take of everyday human communication. In the first few month of life they don't establish eye contact, avoid social interaction, seem indifferent to other people and often prefer being alone.

They may decline to accept attention or passively accept hugs and cuddling. Moreover, they hardly ever look for comfort or react to parent's displays of anger or affection in a typical way. They are attached to their parents but the expression of attachment is strange and difficult to interpret. They may have inability to comprehend other people's actions. In some cases they have difficulty regulating their emotions and this can take the form of immature behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. Sometimes disruptive behaviors and physical aggression also make social relationships difficult for them (Perry & Condillac, 2003).

According to Wing and Gould (1979), children with autism could be categorized according to three main types of impairment in social interaction.

1. *Aloof.* This term is used to describe children who seem at their happiest when left alone. Eye gaze is actively avoided and these children often dislike physical contact. Infants with autistic disorder do not distress at separation

from their parents. Indeed, parents describe them as being 'in a world of their own'.

- 2. *Passive*. These children will not seek out for social contact, however, unlike aloof children, they do not actively avoid it either.
- 3. Active but odd. This group of children most usually includes those who are more intellectually and cognitively able. They have a tendency to talk to people, and show no awareness of social barriers.

It is important to note that these categories are by no means definite. The social skills of children with autism often change as they grow mature, e.g., an initially aloof child may later be considered to be active but odd. Children with autism are unable to understand the basic rules of social communication and this lack of social communication both in receptive and expressive skill, further enhance their problems in social interaction.

Communication. Communication and language problems are the first to be identified by the parents and a major cause of concern for parents. Gray (1994) reported that language and communication deficits were the major cause of stress for parents and one of the reasons for seeking medical help for their child.

Few children with autism stay mute all through their lives. Some infants who afterward show symptoms of autism do babble during the first few months of life, but they soon discontinue this developmental expression. Others may be delayed developing language as late as age 5 to 9 years. Those who have speech often use language in strange ways. They are unable to combine words into meaningful sentences, speak only single words or repeat the same phrase repeatedly. Some

children have a condition called echolalia, which means that they parrot what they hear. Some children with mild autism, might show signs of delays in language, or even have gifted language and strangely have large vocabularies but they have great difficulty in maintaining a conversation.

It is estimated that approximately half of the children with autism are unable to develop functional speech and little to no receptive language ability (Lord, Rutter, & Le Couteur, 1994). Children with autism do not attempt to develop alternative communication methods, such as eye contact or use of gesture, as they age. Furthermore, when children with autism learn to talk, their receptive language skills are usually poorer than their expressive language skills. The abstract concepts are generally difficult for them to understand. Their understanding of spoken language tends to be factual. Particularly, the most noteworthy trait of language impairment in autism is the lack of communication in social circumstances. Language impairment in autism not only influences their ability to communicate and interact in the social world, but also inherently manifests in an inability to develop normal, imaginative patterns of play. Play behavior in children with autism tends to be stereotyped, repetitive and solitary, which itself is an additional drawback. This limits the child's progress of social communication with peers (Howlin & Yates, 1999).

Restricted and repetitive behaviors. Most of the children with autism physically appear normal. They usually have good muscle control, however, repetitive body movements tend to make them different from other typical developing children. These behaviors might be severe and highly obvious. They may spend hours and hours lining up their cars and toys in a particular way, rather than using them for

imaginative play. If someone mistakenly moves one of the toys, the child may be really upset. A slight change in any schedule in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route can be extremely troubling.

Some children spend a lot of time continually flapping their arms or walking on their toes. They usually demand complete uniformity in their surrounding environment.

Continuous interest in frequent environmental movements might be one of the indications for the disorder. This includes opening and closing of doors or rotations of daily items e.g., toys, cooking utensils etc. Strange reaction to surrounding environment is sometimes linked with emotional meltdowns, aggression, temper tantrums, hyperactive behaviors and self- injuring behavior.

Core symptoms mentioned above are usually essentially required for diagnosing a child with autism. On the other hand, associated symptoms are the frequently occurring symptoms. These symptoms usually vary from child to child in frequency and intensity.

Associated symptomology. Due to inadequate information on biological indicator for diagnosing children with autism, a clinician must have expert skills and knowledge in recognizing the associative and behavioral disorders associated with it. These symptoms have been viewed as key symptoms related to autism and may result from their incapability to cope with the environmental demands and physical discomfort. These children might have higher than usual feeling for pain; they are sometime sensitive to different sounds; show dislike on being touched by others; or might show over exaggeration for smell and light (Ruble & Brown, 2003).

These symptoms usually include hyperactive-inattentive cluster symptoms; tics; tourette syndrome; compulsive repetitions; explosive/self-injury symptoms, and mood disorder (Tsai, 1996). With growing age children with autism were found to have a considerably higher occurrence for organic disorder (mental illness that results from a physical cause), mania, anxiety, self-injury, eating and sleeping disorders (Hill & Furniss, 2006). Most noteworthy behavioral manifestations of autism were separation anxiety and obsessive-compulsive disorder (Spence, 1998).

The symptoms associated with autistic disorder place an additional demand on the parents of children with autism. These symptoms vary from child to child in presentation, frequency and intensity. However, they are essential to be identified and catered, especially when formulating the intervention plan for children with autism and their parents. Research literature has been mentioning a lot about core symptoms of autism and its impact on parental stress. However, there is scarcity of information related to associative symptomology and its relationship with parental stress (Ekas & Whitman, 2010; Lyons, Leon, Phelps, & Dunleavy, 2010).

Adaptive behaviors. Children with autism experience deficits in adaptive behaviors because of their tendency to oppose change and to exhibit stereotypical behaviors that hinder obtaining key developmental tasks (Perry, Flanagan, Geier, & Freeman, 2009). Adaptive behaviors usually include tasks carried out routinely by children with autism in various domains of daily functioning such as communication, daily living skills, social interaction, and motor skills.

Children with autism often find their daily tasks difficult to master. Daily skill includes the routine tasks like eating, dressing, clothing etc. These skills enable a

child to develop self sufficiency and independence in their daily lives. However, because of the associated problems like disturbance in sleep pattern, hyperactivity, sensory issues, and restricted behaviors etc. children with autism are not able to develop independence in their daily lives. With growing age and change in situation children with autism require continuous assistance and instructions to master every skill. The foremost purpose of any interventional plan is to inculcate sense of self sufficiency and independence in a child. Thus, the child grows up without placing stress on the parents and a burden on the society. Therefore it is important to assess adaptive behaviors of children with autism (Yang, Paynter, & Gilmore, 2016).

Problem behaviors. Problem behaviors included behavior and emotional problems of children with autism. All children display problematic behaviors, which are sometimes not manageable by the parents. However, with age and maturation the problematic behaviors of typical children can be managed and controlled. In case of children with autism display and presentation of problem behaviors are sometimes difficult to manage and control. They sometimes refuse to ignore the requests, behave in socially unacceptable manner, become aggressive, can hurt themselves or even hurt others. Few of the reasons linked with the problem behaviors are their inability to comprehend what is going around them, inability to effectively communicate their needs and demands, their anxious behavior, sensory overload and transitions in daily routines. The manifestation of their frustration is apparent in form of emotional and behavioral problems.

Emotional and behavioral problems are the widely studied variables with reference to parenting stress (Davis & Carter, 2008). In fact they are found to be one

of the strongest and the consistent predictors of maternal stress (Brobst, Clopton, & Hendrick, 2009; Estes et al., 2009; Lecavalier, Leone, & Wiltz, 2006; Manning, Wainwright, & Bennett, 2011). However, there exists an overlapping between autistic behavior and problem behaviors with reference to parental stress. The clarification of the relationship with reference to parental stress will help clinician to provide suggestions to parents based on empirical finding.

Next section highlights the theoretical background of stress and coping followed by literature related to the parents of children with autism, relationship between child characteristics, maternal and paternal stress, coping in families of children with autism, mediating role of family coping, relationship between family socio demographic factors and maternal and paternal stress. Moreover, status of children with autism in Pakistan will also be discussed.

Theoretical Models of Stress and Coping

Stress is part of everyone's life, however, arrival of a special child in a family enhances this stress. The stress is usually caused by uncertainty in the family, which leads to a change in the family system. This change in the situation, that could be positive or negative, leads to stress. Thus, the influence of change on the family depends on how effectively a family manages stress and how adequately the family's available resources permit them to cope. Stress is usually problematic when the perceived stress creates disturbances within family setup or on its individuals (Madden-Derdich & Herzog, 2005; McKenry & Price, 2005).

Theoretical perspectives that explain the dynamics of stress in family of children with disability are given below:

The ABC-X model. This model of stress helps to clarify why some families fall into crisis, when dealing with stress while other families cope. The model consists of three variables, A, B, and C, which interrelate to bring about a product, X. The event (A) interacting with the family's crisis-meeting resources (B) interacting with the meaning the family gives to the event (C) and produces the crisis (X). This model is being extensively used in research with families of children with disabilities. The ABC-X model describes only pre-crisis variables and the crisis. Despite its limitations, this model is the foundation of many other stress models (Boss & Mulligan, 2003; Hill, 1958).

Lazarus and Folkman model of stress. The model of stress and coping recommended that stress is dependent on the cognitive judgment (appraisal) that occurs from the interface of a person with the environment. The stressor is defined by the subjective judgment of the situation that is appraised as frightening, dangerous, or exceeding the resources. Stress possibly will endanger the person if it is severe or experienced constantly. Lazarus theorizes that two significant processes, cognitive appraisal and coping, mediate the potentially stressful relationship between person and environment. Both cognitive appraisal and coping are theorized to have a potential impact on short and long-term outcomes for the individual (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Cognitive appraisal is a process through which the individual decides whether his/her relationship with the environment is harmful or beneficial. Whereas, coping refers to a person's cognitive and behavioral efforts to manage stress related demands resulting from environmental interactions that are perceived to be more than the personal resources. Coping begins with an emotional environment and is strongly linked with the emotional regulation. The process of coping is supposed to have two distinct functions: managing the stressful situation and providing regulation to the emotion caused by the situation (Folkman & Moskowitz, 2004).

Coping determines whether a stressful event results in adaptive or maladaptive outcomes. There are three ways in which coping affects parental psychological wellbeing. Firstly, coping directly affects psychological well-being irrespective of the effect of stressor or its appraised stressfulness. Secondly, it acts as a moderator between the stressor and psychological well-being. Thirdly, coping also acts as a mediator, where the stressor leads and affects the coping responses, and coping responses in turn affects the psychological well-being. Support for each model can be found in the broader stress and coping literature (Tein, Sandler, & Zautra, 2000).

Double ABCX model. The expansion of Hill's ABCX model is typically called double ABCX model. In this model the pre-crisis variables of the stressor, existing resources, and perceptions of the stressor lead to the crisis, followed by the post-crisis variables of pileup of stressors on top of the initial stressor, the use of existing and new resources, the perception of the pileup and existing and new resources, coping, and adaptation to the postcrisis variables. The major contribution of the Double ABCX Model was the addition of coping, Albeit only post crisis.

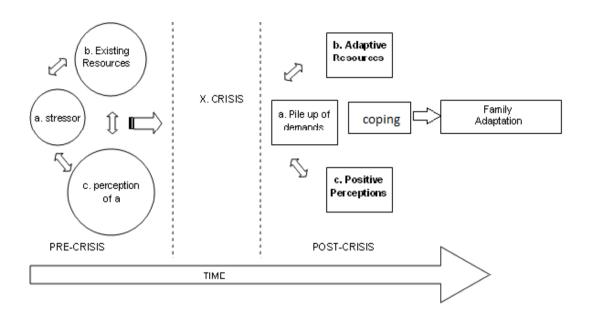


Figure 2. The Double ABCX Model, based on McCubbin and Patterson (1983)

In this model more emphasis is placed on the family's appraisal or perception of the event (the c factor) and also the interactive and additive nature of the events. In this expanded model, "a" refers to the original stressors and the piled up stresses or strain, and "b" denotes the adaptive resources. Factor "c" alludes to the family's perception of the original stressors event and their appraisal of the demands and their own capacity for managing or meeting the challenges (McCubbin & Patterson, 1983).

The Double ABC-X model of stress and coping determines the ability of parents to cope with a stressful situation determined by the interaction of the stressor event with family resources, parental perceptions and coping strategies. The outcome of this interaction is the level of family adaptation ranging from severe stress or crisis to successful adaptation.

All three models are widely used in research related to families of children with autism (Davis & Carter, 2008; Manning et al., 2011). They help in developing

insight about the concept and construct of stress, for both the individual and the family as well. Moreover, these models not only present theoretical explanation regarding the negative influence of stress on individual and the family but also provide the strategies for effective stress management.

Stress in the Parents of Children with Autism

Parents of the children with autism experience more stress when compared with the parents of children afflicted with other disabilities (Dabrowska & Pisula, 2010; Estes et al., 2009; Griffith et al., 2010). Parents of the children with overt disabilities such as severe cerebral palsy or Down syndrome are confronted with obvious signs of disability condition. Although, their child has a serious disability, they are left with no doubt almost from the time of birth. This is not the case for the parents of children with autism. Where difficulty appears slowly and often subject to false explanations, such as deafness, late development, parental mismanagement or temperament etc. Many parents would rather cling to these false explanations than facing the possibility that their child has a life-long disability. The disability that will influence nearly every aspect of his or her development, create enormous problems with regard to education and personal /social growth, negative impact on siblings negatively and make the transition into adulthood a time of great stress for the whole family. Thus far, research continues to explore stress in parents of the children with autism.

Life circumstances of parents of children with autism are often unpredictable and linked with challenging life transitions. Wolf, Noh, Fisman, and Speechley (1989), compared parents of the children with autism, down syndrome and those of typically developing children. They found out that parents of children with autism were at a higher risk for the developing parenting stress than other two groups. The reasons for developing high stress were potentially threatening events and life circumstances linked with parenting an autistic child.

Mothers being the primary care givers are directly affected by the potential treating events. Dumas, Wolf, Fisman, and Culligan (1991) found that mothers of children with autism experience more stress when compared with mothers of children with Down syndrome and typical children. Moreover the intensity of the child's behavior was significantly related to maternal stress in autistic group. Thus, one of the potentially threatening factors is demanding behaviors of the children with autism.

Parents of children with autism continue to show elevated stress when compared with parents of children with other neurodevelopmental disorders. Bouma and Schweitzer (1990) compared the patterns of stress among mothers of children with autism, cystic fibrosis, and typically developing children. As predicted mothers of children with autism reported higher stress scores than did mothers of children with cystic fibrosis and those of typically developing children. Moreover, mothers of children with autism reported greater stress in areas related to dependency and management. Due to the problematic behaviors children with autism are often dependent upon their primary caregiver for daily tasks and day-to-day management.

Impaired social interaction in children with autism is another potential area that causes stress in parents. This often inhibits parent's ability to interact with their community and sometime parents themselves are reluctant to interact because of the stigma attached with the disability. Kasari and Sigman (1997) studied the relationship

between stress in parents, temperament of the child and interaction between parent and the child. The relationship was studied among parents of children with autism, intellectual disability and typically developing children. It was found that parents of children with autism were at a higher risk for developing stress when compared with parents of children with intellectual disability and normally developing children. Parents of children who had impaired social interaction experienced more stress.

Similarly, Abbeduto et al. (2004) also found that problem behaviors were linked with poor maternal mental health. They investigated psychological wellbeing of mothers of children with autism, down syndrome and fragile X syndrome. It was found that mothers of children with autism reported lower level of psychological wellbeing as compared to mothers of children with fragile X and Down syndrome. Behaviors problems in children with autism were the consistent predictors of poor maternal psychological wellbeing.

The daily demands of unique behaviors and developmental needs often lead to parental stress. Pisula (2007) also reported that stress in the mothers of children with autism was high as compared to stress in the mothers of children with Down syndrome. The reason for elevated maternal stress was overprotection, dependency and problematic characteristics of children with autism. In addition, mothers also reported stress related to their children future needs and difficulty in understanding the developmental needs of their children with autism.

Moreover, Dabrowska and Pisula (2010) investigated stress levels among parents of children with autistic disorder, Down syndrome and typically developing children. As expected parents of children with autism experienced more stress as

compared to other two groups. It was also found that stress in parents of the children with autism was associated with the long-term care of their children.

Griffith et al. (2010) conducted a study using matched Groups (child age, gender, and communication skills) to explore child behavior problems and maternal well-being in children with Down syndrome, autism and mixed etiology intellectual disabilities. It was found that children with autistic disorder were reported to have more problem behaviors and poor social competence as compared to the other two groups. Moreover, mothers of the children with autism showed elevated stress level than the other two groups.

Indeed, researches in the area continue to strengthen the notion that parents of the children with autism suffer more stress when compared with parents of typically developing children and parents of children with physical and intellectual disabilities (Abbeduto et al., 2004; Bouma & Schweitzer, 1990; Dabrowska & Pisula, 2010; Dumas et al.,1991; Estes et al., 2009; Griffith et al., 2010; Perry et al., 2005; Pisula, 2007; Wolf et al., 1989) . The identified reasons for the higher stress in parents of the children with autism were difficult and unique characteristics related to the disorder. Most of the characteristics recognized were problem behaviors, poor social interaction, difficult personality traits that might leads to overprotection, poor management and lifelong dependency etc. The unique characteristics are associated with elevated stress in the parents of children with autism.

Child Characteristics, Maternal and Paternal Stress

Research literature continues to assert that elevated stress in parents of children with autism is linked with the unique child characteristics. In an initial study by Holroyd, Brown, Wikler, and Simmons (1975) it was found that child characteristics were predicting the stress rather than parental characteristics. They carried out a study measuring parenting stress in children with autism. The sample consisted of children either institutionalized or living at home with their parents. It was hypothesized that stress will be less in parents of institutionalized children. However, it was found that severity of impairment, physical incapacitation and difficult personality characteristics were sources of maternal stress for both institutionalized and non-institutionalized children. Despite the placement, mothers of the children with autism experienced more stress.

Impact of the child characteristics on parental stress was investigated by Bebko, Konstantareas, and Springer (1987), they found that the parents agreed that communication deficits, uneven cognitive abilities and problems in social relations were the autism-related child characteristics that were most stressful for the parents of school-aged children. Along with the severity of the child's autism symptoms, problematic behaviors have been found to be strongest predictors of parental stress. Interestingly, clinicians rated parents as more stressed than they rated themselves and the stress scale used in the study was not a validated measure of parenting stress.

Milgram and Atzil (1988) further supported the notion that maladaptive behaviors were directly related with stress in parents of the children with autism. The maladaptive behaviors included restricted behaviors, hyperactive behaviors, behaviors not acceptable in social gatherings, self injuring tendencies and disruptive behaviors. Maternal and paternal stress was not separately analyzed with reference to maladaptive behaviors of children with autism.

Furthermore, Konstantareas and Homatidis (1989) investigated the relationship between severity of autism symptoms and stress in parents of the children with autism. It was found that increase in severity of autism symptoms was associated with high stress in the parents. Moreover, mothers experienced more stress because of self injurious behaviour and near-receptor preoccupations (smelling, licking, and rubbing) of their children. Whereas, fathers showed their concern related to impaired communication skills of their children.

Gray (1994) found that autism not only had effect upon parents but the wellbeing of the whole family was also affected. The most serious stressors that parents faced were "absence of adequate language skills". Communication deficits were the first to be identified by the parents and a major reason for seeking medical help. Moreover, "disruptive behaviors at home and public places", "inappropriate sexual expressions" and "poor eating habits" were also indentified as stressful for parents.

Predictors of stress had been explored in primary caregivers in the United Kingdom by Hastings and Johnson (2001). The participants were involved in intensive home-based behavioral intervention programs for young children with autism. It was found that higher autism symptomology was associated with higher reported stress. Autism symptom rating was derived from a parent checklist, and no objective measure of children's autism behaviors was employed. Thus, it is possible that parents who were more stressed rated their children's behaviors as more severe.

According to Hastings (2003), the most frequently studied variable with reference to stress in parents of the children with autism are child's behavior problems and severity of autism disability. Previous studies mentioned above generally supported the notion that behavior problems are the consistent predictors for parental stress. Moreover, stress was found to be higher in mothers than in fathers.

Hastings et al. (2005) explored the relationship between parent, child and partner variables. Parents of the children with autism reported on child characteristics (behavior problems, adaptive behaviors and autism symptoms) and their own stress and mental health. This was the first study to delimit the population to parents of preschool age children. Results revealed no significant difference between maternal and paternal stress. Moreover, it was found that behavior problems of the children with autism were the only predictor for maternal stress. It was suggested to further investigate the relationship between autism child characteristics and parental stress.

Children's inability to perform their daily routine tasks is another source of stress for parents of the children with autism. Tomanik, Harris, and Hawkins (2004) investigated the relationship between adaptive and maladaptive behavior and maternal stress. Mothers of the children with autism reported more stress when their children were not able to communicate or interact with others, they are unable to take care of themselves, more irritable, lethargic and socially withdrawn. However, stereotypic behavior and inappropriate speech were not significantly related to maternal stress. Stress in the mothers was also associated with poor adaptive behaviors related to daily routine tasks e.g., changing clothes, taking bath, washing hands, going to toilet etc. This suggests that children with autism who lack the abilities to cope with the demands of their environment may be particularly challenging and require extra time and energy from their parents. Only mothers were included in the study and age of the

mother was not analyzed as to its possible relationship to stress. Moreover, communication deficits are considered as the primary reason for seeking professional help by parents.

Konstantareas and Papageorgiou (2006) examined the effects of child temperament, symptom severity, and level of functioning on maternal stress. They found that maternal stress was predicted by the problematic temperament. Particularly, child's activity level was related to stress in the mothers. However, rigidity (i.e., a child's adherence to routine and resistance to change) was inversely related to maternal stress. It was also found that children's extreme mood swings were related to greater maternal stress.

Lecavalier et al. (2006) investigated the correlates of caregiver stress over time in parents and teachers of children and adolescents with autism in Ohio State. They found that hyperactivity, stereotypical and ritualistic behaviors were strongly associated with parental stress. Adaptive skills were not significantly associated with caregiver stress. Parental age was not analyzed in relation to stress.

Davis and Carter (2008) investigated the associations between child behavior and parenting stress in mothers and fathers of toddlers with autism. They found that deficit in children's social relatedness was associated with parenting stress. Cognitive functioning, communication deficits, and atypical behaviors were not uniquely associated with parenting stress. Association between child behaviors with reference to the gender of the child is not investigated in this research. Instead, a narrow age range has been considered. The findings were consistent with the previous research by Hastings (2003), that maternal stress was linked with child's behavior problems, and not with other the symptoms, such as level of functioning.

Estes et al. (2009) investigate the contribution of child characteristics (diagnosis, problem behavior, and adaptive functioning) to parenting stress and psychological distress. Fifty one mothers of preschool children with autism were compared with twenty two mothers of children with developmental delay without autism. It was found that mothers of the children with autism reported higher parenting stress than mothers of children in the other group did. As supporting the previous literature problematic behavior of children with autism was the consistent predictor of maternal stress. However, no significant relationship was found between adaptive functioning and maternal stress.

Defining autism severity and its associated autism behaviors is not an easy task. Smith, Seltzer, Tager-Flusberg, Greenberg, and Carter (2008) investigated how the core autism symptoms and multiple coping strategies were associated with maternal psychological functioning. Results revealed that both mothers of the toddlers as well as of adolescents showed signs of significant distress. Mothers of the adolescents reported higher levels of anger and behavioral disengagement in comparison to the mothers of toddlers. The study included only mothers of the children with autistic disorder. However, the relationship of different demographic features like age, education, socioeconomic status with variables of interest was not examined. Moreover, only core autism symptoms (impairments in social reciprocity, impairments in communication, and restricted and repetitive behaviors) were examined the study.

Ekas and Whitman (2010) investigated the stress in mothers who had at least one child younger than eighteen years of age and had been diagnosed with an autistic disorder. Mothers of the children with high severity of core symptoms reported more stress. Only mothers were included in the study and child symptomology was based

on mother's ratings. Lyons et al. (2010) also found that child's autism severity was the strongest and the most consistent predictor of parental stress. Similarly, Bishop, Richler, Cain, and Lord (2007), also supported the notion that higher repetitive behavior, lower adaptive behavior and less perceived social support were significant predictors of higher perceived negative impact in parents of the children with autism.

Thus far, most of the research has been conducted on mothers or parents without mentioning the differences between mother and father. Brobst et al. (2009) found that parental stress was positively related to the perceived severity of the child's disability and problem behaviors. Interestingly, father's stress was more strongly correlated when the child's disability (Autism) was perceived to be more severe and maternal stress was related to problem behaviors of the children with ASD.

Jones, Totsika, Hastings, and Petalas (2013) examined the gender differences in parenting the children with Autism. Results revealed that mothers reported higher levels of stress compared to the fathers, and child behavior problems predicted psychological distress for both mothers as well as fathers. In contrast, the severity of the child's autism symptoms and their adaptive skills were not found to be statistically significant predictors of parental well-being.

Bitsika, Sharpley, and Bell (2013) examined the effect of psychological resilience on stress, anxiety and depression linked with parenting a child with an autism. It was found that over half of the fathers reported feeling stretched beyond their personal limits because of the behavioral difficulties exhibited by their children with autism. In comparison, seventy percent of the mothers reported being stretched beyond their personal capacity. No significant relationship was found between different variables with respect to the age of the individual with autism or age of diagnosis. Most of the parents in this sample identified specific Autistic symptoms

(i.e., behavioral, communication and social skill difficulties) as difficulties while raising their children with autism. Unable to develop independent living was another factor associated with parental stress.

Few studies investigated the impact of adaptive behaviors on parental stress and found mixed results. Hall and Graff (2011) found an association between low adaptive functioning in children with Autistic disorder and increased parenting stress. The stress related to low adaptive behaviors in the children with autism was more in fathers than in mothers. It was suggested that increased stress in families of children with autism creates a need for additional family support. Parents often choose different coping strategies to assist the family with ongoing and new challenges.

Manning et al. (2011) investigated the severity of Autistic disorder and behavior problems along with family adaptation and coping (social support, religious coping, and reframing) in racially diverse families. The study was conducted on school-age children with Autistic disorder. It was found that parents of the children with autism experienced high level of stress as compared to normative sample of families without a child with autism. Moreover, problem behavior severity, and not the severity of autistic symptoms, was the predictor of parental stress. Female caregivers constituted 95% of the sample.

More specific investigation into problem behavior was conducted by Huang et al. (2014). They investigated the impact of emotional and behavior problems of children with autism on caregiver's stress. They found that caregivers of children with severe behavior and conduct problems perceive elevated stress. It was suggested to further investigate the impact of problematic behaviors on parental stress.

Rivard et al. (2014) investigated the impact of the severity of autism symptoms, adaptive behaviours and intelligence on maternal as well as paternal stress. Interestingly, fathers reported elevated stress as compared to mothers. Maternal as well as paternal stress were related with autistic symptoms and adaptive behaviors. However, paternal stress rather than maternal stress was predicted by the severity of autistic symptoms. It was suggested to investigate paternal stress along with maternal stress because it is linked with parent child interaction and can affect the quality of education, intervention and rehabilitation process.

Stress can have negative effect on physical and mental health of the parents and if not effectively managed it can jeopardize the development, independence and growth of their children as well. Knowing this, parent's ability to manage stress is critical for the wellbeing of both the parents and the child.

Coping among Families of Children with Autism

Coping in a family system is a bridging concept and constitutes both behavioral and cognitive aspects. Three aspects that are perceptions, resources and behavioral responses play vital role in the family coping. They interact as family tries to bring balance in its family functioning. McCubbin (1979) acknowledged that the purpose of coping is to strengthen or maintain family resources, protect the family from the demands of stressful encounters and reduce the sources of stress or negative emotions.

McCubbin and Patterson (1981) suggested that coping strategies work at two levels. Level one is individual to family system, or the ways a family internally

handles difficulties and problems between its members (internal). Level two is family to social environment, or the ways in which the family externally handles problems or demands that emerge outside its boundaries, and have effects upon the family unit and its members (external). It was suggested that families operating with more coping behaviors focused on both levels of interaction and adapted to stressful situations more successfully.

Recent trends in research have begun to investigate the specific factors that may serve to directly reduce the negative parental stress in raising a child with autism. Sufficient research literature is available on different types of coping strategies used by families of the children with disabilities, however, Hastings et al. (2005) reported that research on coping among parents of children with autism, in particular, remains scarce. Moreover, Lyons et al. (2010) argued that literature is available related to the identification of coping strategies beneficial for families raising children with autism, however, the role of coping strategies with reference to contextual factors is still unclear. Both qualitative and quantitative researches are available identifying different coping strategies used by families of autistic children and investigating the direct effect of coping on parental stress. Few of the coping behaviors adopted by families of the children with autism are as given below:

Seeking social support. Social supports has been recognized as one of the important and critical factors for parents of the children with autism. Social supports refers to the specific people on whom parents or caregivers rely during times of stress (Bishop et al., 2007; Bromley, Hare, Davison, & Emerson, 2004). Social support can be formal or informal. Formal support is provided by community agencies or from

social work services working both on private level as well as on government level.

Informal support is provided by family, friends and neighbours.

Twoy, Connolly, and Novak (2007) investigated the coping strategies used by Asian American families of the children with autism. It was found that families tend to seek encouragement and support from friends, informal support from other families who faced similar problems, and formal support from agencies and programs.

In one of the pioneering qualitative studies by Gray (1994) the most common strategy that parents employed for coping with an autistic child was to "rely on the services provided by various agencies" and "Coping through family support". Most of the time immediate family members also provided "emotional support" to parent of the child with autism. Later, Gray (2006) reported that parents of children with Autism using informal social support experienced reduced parental stress.

Social support offered by friends and family can be instrumental, tangible, informational, or emotional. Social support received by parents of the children with autism helps in decreasing the stress by increasing the feeling of control in their lives. Hastings and Johnson (2001) explored the impact of social support, coping strategies and autism symptoms on parental stress in families involved in a home-based intensive behavioral intervention for their child with autism. Lower stress levels were associated with greater informal social support and adaptive coping.

Informal social support provided by the family and friends is a source of reduction in stress in parents. Mothers of the children with autism who were perceived to be receiving higher levels of support, especially from their spouses and relatives, reported lower levels of depression-related somatic symptoms and fewer marital problems (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Ekas & Whitman, 2011).

Parents who perceive that they are helped and can attain the understanding, cooperation, assistance, and appraisal of friends and family experience less stress (Bromley et al., 2004).

Indeed, most of the research indicates that more use of social support leads to less parental stress. However, sometimes parents of children with autism avoid taking support from family and friends because of fear of stigma and they usually report elevated mental health problems. Obeid and Daou (2015) found that perceived social support in parents of the children with autism did not predict parental well-being. Similarly, Weiss (2002) reported that even though informal social support was available abundantly in Lebanon but mothers still reported lower perceived social support when compared with mothers of typically developing children. Qualitative study by Gray (1994) also reported that parents sometimes use "social withdrawal" as a coping strategy. Pottie and Ingram (2008) in their longitudinal study found that stressed mothers seeking social support as coping reported greater negative daily mood. Seeking social support leads to daily negative mood, stress and mental health problems in mother was contradictory to what has been said before. Research to date lack clarity about role of seeking social support with reference to families of the children with Autism.

Reframing. Cognitive reframing or reframing is another coping behavior widely talked about in stress and coping literature. It is included in problem focused or positive coping strategies. Reframing is viewing and experiencing the events, ideas and emotions in a way that is more positive way. Twoy etal., (2007) reported that reframing was evident in the families with autism, as they were able to see the stressor

as a fact of life and redefine the stressor in a more positive way so that they could find solutions to the problems. Weiss (2002) found that mothers of the children with autism use different types of coping styles compared to mothers in the typical developing group. Cognitive reframing was used more often than disengagement and distraction coping.

Benson (2010) investigated the influence of four coping styles (engagement, distraction, disengagement, cognitive reframing) on maternal distress (depression and anger) and wellbeing. Mothers who reported higher levels of cognitive reframing were found to report greater wellbeing. More recently, Obeid and Daou (2015) investigated the effects of coping styles, social support, and child's behavioral symptoms on the maternal well-being of children with autism disorder in Lebanon. Cognitive reframing was found to be correlated with better maternal well-being.

Reframing or cognitive reframing implies the situation and to view the situation in a positive way. This helps the family to cognitively redefine the situation, accept their problematic situations and help themselves reduce stress. Luther, Canham, and Cureton (2005) found out that acquiring social support and reframing were the most frequently used coping strategies by the parents of children with autism. Similarly, Manning et al. (2011) also found that coping by relying on family and friends, by seeking spiritual and reframing are related to lower parental stress. Along with reframing, passive appraisal is another type of cognitive coping strategy reported by parents of the children with autism.

Passive appraisal. Cognitive distraction is an emotional focused coping strategy used by parents of the children with autism to overcome stress. One form of

cognitive distraction is passive appraisal. It allows the individual to actively avoid the stressful situation. Sometimes it may help the individual to accept the situation and help minimizing the reactivity to stressful situation. Passive appraisal includes activities e.g., watching television, relying on luck, believing that time will solve the problem, involving oneself in other activities etc. Gray (1994) identified that parents engage themselves in "individual based activities" to avoid stress e.g. some parents are politically active in seeking treatment for their child, some mothers returned to workplace and some involve themselves in domestic schedules. Luong, Yoder, and Canham (2009) investigated coping styles of Southeast Asian parents of children with autism. Passive coping was among the most frequently evolved theme along with empowerment, redirecting energy, shifting of focus, rearranging life and relationships, changed expectations, social withdrawal, spiritual coping and acceptance.

One of the first studies which explored the structure of coping strategies used by parents of preschool and school going children with autism was done by Hastings et al. (2005). Parents completed a measure of the strategies they used to cope with the stresses of raising their child with autism. Results revealed four reliable coping dimensions: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. Only active avoidance coping was found significantly effecting maternal stress. In other words, mothers who used this coping strategy presented greater levels of stress. Yet, the complexity of coping and the variety of strategies enumerated in different studies suggest that people cope in number of ways. Coping through spiritual-religious means is another strategy commonly reported by families of the children with autism.

Spiritual and religious coping. Spiritual coping consists of spiritual beliefs, attitudes or practices. It is used to lessen the emotional distress caused by the stressful events of life, such as loss or change. Spiritual beliefs and practices are used to regulate emotions during times of illness, change, and circumstances that are out of personal control. Some of the families report using religious or spiritual belief as mean of coping, when caring a child with autism. Gray (1994) identified religion as the primary source which parents use to establish coherence in their daily lives. Moreover, Bristol (1984) found that families of children with autism were more likely to emphasize strong moral and/or religious standards for coping than families of the children without autism. Kopolovich (2008) explored coping strategies used by orthodox Jewish mothers of the children with autism. Frequently identified themes were making sense of the situation through religion and social support.

Tarakeshwar and Pargament (2001) found that in Asian families coping through spiritual support (e.g., attending religious services, prayer) is a source of reduced parental stress. If coping through spiritual support is endorsed by the families of children with autistic disorder than families should be encouraged to utilize their faith as means of coping through stress. Religious institutions must show sensitivity towards families of the children with autism by welcoming them and making accommodations according to their needs.

Ekas, Whitman, and Shivers (2009) found that religious belief and spirituality has a positive effect on mother's socio-emotional health. It was further argued that role of religion is complex because it operates on many different levels and in many different ways. Religious beliefs, religious activities and spirituality can either be positive or negative, depending on the context and approach of the individual.

Most of the coping research was cross sectional in nature. In one of the longitudinal research Gray (2006) examined coping in parents of the children with Autistic disorder over time. In this longitudinal study it was found that parents followed up from 1994 study cited using far fewer coping strategies 12 years later. This may be a positive reflection of an improvement in their child's symptoms, and consequently a reduced degree of emotional distress for the parents because their child was easier to live with. Reduced use of coping strategies may also reflect the increased age of their child and the parents being relatively further forward in the adaptation process than they were at the time of the previous study. Parent's use of treatment services had declined as a coping strategy, but again this may be a reflection of their child's increased age, and possibly also reduced availability of services for the parents in this sample. Over time the parents in this study reported increased use of emotion-focused coping strategies, which included the adoption of more philosophical attitudes and emotional responses to difficulties. Other researches also claim the fact that using a variety of coping strategies is more beneficial to parents of the children with autistic disorder (Dunn et al., 2001). One of the limitations of the study was its inability to explain whether parents are less stressed because they have learned to effectively cope or the stressors themselves have changed.

Spirituality and religion form a bridge of contact between human, a composite of body and soul, and the Creator. Its practices develop an awareness that provides to recognize foster positive values in an individual, which supports good health care practices and a way to cope with stress and trauma in life (Chaudhry 2008). Parents of children with autism often use spiritual and religious coping to deal with the phenomenon of disability in family. In a qualitive study conducted in Pakistan to explore the different coping mechanism used by Parents of children with autism,

spiritual coping was found to pay an important role in dealing with every day hassles (Mahmood, Saleemi, Riaz, Hassan, & Khan, 2015).

Croot, Grant, Mathers, and Cooper (2012) found that Coping strategies identified are not specific to the Pakistani population but certain features of the strategies may be distinct to those used by parents with a different heritage. Individual practical and material circumstances and availability of resources influenced the choice of coping strategies and spiritual and religion practices played a role in the coping experiences of parents of children with disability.

Thus far, research literature continues to indentify the coping strategies utilized by the parents of children with autism. Moreover, research does identify the direct relationship of coping with parental stress and wellbeing. However, mediating role of coping is still unexplored. Exploring the mediating role of coping will help devising effective coping strategies that help parents overcome stress (Pisula & Kossakowska, 2010).

Mediating Role of Coping in the Families of Children with Autism

Lazarus and Folkman (1984) postulated that coping affects psychological wellbeing in three different ways. Firstly, it was suggested that coping has a direct effect on psychological well being independent of stressor's effect. Secondly, coping acts as a moderator and finally, coping has been also conceptualized as a mediator between the stressor and the psychological wellbeing.

Despite the practical importance of coping for the parents of children with autism, little research is available examining its indirect affect on variables speculated to effect parental stress. However, studies do cater to moderating/buffering role of coping. Some of the studies didn't found any evidence e.g., Abbeduto et al. (2004)

found no buffering effect of coping on autism behavioral symptoms and maternal psychological wellbeing. Likewise, Higgins, Bailey, and Pearce, (2005) also reported that coping was not related to autism characteristics and family functioning. One potential study providing evidence for buffering effect of coping (problem focused) between autism symptoms and maternal wellbeing was by Smith et al. (2008). Similarly, Dunn et al. (2001) found that distancing and social support were the significant moderators in the relationship between stressors and isolation. Lyons et al. (2010) reported that task-oriented coping was associated with less physical incapacity and emotion-oriented coping increase the impact of autism severity on parental stress. Distraction coping lessens the impact of autism symptom severity on parental stress.

One of the initial studies which provided a strong theoretical frame work for mediating role of coping between stress influencing variables and the outcome variable was conducted by Mausbach et al. (2006). The study explored the mediating effect of coping (escape—avoidance coping) between patient behavior problems (e.g., repeating questions, restlessness, and agitation) and depression in caregivers of individuals with Alzheimer's. It was found out that escape—avoidance coping partially mediates the association between patient behavior problems (e.g., repeating questions, restlessness, and agitation) and depressive symptoms.

One of the few studies which examined the mediating role of coping styles and social support between autism child symptom severity and parenting stress was conducted by Ingersoll and Hambrick (2011). It was found out that the mediation model for adaptive and maladaptive coping styles between child symptom severity and parenting stress was not significant. Interestingly, social support partially mediated the relationship between child symptom severity and parenting stress. Thus, one way that child symptom severity may have an impact upon parental stress is through social support. Parents perceived that less social support was available when

the child impairment was severe, which increased the risk of poor parental mental health. Few of the limitations of this research were that child symptom severity was based on parental report. Parents who were experiencing stress might have rated their child symptom severity as more severe. In addition only adaptive and maladaptive coping styles were included although variety of coping strategies was enumerated in the past researches. Moreover, 91.3% of the sample constitute of mothers only therefore the findings cannot be generalized for fathers.

Cognitive reframing is a psychological technique or a coping behavior utilized to reconsider the things in a positive way. Somewhat near to reframing is Psychological acceptance. It is experiencing a source of stimulation that previously evoked escape, avoidance, or aggression. In one of the studies by Weiss, Cappadocia, MacMullin, Viecili, and Lunsky (2012) investigated the mediating role of acceptance between child problem behaviors and parent mental health. It was found out that Psychological acceptance partially mediates the relationship between child problem behavior and parent mental health problems. Increase in child problem behaviors, decreases parental psychological acceptance resulting in increased mental health problems in parents. These findings suggest that for the problems that are chronic and difficult to address, psychological acceptance may be an important factor. In addition most of the information collected was based on mothers report, thus the finding cannot be generalized for fathers. The only stress- influencing variable included was problem behavior ignoring the importance of the other specific and general characteristics related to autism.

Recognizing that higher symptoms of autism in children are associated with higher maternal stress levels, Mekki (2012) investigated the mediating effect of coping strategies between autism symptom severity and maternal stress. Results of the study indicated that escape-avoidance and confrontive coping were positively

correlated with maternal stress, while seeking social support was negatively correlated with stress. Confrontive coping did not mediate the relationship between autism symptom severity and maternal stress. It was suggested to use multiple areas of child functioning (adaptive behaviors, problem behavior, etc.) and broader coping strategies.

Peer (2011) investigated the mediating role of coping style between stress influencing variables (life orientation, level of disability, and social support) and parental stress. Coping style was found to be a significant predictor of stress for caregivers of children with developmental disabilities. Severity of disability was not fully related to coping style or stress. Therefore it was not utilized as part of the final meditational analysis. It was suggested to strengthen the theoretical model of coping and stress by adding different stress influencing variables to determine the mediating role of the coping strategies.

Pozo and Sarriá (2014) examined stress in Spanish parents of the children with ASD. Based on past researches it was asserted that characteristics of individuals with ASD (severity of disorder and behavior problems) have direct effect on stress and an indirect effect on stress through social support, perception of the problem and coping strategies (positive and problem-focused coping and active avoidance coping strategies). Two separate empirical models emerged for father and mother of children with ASD. As predicted it was found out that both characteristics of individuals with ASD (severity of disorder and behavior problems) were associated with paternal as well maternal stress. Moreover, the direct relationship between behavior problems and maternal, paternal stress was mediated by perception of the problem and active avoidance coping strategies. Interestingly, Social support showed direct negative relationship with maternal stress. However, all disorders (PDD-NOS, Asperger, Rett disorder, autistic disorder) were included in the sample to drive a composite autism

characteristic variable. In fact, all the disorders included have distinct characteristics and they differently impact parental stress. Yet again composite score of coping was utilized ignoring the variety and complexity of the construct.

Thus far, most of the research related to coping behaviors adapted by the families of children with autism included mothers only, ignoring the significance of fathers in the family. Moreover, despite knowing the complexity and variety in coping behaviors reported in past literature, majority of research relied on composite score of coping behaviors. Indeed, it is important to know mediating role of coping between autism child characteristics, maternal and parental stress. Since, it helps the professional to devise interventional plan for the families of children with autistic disorder. Keeping in view the gap indentified in the literature, the focus of the present study is to explore the mediating role of family coping between child characteristics (autism symptom severity, adaptive behaviors and problematic behaviors) and paternal, maternal stress.

Family Socio-Demographic Factors, Maternal and Paternal Stress

Family socio-demographic factors play a very important role in defining parental stress. It helps to understand the role of individual, familial, cultural dynamics and mechanism with reference to stress. Thus far, most of the research in parenting stress was just identifying and comparing families of the children with autism with other families. It was suggested that future research should emphasis in identifying and controlling other variables such as child characteristics and family socio-demographic factors, and their relationship with parental stress (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004).

McCabe (2008) explored stress in Chinese's families of the children with autism. It was found out that parents experience shock and confusion on having a child diagnosed with autism. Differences in the perception of stress were also noted between mothers and fathers. Mothers reported more stress as compared to the fathers of children with autism. Fathers were less involved in everyday tasks related to their child and they appeared to be more distant from their family issues. Mothers perceived more stress in the areas related to "parent and family related problems" as compared to fathers. Mothers left their jobs and devoted more time for caring their children. It was found that lives of the fathers of children with autism usually remained stable and fathers for the most part were able to avoid most tasks associated with care-giving.

Caring for the children with autism may be more costly than caring for children with other disabilities. Most of the time children require educational services, interventional and health care services, which are offered by multiple providers. To put up with financial cost of raising a child with autism, usually both parents work. Cidav, Marcus, and Mandell (2012) found that working mothers of the children with autistic disorder perceive more stress because of their career demands and inflexible workplace timings. Most of the women worked fewer hours to accommodate the needs of their child and sixty percent had suffered financial problems in the previous years. Mothers reported that taking care of an Autistic child along with the job is an added stress for them.

Zablotsky, Bradshaw, and Stuart (2012) found out that mothers with high stress levels were more likely to live below the poverty line, have a child without health insurance, moved three or more times and younger than 27 years of age, when compared to mothers with low stress levels. Moreover, mothers with high stress levels were more likely to have a male child and age of the child ranged between 12 to 17

years. Mothers with high stress levels were less likely to have college education they do not hold regular employment when compared to mothers with lower stress levels. Mothers with high stress levels were less likely to have strong coping skills, emotional supports and social support when compared to mothers with low stress levels. However, only mothers were included in the study and single item measure was used to measure stress and coping. Diagnosis of the children with autism was also based on the parental report.

Living in collective culture might be an additional source of support for parents of the children with autism. Krishnamurthy (2008) reported that families where two or more generations live together provides an excellent support system for parents of children with autism. Although, joint family system is becoming less common because of urbanization but still extended family system is a source of relief for parents of the children with autism. Similarly, Gupta, Mehrotra, and Mehrotra (2012) conducted a study determining the factors related to parental stress in India. They found that informal support from family help parents to better cope with the daily stressor of having a child with disability. In Pakistan, Sajjad (2011) conducted an exploratory study to investigate the stress experienced by the mothers of children with intellectual disabilities including autism. The study depicted that the mothers reported depression and elevated stress, which was negatively affecting the family system. However, the mothers living in joint family system reported less depressive symptoms and stress as compared to the mothers living in nuclear family system.

Family socio-demographic factors play a vital role in understanding the social, cultural and familial background of stress in the families of children with autism. Pakistan is a multicultural and multi ethnic society. It is important to understand the dynamic of different family socio demographic variables with stress and coping in

order to device facilitation and intervention plans for families of the children with autism.

Children with Autism in Pakistan

It is difficult to report exact prevalence of autism in Pakistan, as so far autism is not properly recognized at public sectors. According to last census in 1998, approximately 2.4 percent of the population has some form of disability. This is significantly lower than the World Health Organization (WHO) estimate of approximately 10 percent. Rathore, New, and Iftikhar (2011) noted that the difference is, probably due to a difference in definition of disability. Morton, Sharma, Nicholson, Broderick, and Poyser (2002) investigated the prevalence of child disability in different ethnic groups using health record information. They reported that Pakistani children showed somewhat high prevalence of autism, along with other disabilities.

Few studies reported the prevalence of autism based on the information obtained from special education school and hospitals in different cities of Pakistan e.g., Suhail and Zafar (2008) conducted a study in special education schools in Lahore (Pakistan). Out of 1633 children 142 were identified as the probable cases of the children with autistic disorder. Similarly, Rauf, Haq, Aslam, and Anjum (2014) found that most of the children with autism were misdiagnosed as mentally retarded. Out of 603 children with various disabilities, enrolled in seven different special schools in Rawalpindi and Islamabad (Pakistan), twenty three were identified as potential cases of autism. Unfortunately, the prevalence rate cannot be generalized because the studies were restricted only to hospital and school settings.

Like prevalence, cause of autism is also not known in Pakistan. Usually, interfamily marriages are considered as one of the major cause of disability in Pakistan. Morton et al. (2002) also reported that genetic conditions like inborn errors of metabolism, autosomal recessive condition and consanguinity might be the probable causes of autism in Pakistan.

A lot of myths and misconceptions also exist with reference to causes of autism. Imran and Azeem (2014) reported that most of the health care workers consider parental neglect, aloof and cold parenting styles as the causes of autism. They also believe that autism is more prevalent in educated groups and families with upper socioeconomic status. Moreover, they also consider autism as temporary and preventable.

Birth of an autistic child in family brings in a plethora of challenges for the parents. Initially, they prefer to consult religious scholars, spiritual and traditional faith healer for treatment and explanation. They are reluctant to consult the psychiatrists because many myths are attached with the use of psychotropic drug. Parents think that the medicines are not curing their children instead they are making them addictive. Due to lack of specialized training in the area, health professionals also feel hesitant to make diagnosis because of the fear of labeling the child (Rahbar etal., 2011).

As the child grows the severity and ambiguity related with autism symptomology brings in manifolds challenges for parents. Batool and Khurshid (2015) explored the risk factors of stress among parents of the children with autism in Lahore city. It was found out that severity of autism was the significant predictor of stress in the parents. Moreover, no significant gender difference emerged in terms of parenting stress and no relationship was found between demographic variables and

parenting stress. It was suggested to explore the stress in the parents of children with autism with reference to child characteristics and demographic variables.

Hassan and Inam (2013) conducted a qualitative study in Lahore (Pakistan), they investigated the factors contributing to stress among parents of the children with autism. Psychological, social, educational, financial and future concerns were identified as factors causing stress in parents of the children with autism. It was found that future concern regarding the child was a factor that made the parents experience more stress than any other factor. Mothers suffered elevated stress as compared to the fathers and it was suggested that mothers require more attention and counseling.

Sabih and Sajid (2008) investigated coping strategies and wellbeing among parents having children with autism and Down syndrome. They found out that depression, anxiety and stress were higher in parents of children having autism. Fathers scored significantly higher on psychological wellbeing as compared to mothers. Parents of autistic children used more active avoidance coping strategies. It was suggested that parents must adopt coping behaviors to alleviate physical and mental burden of taking care of the children with autism.

Rationale of the Study

Parents of children with autism experience more stress as compare to parents of children with other disabilities like down syndrome, intellectual disability, cerebral palsy, fragile X syndrome, cystic fibrosis, fetal alcohol spectrum disorder (FASD) and externalizing behaviors (Dumas et al., 1991; Perry et al., 2005; Weiss, 2002; Dabrowska & Pisula, 2010; Estes et al., 2009; Griffith et al., 2010). Stress in parents of children with autism is high because the characteristics related to the disorder can complicate the overall challenges for the parents. The challenges related to the disorder are unknown etiology, complicated diagnosis, unique characteristics (Dyches et al., 2004), severity of autism symptoms (Rivard et al., 2014), emotional and behavioral manifestation of symptoms (Huang et al., 2014).

Previous research related to parental stress in families of children with autism has been conducted on mothers only (Ekas & Whitman, 2011; Estes et al., 2013; McCabe, 2008; Meirsschaut et al., 2010; Tomanik et al., 2004; Zablotsky et al., 2012) or on parents without differentiating between mothers and fathers (Bitsika et al., 2013; Hall & Graff, 2011). Although, raising a child with autism present significant challenges for fathers as well (Ingersoll & Hambrick, 2011; Pozo & Sarriá, 2014). Their is a need to address paternal stress along with maternal stress, because of its potential influence on both mother and the child and in order to better understand the nature and predictors of stress. Moreover, paternal involvement may possibly be a good predictor of child's cognitive, emotional and social developmental outcomes.

Research on child characteristics associated with stress in parents of children with autism primarily addressed core symptoms of autism (Ekas & Whitman, 2010; Lyons et al., 2010), severity of autism (Benson, 2006; Hasting & Johnson, 2001), and problematic behaviors (Davis & Carter, 2008; Smith et al., 2008). Their is dearth of literature addressing the individual and cumulative impact of child characteristics, specifically with reference to paternal as well as maternal stress. The factors in the child's characteristics include autism symptom severity, presence of core and associated symptoms, adaptive behaviors and problem behaviors of children with autism. In order to be able to provide proper services to mothers as well as fathers of children with autism, it necessary to more thoroughly study the factors associated with stress.

Most of the interventions are focused on reducing stress in parents of children with autism. Bitsika et al. (2013) reported that most of the parents adapt successfully or at least partly to the demand of raising children with autism by adopting effective individual and family coping strategies. Previous research do identify different types of adaptive and maladaptive coping strategies used by parents of children with autism and also highlighted the direct relationship of coping with stress but there is dearth of literature available on the mediating role of family coping in child characteristics and paternal, maternal stress (Hastings et al., 2005; Hayes & Watson, 2013; Lyons et al., 2010). Understanding the mediating role of family coping between child characteristics and maternal, paternal stress is important to further our understanding of this relationship, especially in local context. Furthermore, it is helpful in enhancing the practitioners as well as parent's knowledge to address the stress caused by autistic child characteristics.

The family socio-demographic variables play an important role in the way a family experience the stress. The understanding of relationship of parental stress with family socio-demographic variables has also been emphasized by different scholars (e.g. Seltzer et al., 2004; Zablotsky et al., 2012). Pakistan is a multicultural and multiethnic society and to understand the social, cultural and familial background of stress in families of children with autism and to device better intervention plans for parents of children with autism coming from diverse socio-demographic backgrounds. It is important to investigate the relationship of different family socio-demographic factors with paternal and maternal stress.

Chapter II

METHOD

The present study aims at examining the relationship between child characteristics, coping and stress in parents of children with autism. Particularly the following objectives are examined.

Objectives

- To study the relationship between child characteristics (autism symptom severity, adaptive behaviors, problematic behaviors) maternal and paternal stress.
- 2. To study the relationship between autism symptomology (core symptoms and associated symptoms) maternal and paternal stress.
- 3. To study the relationship between adaptive behaviors (personal self-sufficiency, community self-sufficiency and personal social responsibility) maternal and paternal stress.
- 4. To study the relationship between problem behaviors (emotional problem, conduct problem, hyperactivity and peer problem) maternal and paternal stress.
- 5. To study the mediating role of family coping between child characteristics (autism symptom severity, adaptive behaviors, problematic behaviors) maternal and paternal stress.
- 6. To study the relationship of different family socio-demographic factors (e.g. gender of parents , work status of mother, age of autistic child, gender of

autistic child, education of parents, socio economic status, family system) with reference to paternal and maternal stress.

Hypotheses

- 1. Problematic behavior is more predictive of maternal and paternal stress as compared to symptom severity and adaptive behaviors.
- 2. Core symptomology is positively associated with maternal stress.
- 3. Personal self sufficiency is negatively associated with maternal and paternal stress.
- 4. Emotional problem and conduct Problem are positively associated with maternal and paternal stress.
- 5a. Family coping mediates the relationship between autism symptom severity and maternal, paternal stress.
- 5b. Family coping mediates the relationship between adaptive behaviors and maternal, paternal stress.
- 5c. Family coping mediates the relationship between problematic behaviors and maternal, paternal stress.
- 6a Maternal stress will be higher as compared to paternal stress.
- 6b. Maternal stress of employed mothers will be higher as compared to mothers who are not employed.
- 6c. Maternal stress will be higher for mothers living in nuclear family system as compared to mothers living in joint family system.
- 6d. Greater the maternal age, less will be the maternal stress.
- 6e. Greater the family income less will be the paternal and maternal stress.
- 6f. Greater the number of children in family more will be the paternal and maternal stress.

Instruments

Following instruments were used to measure the study variables.

Childhood Autism Rating Scale-2. It is an observational diagnostic assessment tool that rates children on a scale from one to four on fifteen different dimensions. It was developed by Schopler, Van Bourgondien, Wellman, and Love (2010). It was used to assess autism symptom severity, core and associated symptomology of children with autism. It can be used with ages 2 to 13 years and older. The internal consistency of CARS was reported as .89 to .94 (Ekas & Whitman, 2010). Whereas, the inter-rater reliability reported in the manual was also excellent (Schopler et al., 2010). It is further divided into two subscales i.e., Core symptoms and associated symptoms

Core symptoms. It has 6 items. It refers to those symptoms designated in the DSM IV-TR) as being diagnostic criteria of autistic disorder. The rating options ranged from one to four, ranging from normal to severe.

Associated symptoms. It has 9 items. It refers to frequently occurring symptoms. The rating options ranged from one to four, ranging from normal to severe (Ekas & Whitman, 2010). (See Appendix B1).

Adaptive Behavior Scale-School Edition ABS-S: 2 (Part 1). It assess the adaptive behaviors of children with autism. It was developed by Lambert, Nihira, and Leland (1993). Part one of the scale was administered in this study. It can be used with school aged children ages 3 to 16 years, who have emotional maladjustments, intellectual impairments, or developmental deficits. It consists of 67 different items that constitute of nine domains and three factors. Three factors "personal self-

sufficiency", "community self-sufficiency" and "personal social responsibility" were used in the present study. The internal consistency of the factor scores has been reported to be in excess of 0.90 (Nihira etal., 1993). (See Appendix B2).

Strengths and Difficulties Questionnaire (SDQ). It was developed by Goodman, (1997) and translated in Urdu language by Samad, Hollis, Prince, and Goodman, (2005). This instrument was used as a measure of children's behavioral and emotional adjustment, completed by primary caregivers. The scale can be used with children aged 3 to 16 years. It actually consists of 25 item and five different dimensions. In the present study only four dimensions emotional symptoms, conduct problems, hyperactivity, and peer problems were included. That sum up to generates a "total difficulties" behavior problem score. The fifth dimension "pro social behavior" which is not the part of difficulty index was not included (See Appendix B3).

Questionnaire on Resources and Stress (QRS-F). It was developed in 1983 from Holroyd's much longer questionnaire on resources and stress (Holroyd, 1974). The QRS-F consists of 52 items and considered as reliable and valid instrument to measure positive and negative dimension of parental stress (Friedrich, Greenberg, & Crnic, 1983) (See Appendix B4).

For the present study only two dimensions "parent and family problems" and "pessimism" were utilized. It was noted that original QRS was designed to cater families who might need assistance. Therefore besides measuring stresses and strain, it also catered items that measure demands (Glidden, 1993). To focus more on parental stress, items from "child characteristics" and "physical incapacitation" were not included. In the present study the researcher treated child characteristics as independent variables. Therefore, it would have been confusing to include these items

in parental stress instrument. Only items from "parent and family problems", and "pessimism" were included. Additionally, three items (11, 14 & 21) from subscale "child characteristics" were also moved to "parent and family problem". These three items measured parental stress more than the characteristics of the child (Saloviita, Itälinna, & Leinonen, 2003).

The Family Crisis Oriented Personal Evaluation Scales (F-COPES). It was developed in 1991 by Hamilton McCubbin, David Olson, and Andrea Larsen. It contains 30-items that been divided into five coping patterns i.e., acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. It has good psychometric properties, and its subscale scores have been shown to be predictive of stress in various types of families (Twoy et al., 2007) (see Appendix B5).

Pretest of Instruments

Hambleton, Merenda, and Spielberger (2004) suggested that instruments selected should voice the situation, vocabulary and expression that can easily be adapted in the target language. For this purpose instruments of the present research were reviewed by the researcher and then pretested on small sample. The sample constitute of (3 parents of children with autistic disorder and 2 special education teachers). Results of the pretest of instruments were as given below:

Results

Childhood Autism Rating Scale-2. It is an observational tool and usually experts observe and rate the child's behavior. It can easily be understandable and comprehendible in its source language English.

Adaptive Behavior scale-School Edition ABS-S: 2 (Part 1). Culturally inappropriate expressions were identified in 7 items (1, 2, 19,22,31,32 and 57) (See Appendix C, TableA1). List of culturally appropriate expressions was generated in the source language (English) (See Appendix C, Table A2). Culturally inappropriate expressions were replaced by culturally appropriate expression in the above mentioned items before moving to the study I.

Strengths and Difficulties Questionnaire (SDQ). Already available Urdu SDQ was pretested to see its suitability for the present sample. It was found that beside few expressions in item numbers 5, 7, 9, 10, 15, and 18 it was a suitable instrument to measure problem behaviors of children with autism (See Appendix C, Table A). The problematic expressions identified in above mentioned items were modified in translation phase of study I.

Questionnaire on Resources and Stress (QRS-F). Only two subscales "Parent and family problems" and "pessimism" were used in the present study. It was found that the instructions of the QRS-F were bit complex and the target audience might not able to understand the instructions. Three subscales were added in QRS-F to make the questionnaire culturally more relevant. Interviews were conducted with parents and special education experts to explore indigenous stressors (see Appendix

D). After conducting interviews sixteen items and three subscales were added to the QRS-F. The subscales added were Financial stress (4 items), Stress due to lack of Services (7 items) and Stress due to lack of awareness (5 items).

The Family Crisis Oriented Personal Evaluation Scale (F-COPES). In

F-COPES item no 14 "attending church services", item no 23 "participating in church activities' and item 27 "seeking advice from the minister" were culturally inappropriate expressions. A list of culturally appropriate expressions was generated in source language (English). Culturally inappropriate expressions were replaced by appropriate expression in the above mentioned items before moving on to the next study I (See Appendix E, Table A3).

Conclusion

It was concluded that instruments selected for the present research voice the situation, vocabulary and expression that is required for the translation process. Few culturally inappropriate expressions were identified in ABS-S: 2 (Part 1) and F-COPES. They were replaced with the culturally appropriate expressions. In SDQ few expressions were identified that were difficult to comprehend. The problematic expressions identified were modified in translation phase of study I. After conducting interviews with parents and special education experts three subscales "financial stress", "stress due to lack of services" and "stress due to lack of awareness" were added to QRS-F. Hence, all the instruments were ready for study I that caters translation and validation of instruments.

Research Design

The research was carried out in two specific studies, called study I and study II, each with independent sample.

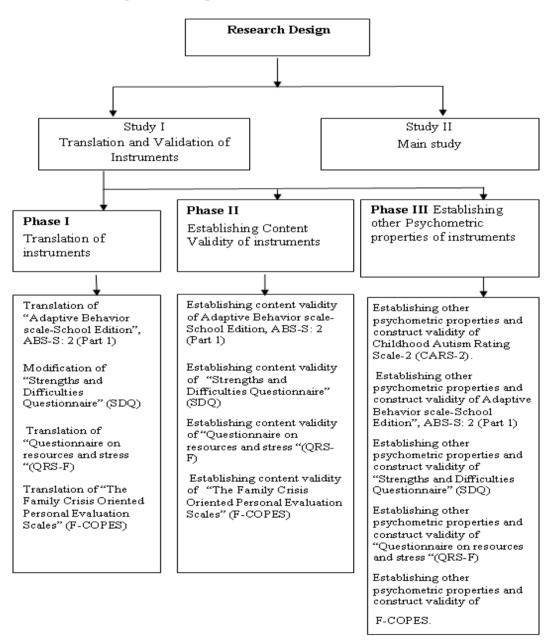


Figure 4. Research Design of the Study

As depicting in figure 4, Study I was aimed at translation and validation of instruments to be used in the main study i.e., study II. Study I was carried out in three phases. Phase I was related to translation and modification of instruments, Phase II was about establishing content validity of instruments and in Phase III, others psychometric properties of instruments were addressed. Study II was the main study and its purpose was test the proposed hypotheses.

Chapter III

STUDY I

Objectives of the study I was as mentioned below:

- 1. To translate "Adaptive Behavior Scale-School Edition" ABS-S: 2, (Part 1) "Questionnaire on Resources and Stress" (QRS-F) "The Family Crisis Oriented Personal Evaluation Scales" (F-COPES) from source language (English) to target language (Urdu) and to modify "Strengths and Difficulties questionnaire (SDQ).
- 2. To establish content validity Index of translated versions of "Adaptive Behavior Scale-School Edition" ABS-S: 2 (Part 1), Maternal and Paternal "Questionnaire on Resources and Stress" (QRS-F), "The Family Crisis Oriented Personal Evaluation Scales" (F-COPES) and modified version of "Strengths and Difficulties Questionnaire (SDQ).
- 3. To establish other psychometric properties of "Childhood Autism Rating Scale-2" (CARS-2) "Adaptive Behavior Scale-School Edition" ABS-S: 2 (Part 1), Maternal and Paternal "Questionnaire on Resources and Stress" (QRS-F), "The Family Crisis Oriented Personal Evaluation Scales" (F-COPES) and modified version of "Strengths and Difficulties Questionnaire (SDQ).

Study I further constitute of three phases. In Phase I translation of instruments was done. In phase II content validity of the instruments was established and in Phase III other psychometric properties and construct validity was addressed.

Phase I: Translation of Instruments

Phase I highlights the process involved in translation of instruments from source language (English) to target language (Urdu). Objective of Phase I was as given below:

Objective

1. To translate "Adaptive Behavior Scale-School Edition" ABS-S:2(Part 1) "Questionnaire on Resources and Stress" (QRS-F) "The Family Crisis Oriented Personal Evaluation Scales" (F-COPES) from source language (English) to target language (Urdu) and to modify "Strengths and Difficulties questionnaire" (SDQ).

Instruments

Instruments used in Phase I were Adaptive Behavior Scale-School Edition ABS-S:2, (Part 1), Two subscales "parent and family problems" and "pessimism" of Questionnaire on Resources and Stress (QRS-F), The Family Crisis Oriented Personal Evaluation Scales (F-COPES) and Strengths and Difficulties Questionnaire (SDQ). SDQ was already available in Urdu language but modifications were done within few items, in order to make it easily comprehendible by target audience.

Procedure

The procedure of phase I consisted of three steps. Step 1, was related to selection of translators, step 2, was about the process involved in the translation and step 3, constitute of judges opinion.

Step 1: Selection of translators. Team of translators was selected, the team was selected keeping in view the following few points.

- 1. The team of translators must have at least post graduate level of education.
- 2. They were all bilingual, proficient in both source and target languages
- Translators with technical knowledge of subject areas of psychology were preferred

Forward translation design was used in the present study and in order to minimize the drawbacks of design, the translators were selected keeping in view the above mentioned criteria. Five translators were selected (Three PhD scholars in psychology, one practicing clinical psychologist and one PhD linguistic). The team of translators was instructed regarding the purpose, process and given knowledge about essentials of translation. Instructions were given both in verbal and written form to the individual team member.

Step 2: Process of translation. During the translation process minimum interference was insured by the researcher. On completion of translation process individual feedback was received from all the members of the team. After compiling all the information and five translated versions of each instrument a team of expert

judges were approached for compilation of one final form of each translated instrument.

Step 3: Judges expert opinion. An expert judges committee was formed to choose the best translated items from five versions of translations available (Hambleton et al., 2004). It constituted of four members one professor in psychology and three PhD scholars. They were proficient in both languages and expert in subject area. The committee reviewed all the translations and selected the best compatible option. After thorough review following suggestion were advised by the judges:

Results

Adaptive Behavior Scale-School Edition ABS-S: 2 (Part 1). In item no 6 "Self care at toilet" there was a statement "Uses Toilet tissue appropriately" it was translated as " Most of the population in Pakistan does not use toilet tissue. They prefer to wash instead of using toilet tissue. It was advised by the expert committee for an additional sentence. "Can properly wash him\herself after toilet " After reviewing the recommendations, translated Urdu version of ABS-S: 2 (Part 1) was finalized.

Strengths and Difficulties Questionnaire (SDQ). As the questionnaire is already available in Urdu language but few problematic expression were identified during the pretest of the instruments. It was suggested by the experts to simplify the expressions within few items of SDQ. In item no 5 & 18 it was suggested by the expert to replace the word "..." "adult" as this might create confusion for the reader. Keeping in view the suggestion given by the experts the word was replaced

with "dults". In item no 7 the word "dults" "squirming" has been replaced with "dults". In item no 9 & 15 the word "dults" "bullied" was placed by "dults". Similarly in item 10 experts suggested to replace the word "dults" "tearful" with "down-hearted" with "down-hearted". After making changes as suggested by the experts, SDQ was finalized.

Questionnaire on Resources and Stress (QRS-F). It was advised by the committee to split item number 27 "Constant demand to care for ______ limits my growth and development" into 27 " limits my growth" and 28 " Constant demand to care for _____ limits my growth" and 28 " Constant demand to care for _____ limits my development". As in Pakistani culture most of the people take the word "growth" in term of health and "development" in terms of progress.

As identified during the pretesting of instruments, the instructions of QRS-F were difficult for the target audience to understand. The statement "There are many blanks in the questionnaire. Imagine the child's name filled in on each blank" was removed from the instructions. It was decided to write the child name on the blanks before administering the questionnaire.

Few statements which address both genders of the parents e.g., item no 3, 8, 11, 12, 15, 16, 25, 29, 30, 31, 34, 35 were creating confusion. To remove the confusion two versions of QRS-F were formulated. One is the paternal version and other is the maternal version of QRS-F.

The original true false structure was also changed to a five point likert scale in order to widen the distribution of the data. Items in the scale ranged from strongly agree, agree, don't know, disagree or strongly disagree.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES). It was advised by judges to remove Item no 30 "Having faith in God" because of social desirability, as most of the sample of the present study have firm faith on God. It was also recommended by the committee to add two new item statements. One was " , "instead of taking any action we leave our matters on God" in passive appraisal subscale and one in seeking spiritual support " , "We use different spiritual method e.g. to taper, use of amulet, going to mausoleums of Sufi saint for special prayer" After incorporating the suggestions given by experts final translated version of F-COPES was finalized.

Conclusion

The Urdu versions of ABS-S: 2 (Part 1) was finalized after translation process. In instrument measuring parental stress, after splitting item number 27 into two items, changing the response format from dichotomous to likert scale, creating maternal and paternal versions of QRS-F and by making the instructions simple, Urdu version of QRS-F was also finalized. After thorough review by expert judges Urdu version of F-COPES and a modified version of SDQ was also finalized.

Phase II: Content Validity Index of the

Translated Versions of Instruments

Content validity index was established in terms of clarity and cultural equivalency. The process was adapted from original CVI work by Lynn (1986).

Objective of the phase II was as given below:

Objective

To establish content validity Index of translated Urdu versions of Adaptive
Behavior Scale-School Edition ABS-S: 2(Part 1), Strengths and Difficulties
Questionnaire (SDQ), Maternal and Paternal versions of Questionnaire on
resources and stress (QRS-F) and The Family Crisis Oriented Personal
Evaluation Scales (F-COPES).

Instruments

Instruments used Phase II, were Urdu version ABS-S: 2(Part 1), modified version of SDQ, In Maternal and paternal Urdu versions of QRS-F, along with two already existing subscales that were "Parent and family problem" and "pessimism". Three more subscales added during the pre testing of instrument were also included. The three subscales added were financial stress (item number 36, 37, 38, 39), stress due to lack of services (item number 40, 41, 42, 43, 44, 45, 46) and stress due to lack

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of awareness (item number 47, 48, 49, 50, 51). The last instrument used was The F-

COPES.

Procedure

Phase II was carried out in three steps

Step1: Selection of qualified bilingual experts

Step 2: Administration

Step 3: Empirical evaluation/ Data analysis

Step 1: Selection of qualified bilingual experts. The recruitment of experts

ranges from 3 to 10 (Domingues et al., 2011; Lynn, 1986). For the present study four

experts were selected on careful consideration of their knowledge about the research

area. All four experts were PhD in psychology and were bilingual, understand both

Urdu and English.

Step 2: Administration. A content validity questionnaire was rated by

experts. The questionnaire was specifically designed for this study and it assessed the

content validity of instruments in terms of the clarity of instructions, items and

response format as well as cultural equivalency of translated items. It has four point

likert scale. The questionnaire was rated individually and independently by each

expert. (See Appendix F)

Step 3: Empirical evaluation/ Data analysis. After completion of content validity questionnaires data was analyzed. The content validity of instruments was rated by experts for the clarity and cultural equivalency of the entire scale (S-CVI) and individually for the instructions, response format, and items (I-CVI).

Item-level Content Validation Index (I-CVI). The I-CVIs were calculated as the proportion of experts who endorsed the validity of each scale (i.e., gave ratings of 3 and 4 on the 4-point Likert scale). To calculate I-CVI total number of valid ratings were divided with the total number of ratings. The I-CVIs should be equal to or greater than 0.80 to confirm the validity of the item (Polit & Beck, 2006).

Scale-Content Validity Index (S-CVI). The Scale-level CVI was calculated by averaging the I-CVIs by summing them and dividing by the number of items. The S-CVIs should be equal to or greater than 0.80 to confirm the validity of the scale (Polit & Beck, 2006).

Results

 additional word " to make the statement more clear.

" The overall scale-level clarity index (S-CVI) of ABS-S: 2 (part 1) was 0.98 which was well above the critical value and making the scale a valid measure (see Appendix G, table A4).

In item number 31 it was suggested by the experts to add the word "change" in the parenthesis and in item number 34 it was advised to add the word "list" The overall item-level and scale level cultural equivalence index was also above the critical value that is 0.99 (see Appendix G, Table A5).

Item-level and scale-level Content Validity Index of Urdu version of SDQ.

The overall scale level clarity index for SDQ was 0.97 which was well above the critical value and making the scale a valid measure. Two experts out of four were of the opinion to revisit the instructions of the SDQ questionnaire. It was suggested by experts to make the instructions of the questionnaire more simple and direct, as the sample of the present study might not able to understand the complex language structure used. The response item " " " " " " " " " " " " " " " " " as suggested by the expert panel (see Appendix G, Table A6).

The overall item and scale level cultural equivalency index for SDQ was 1.0 which was considered as the perfect validity index. The experts didn't suggest any changes in items of SDQ with reference to cultural equilency (see Appendix G, Table A7).

Item-level and scale-level Content Validity Index of Urdu version of QRS-

F. The overall scale level clarity index for maternal and paternal versions of QRS-F was 0.99 which was well above the critical value and making the scale a valid measure. Total two items (39 and 51) were rated less than 0.8 on I-CVI index for clarity. It was suggested by the expert to make the item structure more clear (Appendix G, Table A8).

The cross-cultural equivalence of two subscales "parent and family problem" and "pessimism" of QRS-F was established. On three items (5, 11 and 23), minor changes were suggested by experts. The overall scale level cultural equivalency index for maternal and paternal QRS-F was 0.97 which was well above the critical value and making the scale a valid measure (See Appendix G, Table A9).

Item-level and scale-level Content Validity Index of Urdu version of F-COPEs. On clarity indices of F-COPE except item number 6 and 9 all other items were well above the cutoff point. In item number 6

According to one of the experts the words "guidance /help" might confuse the respondents; both the words convey different meaning. So it was suggested to keep only one word "guidance". In item number 9 "Guidance" one of the experts suggested to remove the options written in the parentheses (doctor, homeopathic, hakeem). The options in the parenthesis might other items, instructions and response format have I-CVI value well above the critical point. In item number 6 create confusion for the readers.

Finally it was decided not to remove the options written in parenthesis. The scale level clarity index for F-COPES was 0.98 which was well above the critical value and making the scale a valid measure (See Appendix G, Table A10).

The experts were instructed to evaluate the cross-cultural equivalence between English F-COPE and Urdu F-COPE. Results showed that except item number 14 " , all other items were deemed content valid greater than .80. And the scale level cultural equivalence index was also above critical value. For item number 14 it was suggested by one of the experts to add the word " . Finally the item was kept as it is. (See Appendix G, Table A11).

Conclusion

It was concluded that the overall scale level clarity index (S-CVI) of Urdu versions of ABS-S: 2 (part 1) was 0.98, SDQ was 0.97, maternal and paternal versions QRS-F was 0.99 and F-COPE was 0.98. Similarly, the overall scale level cultural equivalence index (S-CVI) for ABS-S: 2 (part 1) was 0.99, SDQ was 1.0, for two subscales of maternal and paternal QRS-F it was 0.97 and for F-COPE it was 0.99. The content validity indices for clarity and cultural equivalence of the instruments were well above the critical value of 0.80 hence, making the instruments a valid measure.

Phase III: Establishing other Psychometric Properties of Instruments

The purpose of phase III of the study I was to address the psychometric properties of all the instruments that will be used in study II. Objective of this phase was as given below:

Objective

To establish psychometric properties of CARS-2, Urdu versions ABS-S: 2
 (Part 1), Urdu version of maternal and paternal QRS-F, F-COPES and modified version of SDQ.

Instruments

Childhood Autism Rating Scale-2 (CARS-2). It is a diagnostic assessment tool that rates children on a scale from one to four for various criteria, ranging from normal to severe, and yields a composite score ranging from non-autistic to mildly autistic, moderately autistic, or severely autistic. The scale is used to observe and subjectively rate on fifteen items. The Core symptoms (CARS-C) consisted of six items and the associated symptoms (CARS-O) consisted of eight items (Ekas & Whitman, 2010).

Adaptive Behavior scale-School Edition ABS-S: 2, (Part 1). It consists of 67 different items that constitute of nine domains and three factors. Three factors used

in the present study were Personal self-sufficiency (11 items), Community self-sufficiency (13 items and three domain totals) and Personal social Responsibility (2 items and three domain totals).

The Strengths and Difficulties Questionnaire. It was used as a measure of children's behavioral and emotional adjustment, completed by primary caregivers. Four problem domains included were emotional symptoms (5 items), conduct problems (5 items), hyperactivity (5 items), and peer problems (5 items). The sum of the four problem domains generates a "total difficulties" behavior problem score.

Questionnaire on resources and Stress (QRS-F). Both maternal and paternal versions were used in this phase of study 1. It consists of 51 items and five subscales. The subscales are Parent and family problem (24 items), Pessimism (11 items), Financial stress (4 items), Stress due to lack of Services (7 items) and Stress due to lack of awareness (5 items).

The Family Crisis Oriented Personal Evaluation Scales (F-COPES). It was designed to record problem-solving attitudes and behaviors that parents develop in response to problems or difficulties. The F-COPES contains 30 items divided into five coping subscales: acquiring social support (9 items), reframing (8 items), seeking spiritual support (4 items), mobilizing family to acquire and accept help (4 items), and passive appraisal (5 items). Item number 18 was not included in analysis due to a low factor loading (See Appendix H).

Sample

Initially, 40 families of children with autistic disorder were contacted via school authorities. Only 35 families gave their written consent for participation. The study sample consisted of 35 children with autistic disorder and 51 parents (29 mothers and 22 fathers). For sample details of the phase III of study I (See Appendix I, Table A12)

Procedure

After getting informed consent demographic sheet was filled in order to get back ground information. Children were assessed on CARS-2, Later ABS-S: 2, SDQ, QRS-F (maternal and paternal versions) and FCOPE were administered.

Results

Item-total correlation corrected item-total correlation, inter-rater reliability, and alpha reliability co-efficient and construct validity of CARS-2.

Item-Total and corrected item-total correlation of CARS-2. The item-total correlation of the CARS-2 ranges from .46 to.81. This shows moderate to strong correlation of each item with the total score of the instrument. Whereas, the corrected item-total correlation was also well above the criteria of .30. (See Appendix J, Table A13).

The item-total correlation of (core dimensions) CARS-2 ranges from .67 to .79. Items are significantly correlated with the total score of the subscale. The corrected item-total correlation was also well above the criteria (See Appendix J, Table A14).

Item-total correlation of the (Associated symptoms) of CARS-2 subscale ranges from .52 to .75. This shows that moderate to strong correlation exists between each item and the total score of the subscale. The corrected item-total correlation was also well above the criteria (See Appendix J, Table A15).

Inter-rater reliability and Alpha reliability co-efficient and Construct validity of Childhood Autism rating scale -2.

Table 1Degree of Agreement (Kappa Coefficient) between raters on Childhood Autism Rating scale -2 (N=35)

	Observation of Rater –I									
Observation of Rater -II	Minimal to no	Mild to moderate	Severe	Total						
	symptoms of	symptoms of ASD	symptoms of							
	ASD		ASD							
Minimal to no	3	1	0	4						
symptoms of ASD										
Mild to moderate	0	18	1	19						
symptoms of ASD										
Severe symptoms of	0	0	12	12						
ASD										
Total	3	19	13	35						
Severe symptoms of ASD										

Table 1 shows the inter-rater reliability of two independent observers. On mutually exclusive diagnostic categories of CARS-2, Cohen Kappa was determined. The agreement between two raters was Kappa = 0.89 at 95% CI (0.79, 1.00).

Table 2Descriptive Statistics for Childhood Autism Rating scale-2, Core symptoms and Associated symptoms (N=35)

Scales & subscales	No. of	а	M(SD)	Range		Skew
	items			Actual	Potential	
CARS -2	15	.91	35.30(4.86)	26-47	15-60	.45
Core symptoms	6	.86	13.94 (2.28)	10-20	6-24	.61
Associated symptoms	8	.82	18.64(2.59)	14-24	8-32	.44

Table 2 shows the descriptive statistics of the CARS-2 and its sub dimensions. The alpha reliability co-efficient ranges from .82 to .91, depicting that instrument was reliable and internally consistent. The skewness also falls in desirable ranges.

Table 3Correlation between different dimensions of Childhood Autism Rating scale -2 (N=35)

Items		1	2	3
1.	Total Score on CARS – 2 Core symptoms	-		
2.	Total Score on CARS – 2 Associated symptoms	.87**	-	
3.	Total Score on CARS – 2.	.95**	.97**	-

^{**}*p* < 0.01

Table 3 depicts significant positive correlation between core symptoms, associated symptoms and total score of CARS-2. It provides an evidence for construct validity of Childhood Autism Rating scale -2.

Item-total correlation, corrected item-total correlation, alpha reliability co-efficient and construct validity of Urdu version ABS: 2S (Part 1).

Item-total correlation and corrected item-total correlation of Urdu versions of ABS-S: 2 (Part 1). Except for item number 11, rest of the items in the "Personal self-sufficiency" depicts moderate to strong correlation with the total score. The item-total correlation ranges from .85 to .41. This shows that moderate to strong correlation among each item and the total score of subscale. The corrected item-total correlation was also well above the criteria for all items except for item number 11. This Item was about "posture" the item-total correlation and corrected item-total correlation were below the cut off criteria of .3. (See Appendix J, Table A16).

Community self-sufficiency sub factor of Urdu version of ABS-S: 2 (Part 1) is composed of thirteen items and total scores of three domains that are Economic Activity, Language development and number and time. Except for three items 12, 21 and 24 remaining items have item total correlation ranging from .33 to .69. Similarly, except for above mentioned items the corrected item-total correlation also fulfills the criteria of .3 and above. Item number 12 that was about "clothing" the item total correlation was r = .17 and corrected item total correlation was also below the cut off criteria of .3. Item 21 "Safety on street or school ground" also illustrate very low item total correlation r = .09 and corrected item-total correlation that is .04. Similarly, item 24 that caters "Safety at Residential Facility or Home" also have low item-total correlation r = .16 and corrected item-total correlation of .11, which is below the criteria of .3. All three items appears to be non functional in current scenario and dropped from the scale. All three domains illustrate strong item total correlation ranging from .57 to .95. Corrected item total correlation was also above the criteria of .3 (See Appendix J, Table A17).

The total score of sub factor Personal social Responsibility of Urdu version of ABS-S: 2 (Part 1) is composed of item number 51 and 52 and three Domains that are Domain VII= Self Direction, Domain VIII= Responsibility and Domain IX= Socialization. The item-total correlation of item 51 "Work/school Job performance" is r = .36 and item 52 "Work/School Habits" is r = .61 significant. The corrected item-total correlation also fulfills the criteria of .3. The item total correlation of domain scores also ranges from .62 to .90. The corrected item total correlation was above the criteria of .3 (See Appendix J, Table A18).

Alpha reliability coefficient and construct validity of Urdu versions of ABS-S: 2 (Part 1).

Table 4Descriptive Statistics of Urdu version of Adaptive Behavior Scale-School Edition ABS-S: 2

(part 1) (N=35)

Factors of ABS-S: 2 (part 1)	No. of	а	M(SD)	Range		Skew
	items			Actual	Potential	-
Personal Self-Sufficiency	12	.90	49.94(13.48)	18-73	0-83	47
Community Self-Sufficiency	13	.71	43.74(22.90)	09-84	0-132	.43
Personal Social Responsibility	05	.71	22.25(9.75)	04-38	0-63	.13
Total Score ABS: 2S (part 1)	63	.95	98.08(36.21)	28-151	0-274	02

Table 4 shows that "personal self-sufficiency" is composed of 11 items and a domain total. Item 11 was dropped because of low item total correlation and corrected item total correlation. By removing item 11 the alpha reliability also increases from .88 to .90 and depicts good alpha reliability. After dropping three

items from "Community Self-Sufficiency" the alpha value raised from .67 to .71. The alpha reliability of "personal social responsibility" is .71, which is considered as good. The shewness value also well within the range. The alpha reliability co-efficient of Urdu version ABS-S: 2 (part 1) as mentioned above is .95, which is considered as an excellent depiction of internal consistency of the scale.

Table 5Correlation between different dimensions of Urdu version of Adaptive Behavior Scale-School

Edition ABS-S: 2 (part 1) and chronological age of the sample (N=35)

	Items	1	2	3	4	5
1.	Personal Self-Sufficiency	-				
2.	Community Self-Sufficiency	.68**	-			
3.	Personal Social Responsibility	.64**	.80**	-		
4.	ABS-S: 2 (Part one)	.86**	.93**	.88**	-	
5.	Chronological age	.66**	.55**	.37*	.61**	-

^{*}*p* < 0.05, ***p* < 0.01

Table 5 shows that with increase in chronological age of an autistic child their adaptive behaviors also improves. The behaviors measured by ABS-S: 2 (Part 1) are developmental in nature. Providing the strong evidence for construct validity of the instrument. Above table also depicts that different dimension of ABS-S: 2 (Part 1) are strongly inter-correlated with each other and with total score. Hence, providing empirical basis for good construct validity of the instrument.

Item-total correlation corrected Item total Correlation, alpha reliability co-efficient and Construct Validity of Urdu version of SDQ.

Item-total and corrected item-total correlation of Urdu versions of SDQ. The item-total correlation and corrected item-total correlation of items in subscale representing the Emotional Symptom Scale of Urdu Version of SDQ depicts that the item total correlation ranges from .43 to .80. Similarly, corrected- item total correlation for items also lies within the acceptable range. All items in the subscale are functional for the present sample and internally consistent (See Appendix J, Table A19).

In the subscale Conduct Problems, the item total correlation of items ranges from .15 to .82. The corrected item total correlation was also above the cut of criteria of .30 (excluding item 14 & 17). Item number 14 and 17 were dropped for further analysis because they appeared to be non functional in the present context (See Appendix J, Table A20).

The item total correlation for the hyperactivity scale ranges from .54 to .73. The corrected item total correlation was also within the acceptable range (See Appendix J, Table A21).

In the peer problem scale except for item number 8, rests of the items have item total correlation ranging from .66 to .84.Corrected item total correlation was also within the acceptable range (See Appendix J, Table A22).

Alpha reliability coefficient and Construct Validity of Urdu version of SDQ.

Table 6Descriptive Statistics for subscales of Urdu Version Strengths and Difficulties Questionnaire (SDQ) (N=29)

Subscales	No. of	а	M(SD)	Range		Skew
	items			Actual	Potential	
Emotional symptom Scale	5	.62	2.17(2.00)	0-10	0-6	.52
Conduct problem Scale	3	.65	3.75(1.43)	0-06	2-6	.30
Hyperactivity Scale	5	.60	6.34(2.17)	0-10	3-10	16
Peer Problem Scale	4	.80	6.34(1.73)	0-08	3-8	70
Total Difficulty index	17	.70	18.62(4.50)	0-34	08-26	18

Table 6 shows that after dropping three items (11, 18 and 22) due to low item total correlation from the total SDQ scale, the alpha reliability of the difficulty index of SDQ raised to .70, which was considered as good. The alpha reliability co-efficient of emotion symptom subscale was .62. After dropping two items (18 and 22) because of low item total correlation subscale conduct problem. The alpha reliability of the subscale increased from .55 to .65, which was considered as acceptable. For the third subscale that is hyperactivity scale the alpha reliability was .60. After dropping item number 11 due low item total correlation from the subscale "peer problem", the alpha reliability changes from .67 to .80. The overall alpha reliability co-efficient of Urdu version of SDQ ranges from .60 to .80, depicting acceptable to good internal consistency of the scale. The shewness value is also well within the range.

Table 7Correlation between subscales and total score of Urdu Version of Strengths and Difficulties Questionnaire (SDQ) (N=29)

Sub s	scales	1	2	3	4	5
1.	Emotional symptom Scale	-				
2.	Conduct problem Scale	.42*	-			
3.	Hyperactivity Scale	.55**	.47**	-		
4.	Peer Problem Scale	.59**	.40*	.46*	-	
5.	Total Difficulty Score	.49**	.35*	.43*	.36*	

^{*}*p* < 0.05., ***p* < 0.01.

Table 7 depicts the significant positive correlation between different subscales and the total score of the Urdu version of SDQ. All subscales within the instrument are very well inter-correlated, hence providing evidence for good construct validity of the instrument.

Item-total correlation Corrected Item-total Correlation, alpha reliability co-efficient and Construct Validity of Urdu version of maternal and paternal QRS-F.

Item-total and Corrected Item-total Correlation of Urdu versions of maternal and paternal QRS-F. In subscale Parent and family problems most of the items have positive and significant item-total correlation. Corrected item-total correlation was also at and above .30. In case of item numbers 2 corrected item total correlation was less than .30, Item number 2 hence dropped from maternal and paternal version of QRS-F. (See Appendix J, Table A23).

In subscale Pessimism except for two items that were item numbers 19 and 22 other items in both maternal and paternal versions of QRS-F had good item-total correlation and corrected item-total correlation was also at and above .30. Item 19 and 22 were dropped from the scale because of negative and very low item-total and corrected item-total correlation (See Appendix J, Table A24).

In subscale of Financial stress all the items have significant positive item total correlation and corrected item total correlation. In the maternal version the correlation coefficient for item total correlation ranges from .97 to .93. Similarly in paternal version of QRS-F the correlation coefficient for item total correlation ranges from .96 to .81.Corrected item total correlation was well above the criteria (See Appendix J, Table A25).

In subscale Stress due to lack of services the correlation coefficient ranges from .60 to .86. This shows strong (large effect size) and positive relationship between different items of the subscale with the total score of the subscale. The corrected item total correlation ranges between .40 to .79, which is also well above the criteria of .30 (Andy, 2005) (See Appendix J, Table A26).

The item-total correlation and corrected item-total correlation of item number (Generally people do not know about autism) subscale of stress due to lack of awareness in both maternal and paternal QRS-F was less than the criteria of .30. This item is not correlating with the total score of the subscale. Beside this item, rests of the items are very well correlated with the total score of the scale. The corrected item total correlation was also at and above the criteria of .30 in both versions of QRS-F (See Appendix J, Table A27).

Alpha reliability and Construct Validity of Urdu versions of maternal and paternal QRS-F.

Table 8Descriptive Statistics for Maternal Version of Urdu Questionnaire on Resources and Stress

(QRS-F) (N=29)

Subscales	No. of	а	M(SD)	Range		Skew
	items			Actual	Potential	•
Parent and family problems	24	.88	70.82(17.89)	37-108	24-120	.31
Pessimism	09	.73	28.37(6.02)	15-37	09-45	71
Finance	04	.97	10.75(5.67)	04-20	04-20	.24
Services	07	.84	23.51(7.51)	07-35	07-35	64
Awareness	04	.56	11.13(3.69)	05-20	04-20	.49
Total Scale	48	.93	144.62(32.82)	84-216	48-240	.26

Table 8, depicts that after dropping one item from the subscale of "Parent and family problems" the alpha reliability of the scale increases from .86 to .88. After removing item 25 and 29 from the subscale "Pessimism" the alpha reliability coefficient increases from .70 to .73, which is consider as good. The alpha reliability for the subscale "Financial stress" is .97 and for subscale "stress due to lack of Services" is .84 which is considered as good. After removing the one item with low item total correlation the alpha for the subscale "stress due to lack of awareness" increases from .51 to .56. The alpha reliability of maternal version of QRS-F is .93.

Table 9Descriptive Statistics for Paternal Version of Urdu Questionnaire on Resources and Stress (QRS-F) (N=22)

Subscales	No. of	α	M(SD)	Range		Skew
	items		-	Actual	Potential	-
Parent and Family problems	24	.84	62.27(15.22)	31-93	24-120	.27
Pessimism	09	.83	31.27(7.77)	16-41	09-45	75
Finance	04	.93	11.00(5.10)	4-20	04-20	.28
Services	07	.82	26.81(6.98)	7-35	07-35	-1.33
Awareness	04	.56	13.04(3.64)	5-20	04-20	29
Total Scale	48	.90	144.40(28.69)	94-209	48-240	.40

Table 9 shows the descriptive statistics for Urdu version of *QRS-F*. Alpha reliability co-efficient of subscale "Parent and family problems" is .84. After removing two items with low item total correlation the alpha reliability of the subscale "Pessimism" increases from .74 to .83. The alpha reliability of subscales "financial stress" and "stress due to lack of Services" was also considered in the category of good and excellent. After removing one item with low item total correlation in subscale of "stress due to lack of Awareness" the alpha reliability increased from .52 to .56. The alpha reliability for the paternal version of QRS-F is .90.

Table 10Correlation between Total score of CARS-2, Urdu version of ABS-S: 2 (part 1),

Maternal and Paternal version of Urdu ORS-F

Scale	S	1	2	3	4
1.	TSCARS-2	-			
2.	TS ABS-S:2	37**	-		
3.	TSQRSP	.52**	32**	-	
4.	TSQRSM	.48**	56**	.45**	-

Note. TSCARS-2= Total score on Childhood Autism Rating scale -2; TS ABS-S: 2= Total score on Adaptive Behavior Scale-School Edition ABS: 2S (part 1); TSQRSP= Total score on Paternal Version of questionnaire on resources and stress "Short form"; TSQRSM= Total score on Maternal Version of questionnaire on resources and stress "Short form" **p < 0.01.

Table 10 depicts the evidences for the construct validity evidences of QRS-F. With increase in autism symptom severity, maternal and paternal stress also get elevated. Low adaptive functioning in children with autistic disorder leads to high level of stress in both parents. Similarly inverse relationship between autism symptom severity and adaptive behaviors further provides empirical evidence for construct validity.

Item total correlation, Corrected Item total Correlation, alpha reliability co-efficient and Construct Validity of Urdu version of F-COPES.

Item-total and corrected item-total correlation of Urdu versions of F-COPES. The item total correlation of the sub scale Acquiring Social Support ranges from .37 to.88. Reframing sub Scale ranges from .54 to.89. Item-total correlation for seeking spiritual support ranges from .49 to.64 and for Mobilizing Family to Acquire and Accept, the correlation ranges from .47 to.73. Item-total correlation of Passive

Appraisal ranges from .42 to.71. All subscales of F-COPE depicted moderate to strong effect size of correlation between each item and with the total score of the scale. The corrected item total correlation was also at and above the cut off criteria of .30 for all items (See Appendix J, Table A28 to Table A32).

Alpha reliability and Construct Validity of Urdu versions of F-COPES.

Table 11Descriptive Statistics of Urdu version of The Family Crisis Oriented Personal Evaluation

Scale (F-COPES) (N=29)

Subscales	No. of	α	M(SD)	Ra	ange	Skew
	items			Actual	Potential	
Acquiring Social Support	9	.87	26.48(9.95)	9-45	9-45	04
Reframing	8	.90	31.65(7.76)	14-40	8-40	.1.0
Seeking Spiritual Support	4	.50	13.72(3.19)	5-19	4-20	42
Mobilizing Family to	4	.51	13.03(3.74)	2-20	4-20	.08
Acquire and Accept Help						
Passive Appraisal	5	.56	17.31(3.94)	6-22	5-25	-1.0
Total Scale	30	.87	104.41(19.96)	51-141	30-150	62

Table 11 illustrates the descriptive statistics of Urdu version of F-COPES. The alpha reliability co-efficient of subscales ranges from .50 to .90 and for the total scale it was .87, which shows that a scale is reliable measure to be used with present sample.

Table 12

Correlation between subscales and total score of Urdu version of The Family Crisis

Oriented Personal Evaluation Scale (F-COPES)

Sub s	cales	1	2	3	4	5	6
1.	ASS	-					
2.	REF	.60**	-				
3.	SSS	.43*	.40*	-			
4.	MFAH	.39*	.42*	.49**	-		
5.	PSA	.64**	.59**	.48**	.43*	-	
6.	TS	.72**	.63**	.68**	.55**	.82**	-

Note. ASS= Acquiring Social Support; REF= Reframing; SSS= Seeking Spiritual Support; MFAH= Mobilizing Family to Acquire and Accept Help; PSA= Passive Appraisal; TS= Total Score FCOPE. *p < 0.05, **p < 0.01.

Table 12 depicts the findings to establish the construct validity of Urdu version of F-COPES. The correlation between subscales and total score was established. Significant positive correlation exists between all subscales and total score of F-COPES. This analysis is evidence of strong construct validity of the Urdu version of F-COPES for the present sample.

Discussion (Study 1)

The purpose of study I was to translate and validate instruments for the main study (study II). It constitute of three different phases. Phase I was related to translation and modification of instruments. In phase II content validity index of translated and modified instruments was established and in Phase III other psychometric properties and construct validity of instruments were addressed.

Since, the national language of Pakistan is Urdu and most of the population can easily understand and comprehend Urdu language (Rahman, 1999). Thus, in phase I, all self report instruments were translated from English language to Urdu language. The Forward translation method was used to translate the instruments from English to Urdu language. This method was used because of its cost effective nature. The instruments translated were ABS-S: 2 (Part 1), QRS-F and F-COPES. Whereas, modifications were done within few items of already existing Urdu version of SDQ.

After translation and through review by committee of expert judges Urdu version of ABS-S: 2 (Part 1) was finalized. To make SDQ more comprehendible by the target audience modification suggested by experts were done in item numbers (5, 7, 8, 10, 15, and 18) of already available Urdu version of SDQ. As recommended by committee item number 27 in QRS was divided into two items for better understanding of the target audience. According to Hambleton et al. (2004), instructions of instrument should be clear with minimal reliance on verbal communication. Thus, few modifications were done to make the instructions of QRS-F clear and self explanatory. The gender confusion has been removed on items (3, 8, 11, 12, 15, 16, 25, 29, 30, 31, 34, and 35) by making two versions of QRS-F. One is

the paternal version and other is the maternal version of QRS-F. Since, the Urdu language has its own grammar and gender agreement is marked by suffixes on verbs and adjectives; verbs show agreement either with the subject or with the direct object, although not both at once (Schmidt, 1999). To widen the distribution of data dichotomous response items in QRS-F were converted to five point likert scale (Saloviita et al., 2003). In F-COPES item number 30 was removed because of social desirability and two more items were added one in passive appraisal scale and one in seeking spiritual support. Two item statements were added because in local context spirituality and religion are often used interchangeably and it has also been described as an individual search for meaning and a way of coping as well. After translation/modification and extensive review by committee of expert judges Urdu version of ABS-S: 2, (Part 1), SDQ, QRS-F and F-COPES were finalized.

In phase II content validity of instruments was established as rated by experts for the clarity and cultural equivalency of the entire scale (S-CVI) and individually for the instructions, response format, and items (I-CVI). The process was adapted from original content validity work by Lynn (1986). The scale and item indices on clarity ranges from .97 to .98 for ABS-S: 2, (Part 1), SDQ, QRS-F and F-COPES. Language structure of few items (ABS-S: 2: 4, 12; QRS-F: 39, 51; F-COPES: 6, 9) with low I-CVI was modified as suggested by experts. Few changes were done in items (ABS-S: 2: 31, 34; QRS-F: 5, 11, 23; F-COPES: 14) with low I-CVI on cultural equivalence as suggested by experts. The clarity and cultural equivalency of the entire scale (S-CVI) and individually for the instructions, response format, and items (I-CVI) was well above the cut off criteria of 0.8 (Polit & Beck, 2006). Hence providing evidence for good content validity of the instruments.

In Phase III of study I other psychometric properties of instruments were addressed. Along with instruments translated and modified in phase I, CARS-2 was also included. Other psychometric analysis included Item-total correlation, Corrected Item-total Correlation, inter-rater reliability, alpha reliability co-efficient and Construct Validity of the instruments.

The item-total correlation and corrected item-total correlation for core and associated symptoms of CARS-2 were well above the criteria and provide strong evidence of sound psychometric of the scale. The agreement between two independent raters was perfect (Kappa = $0.89 \ (p < .0.005)$, 95% CI (0.79, 1.00) on diagnostic categories of CARS-2 (Landis & Koch, 1977). The alpha reliability of CARS-2, core and associated symptoms ranges from .82 to .91, depicting that the scale was reliable and internally consistent. The overall reliability of the scale was .91. Positive correlation exists between different dimensions and the total score on CARS-2 depicting an evidence for construct validity of CARS-2.

In ABS-S:2 (Part 1) item numbers 11, 12, 21 and 24 were dropped for further analysis because of low item-total and corrected item-total correlation. After removing item number 11 from factor "personal self-sufficiency", the alpha reliability increases from .88 to .90. The item was about the physical appearance of the child that particularly related to posture. Children with autism usually don't have issues related to posture. In factor "community self-sufficiency", item number 12 that was about "clothing", Item 21 which is about "Safety on street or school ground" and item 24 that caters "safety at residential facility or home" were dropped from main analysis because of low item total correlation and corrected item total correlation. The alpha reliability of three factors of Urdu versions of ABS: 2S (Part 1) ranges from .71 to

.95 considered as good to excellent reliability and depiction of internal consistency of the scale (Kline, 2013). Moderate to strong correlation between different factors and total scores of ABS: 2S, (Part 1) depicted strong evidence for construct validity of the instrument. The adaptive behaviors measured in ABS: 2S, (Part 1) are developmental in nature and all three factors are related to each other (Lambert et al., 1993).

In Urdu versions of SDQ three items (8, 14, and 17) were dropped for further analysis because of low item-total and corrected item-total correlation. Item number 8 which is about "friendship", Item 14 is about "lying behavior" and item 17 is about "stealing behavior. All three behaviors are bit complex for children with autism to understand and act upon. After dropping these three items the alpha reliability of the difficulty index of SDQ increased from .60 to .70, which was considered as fair to good. Four subscales that are "emotional symptom Scale", "conduct problem scale", "hyperactivity scale and peer problem Scale" are measuring the same construct that is problematic behavior of the child. The significant positive correlation between the subscales and the total difficulty score clearly support the evidence for the construct validity.

In maternal and paternal versions of QRS-F because of low item-total correlation item number 2 from "Parent and family problem", item numbers 19 and 22 from "Pessimism" and item number 47 from "Stress due to lack of awareness" were dropped for further analysis. The alpha reliably co-efficient of both maternal and paternal QRS-F ranges from .56 to .97. Increase autism symptom severity and poor adaptive behaviors in children with autistic disorder leads to high maternal and paternal stress. Hence, provides evidence for good construct validity for maternal and paternal versions of QRS-F.

The Cronbach's alpha coefficient was calculated for estimating the reliability of FCOPES and its subscales. Findings show pretty satisfactory values i.e., .87 for the total FCOPES scale, .87 for "acquiring social support", .90 for "Reframing". Three subscales of FCOPES depicted unsatisfactory values i.e., .50 for "seeking spiritual support", .51 for "mobilizing family to acquire and accept help" and .56 for "passive appraisal". One of the reasons for low alpha value might be the less number of items in all three subscales. As Gliem and Gliem (2003) argued that value of alpha is partially dependent upon the number of items in the scale. Item total correlation was also computed to strengthen the assumption for internal consistency. All items were found to be positively correlated with the total scores of subscales. The coefficient ranges from .37 to .88 for "acquiring social support", .54 to .89 for "reframing", .49 to .64 for "seeking spiritual support", .47 to .73 for "mobilizing family to acquire and accept help" and .42 to .71 for "passive appraisal".

Beside item total correlation and reliability estimates, correlation between different subscales and total score of FCOPES was also computed for evidence of construct validity. The significant correlation between subscales and total score of FCOPES further strengthen the validity evidences for Urdu version of FCOPES.

Over all the results provide evidence that translated Urdu version of ABS-S: 2 (Part 1), Maternal and Paternal QRS-F, F-COPES and SDQ are the reliable and valid measures to be used in Study II (Main Study).

STUDY II

This study dealt with the main study of present research and focused on hypothesis testing. Following are the objectives and hypotheses:

Objectives

- To study the relationship between child characteristics (autism symptom severity, adaptive behaviors, problematic behaviors) maternal and paternal stress.
- 2. To study the relationship between autism symptomology (core symptoms and associated symptoms) maternal and paternal stress.
- 3. To study the relationship between adaptive behaviors (personal self-sufficiency, community self-sufficiency and personal social responsibility) maternal and paternal stress.
- 4. To study the relationship between problem behaviors (emotional problem, conduct problem, hyperactivity and peer problem) maternal and paternal stress.
- 5. To study the mediating role of family coping between child characteristics (autism symptom severity, adaptive behaviors, problematic behaviors) maternal and paternal stress.
- 6. To study the relationship of different family socio-demographic factors (e.g. gender of parents, work status of mother, age of autistic child, gender of autistic child, education of parents, socio economic status, family system) with reference to paternal and maternal stress.

Hypotheses

- 1. Problematic behavior is more predictive of maternal and paternal stress as compared to symptom severity and adaptive behaviors.
- 2. Core symptomology is positively associated with maternal stress.
- 3. Personal self sufficiency is negatively associated with maternal and paternal stress.
- 4. Emotional problem and conduct Problem are positively associated with maternal and paternal stress.
- 5a. Family coping mediates the relationship between autism symptom severity and maternal, paternal stress.
- 5b. Family coping mediates the relationship between adaptive behaviors and maternal, paternal stress.
- 5c. Family coping mediates the relationship between problematic behaviors and maternal, paternal stress.
- 6a Maternal stress will be higher as compared to paternal stress.
- 6b. Maternal stress of employed mothers will be higher as compared to mothers who are not employed.
- 6c. Maternal stress will be higher for mothers living in nuclear family system as compared to mothers living in joint family system.
- 6d. Greater the maternal age, less will be the maternal stress.
- 6e. Greater the family income less will be the paternal and maternal stress.
- 6f. Greater the number of children in family more will be the paternal and maternal stress.

Operational Definitions of Variables

Autism symptom severity. Autism symptom severity is measured using CARS-2 full scale. For the present study a sum score of CARS-2 scale was computed, high scores on the scale indicated higher level of autism symptom severity (Schopler et al., 2010).

Autism symptomology. Autism symptomology are the characteristics or symptoms of autism and measured in two dimensions that are core symptoms and associated symptoms (Ekas & Whitman, 2010; Schopler et al., 2010).

Core symptoms. Core symptoms refer to those symptoms designated in the DSM IV-TR as being diagnostic criteria of autism. Higher the score higher will be the severity of autism core symptoms

Associated symptoms. Associated symptoms are the frequently occurring symptoms. Higher the score higher will be the severity of autism associated symptoms.

Adaptive behaviors. The assessment of adaptive behavior encompasses tasks carried out routinely by an individual in various domains of daily functioning, such as communication, daily living skills, social interaction, and motor skills (Nihira et al., 1993). In the present study adaptive behavior will be measured using ABS-2S (Part

1). Low scores on the first part of the scale show poor adaptive functioning. It was further divided into three dimensions.

Personal self-sufficiency. It deals with people's ability to take care of themselves on the daily basis. High score on this factor is indicative of efficient Personal self-sufficiency and low score indicates that the individual is deficient on the particular skills.

Community self-sufficiency. It deals with people's ability to function in society. How they are able to interact with others and use community resources.

High score on this factor is indicative of efficient Community self-sufficiency and low score indicates that the individual is deficient on the particular skills.

Personal social responsibility. It deals with people's ability to take care of them and interact with their environment. High score on this factor is indicative of efficient Personal social Responsibility and low score indicates that the individual is deficient on the particular skills.

Problematic behaviors. Problematic behavior is the individual's behavior and emotional problems. It is constitute of four different dimensions.

Emotional Symptom. High score is indicative of greater emotional problems and vice versa

Conduct Problem. High score is indicative of greater Conduct Problems and vice versa

Hyperactivity Scale. High score is indicative of greater hyperactivity problems and vice versa

Peer Problem Scale. High score is indicative of greater problems related to peers and vice versa

The sum of the four problem domains generates a "total difficulties" behavior problem score, which was used in the present study. Higher the score higher will be the behavior problem (Goodman, 1997).

Parental stress. It results when the balance between parent's perceptions of the demands of parenting outweigh their perceptions of their resources for meeting those demands (Deater-Deckard et al., 2005; Holroyd et al., 1975).

In the present study paternal and maternal stress has measured using short form of QRS-F. Higher scores on QRS-F can be taken as indicative of greater paternal and maternal stress within family (Friedrich et al., 1983)

Family coping strategies. Family coping is a bridging concept which has both cognitive and behavioral components. Where in resources, perception, and behavioral responses interact as families try to achieve a balance in family functioning (McCubbin & Patterson, 1983).

Higher score on F-COPES indicates that families operating with more coping strategies and low score was indicative of utilization of less coping strategies within

family (McCubbin et al.,1991). Various dimension of family coping are as given below:

Acquiring social support. It is the family's ability to actively engage in acquiring support from relatives, friends, neighbors and extended family. Higher score on subscale will indicative of families operating more with this coping strategy.

Reframing. It is the family's capability to redefine stressful events in order to make them more manageable. Higher score on subscale will indicative of families operating more with this reframing coping strategy.

Seeking spiritual support. It is the family's ability to acquire spiritual support. Higher score on subscale will indicative of families operating more with this coping strategy.

Mobilizing family to acquire and accept help. The family's ability to seek out community resources and accept help from others. Higher score on subscale will indicative of families operating more with this coping strategy.

Passive Appraisal. It is the family's ability to accept problematic issues minimizing reactivity. Higher score on subscale will indicative of families operating more with this coping strategy.

Instruments

Descriptions of the instruments used in main study (study II) were given below.

Childhood Autism Rating Scale-2 (CARS-2). It is a diagnostic assessment tool developed by (Schopler et al., 2010). CARS-2 rates children on a scale from one to four, ranging from normal to severe, and yields a composite score. The scale is used to observe and subjectively rate on fifteen items. It is further divided into two subscales i.e., Core symptoms and associated symptoms. (See Appendix B1).

Core symptoms. It has 6 items. It refers to those symptoms designated in the DSM IV-TR as being diagnostic criteria of autistic disorder. The rating options ranged from one to four, ranging from normal to severe.

Associated symptoms. It has 9 items. It refers to frequently occurring symptoms. The rating options ranged from one to four, ranging from normal to severe (Ekas & Whitman, 2010).

Adaptive Behavior scale-School Edition ABS-S: 2 (Part-1). It aims at assessing the adaptive behaviors of children with autistic disorder. It was developed by (Lambert et al., 1993). In main study Urdu version of ABS-S: 2 (Part-1) translated in study 1 of the present research was used. It consists of 67 items. It further constitute of three factors. (See Appendix L1).

Personal self-sufficiency. It measures people's ability to take care of them on the daily basis. It consists of 12 items and one domain score.

Community self-sufficiency. It deals with people's ability to function in society. How they are able to interact with others and use community resources. It consists of 13 items and three domains scores.

Personal social responsibility. It measure people's ability to take care of them and interact with their environment. It consists of 2 items and three domain scores.

The Strengths and Difficulties Questionnaire. SDQ was originally developed by Goodman (1997) and translated in Urdu by Samad et al. (2005). For the present study modifications were made within few items of already developed Urdu version of SDQ to cater the needs of target population (study I). It was used to measure the children's behavioral and emotional adjustment, completed by primary caregivers. Respondent's rate statements about their child as not true, somewhat true, or certainly true, based on the child's behavior over the past 6 months. The sum of the four problem subscales generates a "total difficulties" behavior problem score, which was used in the present study. It consists of four subscales Emotional Symptom Scale (5 items), Conduct Problem Scale (5 items), Hyperactivity Scale (5 items) and Peer Problem Scale (5 items). Five items are reversed scored. (See Appendix L2).

Questionnaire on resources and Stress (QRS-F). The Friedrich short form of questionnaire on resources and stress (QRS-F) was developed in 1983 from Holroyd's much longer Questionnaire on resources and stress (1974). Two subscales "Parent and family problems" and "pessimism" were translated from English to Urdu in study I, while three subscales (Financial stress, Stress due to lack of Services and Stress due to lack of awareness) were added after pretest of instrument. It was used to assess stress levels in parents of children with autism. It was rated on five point Likert

scale and consists of five subscales; Parent and family problem (24 items), Pessimism (11 items), Financial stress (4 items), Stress due to lack of Services (7 items) and Stress due to lack of awareness (5 items). Eight items were reversed scored. (See Appendix L3).

The Family Crisis Oriented Personal Evaluation Scales (F-COPES). The instrument was originally developed by McCubbin, Olson, and Larsen (1991) and adapted in study I. It is designed to record problem-solving attitudes and behaviors that parents develop in response to problems or difficulties. It consists of 31 items and item number 18 was not included in the scoring of the instrument. The scale indicates the point at which a person agrees or disagrees with each statement (1= strongly disagree to 5 = strongly agree). It consist of five subscales Acquiring Social Support (9 items), Reframing (8 items), Seeking Spiritual Support (4 items), Mobilizing Family Support (4 items) and Passive Appraisal (5 items). All items in passive appraisal scale were reversed scored. (See Appendix L4).

Sample

The sample of present study consists of 110 children with autism, 186 parents, consisting of 103 mothers and 83 fathers. In the present study 34.5% children fall between age range of 3 years to 6 years, while 36.4% children were between age range 7 to 10 years and 29.1% fall in the age range of 11 years to 14 years (M = 8.4, SD = 3.22). Most of the sample constitute of male (80.9%) children with autism, while 19.1% were females children with autism.

The sample characteristics depicted that 50% of the fathers (M = 41.18, SD = 5.65) and 70 % mothers (M = 34.01, SD = 4.22) fall in age range from 32 to 42 years. A good number of the mothers in the present

sample were house wives (67%) and they were not fulltime employed. Only four mothers (3.6%) reported that they were not living with their husbands, either they were divorced or separated. 56.4% of the parents reported that were not relatives or cousins, where as 28.2% parents reported that they were first cousins. 61.8% parents living in nuclear family setups, whereas 38.2% were residing in joint family setup. 60.4% of the sample was earning between 5,000 to 30,000 Pakistani rupees per month. Majority of the parents had 1 to 3 children (76.4%) in their family (See Appendix K).

For the selection of sample of children with autism, non probability sampling technique was used. Children of age range of 3 years to 14 years were included in the sample. Children fulfilling the diagnosis criteria of Autistic disorder on CARS-2 were catered. Only children with Autism living with their parents were included in the sample. Children with any co- morbid disorders like, genetic disorders, intellectual disability or global delays were not included in the present sample.

Sample was collected from different special education schools in Rawalpindi and Islamabad. Initially, 12 Special schools including both government and private schools were approached for data collection, however, only 8 schools allowed to collect data from their schools. Four schools decline the invitation to take part in the research.

Procedure

Firstly, telephonic permission was taken from parents of children age ranged between 3 to 14 years. Written Permission was also acquired for their willingness to take part in study. After their permission demographic sheets was filled in order to get background information. In initial screening children were observed by two independent observers on CARS-2. Total 110 children were identified as the probable cases of autistic disorder on CARS-2; information about adaptive behaviors was completed with the help of teachers and parents. Only 105 parents reported about their child behavior difficulties on SDQ. Total of 103 mothers responded on maternal version of QRS-F, while seven mothers did not fill up the instrument due to their personal commitments. It was really hard to get information from the fathers and only 83 fathers took part in the research. In last FCOPE, was administered on 103 parents. Data was collected in person during home visits and in case if the parents were attending their children school they were asked if they would be willing to complete the questionnaires.

Consent and ethics. The inform consent was signed by both parents and they were informed verbally and as well as in written form that their participation was not obligatory and they can withdraw any time during the research. They were also assured that the information provided will be confidential and will be used only for research purpose.

Data Analysis

The data was cheeked for missing values and normality assumptions through frequencies and description. The missing items were imputed using mean substation on that particular variable. Although this approach has limitation but list wise or pair wise deletion was avoided.

Results

In order to fulfill the objectives of the study and to test the hypotheses formulated, a series of statistical analysis were done.

 Table 13

 Descriptive Statistics and Alpha Reliability coefficient for the Study Variables

Variables	No of				Ra	nge	Skew
	items	N	а	M(SD)	Actual	Potential	
Symptom Severity	15	110	.90	37.33(6.54)	25-51	15-60	.41
Core symptoms	6	110	.87	15.06 (3.02)	10-21	6-24	.42
Associated Symptoms	8	110	.81	19.60(3.51)	13-28	8-32	.40
Adaptive behaviors	63	110	.90	100.01(37.69)	28-164	0-274	09
Personal self-sufficiency	12	110	.91	49.67(14.14)	18-73	0-83	60
Community self-sufficiency	13	110	.71	26.40(17.41)	05-55	0-132	.40
Personal social responsibility	05	110	.72	23.93(10.50)	02-38	0-63	27
Problem behaviors	17	105	.86	21.76(6.02)	09-31	0-34	38
Emotional symptoms	5	105	.65	3.42(2.26)	01-10	0-10	.83
Conduct problems	3	105	.66	3.82(1.23)	02-6	0-06	.27
Hyperactivity	5	105	.83	8.01(2.31)	3-10	0-10	81
Peer Problem	4	105	.87	6.48(1.81)	3-8	0-08	75

Continued...

Variables	No of				Ra	inge	Skew
	items	N	а	M(SD)	Actual	Potential	
Paternal Stress	48	83	.91	135.64(28.38)	70-209	48-240	02
Parent and family problems	24	83	.90	59.56(16.95)	34-96	24-120	.12
Pessimism	09	83	.83	26.37(8.24)	10-40	09-45	23
Finance	04	83	.88	11.14(4.36)	04-20	04-20	.26
Services	07	83	.69	25.68(6.30)	07-35	07-35	-1.19
Awareness	04	83	.62	12.87(3.17)	05-20	04-20	16
Maternal Stress	48	103	.90	144.79(30.82)	76-212	48-240	.36
Parent and family problems	24	103	.83	69.16(17.39)	37-107	24-120	.05
Pessimism	09	103	.72	28.72(8.81)	12-45	09-45	.10
Finance	04	103	.87	11.44(4.74)	04-20	04-20	12
Services	07	103	.73	22.55(6.12)	10-34	07-35	21
Awareness	04	103	.60	12.91(3.07)	05-20	04-20	25
Family Coping	30	103	.87	101.96(20.43)	50-141	30-150	20
Acquiring Social Support	9	103	.63	27.86(7.00)	15-45	9-45	.40
Reframing	8	103	.76	28.06(6.86)	15-37	8-40	26
Seeking Spiritual Support	4	103	.60	13.72(3.72)	5-19	4-20	47
Mobilizing Family to	4	103	.72	14.23(4.28)	4-20	4-20	40
Acquire and Accept Help							
Passive Appraisal	5	103	.61	18.07(4.51)	7-25	5-25	56

Table 13 shows the descriptive statistics including Cronbach's coefficients, means, standard deviations, and score range and skewness details. The magnitude of alpha reliability for instruments used in the study ranged from .60 to .91, which depicted that all the instruments of the present study were internally consistent and aims at measuring their respective constructs reliably. The table also presents skewness values, which were well within the range that explains the normal distribution of the data.

 Table 14

 Correlation matrix among the study variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. SER	-																			
2. COR	.94**	-																		
3. ASS	.95**	.82**	-																	
4. ADB	35**	34**	32**	-																
5. PSS	33**	33**	29**	.85**	-															
6. CSS	30**	28**	28**	.92**	.63**	-														
7. PSR	31**	30**	27**	.90**	.68**	.79**	-													
8. PBH	.43**	.41**	.41**	45**	37**	38**	44**	-												
9. ES	.39**	.36**	.37**	49**	35**	46**	51**	.72**	-											
10. CP	.25**	.23*	.23*	27**	25*	17	30**	.53**	.24	-										
11. HP	.34**	.34**	.33**	27**	24*	24*	23*	.91**	.45**	.35**	-									
12. PP	.33**	.33**	.32**	31**	31**	20*	29**	.88**	.41**	.32**	.93**	-								
13. PS	.54**	.50**	.50**	29**	32**	23*	21	.33**	.22*	.17	.30*	.33*	-							
14. MS	.48**	.46**	.44**	44**	45**	33**	30**	.43**	.28**	.50**	.33*	.30**	.45**	-						
15. FCO	26**	22*	24*	.17	.13	.18	.15	25*	19	14	26*	16	31**	42**	-					
16. ASS	16	17	10	.06	.06	.08	.01	15	11	16	16	06	24*	28**	.64**	-				
17. REF	26**	2*	26**	.23*	.14	.19*	.24*	24*	14	02	28**	24*	28*	34**	.83**	.21*	-			
18. SSS	16	13	15	.10	.08	.12	.06	14	17	07	14	01	18	32**	.79**	.31**	.59**	-		
19. MFA	27**	22*	27**	.25**	.14	.22*	.20*	17	20*	01	15	09	24*	-32**	.84**	.30**	.81**	.79**	-	
20. PA	14	10	13	.10	.08	.08	.12	24*	14	29**	22*	14	23*	39**	.81**	.48**	.62**	.62**	.48**	-

Note. SER=Symptom Severity; COR= Core symptoms; ASS=Associated symptoms; ADB= Adaptive Behaviors; PSS= personal self-sufficiency; CSS=Community self-sufficiency; PSR=Personal social Responsibility; PBH= Problem behaviors; ES= Emotional symptoms; CP= Conduct problems; HP= Hyperactivity; PP= Peer Problem; PS= Paternal stress; MS= Maternal stress; FCO=Family coping; ASS= Acquiring Social Support; REF= Reframing; SSS= Seeking Spiritual Support; MFA= Mobilizing Family to Acquire and Accept Help; PA= Passive Appraisal

^{*} *p*<.05,***p*<.01,

Table 14 show the relationship between all study variables. Autism Symptom Severity and its sub variables that are core symptoms and associated symptoms depict significant positive correlation with the maternal stress as well as paternal stress. Adaptive behaviors and its sub variables (personal self-sufficiency and Community self-sufficiency) showed significant negative correlation with the paternal stress. Similarly, adaptive behaviors and its sub variables (personal self-sufficiency, community self-sufficiency and personal social Responsibility) were negatively correlated with the maternal stress. Problematic behaviors its sub variables (problem behaviors, emotional symptoms, hyperactivity and peer problems) were positive correlation with paternal stress. Similarly, problem behavior and its sub variables (problem behaviors, emotional symptoms, conduct problems, hyperactivity and peer problems) depicted significant positive correlation with mother's stress. Family coping and its sub variables (reframing and mobilizing family to acquire and accept help) showed significant negative correlation with the symptom severity, significant positive correlation with adaptive behaviors and significant negative correlation with problematic behavior.

Family coping and its sub variables (acquiring social support, reframing, mobilizing family to acquire and accept help and passive appraisal) have significant negative correlation with paternal stress. Similarly, family coping and its sub variables (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help and passive appraisal) shows significant negative correlation with maternal stress.

Predictors of maternal and paternal stress. To test hypothesis multiple regression was carried out. Only significant relationships were carried for further analysis. Initially data was ensured for probable multicollinearity and Variance Inflation Factor (VIF) values, all variables were below 10, indicating no multicollinearity.

Table 15

Hierarchical multiple regression for child characteristic (problem behaviors, symptom severity, adaptive behavior) predicting maternal and paternal stress (N = 186)

	Parental Stress								
	Materna	l stress	Patern	al stress					
Predictors	ΔR^2	β	ΔR^2	β					
Model 1	.258 ***		.115*						
Problem Behaviors		.50***		.33**					
Model 2	.093***		.198**						
Problem Behaviors		.36***		.15					
Autism symptom Severity		.33***		.48***					
Model 3	.027*		.006						
Problem Behaviors		.31***		.13					
Autism Symptom Severity		.27**		.45***					
Adaptive Behavior		19*		08					
Total R^2	.378***			.319***					
N		103		83					

^{*}*p* < .05. ***p* < .01. ****p* < .001

Hierarchical multiple regression was run to determine the impact of problematic behavior, symptom severity and adaptive behaviors of children with

autism on paternal and maternal stress. The full model depicted that problem behaviors, symptom severity and adaptive behaviors were regressed on maternal stress was statistically significant $R^2 = .378$, F(3, 95) = 19.26, at p < .001. The addition of symptom severity to the model 2 led to statistically significant increase in R^2 of .093 F(1, 96) = 13.72, p < .001. The addition of adaptive behavior to the prediction of mother stress led to a statistically significant increase in R^2 of .027 F(1, 95) = 4.20, p < .005. All three child characteristics were explaining 37.8% of maternal stress.

The final model was statistically significant R^2 = .319, F (3, 77) = 12.05, p < .001 when problem behaviors, autism symptom severity and adaptive behaviors were regressed on Paternal stress. The addition of symptom severity to the model 2 led to statistically significant increase in R^2 of .198 F (1, 78) =22.53, p < .01. The addition of adaptive behavior to the prediction of paternal stress led to non-significant increase in R^2 of .006 F (1, 77) = .67. In the final model only symptom severity significantly predict paternal stress.

Table 16

Multiple Regression Analysis for autism symptomology (core symptoms and associative symptoms) predicting maternal and paternal stress (N = 186)

	Matern	al stress	s (n = 103)	Paternal stress $(n = 83)$			
	В	β	t	В	β	t	
Constant	64.46		4.04***	50.81		3.18	
Core symptoms	3.24	.31	2.02*	2.67	.28	1.65	
Associated symptoms	1.64	.18	1.15	2.28	.27	1.58	

^{*}*p* < .05, ****p* < .001

Maternal stress: R^2 = .227, Ad j R^2 =.211, F= 14.67, p < .001; Paternal stress: R^2 = .277 Adj R^2 =.259, F= 15.32 p < .001

Table 16 shows that only core symptoms of autism significantly predict maternal stress and both core and associated symptoms accounted for 22 % of the explained variability in maternal stress.

Table 17Multiple Regression Analysis for adaptive Behaviors (Personal self- sufficiency,

Community self- sufficiency and Personal social responsibility) predicting maternal

and paternal stress (N = 186)

	Materna	al stres	s (n = 103)	Paternal stress ($n = 83$)		
	В	β	t	В	β	t
Constant	192.93		19.44***	166.84		15.13***
Personal self-sufficiency	790	36	-3.24**	617	300	-2.22*
Community self-sufficiency	023	01	088	081	047	349
Personal social Responsibility	428	14	-1.03			

p < .05, p < .01, p < .001

Maternal stress: R^2 = .223, Adj R^2 =.200, F= 9.47; p < .001; Paternal stress: R^2 = .110 Adj R^2 =.083, F= 4.920 , p < .05

Table 17 shows that only Personal self-sufficiency one of the facets of adaptive behavior is significantly predicting maternal stress. And all three facets of adaptive behaviors accounted for 22.3 % of the explained variability in maternal stress. Similarly, in case of paternal stress only personal self-sufficiency was the only significant predictor. Personal self-sufficiency and community self –sufficiency were accounted for 8.3 % of explained variance in paternal stress.

Table 18Multiple Regression Analysis for problem behaviors (Emotional problem, Conduct Problem, Hyperactivity and Peer Problem) predicting maternal and paternal stress (N = 186)

	Matern	al stress	s(n = 103)	Patern	al stress	(n = 83)
	В	β	t	B	β	t
Constant	80.42		6.97***	101.64		8.53***
Emotional symptoms	2.69	.20	2.13*	.965	.083	.677
Conduct problems	9.44	.38	4.19***			
Hyperactivity	2.07	.14	.370	.944	.073	.383
Peer problems	.30	.01	.911	3.49	.233	1.20

^{*}p < .05, ***p < .001

Maternal stress: R^2 = .331, Adj R^2 =.303, F= 11.64, p < .001; Paternal stress: R^2 = .117 Adj R^2 =.083, F= 3.41, *p < .05

Table 18 shows that its only emotional symptoms and conduct problems aspects of problematic behaviors that significantly effects the maternal stress, whereas, none of the aspects of problematic behavior significantly effect paternal stress. Problem behaviors accounted for 33.1 % of variance in maternal stress.

Mediating effect of family coping on child characteristics, maternal and paternal stress. The mediating effect of family coping (Reframing, Mobilizing Family Support and Passive Appraisal) on child characteristics (autism symptom severity, Adaptive Behaviors, Problematic behaviors) maternal and paternal stress was tested using boot strap method (Shrout & Bolger, 2002). Only those relationships were taken to mediation analysis that showed significant correlation. Separate mediation analysis was run for maternal and paternal stress in PROCESS. Utilizing

the bootstrap method 5000 bootstrap samples was used for the analysis. All assumptions of mediation analysis were checked before conducting the analysis. Errors in estimation were meeting the standard assumption of normality, independence, and homoscedasticity.

Table 19The mediating role of "reframing" between "autism symptom severity" and "maternal stress" (N = 103).

Model	В	SE B	p	Cl (lower)	Cl (upper)					
Model without Mediator										
Constant	60.49	16.05	.001	28.65	92.34					
$SER \longrightarrow MS(c)$	2.26	.43	.001	1.41	3.11					
R^2 (Y,X)	.22	-	-	-	-					
	M	odel with M	I ediator							
Model 1: REF as depend	lent variab	le								
Constant	38.46	3.93	.001	30.66	46.26					
SER \longrightarrow REF (a)	28	.10	.001	48	07					
Model 2: MS as depende	ent variable	e								
$REF \longrightarrow MS(b)$	-1.05	.40	.001	-1.85	25					
$SER \longrightarrow MS(c')$	1.97	.43	.001	1.12	2.82					
Indirect effect $(a \times b)$.29	.17	.05	.06	.76					
R^2 (M,X)	.07									
R^2 (Y,M,X)	.27									

Note. R2 (y, x) is the proportion of variance in y explained by x, R2 (m, x) is the proportion of variance in m explained by x and m. The 95 % CI for a \times b is obtained by the bias-corrected bootstrap with 5000 re-samples. SER (autism symptom severity) is the independent variable (X), REF (reframing) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lower bound of 95% confidence interval; CI (upper) = upper bound.

Table 19 shows the mediating effect of reframing on autism symptom severity and maternal stress. The first part of the table (without mediator) depicts that maternal stress was significantly predicted by autism symptom severity. 22% of variance in maternal stress was explained by autism symptom severity and with increase in autism symptom severity maternal stress also increases. In model 1 shows that autism symptom severity significantly predicts "reframing. 7 % of variance in "reframing" was explained by symptom severity. In Model 2 it was depicted that both reframing and autism symptom severity are significant predictors of maternal stress. Whereas, "reframing" had inverse relationship with maternal stress.

The point estimate of K^2 was .07 (95%CI = 0.1, 0.16). The mediating effect size of autism symptom severity on maternal stress through reframing was there but it was small. The point estimate of R^2 med was .06 (95%CI = 0.2, 0.16) indicating that 6% of the variance in maternal stress was attributable to the indirect effect of autism symptom severity through reframing. The point estimate of R^2 med was considered as a small effect size.

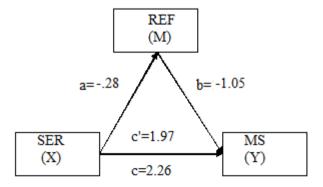


Figure 4. Mediating role of "reframing" on autism symptom severity and maternal stress

Figure 4 shows that the measurement effect between "autism symptom severity" and "maternal stress" is not zero on fixing the mediator variable that is "reframing". The direct effect also remained significant and smaller than the total effect (|1.97| < |2.26|), indicating that the mediation model in the current study was a partially mediated model.

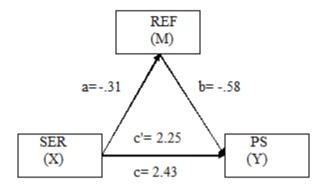


Figure 5. Mediating role of "reframing" on autism symptom severity and paternal stress

Figure 5 shows that mediating effect of "reframing" between "autism symptom severity" and paternal stress was not significant.

Table 20The mediating role of "Mobilizing Family to Acquire and Accept Help" between "autism symptom severity" and "maternal stress" (N = 103)

Model	В	SE B	p	Cl (lower)	Cl (upper)					
Model without Mediator										
Constant	60.49	16.05	.001	28.65	92.34					
SER→MS (c)	2.26	.43	.001	1.41	3.11					
R^2 (Y,X)	.22									
	N	Model with M	l ediator							
Model 1: MFA as dependent variable										
Constant	20.83	2.40	.001	16.06	25.59					
SER → MFA (a)	17	.06	.05	30	05					
Model 2: MS as depend	lent variab	le								
$MFA \longrightarrow MS$ (b)	-1.59	.66	.05	-2.91	28					
$SER \longrightarrow MS(c')$	1.98	.43	.001	1.12	2.84					
Indirect effect (a×b)	.28	.16	.05	.05	.69					
R^2 (M,X)	.07									
R^2 (Y,M,X)	.27									

Note. R^2 (y, x) is the proportion of variance in y explained by x, R^2 (m, x) is the proportion of variance in m explained by x and m. The 95 % CI for a × b is obtained by the bias-corrected bootstrap with 5000 re-samples. SER (autism symptom severity) is the independent variable (X), MFA (Mobilizing Family to Acquire and Accept Help) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lowerboundof95%confidenceinterval; CI (upper) = upper bound.

Table 20 depicts the mediating role of "Mobilizing Family to Acquire and Accept Help" between "autism symptom severity" and "maternal stress". First part of above table (without mediator) depicts that 22% variance in maternal stress was explained by autism symptom severity. In model 1 the mediator "Mobilizing Family

to Acquire and Accept Help" was regressed on autism symptom severity and its shows that symptom severity significantly predicts "Mobilizing Family to Acquire and Accept Help". 7 % of variance in "Mobilizing Family to Acquire and Accept Help" was explained by symptom severity. In Model 2 it was depicted that both "Mobilizing Family to Acquire and Accept Help" and autism symptom severity are significant predictors of maternal stress.

The point estimate of K^2 was .06 (95%CI = 0.1, 0.15) indicating that the mediating effect size of autism symptom severity on maternal stress through "Mobilizing Family to Acquire and Accept Help" was there but it was too small. The point estimate of R^2 med was .06 (95% CI = 0.1, 0.15) indicating that 6% of the variance in maternal stress was attributable to the indirect effect of symptom severity through "Mobilizing Family to Acquire and Accept Help". The point estimate of R^2 med was considered as a small effect size.

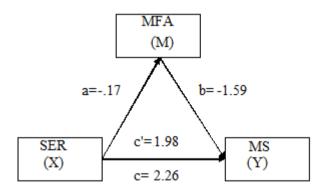


Figure 6. Mediating role of "Mobilizing Family to Acquire and Accept Help" between autism symptom severity and maternal stress

Figure 6 shows that the measurement effect between "autism symptom severity" and "maternal stress" is not zero on fixing the mediator variable (Preacher and Hayes, 2008). The direct effect remained significant and smaller than the total effect (|1.98| < |2.26|), which indicated that the mediation model was a partially mediated model.

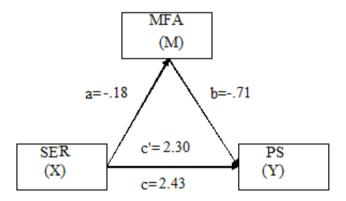


Figure 7. Mediating role of "Mobilizing Family to Acquire and Accept Help" between autism symptom severity and paternal stress

The figure 7 depicts that the mediating effect of "Mobilizing Family to Acquire and Accept Help" between autism symptom severity and paternal stress was not found significant.

Table 21The mediating role of "reframing" between "adaptive Behaviors" and "maternal stress" (N = 103)

Model	В	SE B	p	Cl (lower)	Cl (upper)					
Model without Mediator										
Constant	180.77	8.24	.001	184.38	234.55					
ADB→MS (c)	38	.08	.001	53	22					
R^2 (Y,X)	19	-	-	-	-					
	Me	odel with M	I ediator							
Model 1: REF as dependent variable										
Constant	24.38	2.00	.001	30.66	46.26					
$ADB \longrightarrow REF(a)$.04	.02	.05	.00	.08					
Model 2: MS as depend	lent variable	e								
$REF \longrightarrow MS(b)$	-1.18	.40	.001	-1.98	38					
$ADB \longrightarrow MS(c')$	33	.08	.001	48	17					
Indirect effect (a \times b)	05	.03	.05	13	01					
R^2 (M,X)	.04									
R^2 (Y,M,X)	.25									

Note. R^2 (y, x) is the proportion of variance in y explained by x, R^2 (m, x) is the proportion of variance in m explained by x and m. The 95 % CI for a × b is obtained by the bias-corrected bootstrap with 5000 re-samples. ADB(adaptive behaviors) is the independent variable (X), REF (reframing) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lowerboundof95%confidenceinterval; CI (upper) = upper bound.

Above table shows the mediating role of reframing between adaptive behaviors and maternal stress. The first part of the table (without mediator) depicts that 19 % variance in maternal stress was explained by adaptive behaviors. In model

1 the mediator "reframing" was regressed on adaptive behaviors and its shows that adaptive behaviors significantly predicts "reframing. In Model 2 it was depicted that both reframing and adaptive behaviors are the significant predictors of maternal stress. Increase in reframing leads to decrease maternal stress.

The point estimate of K^2 was .06 (95%CI = 0.1, 0.15) indicating that the mediating effect of adaptive behaviors on maternal stress through reframing was there but it was small. The point estimate of R^2 med was .05 (95%CI = 0.1, 0.14) indicating that 5% of the variance in maternal stress was attributable to the indirect effect of adaptive behaviors through reframing. The point estimate of R^2 med was considered as a small effect size.

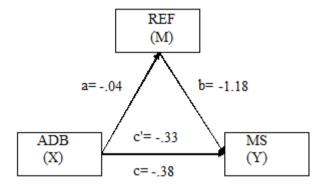


Figure 8. Mediating role of "reframing" on adaptive behaviors and maternal stress

Figure 8 shows that the measurement effect between "adaptive behaviors" and "mother stress" is not zero on fixing the mediator variable that is "reframing" (Preacher and Hayes, 2008). The direct effect also remained significant and smaller

than the total effect (|-.33| < |-.38|), which indicated that the mediation model in the current study was a partially mediated model.

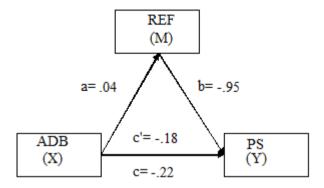


Figure 9. Mediating role of "reframing" on Adaptive behaviors and Paternal stress

Above Figure 9 depicts that the mediating effect of "Reframing" between Adaptive behaviors and paternal stress was not significant.

Table 22The mediating role of "Mobilizing Family to Acquire and Accept Help" between "adaptive behaviors" and "maternal stress" (N = 103)

Model	В	SE B	p	Cl (lower)	Cl (upper)			
Model without Mediator								
Constant	180.77	8.24	.001	164.44	197.33			
ADB→MS (c)	38	.08	.001	53	22			
R^2 (Y,X)	19	-	-	-	-			
	Me	odel with M	1 ediator					
Model 1: MFA as dependent variable								
Constant	11.88	1.22	.001	9.45	14.30			
ABD → MFA (a)	.03	.01	.05	.00	.05			
Model 2: MS as depend	dent variable	e						
$MFA \longrightarrow MS (b)$	-1.80	.66	.05	-3.11	48			
$ADB \longrightarrow MS(c')$	33	.08	.001	49	17			
Indirect effect (a×b)	05	.03	.05	12	01			
R^2 (M,X)	.05							
R^2 (Y,M,X)	.25							

Note. R^2 (y, x) is the proportion of variance in y explained by x, R^2 (m, x) is the proportion of variance in m explained by x and m. The 95 % CI for a × b is obtained by the bias-corrected bootstrap with 5000 re-samples. ADB (adaptive behaviors) is the independent variable (X), MFA (Mobilizing Family to Acquire and Accept Help) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lower bound of 95% confidence interval; CI (upper) = upper bound.

The first part of the table 22 (without mediator) depicts 19% of variance in maternal stress was explained by low adaptive behaviors. In model 1 the mediator

"Mobilizing Family to Acquire and Accept Help" was regressed on adaptive behaviors and its shows that adaptive behaviors significantly predict "Mobilizing Family to Acquire and Accept Help". In Model 2 it was depicted that both "Mobilizing Family to Acquire and Accept Help" and Adaptive behaviors are the significant predictors of maternal stress.

The point estimate of K^2 was .06 (95%CI = 0.1, 0.15) indicating that the mediation effect size was there but it was too small. The point estimate of R^2 med was .05 (95%CI = .01, 0.13) indicating that 5% of the variance in maternal stress was attributable to the indirect effect of adaptive behaviors through "Mobilizing Family to Acquire and Accept Help". The point estimate of R^2 med was considered as a small effect size.

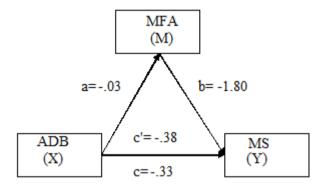


Figure 10. Mediating role of "Mobilizing Family to Acquire and Accept Help" between "adaptive behaviors" and "maternal stress"

Figure 10 illustrate that partial mediation exist on fixing the mediating variable "Mobilizing Family to Acquire and Accept Help" between "adaptive behaviors" and "maternal stress". The direct effect remained significant and smaller

than the total effect (|-.33| < |-.38|), which indicated that the mediation model in the current study was a partially mediated model.

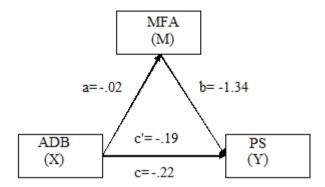


Figure 11. Mediating role of "Mobilizing Family to Acquire and Accept Help" on adaptive behaviors and paternal stress

Figure 11 depicts that the mediating effect of "Mobilizing Family to Acquire and Accept Help" on adaptive behaviors and paternal stress was not significant.

Table 23The mediating role of "reframing" between "problem behaviors" and "maternal stress" (N = 103)

Model	В	SE B	p	Cl (lower)	Cl (upper)				
Model without Mediator									
Constant	87.18	10.76	.001	65.80	108.56				
PBH→MS (c)	2.62	.48	.001	1.68	3.59				
R^2 (Y,X)	.24		-						
	M	odel with M	Iediator						
Model 1: REF as depend	dent variab	le							
Constant	33.73	2.65	.001	28.48	38.99				
PBH→ REF (a)	25	.12	.05	48	01				
Model 2: MS as depend	ent variable	e							
REF \longrightarrow MS (b)	-1.15	.41	.001	-1.96	34				
$PBH \longrightarrow MS(c')$	2.35	.47	.001	1.41	3.30				
Indirect effect (a \times b)	.29	.18	.05	.03	.81				
R^2 (M,X)	.05								
R^2 (Y,M,X)	.31								

Note. Regression weights a, b, c, and c' are illustrated in Figure:7 Appendix L . R^2 (y, x) is the proportion of variance in y explained by x, R^2 (m, x) is the proportion of variance in m explained by x and m. The 95 % CI for a × b is obtained by the bias-corrected bootstrap with 5000 re-samples. PBH (problem behaviors) is the independent variable (X), REF (reframing) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lower bound of 95% confidence interval; CI (upper) = upper bound.

The first part of the table 23 (without mediator) depicts that 24 % variance in maternal stress was explained by problem behaviors. In model 1, 5 % variance in "reframing" was explained by problem behaviors. In Model 2 it was depicted that both reframing and problematic behaviors are significant predictors of maternal stress. Whereas with family coping (reframing) had positive relationship with mother stress, which means that mother who use more reframing as coping behaviors experience less stress.

The point estimate of K^2 was .06 (95%CI = 0.1, 0.16) indicating that the mediating effect of problem behaviors on maternal stress through reframing was there but it was small. The point estimate of R^2 med was .06 (95%CI = 0.1, 0.16) indicating that 6% of the variance in maternal stress was attributable to the indirect effect of problem behaviors through reframing. The point estimate of R^2 med was considered as a small effect size.

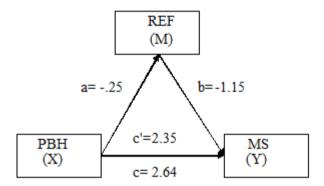


Figure 12. Mediating role of "Reframing" between "problem behaviors" and "maternal stress".

Above figure depicts that measurement effect between "problem behaviors" and "maternal stress" is not zero on fixing the mediator variable that is "reframing". The direct effect remained significant and smaller than the total effect (|2.35| < |2.64|), which indicated that the mediation model in the current study was a partially mediated model.

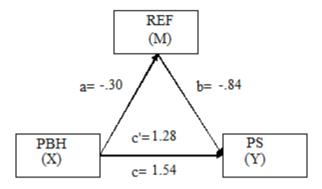


Figure 13. Mediating role of "Reframing" between "problem behaviors" and "Paternal stress".

Figure 13 shows that the mediating effect of "Reframing" on problem behaviour and paternal stress was not significant.

Table 24

The mediating role of "Passive appraisal" between "problem behaviors" and "maternal stress" (N = 103)

Model	В	SE B	p	Cl (lower)	Cl (upper)			
Model without Mediator								
Constant	87.18	10.76	.001	65.80	108.56			
PBH → MS (c)	2.64	.48	.001	1.68	3.59			
R^2 (Y,X)	.24		-					
	M	odel with M	Iediator					
Model 1: PA as depend	ent variable	;						
Constant	22.44	1.74	.001	18.98	25.90			
PBH → PA (a)	20	.08	0.01	36	05			
Model 2: MS as depend	lent variable	e						
$PA \longrightarrow MS(b)$	-2.04	.61	0.01	-3.24	83			
$PBH \longrightarrow MS(c')$	2.23	.47	.001	1.29	3.17			
Indirect effect (a× b)	.41	.20	.05	.11	.92			
R^2 (M,X)	.07							
R^2 (Y,M,X)	.33							

Note. Regression weights a, b, c, and c' are illustrated in Figure:7 Appendix L . $R^2(y, x)$ is the proportion of variance in y explained by x $R^2((m, x))$ is the proportion of variance in m explained by x and m. The 95 % CI for a × b is obtained by the bias-corrected bootstrap with 5000 re-samples. PBH (problematic behaviors) is the independent variable (X), PA (Passive appraisal) is the mediator (M), and MS (maternal stress) is the outcome (y). CI (lower = lower bound of 95%confidenceinterval; CI (upper) = upper bound.

Table 24 depicts that maternal stress was significantly predicted by problematic behaviors of their autistic child. And 24% variance in maternal stress was explained by problematic behaviors of children with autism. Model 1 shows that 7 %

variance in "passive appraisal" was explained by problem behaviors. In Model 2 it was depicted that both "passive appraisal" and problematic behaviors are significant predictors of maternal stress.

The point estimate of K^2 was .09 (95%CI = .02, 0.18). The mediating effect size of problematic behaviors on maternal stress through "passive appraisal" was there but it was of medium effect. The point estimate of R^2 med was .08 (95%CI = .02, 0.18) indicating that the value of R^2 Med was 8% of the variance in maternal stress was attributable to the indirect effect of problematic behaviors of children with autism through "passive appraisal". The point estimate of R^2 med was considered as of a medium effect size.

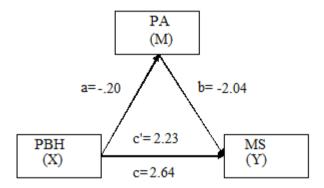


Figure 14. Mediating role of "Passive appraisal" between "problem behaviors" and "maternal stress".

Figure 14 depicts that there exist a partial mediation because the measurement effect between "problem behaviors" and "maternal stress" is not zero on fixing the mediator variable that is "passive appraisal" (Preacher and Hayes, 2008). The direct

effect remained significant and smaller than the total effect (|2.23| < |2.64|), indicating that partially mediation exist.

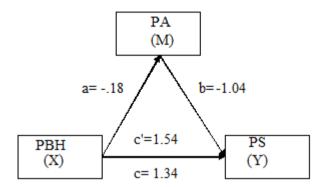


Figure 15. Mediating role of "Passive appraisal" between "problem behaviors" and "Paternal stress".

Above figure shows that the mediating effect of problematic behavior on paternal stress via "passive appraisal" was not significant.

Table 25Mean, Standard deviation, and t-values for gender differences of parents on various dimension of stress (N = 186)

	Mot	her	Fatl	her					
	(n =	103)	(<i>n</i> =	83)					
Scales	M	SD	M	SD	t(184)	p	95%	ω CI	Cohen's d
							LL	UL	
PFP	69.23	17.45	59.56	16.95	3.8	.00	4.65	14.68	.56
PES	28.89	8.64	26.37	8.24	2.0	.04	.055	4.98	.29
FIN	11.44	4.74	11.14	4.36	.44	.65	-1.03	1.63	.06
SER	22.59	6.16	25.68	6.30	3.3	.00	-4.89	-1.27	.49
AWN	12.93	3.07	12.87	3.17	.11	.90	855	.960	.01
TS	145.10	31.04	135.64	28.38	2.14	.03	.762	18.15	.31

Note. PFP= Parent and family problems; PES= Pessimism; FIN = Financial stress; SER= stress due to lack of services; AWN = stress due to lack of awareness; TS= Total Stress CI= Confidence Interval, LL= Lower limit, UL= Upper limit.

Table 25 shows that mothers (M = 145.10, SD = 31.04) of children with autistic disorder were more stressed as compared to fathers (M = 135.64, SD = 28.38). Further analysis revealed that mothers perceive more stress related to "Parent and family problems" and "Pessimism" as compared to fathers. Fathers of children with autistic disorder perceive more stress with reference to unavailability of services for their autistic children as compared to mothers.

Table 26Mean, Standard deviation, and t-values for difference between fulltime employed mothers and not employed mothers on various dimension of stress (N = 103)

	Full 1	time	Not employed						
	emplo	oyed	mothers						
	moth	ners							
	(n = 36)	5)	(n = 67)	')					
	M	SD	М	SD	t(101)	p	95%	CI	Cohen's d
Scales						-	LL	UL	
PFP	77.03	14.31	65.46	17.57	3.2	.00	4.60	18.52	.72
PES	28.81	10.34	28.68	8.07	.07	.94	-3.57	3.84	.01
FIN	12.42	4.60	10.98	4.76	1.4	.15	537	3.41	.30
SER	22.22	6.45	22.70	5.99	.37	.71	-3.05	2.09	.07
AWN	13.06	3.13	12.84	3.06	.33	.73	-1.07	1.51	.18
TS	153.64	29.85	140.65	30.60	2.01	.04	.206	25.65	.42

Note. PFP= Parent and family problems; PES= Pessimism; FIN = Finance; SER= services; AWN = awareness; TS= Mother Total Stress CI= Confidence Interval, LL= Lower limit, UL= Upper limit.

Table 26 shows that the maternal stress was more in "full time employed" mothers (M = 153.64, SD = 29.85) as compared to "not employed mothers" (M = 140.65, SD = 30.60). Further, analysis on subscales revealed that full time employed mothers of children with autistic disorder were more stressed with reference to parents and family problems (M = 77.03, SD = 14.31) as compared to not employed mothers.

Table 27 *Mean, Standard deviation, and t-values for difference between nuclear and joint families on various dimension of maternal stress* (N = 110)

	Nuclea	r family	Joint f	amily					
	(n =	68)	(<i>n</i> =	42)					
Scales	M	SD	М	SD	t(108)	p	959	% <i>CI</i>	Cohen's d
							LL	UL	
PFP	71.90	17.46	65.02	16.66	1.99	.04	.03	13.73	.40
PES	30.00	9.33	26.80	7.67	1.82	.07	28	6.67	.37
FIN	12.25	4.84	10.21	4.36	2.17	.03	17	3.89	.44
SER	23.35	6.34	21.33	5.63	1.65	.10	40	4.44	.33
AWN	13.43	2.79	12.12	3.34	2.16	.03	.10	2.51	.42
TS	150.94	32.43	135.50	25.91	2.55	.01	3.45	27.43	.52

Note. PFP= Parent and family problems; PES= Pessimism; FIN = Finance; SER= services; AWN = awareness; TS= Mother total Stress CI= Confidence Interval, LL= Lower limit, UL= Upper limit.

Table 27 shows that stress was high in mothers living in nuclear families (M = 150.94, SD = 32.43) as compared to mother living in joint families (M = 135.50, SD = 25.91). Further, analysis on subscales revealed mother living in nuclear families setup perceive more stress with reference to parents and family problems (M = 71.90, SD = 17.46) as compared to mothers living in joint families (M = 65.02, SD = 16.66). Similarly, mothers living in nuclear families setups perceive more stress (M = 12.25, SD = 4.84) with reference to financial problems related to education, therapy and treatment as compared to mother living in joint family setups (M = 10.21, SD = 4.36).

Results also revealed that mothers living in nuclear family (M = 13.43, SD = 2.79), setups perceive more stress with reference to lack of awareness as compared to mothers living in joint family setups (M = 12.12, SD = 3.34).

Table 28

Correlation matrix between demographic variables (maternal age, monthly family income and number of children in family) maternal stress and paternal stress (N = 186)

Variables	Maternal stress	Paternal stress
Maternal Age	22*	-
Monthly income	20*	13
Number of children in family	.22**	.26*

^{*} *p* < .05,***p* < .01

Table 28 depicts that with increase in mother's age and monthly income in family maternal stress decreases. Increase in total number of children in family leads to elevated maternal as well as paternal stress.

Discussion

The relationship between child characteristics, coping and stress in parents of children with autism was studied in the present research. One of the objectives was to examine the impact of child characteristics on stress of parents of children with autism. Both maternal as well as paternal stress were included. The factors included in the child's characteristics were autism severity, autism symptomology, adaptive behaviors and problem behaviors of children with autism.

The autism symptomology included presence of core and associated symptoms; the core symptoms refer to those symptoms designated in the diagnostic and statistical manual (DSM IV-TR) as being essential to diagnose autism in children. Whereas, associated symptoms are the frequently occurring symptoms that may be present but are not necessary to diagnose autism. Whereas, the adaptive behaviors encompasses tasks carried out routinely by children with autism in various domains of daily functioning, such as communication, daily living skills, social interaction, and motor skills. Three aspects of adaptive behaviors that are personal self- sufficiency, community self- sufficiency and personal social responsibility dealt with in the present study.

Moreover, the problem behaviors included behavioral and emotional problems of children with autism e.g., issues related to conduct problems, hyperactivity and peer problems. Furthermore, the present study also examined the mediating effect of family coping between child characteristics (autism symptom severity, adaptive behaviors and problems behaviors) and maternal, paternal stress. Moreover, the

relationships of different family socio-demographic variables were also examined with reference to paternal and maternal stress.

The present research constitutes of a pretest of instruments, study I and study II. The pretest of the instruments was done to check the compatibility of the instruments for the target population. Whereas, Study I was based on translation and validation of instruments measuring the study variables and study II was the main study. This was carried out to test the hypothesis of the study.

The pretest was conducted to check the compatibility of the instruments for the target population. As, according to Hambleton et al. (2004), instruments selected for the research should be appropriate for every context, its vocabulary and expression should easily be understandable in the target population. It was found that certain expressions within few items of ABS-S: 2, (Part 1) and F-COPES were culturally inappropriate and were replaced with culturally appropriate expressions. Similarly, in SDQ which was already available in Urdu language certain expressions within items were found difficult to comprehend. The problematic expressions identified in SDQ were modified in translation phase of study I. Three subscales were added to the already existing scales measuring parental stress. The three subscales added were "financial stress", "stress due to lack of Services" and "stress due to lack of awareness". All of these subscales contained 16 items in all. This was decided on the basis of the pretest carried out before study I. It was felt that the stress was being caused by certain indigenous factors that were not covered by existing items.

Study I was based on translation and validation of instruments measuring the study variables. Study I, further constituted of three phases. In phase I, self reported instruments ABS-S: 2, (Part 1), QRS-F and F-COPES were translated from source

language (English) to target language (Urdu) (Hambleton et al., 2004). Moreover, Urdu version of SDQ was also modified. Modifications were done within certain items of the instrument. In phase II content validity of translated and modified instruments was established. The content validity index as calculated for items and full scale was established for the clarity and cultural equivalence of the instruments. Which was found to be well above the critical value of 0.80 as suggested by Polit and Beck (2006). In Phase III of study I, psychometric properties including Item-total correlation, corrected item-total correlation, inter-rater reliability, alpha reliability coefficient and construct validity were addressed. Due to low item-total and corrected item-total correlation 4 items (11,12,21,24) from ABS-S:2 (Part 1), 3 items (8,14,17) from SDQ, 4 items (2,19,11,17) from maternal and parental versions of QRS-F were dropped from main study analysis. Study I was concluded after making sure that all the instruments were validated and thus ready to be yielded in the main study.

In Study II, the data was initially subjected to normality testing. This was implemented in order to establish whether the data has been drawn from normally distributed population. Descriptive statistics shown in table 13 depicted that the data is normally distributed. The Cronbach's alpha of the instruments ranged from .60 to .91. The alpha reliability coefficient for CARS-2 was .90, which was consistent with the alpha reliabilities mentioned in the CARS-2 manual (Schopler et al., 2010). Following the suggestions of Tavakol and Dennick (2011) four items from Urdu version of ABS-S: 2 (Part 1), three items from Urdu version of SDQ and three items from Urdu version of maternal and paternal QRS-F were deleted because of low itemtotal correlation coefficients. After removing the items with low item-total correlation the alpha reliability of instruments also improved. The alpha reliability coefficient of

translated Urdu version of ABS-S:2 (part 1) ranged from .71 to .90, which was consistent with the alpha reliabilities found in Spanish version of ABS: 2S (part 1) (García Alonso, De La Fuente Anuncibay, & Fernández Hawrylak, 2010). The Strengths and difficulties questionnaire measuring the problematic behaviors also depicted satisfactory internal consistency with alpha reliability coefficient ranging from .65 to .87, which was in line with the past research (Samad etal., 2005). Similarly the reliability coefficient for translated Urdu version of maternal and paternal QRS-F ranges from .60 to .90, which was judged to be satisfactory. Urdu version of F-COPES measuring family coping also shows alpha reliability from .60 to .87, Which is quite consistent with the alpha reliability mentioned in adapted version of F-COPES in Hebrew language (Botkin et al., 1996).

Relationship between study variables. The correlation analysis (table 14) indicated an interesting relationship between the study variables. Some relationships predicted by previous literature were verified, others were not found to be significant. As predicted by previous literature, increase in autism symptom severity was positively associated with paternal and maternal stress. Thus, parental stress increases with increase in symptom severity. Similarly, severity of core and associated symptomology was highly associated with paternal and maternal stress. These finding are in line with the previous literature (Bebko et al., 1987; Ekas & Whitman, 2010; Hastings & Johnson, 2001; Kasari & Sigman, 1997; Konstantareas & Homatidis, 1989).

Furthermore, consistent with previous literature (e.g., Hall & Graff, 2011; Rivard etal., 2014; Tomanik et al., 2004) it was found that poor adaptive behaviors

lead to elevated stress in both parents. Analyzing different aspects of adaptive behaviors showed that poor personal self-sufficiency, lower community self-sufficiency and poor personal social responsibility were associated with stress in mothers. However, only poor personal self-sufficiency and lower community self-sufficiency were related to paternal stress. Interestingly, no relationship was found between personal social responsibility and paternal stress.

Moreover, it was found that problem behaviors of children with autism were associated with stress in their parents. Different aspects of problem behaviors depicted that increase in emotional problems, conduct problems, hyperactivity and peer problem were associated with maternal stress. Similarly, increase in emotional symptoms, hyperactivity, peer problem were related to paternal stress; except for conduct problems, which did not show strong association with paternal stress. These findings are consistent with the previous literature. It has been reported that increase in problematic behaviors leads to more stress in parents of children with autism (Brobst et al., 2009; Davis & Carter, 2008; Estes et al., 2013; Hastings, 2003; Huang et al., 2014).

The significant relationship was found between child characteristics (autism symptom severity, adaptive behaviors and problem behaviors) and stress in mothers and fathers of children with autism. This was because of the fact that autism comes with hidden characteristics and symptoms of each child are unique. So parents have to be very vigilant in understanding the needs and deficiencies of their children. Due to this, management of autism in children is a challenge on daily basis. Parents cannot assure with any one form of treatment. In reference to Pakistan, the management is even more challenging. Parents are usually not aware of the basic characteristics and

associated problems related to autism. For parents the unpredictable changes in child characteristics, which are not effectively managed by parents, might lead to more stress.

The correlation analysis also shows (see Table 14) that more use of family coping behaviors leads to less stress in mothers and fathers of children with autism. Analysis of different dimensions of coping behaviors showed that the parents acquiring more social support experience less stress.

Previous literature reported mix finding, some researches asserted that parents of children with autism were reluctant to seek social support because of the fear of labeling and attached stigma. (Gray,1994; Obeid & Daou, 2015; Pottie & Ingram, 2008; Weiss, 2002). However, some of the literature does support the findings of the present study that there exist a positive relationship between social support and parental stress (Bromley et al., 2004; Dunn et al., 2001; Ekas & Whitman, 2011). As, Pakistani society is collectivistic society and parents who perceive that they are helped and can attain the understanding, cooperation, assistance, and appraisal of friends and family might experience less stress.

Similarly, it was found that more use of reframing helps parents experience less stress. The findings are in line with the previous literature depicting that mothers who reported using more cognitive reframing reported greater wellbeing (Benson, 2010; Luther et al., 2005; Obeid & Daou, 2015). Accepting the disability of their child and to view the situation in positive manner helps the family to cognitively redefine the situation. This helps in effectively managing stress in families of children with autism.

The correlation analysis (Table 14) shows mothers using spiritual support as coping experience less stress. Spiritual beliefs sometimes play important role in social and personal growth and it is a powerful medium that can aid in coping with daily stressors. However, spiritual beliefs do vary from person to person and culture to culture. Previous research on autism has reported that mothers who were more spiritually inclined experience less stress (Ekas et al., 2009; Kopolovich, 2008; Tarakeshwar & Pargament, 2001). Most of these researchers do not focus on the spiritual inclination of the fathers and its impact on stress. Interestingly, the present research found a non significant relationship between seeking spiritual support and paternal stress.

Impact of child characteristics on maternal and paternal stress. Hypothesis 1 stated that problem behavior is more predictive of maternal stress as compared to autism symptom severity and adaptive behaviors. Autism symptom severity, adaptive behaviors and problem behaviors were regressed on maternal and paternal stress (See Table 15). It was revealed that all three child characteristics that were autism symptom severity, adaptive behaviors, problem behaviors were the significant predictors of maternal stress. The major contributor in the maternal stress were problematic behaviors followed by autism symptom severity and adaptive behaviors. However, it was found that only autism symptom severity was the significant predictor for paternal stress.

This finding of the present study supported hypothesis 1 and is in confirmity with the past research that problem behaviors of children with autism are strongest and consistent predictors for the maternal stress (Brobst et al., 2009; Estes et al., 2009;

Lecavalier et al., 2006; Manning et al., 2011). Moreover, it was also found that problem behavior was the significant predictor for maternal stress but not for the paternal stress. Hastings (2003) also reported that child behavior problems were related to maternal stress but nothing to do with the paternal stress.

A plausible reason for this finding might be that mothers are usually considered responsible for not only taking care of their children but also their upbringing. It is stressful for mothers when their child has autism and cannot communicate his/her needs. It becomes even more problematic if the child has hyperactive or have aggressive tendencies. It becomes even more challenging when these behaviors and malfunctions appear in social gathering. It may also be due to societal norms, as mothers are generally, blamed for poor child rearing practices.

Another reason for elevated maternal stress in present population is mother's lack of awareness about autism. Lack of information and understanding may cause stress levels to increase ten folds. The mother is not only stressed about managing the child but also has to suffer from an increased level of her own personal stress. As a corollary of this children of stressed mothers exhibit more problem behaviors as compare to mother who are not stressed. So, there is need to create awareness in parents about importance of behaviors therapy and to counsel both mothers and fathers to accept their child in every good and bad situation and to take ups and downs as part of the spectrum.

Interestingly, poor adaptive behavior and severe autism symptoms were also sources of stress for mothers of children with autism. However, problem behaviors were the major contributors in maternal stress. This may be owing to the fact that once a child is diagnosed with autism, and his/her symptom severity has been

specified, parents tend to adjust to the label given to their child. However, problematic behaviors tend to be recurring and they need to be managed on a day to day basis. This may cause the parents to feel more stress related to problem behaviors child with autism.

Finding of the present study is in compatible with the past research where child problem behaviors along with high autism symptom severity were found to be the significant predictors of maternal stress (Bebko et al., 1987; Beck, Hastings, Daley, & Stevenson, 2004; Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989; Konstantareas & Papageorgiou, 2006; Milgram & Atzil, 1988). Similarly, Bishop et al. (2007) reported that severity of autism and low adaptive behaviors were the significant predictors of perceived negative impact on African American mothers. Rivard etal. (2014) also reported that parental stress was related to severity of autism symptoms and adaptive behaviors.

In the present study all three child characteristics were significant predictor of maternal stress and possible reasons for this finding is lack of educational, interventional and rehabilitation facilities for children with autism. Due to lack of awareness every new behavior of an autistic child is a surprise for parents. In the process of trial and error parents often felt exhausted. In addition, contextual factors e.g., low literacy rate, poor finical status, stigma from the society etc. and personal factors e.g. feeling of guilt, denial and being blame etc. are the added ingredients for the already existing stress.

Additionally, the present study indicated that autism symptom severity was the only significant predictor of paternal stress (See Table 15). Few studies have focused on the stress experienced by fathers of children with autism and found that fathers do

feel difficulty in communicating with their autistic children and certain behaviors of child do cause stress in fathers (Brobst et al., 2009; Davis & Carter, 2008; Rivard et al., 2014). In past literature fathers of children with autism are often taken as invisible parents (Ballard, Bray, Shelton, & Clarkson, 1997). Past research was mostly designed to specifically address the maternal care giving needs (MacDonald, Hastings, & Fitzsimons, 2010). Whereas, the present study tried to address this limitation by including a representative sample of fathers as compared to previous studies. Therefore, the current study manages to identify the stress experienced by fathers. This is a positive contribution to literature; this can help researchers identify factors that may lead to stress in fathers and can help design better interventions for fathers.

Impact of core and associative symptoms on maternal and paternal stress.

Hypothesis 2 assumed that core symptoms are positively associated with maternal stress. When both core and associative symptoms were regressed on maternal and paternal stress (See Table 16), it was discovered that only core symptoms were the significant positive predictor of maternal stress. Ekas and Whitman (2010) also found that impact of core symptoms like limitation in relating to people, imitation, object use, adaptation to change, verbal communication and non verbal communication were related to maternal stress.

Bitsika et al. (2013) found that inability to develop social interaction and lack of communication skill in children with autism were the sources of stress for parents of children with autism. A probable reason for this finding is the severity in core symptoms like limitation in communication skill, poor social skills and restricted

behaviors may inhibit the relationship between the child and the family. This in turn, is another cause of stress for mothers. Not only is she concerned about reaching out to her child, but also concerned with making the child accessible to the immediate family. Moreover, preference for constancy and routine usually restricts or disrupts family activities and prevents families from engaging in non-routine events, such as birthday parties, holiday activities, and family outings.

Impact of personal self- sufficiency, community self- sufficiency and personal social responsibility on maternal and paternal stress. Hypothesis 3 assumed that personal self- sufficiency is negatively associated with maternal and paternal stress. To see the impact of different facets of adaptive behaviors including personal self-sufficiency, community self- sufficiency and personal social responsibility on maternal and paternal stress, a regression analysis was done (See Table 17). It was established that only personal self-sufficiency was significantly impacting both maternal and paternal stress. The impact was more on maternal stress as compared to paternal stress. Maternal stress was related to child's inability to take care of him or herself vis-a-vis daily tasks like eating, brushing teeth, going to toilet, changing clothes, washing hands etc. This finding of the present study is consistent with past studies (Bishop et al., 2007; Bitsika et al., 2013; Tomanik et al., 2004).

Findings of the current study also suggested a relationship between low personal self-sufficiency and paternal stress. This finding is consistent with the previous research by Hall and Graff (2011). One of the reasons for elevated maternal and paternal stress with reference to personal self-sufficiency in the present population is over compensation due to guilt. Guilt about having a child with autism

tends to make parents over compensate for their child's abilities. Because of this over compensation children are dependent on their parents for daily routine tasks. Especially mother's over commitment with an autistic child is effecting her psychological as well as her physical health.

Impact of emotional problem, conduct problem, hyperactivity and peer problem on maternal and paternal stress. Hypothesis 4 assumed that emotional problem and conduct problems are positively associated with maternal and paternal stress. However, findings of the present study depicted that emotional problem and conduct problems are positively associated with maternal stress but not with the paternal stress. Additionally it was found that the presence of conduct problems was influencing maternal stress more than emotional problems (See Table 18). It supports the past research that behavioral problems in children with autistic disorder are the major predictor of maternal stress (Bitsika et al., 2013; Davis & Carter, 2008; Estes et al., 2009; Estes et al., 2013; Hastings, 2003; Hastings & Brown, 2002; Jones et al., 2013; Lecavalier et al., 2006; Walsh et al., 2013). Also, Huang et al. (2014) found that compared to emotional symptoms conduct problems were the main precursor for stress in parents of children with autism. However, he did not cater to the stress faced by mothers and fathers separately. Conduct problems are disruptive as well as against social norms and contradicts parents expectations. It is because of conduct problems in children with autism that such families often feel isolated from society and exclusion from special school also results in increased maternal stress.

Mediating role of family coping. One of the major objectives of present research was to investigate the mediating role of family coping between child characteristics and maternal, paternal stress. Preliminarily analysis indicated that reframing, mobilizing family support and passive appraisal are the three facets of family coping that significantly correlated with child characteristics including autism symptom severity, adaptive behaviors, problem behaviors and maternal, paternal stress.

The bootstrap method was employed in order to study the mediating role of reframing, mobilizing family support and passive appraisal on child characteristic (symptom severity, adaptive behaviors and problem behaviors) and maternal, paternal stress. This method samples observations repeatedly from the dataset, estimating the indirect effect with each re-sampled dataset (Preacher & Hayes, 2008). This process is usually required or recommended for such rare sample groups.

Mediating role of "reframing" and "mobilizing family to acquire and accept help" between autism symptom severity and maternal, paternal stress. Based on the previous literature it was assumed in hypothesis 5a, that family coping mediates the relationship between autism symptom severity and maternal, paternal stress. Finding of the present study depicts that "reframing" and "mobilizing family to acquire and accept help" sub facets of family coping partially mediates the relationship between autism symptom severity and maternal stress (See Table 19 and 20). Autism symptom severity negatively effects reframing and in turn, reframing has negative impact on maternal stress. In other words when autism symptoms of a child

are severe, it leads to less use of reframing by the mothers and this in turn leads to stress.

Previous research has not addressed the mediating role that reframing plays between autism symptom severity and maternal stress, even though this issue has been indirectly reported. For example Meikki, (2012) studied role of confronting coping strategy between symptom severity and maternal stress. Similarly Pozo and Sarriá, (2014) used composite scores of coping strategies with autism severity and maternal stress. Similarly, Peer (2011) studied coping styles in relations to symptom severity and maternal stress.

These researches did not find any mediation effect and relied mostly on composite score of coping. The finding in the present study though not previously reported, is interesting, in a way that it shows that reframing really works for mother of children with autism in Pakistan. It implies that accepting the situation and approaching the problem with optimism can help mothers reduce stress caused by severity of autism.

In addition, it was established that "Mobilizing family to acquire and accept help" partially mediates the relationship between autism symptom severity and maternal stress. "Mobilizing family to acquire and accept help" is form of formal social support that parents avail when confronted with a problematic situation. Formal social support includes support from organizations working with autism or other parents facing similar problems. Existing empirical evidence available claim that social supports from family and friends and other social supports groups in the form of medical or professional care can also help minimize parental stress (Boyd, 2002; Twoy et al., 2007; Zablotsky et al., 2012).

In the current study autism symptom severity negatively effects "mobilizing family to acquire and accept help", which in turn has negative effect upon maternal stress. In other words severity of autism symptom leads to less use of "Mobilizing family to acquire and accept help" which leads to more maternal stress. Findings of the present study was congruous with previous work done by Ingersoll and Hambrick (2011) reporting that social support partially mediated the relationship between child symptom severity and parenting stress.

Therefore, one way that child symptom severity may effect parental stress is through social support. Parents perceive that less social support was available when the child impairment was severe, which increases the risk of poor parental mental health. It has been reported that sometimes families are reluctant to accept or approach for formal as well informal support, this may be due to the fear of stigma attached with disability (Obeid & Daou, 2015).

It was also found that "reframing" and "Mobilizing family to acquire and accept help" didn't mediate the relationship between autism symptom severity and paternal stress (See Figure 5 and 7). The finding was somewhat consistent with a study by Pozo and Sarriá (2014), in which no mediation effect of coping was observed between severity of autism and paternal stress.

Mediating role of "reframing" and "mobilizing family to acquire and accept help" between adaptive behaviors and maternal, paternal stress. Hypothesis 5b assumed that family coping mediates the relationship between adaptive behaviors and maternal, paternal stress. Present study revealed that "reframing" and "mobilizing family to acquire and accept help" partially mediates the relationship

between adaptive behaviors and maternal stress (See Table 21 and 22). In other words poor adaptive behaviors leads to less use of "Reframing" and "Mobilizing family to acquire and accept Help", which in turn results in elevated maternal stress. Moreover, "Reframing" and "Mobilizing Family to acquire and Accept Help" don't mediate the relationship between adaptive behaviors and paternal stress (See Figure 9 and 11). So far, previous literature reported that poor adaptive behavior in children with autism leads to elevated maternal stress (Bishop et al., 2007; Bitsika et al., 2013; Tomanik et al., 2004) as well as paternal stress (Hall & Graff, 2011).

However, the mediating role of coping between adaptive behavior and parental stress was yet to be explored in literature. In present study elevated maternal stress due to poor adaptive behavior of children with autism can be intervened via "reframing" and "mobilizing family to acquire and accept help". Accepting and restructuring the problem in positive way can help mothers reduce stress related to poor adaptive behaviors of children with autism. In addition seeking formal support from organizations, practitioners, and other families facing similar issues is another source of coping that can help mothers reduce stress. This finding can help the practitioners and researchers to design their interventions in a better way.

Mediating role of "reframing" and "Passive appraisal" between problem behavior and maternal, paternal stress. Hypothesis 5c assumed that family coping mediates the relationship between problem behaviors and maternal, paternal stress. Finding of the present study shows that "reframing" and "passive appraisal" partially mediates the relationship between problem behavior and maternal stress (See Table 23 and 24). In the case of fathers the mediation effect was not found significant (See

Figure 13 and 15). In other words more problematic behaviors lead to less use of "reframing" and "reframing" leads to elevated maternal stress.

Finding of the present study is line with a previous research conducted by Weiss et al. (2012). They found that psychological acceptance emerged as a significant partial mediator between child problem behavior and parental mental health problems. Reframing and psychological acceptance are closely linked with coping behaviors. Both share the property to accept the problematic situation and to look for possible solutions. Moreover, it was found that relationship between problematic behaviors and maternal stress was mediated by "passive appraisal". Pozo and Sarriá (2014) also found that the direct relationship between behavior problems and maternal, paternal stress was mediated by active avoidance coping strategies. Passive appraisal is form of cognitive distraction, which people use to avoid the stressful situation. Although it's an emotional focused coping strategy but sometimes it may help the individual to accept the situation and help minimizing the reactivity to stressful situation. In conclusion reframing along with passive appraisal can help mothers reduce stress related to problematic behaviors of children with autism.

Family socio-demographic factors, maternal and paternal stress. Hypothesis 6a stated that mothers perceive more stress as compare to fathers of children with autism (See Table 25). Finding of the present study is in line with the previous literature (Estes et al., 2013; Hastings, 2003; Hastings & Brown, 2002; Huang et al., 2014; Lecavalier et al., 2006). Taking a more in-depth look at stress in parents finding depicted that mother of children with autism perceives more stress in areas related to "Parent and family problems" and "pessimism" as compare to fathers.

In a study by McCabe (2008) it was found that mothers of children with autism were more pessimistic about their child's future. They have worries related to independent living of the child in her absence, source of income that are needed or may be needed in the future for sustenance, lack of future prospects for the child, worries related to marriage and companionship etc. The mothers feel the burden of having a child with special needs also. They may feel restricted and unable to work for their own deployment and growth because apart from the child with the autism, they also have obligations towards their families, husbands and other children.

One of the major objectives of the study was to highlight the needs of father of children with autism. Therefore, the present study found that fathers were more likely to perceive more stress due to lack of unavailability of proper services for their children. Previous researchers have identified lack of proper services related to education, intervention and rehabilitation for children with autistic disorder is one of the stress causing factor for parents (Rahbar et al., 2011).

In Pakistan autism is not properly recognized at government level and parents who can afford have to rely on private educational setup and clinics for therapy and intervention. These are usually very expensive set ups for children. Parents perceive that financial burden for getting services for children with autism is an additional stress for them.

It was also revealed in the present study that parent perceive stress due to lack of awareness about autism in general public, school staff and sometimes in professionals. It is sometimes stressful for parents to take their children in public places and social gathering because people usually do not understand the need and requirement of children with autism. The negative attitude people display towards

families of children with autism was actually because of their lack of awareness (Huws & Jones, 2010). Findings of the present study can thus help in developing multipurpose awareness campaigns for parents with children with autism, practitioners and general public. This will help in cultivating a more inclusive approach about dealing with the needs of the children with autism and their caregiver.

Consistent with the previous studies (Cidav et al., 2012; Zablotsky et al., 2012), the results showed that full time employed mothers of children with autism perceive more stress as compared to mothers who are not employed (Table 26). Mothers of children with autism usually seek employment to bear the costly charges of intervention, education and other services. Long working hour, work demand and keeping the balance between work and family put extra demands on them. They usually feel stretched out beyond their limits. In addition, it was found that most of the mothers in the present study were educated but were not working in order to fulfill the demands of their autistic child. It was reported by few mothers that they had left the job just to take care of their autistic child. In a typical Pakistani culture having a child with disability is considered as a stigma and usually mothers of children with disabilities develop sense of guilt and it was usually observed that to overcome this guilt they usually quit their jobs and other activities to take care of their child with autism.

Asian culture is a collective culture and family members are linked together in a special bound but with growing trend of urbanization the concept of joint family system is fading day by day. In the present study more families are living in nuclear family setup (61.8%) and less families (38.2%) are living in joint family system. Finding of the present study depicted that mothers living in joint family system

perceive less stress as compared to mothers living in nuclear family system (Table 27). Hypothesis 6c is supported by previous literature (Gupta & Singhal, 2004; Krishnamurthy,2008; Sajjad, 2011). Mothers reported living in joint family is immensely supportive for them, in terms of emotional support and sometimes in terms of financial support as well. Informal support from extended family is also a source of coping for the family.

Hypothesis 6d assumed that with increase in mother's age reduces the stress. The finding is in line with the past research by Zablotsky et al. (2012). With experience and exposure mothers of children with autistic disorder get familiar how to handle their child. With the passage of time they learn approaches to cope with difficult scenarios. With growing age their ability to respond to the stressors effectively also improves. This may be due to the reasons that with growing age of the child mother get used to the problems related to his/her disability. Social expectation on the mother tends to decrease as the child grows. Additionally, with a advancing age autistic children need more help in intellectual and skill development rather than day to day management.

Hypothesis 6e assumed that with increase in family income paternal and maternal stress decreases. The hypothesis is partially supported by the results of the present study (See Table 28). It was found that increase in family income lessens the maternal stress but not the paternal stress. Zablotsky et al. (2012) also reported that stress is less in high income families. This is a natural outcome as in Pakistan gender roles dictate that fathers should be major bread earners in the family, therefore father perceive the burden of finances more than mothers. Mothers can feel more support with the availability of additional services for their children with autism. With

financial stability parents can afford better educational and treatment facilities. It has been observed that few of the well-off parents prefer sending their children to private schools they can even afford trained ABA therapist and speech therapist. However, parents with low income resources cannot afford such services for their children.

The last hypothesis assumed that greater number of children in family leads to elevated maternal and paternal stress. Zablotsky et al. (2012) reported that increase in household members in a family leads to more paternal stress. One possible reason for this finding is the increase in financial burden. Hence, inability of both parents to properly care and give attention to an autistic child might lead to more stress.

Conclusion

The present study concludes that, child characteristics of children with autism were source of stress for both parents. However, mothers experienced more stress as compared to fathers. The impact of problematic behavior of children with autism was a major factor associated with maternal stress followed by severity of autism symptom and poor adaptive behaviors. Fathers do experience stress of having a child with autism and in present study severity of autism symptom was the only identified predictor for paternal stress. Furthermore, core symptoms e.g., communication deficits, poor social interaction skill, restricted and repetitive behaviors etc. Impacted maternal stress more as compared to other associated symptoms.

Personal self-sufficiency is usually an indicator of how well an autistic child can take care of themselves; it includes daily care needs. It was found that both mother and father of children who were unable to fulfill their daily need e.g. eating, drinking, bathing etc experienced more stress. Similarly, problematic behaviors, especially issues related to emotional instability and conduct problems were the major source of stress for mothers.

Family coping strategies are important as the kind of coping behaviors that parents use tend to reflect directly on how they relate to their child with autism. Therefore effective coping strategies can not only reduce parental stress, it can also affect the way families respond to the needs of their children with autism. Thus, present study highlighted that more use of informal social support in the form of mobilizing family to acquire and accept help from other families and organizations can help in reducing the stress in mothers caused by severity of child characteristics.

Similarly, reframing e.g., thinking in positive way, accepting the child's disability, redefining the situation might also help parents to overcome the stress.

Family socio-demographic factors, with reference to stress in mothers and fathers of children with autism are very important especially when the designing the intervention for specific population. In present study it was found that mothers were more pessimistic as compared to fathers. They have worries related to his/her child future placement, their management and acceptance in the community. Moreover, mothers perceived more stress related to parenting and family problems as compared to fathers. They have worries related to acceptance of their autistic child in family and community, reaction of others towards the child, adjustment of their autistic child in immediate family etc. Fathers of children with autism experience more stress as compared to mothers in the areas related to unavailability of proper services by government and financial burden for affording resources and services for their children with autism. Thus, stress in fathers of children with autism was associated with external factors. The factors are associated with their child's need, availability of resources, providing facilities etc. They did not report stress related to behavioral or emotional problems of their children. This could be due to the cultural factors also as men in Pakistan are not expected to get involved with day-to-day care of their children. Thus they may be less aware of issues related to management of their children. In addition, mothers who were full time employed and living in nuclear family system perceive more stress. Maternal Stress was relatively less in those families having high monthly income and less number of children.

Limitation and Suggestions

Like others, this study has limitations which should be considered when designing a similar study on children with autsim.

- 1. The present study tried to provide a holistic picture of stress and coping in parents of children with autism. However, future studies should investigate stress and coping in families of children with Asperger's and other Pervasive Developmental disorders. Conducting research on similar lines as this research will not only help in understanding the true burden of these disorders on parents, it will also help in development of intervention plans that help parents of children with these disorders.
- 2. Research on autsim can be widened by understanding of the factors associated with this disorder. Although a broad age range of children from three to fourteen years was included in the present study. Further studies should also investigate the life and family dynamics of adults with autism.
- 3. Parents of children with autism are their primary care-givers; the present studied focused only on stress and coping of parents. However, during research it was evident that siblings and other immediate family members e.g. grand parents also pay important role in care giving process. Future studies can also focus on the mental health needs of siblings and other family members.
- 4. Present study focused on role of coping with stress in families of children with autism. This is useful information and can help in planning intervention for families of children with autism. Future studies should focus on exploring additional adaptive factors e.g. resilience, family coherence, positive perception etc.

5. There is a dire need in Pakistan to conduct prevalence studies on massive level so we can clearly get an idea about the exact picture of ASD in Pakistan.

Implications

The present study has many theoretical as well as applied contributions for families with autism and for professionals working with them.

- 1. The present study tried to present a holistic picture of child characteristics, family coping and stress in families of children with autism. This will help be of great for counselor and clinical practitioners to make suitable assessment and interventional plan for the parents of children with autism.
- 2. Moreover, the identified issues will be of great help for the researchers while designing interventional plans and self-help programs for parents e.g. the maternal and paternal needs should be catered separately as both parents react differently to autism child characteristics.
- 3. Similarly, the research highlights that adaptive behavior should be given importance both on assessment and intervention level. Since, the ultimate outcome is to reduce stress in parents and this can only be possible by cultivating the sense of independence in the child and by educating the parents about importance of independent living for the children.
- 4. Present research revealed that behavior problems of children were the strongest predictor of stress in parents. This finding is important for different educational programs that cater to involvement of parents in taking care of their autistic children; it would be a good step to incorporate behavior skill training to reduce the severity of behavior problems in children. Parents should also be encouraged to build positive environments that are predictable

- and to provide their children with basic communication skills and social regulation, which will result in a reduction in their behavior problems
- 5. One of the strength of the present study was to highlight the needs and requirements of fathers of children with autism. Research highlighted that despite their absence in previous literature, fathers do experience stress but are reluctant to express their emotions. Consistent efforts are required to keep fathers on-board treatment and care management plans.
- 6. As mothers are involved in day to day care of their children with autism and the elevated maternal stress is not only affecting their own physical and mental health but also affecting the whole family as well as the development of their children with autism. Thus, present study provides evidence that along with the child needs and concerns of the mothers should also be given due importance.
- 7. Most of the parents of children with autism look for answers within their surrounding instead of consulting the practitioners. This may sometimes misguide them. Present study provides hands-on knowledge about their stressors and coping behaviors that they may use to manage their stress.
- 8. Investigating the role of family coping and its impact on parental stress is important because it generates information about indigenous cultural factors. This is information is important for clinician, for researchers planning interventions and for management of home-based children with autism.
- 9. Instruments of the study were validated with utmost quality and statistical vigor. Thus indigenously modified, Urdu version of QRS-F can be helpful in assessing parental stress in future research. Similarly, Urdu version of Adaptive Behavior Scale-School Edition ABS: 2S (Part 1) and Strengths and Difficulties Questionnaire (SDQ) are useful tools to identify adaptive behaviors and problematic behavior of children in clinical setups.

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Appendix A

DSM-IV-TR diagnostic criteria for Autistic disorder

Autistic Disorder

- A. A total of six (or more) items from (1), (2) and (3), with at least two from (1), and one each from (2) and (3):
 - (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) Failure to develop peer relationships appropriate to developmental level
 - (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing, or pointing out objects of interest)
 - (d) Lack of social or emotional reciprocity
 - (2) Qualitative impairments in as manifested by at least one of the following:
 - (a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
 - (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) Stereotyped and repetitive use of language or idiosyncratic language
 - (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:
 - (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) Apparently inflexible adherence to specific, non-functional

routines or rituals

- (c) Stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole body movements)
- (d) Persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication or (3) symbolic or imaginative play
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

Appendix B

Original instruments of the study

Childhood Autism Rating Scale-2 (CARS-2)

Adaptive Behavior scale-School Edition (ABS-S: 2 Part-1)

Strengths and Difficulties Questionnaire (SDQ)

Questionnaire on resources and stress (QRS-F)

The Family Crisis Oriented Personal Evaluation Scale (F-COPES).

Appendix B 1

CARS2-ST

Childhood Autism Rating Scale, Eric Schopler, Ph.D., Robert J. Reichler, M.D.,



Standard Version

Second Edition	and Barbara Roche	ar weinier, File		Test with Confidence	Ka	ting Booklet	
E			ase ID Number:			Test date:	
r: Ethnic background	Ethnic background: Rater's name:					Date of birth:	
on information from:					Age:	years mon	
licate the corresponding Severity Group.	fer the ratings from the inside pages to the c Circle the Total raw score value in the table i printed to the left of each value you have ci	n the column lab	eled All age				
SUMMA	ARY	Ir		mptom Level			
CATEGORY RATINGS		Individuals With Autism Spectrum Diagnoses Raw score					
1. Relating to People		Percentile	T-score	All ages	Ages 2-12	Ages 13 and olde	
median = 2.5 (3.0, 2.5)			>70	>54	>54	>54	
2. Imitation		>97	70	54	54	54	
median = 2.5 (2.5, 2.0)	538 S 8 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	97	69 68	53.5 52-53	53.5 52.5-53	52-53.5 49.5-51.5	
3. Emotional Response		96	67	51-51.5	51.5-52	49.5-51.5	
median = 3.0 (3.0, 3.0)		95	66	50-50.5	51,5-52		
A STATE OF THE STA		93	65	49.5	50-50.5	49	
4. Body Use		92	64	49	49.5	47.5-48.5	
median = 2.5 (2.5, 2.5)		90	63	48-48.5	48.5-49	46-47	
5. Object Use		88	62	47-47.5	47.5-48	45-45.5	
median = 2.5 (2.5, 2.0)		86	61	46.5	46.5-47	44-44.5	
6. Adaptation to Change		84	60	45.5-46	46		
median = 2.5 (2.5, 2.5)		82 79	59 58	44.5-45 44	45-45.5 44.5	43.5 43	
7. Visual Response	9.000091	76	57	43.5	44.5	42.5	
median = 2.5 (2.5, 2.0)		72	56	42.5-43	43-43.5	42,5	
		69	55	42.3-43	42-42.5	41-41.5	
8. Listening Response		65	54	41-41.5	41.5	40-40.5	
median = 2.5 (2.5, 2.0)		62	53	40-40.5	40.5-41	39.5	
9. Taste, Smell, and Touch Response an	d Use	58	52	39-39.5	39.5-40	38.5-39	
median = 2.0 (2.0, 2.0)		54	51	38.5	39	37.5-38	
O. Fear or Nervousness		50	50	37.5-38	38-38.5	36.5-37	
median = 2.5 (2.5, 2.5)		46	49 -	37	37.5	35-36	
1. Verbal Communication		42	48	36-36.5	36.5-37	34-34.5	
median = 3.0 (3.0, 3.0)		38	47	35-35.5	35.5-36	33.5	
	- /	35 31	46	34-34.5	35	33	
2. Nonverbal Communication		28	45	33.5	34-34.5 33.5	32.5 31-32	
median = 2.5 (2.5, 2.0)		26	43	32-32.5	32.5-33	30-30.5	
3. Activity Level		21	42	31.5	32	29-29.5	
median = 2.5 (2.5, 2.0)		19	41	30.5-31	31.5	27.5-28.5	
4. Level and Consistency of Intellectual	Response	16	40	30	30.5-31	26.5-27	
median = 2.5 (2.5, 2.5)		14	39	28.5-29.5	30	26	
5. General Impressions	A. S. C.	12	38	27.5-28	29-29.5	25-25.5	
median = 3.0 (3.0, 3.0)		10	37	26-27	28-28.5	23.5-24.5	
	CARROW OF DEPARTMENT OF THE PARTMENT OF THE PA	8 7	36 35	25.5 24.5-25	26-27.5 25.5	23 21-22.5	
. The numbers in parentheses are medians for	individuals aged 2-12 or 13+, respectively.	6	35	24.5-25	25.5	21-22.5	
		5	33	23-23.5	24.5-25	20.5	
		4	32	22.5	23.5		
Total raw score =		3	31	21.5-22	23		
Total law Score -	Note. SEM = 0.68.	2	30	21	22-22.5	20	
			29	20.5			
		1	28		21.5		
SEVERITY GROUP		<1	27	20	21		
			26		20.5	7,000	
Minimal-to-No Symptoms of Autism Spectrum Disorder			25	19.5	20	19.5	
(15-29.5; 15-27.5 for ages 13+)			23	19.5	19.5		
2 8 100 100 100 100 100 100 100 100 100 1	100 rg 1 100 v	11	23		19.5		
Mild-to-Moderate Symptoms of A	utism Spectrum Disorder		21				
(30-36.5; 28-34.5 for ages 13+)			20	19	19		
Severe Symptoms of Autism Spectrum Disorder			<20	<19	<19	<19.5	
(37 and higher; 35 and higher for ages 13+)							

DIRECTIONS

For each category, use the space provided in the Observations section for taking notes concerning the behaviors relevant to that item. After you have finished observing the child, rate the behaviors relevant to each item by circling the number that corresponds to the statement that best describes the child. You may indicate that the child's behavior falls between two descriptions by circling ratings of 1.5, 2.5, or 3.5. Abbreviated rating criteria are presented for each item. See chapter 2 of the Manual for detailed rating criteria.

Imitation

2. Imitation

- Appropriate imitation. The child can imitate sounds, words, and movements that are appropriate for his or her skill level.
- Mildly abnormal imitation. The child imitates simple behaviors such as clapping or single verbal sounds most of the time; occasionally, imitates only after prodding or after a delay.
- Moderately abnormal imitation. The child imitates only part of the time and requires a great deal of persistence and help from the adult; frequently imitates only after a delay.
- 3.5

 Severely abnormal imitation. The child rarely or never imitates sounds, words, or movements even with prodding and assistance from the adult.

Observations

2.5

Relating to people

1. Relating to People

- No evidence of difficulty or abnormality in relating to people.

 The child's behavior is appropriate for his or her age. Some shyness, fussiness, or annoyance at being told what to do may be observed, but not to an atypical degree.
- Mildly abnormal relationships. The child may avoid looking the adult in the eye, avoid the adult or become fussy if interaction is forced, be excessively shy, not be as responsive to the adult as is typical, or cling to parents somewhat more than most
- Moderately abnormal relationships. The child shows aloofness (seems unaware of adult) at times. Persistent and forceful attempts are necessary to get the child's attention at times. Minimal contact is initiated by the child.
- Severely abnormal relationships. The child is consistently aloof or unaware of what the adult is doing. He or she almost never responds to or initiates contact with the adult. Only the most persistent attempts to get the child's attention have any effect.

Emotional Response

3. Emotional Response

- Age-appropriate and situation-appropriate emotional response.

 The child shows the appropriate type and degree of emotional response, as indicated by a change in facial expression, posture, and manner.
- Mildly abnormal emotional response. The child occasionally displays a somewhat inappropriate type or degree of emotional reaction. Reactions are sometimes unrelated to the objects or events surrounding him or her.
- unrelated to the objects or events surrounding him or her.
 2.5

 Moderately abnormal emotional response. The child shows definite signs
- of inappropriate type and/or degree of emotional response. Reactions may be quite inhibited or excessive and unrelated to the situation; thild may grimace, laugh, or become rigid even though no apparent emotion-producing objects or events are present.
- Severely abnormal emotional response. Responses are seldom appropriate to the situation; once the child gets in a certain mood, it is very difficult to change the mood. Conversely, the child may show wildly different emotions when nothing has changed.

Observation

Body Use

4. Body Use

Age-appropriate body use. The child moves with the same ease, agility, and pordination as a normal child of the same age.

Mildly abnormal body use. Some minor peculiarities may be present, such as clumsiness, repetitive movements, poor coordination, or the rare appearance of more

Moderately abnormal body use. Behaviors that are clearly strange or unusual for a child of this age may include strange finger movements, peculiar finger or body posturing, staring or picking at the body, self-directed aggression, rocking, spinning, finger-wiggling, or toe-walking.

Severely abnormal body use. Intense or frequent movements of the type listed above are signs of severely abnormal body use. These behaviors may persist despite attempts to discourage them or involve the child in other activities.

object use

5. Object Use

Appropriate interest in, or use of, toys and other objects. The child ows normal interest in toys and other objects appropriate for his or her skill level and uses these toys in an appropriate manner.

Mildly inappropriate interest in, or use of, toys and other objects. 2 The child may show atypical interest in a toy or play with it in an inappropriately childish way (e.g., banging or sucking on the toy).

75

Moderately inappropriate interest in, or use of, toys and other 3 objects. The child may show little interest in toys or other objects, or may be preoccupied with using an object or toy in some strange way. He or she may focus on ome insignificant part of a toy, become fascinated with light reflecting off the object, repetitively move some part of the object, or play with one object exclusively.

Severely inappropriate interest in, or use of, toys and other objects. The child may engage in the same behaviors as above, with greater frequency and intensity. The child is difficult to distract when engaged in these

Adaptation to change

6. Adaptation to Change

- Age-appropriate adaptation to change. While the child may notice or nt on changes in routine, he or she accepts these changes without undue distress.
- Mildly abnormal adaptation to change. When an adult tries to change 2

Moderately abnormal adaptation to change. The child actively resists changes in routine, tries to continue the old activity, and is difficult to distract. He or 3 she may become angry and unhappy when an established routine is altered.

Severely abnormal adaptation to change. The child shows severe reactions to change. If a change is forced, he or she may become extremely angry or uncooperative and respond with tantrums.

Visual Response

7. Visual Response

Age-appropriate visual response. The child's visual behavior is normal and appropriate for his or her age. Vision is used together with other senses as a way to

Mildly abnormal visual response. The child must be occasionally reminded to look at objects. The child may be more interested in looking at mirrors or lighting than are his or her peers, may occasionally stare off into space, or may also avoid looking people in the eye.

Moderately abnormal visual response. The child must be reminded frequently to look at what he or she is doing. He or she may stare into space, avoid looking people in the eye, look at objects from an unusual angle, or hold objects very

Severely abnormal visual response. The child consistently avoids tooking at people or certain objects and may show extreme forms of other visual peculiarities described above.

listening Response

8. Listening Response

- Age-appropriate listening response. The child's listening behavior is normal and appropriate for his or her age. Listening is used together with other senses,
- Mildly abnormal listening response. There may be some lack of response or mild overreaction to certain sounds. Responses to sounds may be delayed, and sounds may need repetition to catch the child's attention. The child may be distracted by extraceure counds.
- Moderately abnormal listening response. The child's responses to sounds vary; often ignores a sound the first few times it is made; may be startled or cover ears when hearing some everyday sounds.
- Severely abnormal listening response. The child overreacts and/or underreacts to sounds to an extremely marked degree, regardless of the type of sound.

Observations

Taste, Smell & Touch Response & use

9. Taste, Smell, and Touch Response and Use

- Normal use of, and response to, taste, smell, and touch. The child explores new objects in an age-appropriate manner, generally by feeling and looking. Taste or smell may be used when appropriate. When reacting to minor everyday pain, the child expresses discomfort but does not overreact.
- Mildly abnormal use of, and response to, taste, smell, and touch. The child may persist in putting objects in his or her mouth; may smell or taste inedible objects; may ignore or overreact to mild pain that a normal child would express as discomfort.
 2.5
- Moderately abnormal use of, and response to, taste, smell, and touch. The child may be moderately preoccupied with touching, smelling, or tasting objects or people. The child may either react too much or too little.
- Severely abnormal use of, and response to, taste, smell, and touch.
 The child is preoccupied with smelling, tasting, or feeling objects more for the sensation than for normal exploration or use of the objects. The child may completely ignore pain or react very strongly to slight discomfort.

Observations

Fear or Nervousness

10. Fear or Nervousness

- Normal fear or nervousness. The child's behavior is appropriate both to the situation and for his or her age.
- Mildly abnormal fear or nervousness. The child occasionally shows too much or too little fear or nervousness compared to the reaction of a normal child of the same age in a similar situation.
- 3 Moderately abnormal fear or nervousness. The child shows either quite a bit more or quite a bit less fear than is typical even for a younger child in a similar situation.
- Severely abnormal fear or nervousness. Fear persists even after repeated experience with harmless events or objects. It is extremely difficult to calm or comfort the child. The child may, conversely, fail to show appropriate regard for hazards that other children of the same age avoid.

Observations

3.5

Verbal Communication

11. Verbal Communication

Normal verbal communication, age and situation appropriate.

1.5

- Mildly abnormal verbal communication. Speech shows overall retardation.

 Most speech is meaningful: however, some echolalia or pronoun reversal may occur.

 Some peculiar words or jargon may be used occasionally.

 2.5
- Moderately abnormal verbal communication. Speech may be absent.

 When present, verbal communication may be a mixture of some meaningful speech and some peculiar speech such as Jargon, echobalia, or pronoun reversal. Peculiarities in meaningful speech include excessive questioning or preoccupation with particular topics.
- Severely abnormal verbal communication. Meaningful speech is not used.

 The child may make infantile squeals, weird or animal-like sounds, or complex noises approximating speech, or may show persistent, bizarre use of some recognizable words or or brasses.

Observation

12. Nonverbal Communication 1 Normal use of nonverbal communication, age and situation appropriate.

Mildly abnormal use of nonverbal communication. Immature use of nonverbal communication; may only point vaguely, or reach for what he or she wants, in situations where a typically developing same-age child may point or gesture more specifically to indicate what he or she wants.

Moderately abnormal use of nonverbal communication. The child is generally unable to express needs or desires nonverbally and cannot understand the nonverbal communication of others.

Severely abnormal use of nonverbal communication. The child uses only bizarre or peculiar gestures that have no apparent meaning and shows no awareness of the meanings associated with the gestures or facial expressions of others.

Observations

Activity level

13. Activity Level

- 1 Normal activity level for age and circumstances. The child is neither more active nor less active than a normal child of the same age in a similar situation.
- Mildly abnormal activity level. The child may either be mildly restless or somewhat "lazy" and slow moving at times. The child's activity level interferes only slightly with his or her performance.
- Moderately abnormal activity level. The child may be quite active and difficult to restrain. He or she may have boundless energy and may not go to sleep readily at night. Conversely, the child may be quite lethargic and need a great deal of prodding to get him or her to move about.
- Severely abnormal activity level. The child exhibits extremes of activity or inactivity and may even shift from one extreme to the other.

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Level & Consistency of intellectual

tul General Impressions

14. Level and Consistency of Intellectual Response

To rate this item, it is essential to read the expanded definitions in the Manual

- 1 Intelligence is normal and reasonably consistent across various areas. The child is as intelligent as typical children of the same age and does not have any unusual intellectual skills or problems.
- 1.5 The child has low intelligence (IQ score between 71 and 85) and does not have any unusual intellectual skills or problems.
- Mildly abnormal intellectual functioning. The child has very low intelligence (IQ score is 70 or lower) and his or her skills appear fairly evenly delayed across all areas.
- The child has very low intelligence (IQ score is 70 or lower) and skills appear to vary ocross areas, but none is at or above average.

 The child has very low intelligence (IQ score is 70 or lower) and skills appear to vary ocross areas, but none is at or above average.
- Moderately abnormal intellectual functioning. The child's overall intelligence is in the range from intellectually disabled to average (IQ score less than 115), and there is significant variability in skills. At least one skill is in average range.
- The child's overall intelligence is in the range from intellectual disability to average (IQ score less than 115), and there is significant variability in skills. At least one skill in above average range. Extreme savant skills are not included here but are rated in category 4.
- Severely abnormal intellectual functioning. A rating of 4 is given when extreme savant skills are present, regardless of overall level of intelligence.

Discreption

15. General Impressions

- No autism spectrum disorder. The child shows none of the symptoms characteristic of system
- teristic of autism.
- Mild autism spectrum disorder. The child shows only a few symptoms or only a mild degree of autism.
 - Moderate autism spectrum disorder. The child shows a number of symptoms
- or a moderate degree of autism.

 3.5

 Severe autism spectrum disorder. The child shows many symptoms or an

extreme degree of autism.

Observations

Appendix B 2



Nadine Lambert, Kazuo Nihira, and Henry Leland

Adaptive Behavior Scale – School

Second Edition

Examination Booklet

Examinee's Name	
Rater's Name	
Date of Rating	
School	

PART ONE DOMAIN I.

A. Eating			ITEM 7 Washing Hands and Face	
	11		(Circle all answers)	
TEM 1	Use of Table Utensils (Circle highest level)		Yes	No
	Uses table knife for cutting or spreading 6		Washes hands and face with soap	0
	Feeds self neatly with spoon and fork		and water without prompting 1	0
ſo	or appropriate alternate utensil, e.g., chopsticks) 5		Washes hands with soap 1	0
	elf causing considerable spilling with spoon and		Washes face with soap 1	0
	or appropriate alternate utensil, e.g., chopsticks) 4		Washes hands and face with water 1	0
	Feeds self with spoon—neatly 3		Dries hands and face 1	0
	Feeds self with spoon—considerable spilling 2		ITEM 8 Bathing	
	Feeds self with fingers 1		(Circle highest level)	
	Does not feed self or must be fed 0		Prepares and completes bathing unaided 6	
TEM 2	Eating in Public (Circle highest level)		Washes and dries self completely without prompting or helping 5	
	Orders complete meals in restaurants 3		Washes and dries self reasonably well with prompting 4	
0	orders simple meals like hamburgers or hot dogs 2		Washes and dries self with help 3	
	gle items, e.g., soft drinks, ice cream, donuts, etc.		Attempts to soap and wash self 2	
a raisin in fig	at soda fountain or canteen 1		Cooperates when being washed and dried by others 1	
	Does not order in public eating places 0		Makes no attempt to wash or dry self 0	L
TEM 3	Drinking (Circle highest level)		ITEM 9 Personal Hygiene (Circle all answers)	
i	Drinks without spilling, holding glass in one hand 3		If these items do not apply to the individual,	
	Drinks from cup or glass unassisted—neatly 2		e.a., because he or she is completely dependent on	
Drinks from	n cup or glass unassisted—considerable spilling 1		others, place a check in the blank and mark "Yes"	
	Does not drink from cup or glass unassisted 0		for all statements	
TEM 4	Table Manners		Yes	
i Lini 4	(Circle all answers)		Has strong underarm odor 0	1
If these ite	ems do not apply to the individual, e.g., because		Does not change underwear regularly by self 0	1
he or sh	e is bedfast and/or has liquid food only, place a		Skin is often dirty if not assisted 0	1 [
chec	ck in the blank and mark "Yes" for all statements		Does not keep nails clean by self 0	1 L
	0.77	No	ITEM 10 Toothbrushing	
	Throws food 0	1	(Circle highest level)	
	Swallows food without chewing 0	1	Cleans dentures appropriately 5	
	Chews food with mouth open 0	1	Applies toothpaste and brushes teeth	
	Drops food on table or floor 0	1	with up and down motion 5	
	Does not use napkin 0	1	Applies toothpaste and brushes teeth with	
	Talks with mouth full 0	1	sideways motion 4	
	Takes food off others' plates 0	1	Brushes teeth without help, but cannot apply toothpaste 3	
	Eats too fast or too slow 0	1 1	Brushes teeth with supervision 2	
	Plays in food with fingers 0		Cooperates in having teeth brushed 1	
B. Toilet Us	e		Makes no attempt to brush teeth 0	Γ
ITEM 5	Tollet Training		Does not clean dentures 0	
	(Circle highest level)		0.4	
	Never has tollet accidents 4		D. Appearance	
	Has toilet accidents only at night 3		ITEM 11 Posture	
(Occasionally has toilet accidents during the day 2		(Circle all answers)	
	Frequently has toilet accidents during the day 1		If these items do not apply to the Individual, e.g.,	
	Is not toilet trained at all 0		because he or she is bedfast or non-ambulatory, place check in the blank and mark "Yes" for all statements.	
ITEM 6	Self-Care at Tollet		Yes	No
	(Circle all answers)		Mouth hangs open 0	1
		No	Head hangs down 0	1
	Lowers pants at the toilet without help 1	0	Stomach sticks out because of posture 0	
	Sits on toilet seat without help 1	0	Shoulders slumped forward and back bent 0	1
	Uses toilet tissue appropriately 1	0	Walks with toes out or toes in 0	1
	Flushes toilet after use 1	0	Walks with feet far apart 0	1
	Puts on clothes without help 1 Washes hands without help 1	0 0	Shuffles, drags, or stamps feet when walking 0 Walks on tiptoe 0	3

ITEM 12	Clothing			ITEM 17	Shoes			
If those Horse de set -	(Circle all answers)				(Circle all answers)	es l	No	
	pply to the individual, e.g., because etely dependent on others, place a				Puts on shoes correctly without assistance		0	
	nk and mark "Yes" for all statements.		- 1		Ties shoelaces without assistance	1	0	
	Yes	s No			Unties shoelaces without assistance	1	0	
Wears clothes t	that do not fit properly if not assisted 0	1			Removes shoes without assistance	1	0	
Wears torn or	unpressed clothing if not prompted 0	1			Attaches or detaches Velcro on shoes	1	0	
Rewears dirt	ty or soiled clothing if not prompted 0	1						
Wears clashing	color combinations if not prompted 0	1		G. Travel				
Doe	es not know the difference between work shoes and dress shoes 0	1		ITEM 18	Sense of Direction (Circle highest level)			
Does not choo	ose different clothing for formal and informal occasions 0	1		Go	bes a few blocks from facility or school ground or	2		
Does not wear specia	ol clothing (raincoat, overshoes, etc.) for different weather conditions 0	1		Goes	several blocks from home without getting lost 3 around facility ground or few blocks from home without getting lost 3			
E. Care of Clothing					Goes around ground of facility or home alone			
ITEM 13	Care of Clothina				Gets lost whenever leaving own living area ()		
IIEM 13	(Circle all answers)			ITEM 19	Transportation			
146-		s No			(Circle all answers)	Marie Co.		
	pes and cleans shoes when needed 1	0				es l		
	othes in drawer, chest, or cupboard 1	0		D	Rides safely in private cars		0	
	dangs up clothes without prompting 1 tention to missing buttons and holes	0		Rides on	train, long-distance bus, or plane independently Rides in taxi independently		0	
	and/or repairs clothing 1	0	\Box		Rides subway or city bus for unfamiliar		(55)	
ITEM 14	Laundry				journeys independently	1	0	
IIEWI 14	(Circle highest level)				Rides subway or city bus for familiar journeys independently	4	0	Г
Uses la	aundromat or home washer or dryer without assistance 3					'	U	_
Puts clothes in wash	er and driver; starts it with assistance 2			ITEM 20	(Circle all answers)			
1 dis cionico il ricoli	Sorts clothing with assistance 1					es	No	
Do	es not participate in laundry chores 0				Can cross street safely, by self	1	0	
					Can go to school or work unattended	1	0	
F. Dressing and Undres	ssing			C	an return home from school or work unattended	1	0	
ITEM 15	Dressing				Can go to and return from recreation activities		0500	
ILLW 10	(Circle highest level)				unattended (movies, games, etc.)		0	Г
	Completely dresses self 5				Has driver's license	1	0	Щ
Completely dre	esses self with verbal prompting only 4			ITEM 21	Safety on Street or School Ground			
	or putting on all clothes with verbal				(Circle highest level)			
	and by fastening (zipping, buttoning, snapping, Velcro) them with help 3				awareness of possible dangers (e.g., avoids deep r in pool, uses handrall on stairs, does not accept			
Dresses self with help	in pulling or putting on most clothes				rides from strangers, uses seat belt in cars, etc.)			
	and fastening them 2				Obeys traffic signals and "Walk/Don't Walk" signs :	2		
Cooperate	s when being dressed by extending				Looks both ways and waits as necessary			_
	arms or legs 1 Must be dressed completely 0				before crossing the street			
	Musi be diessed completely o				Fails to recognize possible danger	J		_
ITEM 16	Undressing at Appropriate Times (Circle highest level)			H. Other	Independent Functioning			
	Completely undresses self 5			ITEM 22	Telephone			
Completely undre	esses self with verbal prompting only 4				(Circle all answers)	-	M-	
Undresses self by u	infastening (unzipping, unbuttoning,				Uses telephone directory	es 1	0	
	cro) clothes with help and pulling or				Uses pay telephone		0	
	king them off with verbal prompting 3				Makes telephone calls from private telephone		0	
undresses self	with help in unfastening and pulling or taking off most clothes 2				Answers telephone appropriately		0	
	Cooperates when being undressed				Takes telephone messages		0	1
	by extending arms or legs 1					31	1935	
	Must be completely undressed 0							
				50				

ITEM 23 Miscellaneous Independent Functioning (Circle all answers) Yes No Yes No Has ordinary control of appetite, eats moderately 1 0 Knows postage rates, buys stamps from post office 1 0 Looks after personal health, e.g., changes wet clothing 1 0 Deats with simple injuries, e.g., cuts, burns 1 0 Knows how and where to obtain a doctor's or denthis's help 1 0 Knows about welfare facilities in the community 1 0 Knows awn address 1 0 ITEM 24 Safety at Residential Facility or Home (Circle highest level) Asks whether an unfamiliar object is safe to fouch or consume 3 is careful about dangers of electrical outlets and sockets 2 Is careful about danger of hot foods and beverages or hot dishes or pans 1 Is not careful about possible danger 0	ITEM 29 Control of Hands (Circle all answers) Yes No Catches a ball 1 0 Throws a ball overhand 1 0 Lifts cup or glass 1 0 Grasps with thumb and finger 1 0 ITEM 30 Limb Function (Circle all answers) Yes No Has effective use of right arm 1 0 Has effective use of right arm 1 0 Has effective use of left leg 1 0 PHYSICAL DEVELOPMENT DOMAIN TOTAL (add items 25–30)
INDEPENDENT FUNCTIONING DOMAIN TOTAL [add items 1-24]	DOMAIN III.
	Economic Activity
DOMAIN II. Physical Development	A. Money Handling and Budgeting ITEM 31 Money Handling (Circle highest level) Takes complete care of own money 4
A. Sensory Development (Observable ability)	Makes change correctly but does not use banking facilities 3
TEM 25 Vision (with glasses, if used) (Circle highest level) Has no difficulty seeing 3 Has some difficulty seeing 2 Has great difficulty seeing 1 Has no vision at all 0 TEM 26 Hearing (with hearing aid, if used)	Adds coins of various denominations, up to one dollar 2 Uses money but does not make change correctly 1 Does not use money 0 ITEM 32 Banking (Circle all answers) Yes No Uses banking facilities independently 1 0
(Circle highest level) Has no difficulty hearing 3 Has some difficulty hearing 2 Has great difficulty hearing 1 Has no hearing at all 0	Maintains account with assistance 1 0 Can fill out deposit and withdrawal slips 1 0 Has bank card—can use money machine 1 0 ITEM 33 Budgeting (Circle all answers)
B. Motor Development	Yes No Saves money or tokens for a particular purpose 1 0
ITEM 27 Body Balance (Circle highest level) Note: If toe-walker (see item 11h), score 0. Able to stand on tiptoes for ten seconds if asked 5 Able to stand on one foot for two seconds if asked 4 Stands without support for five minutes or more 3	Budgets fares, meals, etc. 1 0 Spends money with some planning 1 0 Controls own major expenditures 1 0 B. Shopping Skills
Stands with support for five minutes or more 2 Sits without support for ten minutes or more 1 Can do none of the above 0	(Circle highest level) Goes to several shops and specifies different items 4 Goes to one shop and specifies one Item 3 Goes on errands for simple purchasing without a note 2
Walking and Running (Circle all answers) Yes No Walks alone 1 0 Walks up and down stairs alone 1 0 Walks down stairs by alternating feet 1 0 Runs without often falling 1 0 Hops, skips or jumps 1 0	Goes on errands for simple purchasing with a note 1 Cannot be sent on shopping errands 0

ITEM 35	Purchasing		ITEM 41 Sentences [Circle highest level]	
	(Circle highest level) Buys own clothing 5		Sometimes uses complex sentences containing	
	Buys own clothing accessories 4		"because," "but," etc. 3	
	Makes minor purchases without help		Asks questions using words such as "why," "how,"	
	(candy, soft drinks, etc.) 3		"what," etc. 2	2
	Does shopping with slight supervision 2		Speaks in simple sentences 1	
	Does shopping with close supervision 1		Speaks in primitive phrases only or is nonverbal (
	Does no shopping 0		ITEM 42 Word Usage	
ITEM 36	Shopping Resources		(Circle highest level)	
	(Circle all answers)		Talks about action when describing pictures 4	
	1.5	s No	Names people or objects when describing pictures 3	
Har appare	Has charge card for specific stores 1 of credit cards or other credit arrangements 1	0	Names familiar objects 2	
rius geriero	Carries appropriate identification 1	0 [Asks for things by their appropriate names 1	
	Can endorse check 1	0	is nonverbal or nearly nonverbal 0	
	our order of		B. Verbal Comprehension	
ECONOMIC D			ITEM 43 Reading Comprehension	
(add items 31	-36)		(Circle highest level) Reads books suitable for children nine years or older 5	
2014411	NI IV		Reads books suitable for children seven or eight years old 4	
DOMAII			Reads simple stories or comics 3	
angua	ige Development		Reads various signs, e.g., "NO PARKING," "ONE WAY," "MEN," "WOMEN," etc. 2	
A. Expression			Recognizes for more words by sight 1	
TEM 27			Recognizes fewer than ten words 0	_
TEM 37	Writing (Circle highest level)	HAN!	ITEM 44 Comprehension of Spoken Instructions	
Writes und	erstandable and complete letters or stories 5		(Circle highest level)	
	Writes short notes or memos 4		Understands complex instructions involving a decision, "If, do this, but if not, do" 4	
	Writes or prints whole sentences 3		Understands instructions involving a series of steps,	
	Writes or prints at least ten words 2		e.g., "First do, then do," 3	
	Writes or prints name 1		Answers simple questions such as "What is your name?"	
	Cannot write or print any words 0		or "What are you doing?" 2	
TEM 38	Handwriting		Responds correctly to simple phrases, e.g., "stop," "sit down," "come here" 1	
Williams 27 is a	(Circle all answers)		Is unable to understand even very simple	
ir nem 37 is n	narked "0," place a check in the blank and mark "Yes" for all statements.		verbal communications 0	
		s No	C. Social Language Development	
	Writes backwards 0	1	C. Social Earlyadge Development	
	Reverses some letters 0	1	ITEM 45 Conversation	
	Writing is generally illegible 0		(Circle all answers)	s No
	Unable to hold pencil or crayon 0	1 🔲	Uses phrases such as "please" and "thank you" 1	
TEM 39	Preverbal Expression		Is sociable and talks during meals 1	0 [
If nomen is al-	(Circle all answers)		Talks to others about sports, family, group activities, etc. 1	0
	le to say at least a few words, then place a the blank and mark "Yes" for all statements.		ITEM 46 Miscellaneous Language Development	
and the state of the	Ye	s No	(Circle all answers)	
	Nods head or smiles to express happiness 1	0		s No
	Indicates hunger 1	0	Can be reasoned with 1	
	Indicates wants by pointing or vocal noises 1 Imitates sounds of objects or animals	0	Obviously responds when talked to 1 Talks sensibly 1	
	(choo-choo, bow-wow, etc.) 1	0 [Reads books, newspapers, or magazines for enjoyment 1	
E	expresses pleasure or anger by vocal noises 1	0 🔲	Repeats a story with little or no difficulty 1	
		8.0	Fills in the main items on application form	
TEM 40	Articulation (Circle all answers)		reasonably well 1	0
If person has i	no speech at all, then place a check in the			
	blank and mark "Yes" for all statements.		LANGUAGE DEVELOPMENT DOMAIN TOTAL	7
Connect	Ye is low, weak, whispered, or difficult to hear 0	s No	(add items 37–46)	
speecr	Speech is slowed, deliberate, or labored 0	1		
	Speech is hurried, accelerated, or pushed 0	1		
	Speaks with blocking, halting, or			
	other irregular interruptions 0	1		

DOMAIN V.	ITEM 52 Work/School Habits (Circle all answers)
Numbers and Time TEM 47 Numbers (Circle highest level) Performs division and multiplication 6 Does simple addition and subtraction 5 Counts ten or more objects 4 Mechanically counts to ten 3 Counts two objects by saying "one two" 2 Discriminates between "one" and "many" or "a lot" 1	Is late for work/school without good reason 0 1 Is often absent from work/school 0 1 Does not complete jobs without constant supervision/encouragement 0 1 Leaves work station/seat without permission 0 1 Grumbles or gripes about work/school 0 1 PREVOCATIONAL/VOCATIONAL ACTIVITY DOMAIN TOTAL (add items 50–52)
Has no understanding of numbers 0 L TIME (Circle all answers) Yes No	DOMAIN VII. Self-Direction
Tells time by regular clock or watch correctly to the minute 1 0 Reads time on digital clock or digital watch correctly 1 0 Understands time intervals, e.g., between "3:30" and "4:30" 1 0 Understands time equivalents, e.g., "9:15" is the same as "quarter past nine" 1 0 Associates time on clock with various actions and events 1 0	A. Initiative ITEM 53 (Circle highest level) Initiates most of own activities, e.g., tasks, games, etc. 3 Asks if there is something to do or explores surroundings, e.g., home, yard, school, classroom, etc. 2 Will engage in activities only if assigned or directed 1
Time Concept (Circle all answers) Yes No Names the days of the week 1 0 Refers correctly to "morning" and "afternoon" 1 0 Understands difference between day-week, minute-hour, month-year, etc. 1 0	Will not engage in assigned activities, e.g., putting away toys, etc. 0 ITEM 54 Passivity (Circle all answers) If these items do not apply to the individual, e.g., because he or she is totally dependent on others, then place a check in the blank and mark "Yes" for all statements. Yes No
DOMAIN VI. Prevocational/Vocational Activity	Needs constant encouragement to complete task 0 1 Has to be made to do things 0 1 Has no ambition 0 1 Seems to have no interest in things 0 1 Finishes task last because of wasted time 0 1 Is unnecessarily dependent on others for help 0 1 Movement is slow and sluggish 0 1
(Circle highest level) Can perform a job requiring use of tools or machinery, e.g., shop work, sewing, etc. 2 Can perform simple work, e.g., simple gardening, mopping floors, emptying trash, cleaning chalkboard erasers, etc. 1 Can perform no work at all 0 ITEM 51 Work/School—Job Performance (Circle all answers) If "0" is marked in item 50, place a check in the blank and mark "No" for all statements. Yes No	B. Perseverance ITEM 55 (Circle highest level) Will pay attention to purposeful activities for more than 15 minutes, e.g., playing games, reading, cleaning up 4 Will pay attention to purposeful activities for up to 15 minutes 3 Will pay attention to purposeful activities for up to 10 minutes 2 Will pay attention to purposeful activities for up to 5 minutes 1 Will not pay attention to purposeful activities for as long as 5 minutes 0
Is a careful worker—avoids accidents to self and others 1 0 Looks after tools, equipment, supplies, etc. 1 0 Warks steadily and productively 1 0 Is neat and accurate 1 0	ITEM 56 Persistence (Circle all answers) If these items do not apply to the individual, e.g., because he or she is totally incapable of any organized activities, then place check in the blank and mark "Yes" for all statements
	Yes No Cannot organize task 0 1 Becomes easily discouraged 0 1 Falls to carry out tasks 0 1 Jumps from one activity to another 0 1 Needs constant encouragement to complete task 0 1

C. Leisure Time		DOMAIN I					
ITEM 57	Leisure Time Activity (Circle highest level)	Socialization	Socialization				
e.g., going on a fis schedulin	Organize leisure time activities on a fairly complex level, e.g., going on a fishing trip, arranging to play billiards, scheduling time to do computer games, etc. 4 Has active interest in hobby, e.g., painting, embroidery,		Cooperation (Circle highest level) Offers assistance to others 2 Is willing to help if asked 1				
collecting	stamps, coins, baseball cards, etc. 3 organized leisure time activity when		Never helps others 0				
Engages in le	arranged for him or her 2 sisure activity on a simple level, e.g.,	ITEM 62	Consideration for Others (Circle all answers)				
is unable to arran	watching TV, listening to radio, etc. 1 age leisure time activity, even of the simplest nature 0		Yes No Shows interest in the affairs of others 1 0 Takes care of others' belongings 1 0				
			ges the affairs of others when needed 1 0 hows consideration for others' feelings 1 0				
SELF-DIRECTION DOMA (add Items 53-57)	IN TOTAL	ITEM 63	Awareness of Others				
		incin ou	(Circle all answers) Yes No				
		-	Recognizes own family 1 0 Recognizes people other than family 1 0				
N MIAMOC	II.	Has inform	mation about others, e.g., job, address, relation to self 1 0				
Responsibili	ty	Knows the nan	nes of people close to him or her, e.g., classmates, neighbors 1 0 [
TEM 58	Personal Belongings (Circle highest level)	Knows the name	s of people not regularly encountered 1 0				
Ver	ry dependable—always takes care of personal belongings 3	ITEM 64	Interaction with Others (Circle highest level)				
	ly dependable—usually takes care of personal belongings 2	Interacts with of	with others in group games or activities 3 thers for at least a short period of time, ing or offering toys, clothing, or objects 2				
	takes care of personal belongings 1 consible at all—does not take care	Interacts with	others imitatively with little interaction 1				
	of personal belongings 0	_	Opes not respond to others in a socially acceptable manner 0				
TEM 59	General Responsibility (Circle highest level)	ITEM 65	Participation in Group Activities (Circle highest level)				
	and assumes much responsibility— a special effort; assigned activities are always performed 3		group activities (leader and organizer) 3 s in group activities spontaneously and				
responsibilities; o	able—makes an effort to carry out one can be reasonably certain that		eagerly (active participant) 2 group activities if encouraged to do so (passive participant) 1				
Unreliable—makes litt	ssigned activities will be performed 2 le effort to carry out responsibilities; ncertain that the assigned activities will be performed 1	Does not participo	ate in or withdraw from group activities 0				
Not given re	esponsibilities; is unable to carry out responsibilities at all 0						
TEM 60	Personal Responsibility (Circle all answers) Yes No						
ne.	Usually maintains self-control 1 0						
	lerstands concept of being on time 1 0 ks and accepts help on instructions 1 0 Γ	-					
500	- a - a according troub of the letter from the tr	H [/					

ITEM 66	Selfishness (Circle all answers)	
If these items do	not apply to the individual, e.g.,	
because he or she t	nas no social life or is profoundly	
withdrawn, place a ch	eck in the blank and mark "Yes" for all statements.	
	Yes No	
	Refuses to take turns 0 1	
923	Does not share with others 0 1	
	ets mad if does not get own way 0 1	
Interrupts aide or teache	r who is helping another person 0 $$ 1 $$ L	
TEM 67	Social Maturity	
14 H H	(Circle all answers)	
	not apply to the individual, e.g., has no social life or is profoundly	
	eck in the blank and mark "Yes"	
	for all statements Yes No	
	Is too familiar with strangers 0 1	
	Is afraid of strangers 0 1	
	Does anything to make friends 0 1	
	kes to hold hands with everyone 0 1	
1	s at someone's elbow constantly 0 1	- 10101A3750
SOCIALIZATION DOMAIN 1	TOTAL	Turnizioa A
(add items 61-67)		
(000 1101110 01 07)		
SUPPLEMENTAL ITEM FOR		I populational population
	(Circle highest level)	Accordance for the second
Cares for self con	npletely for menstruation without assistance or reminder 5	The second second second
Cares for self reas	conably well during menstruation 4	
	inging pads during menstruation 3	
	ds changing during menstruation 2	
	tes that menstruation has begun 1	The state of the s
	Does none of the above 0	
10		
10		

ABS-S:2

AAMR Adaptive Behavior Scale-School Second Edition

PROFILE/SUMMARY FORM

Name			Male Female
	Year	Month	Day
Date of Rating			
Date of Birth			
Age			
School			
Examiner's Name _			
Examiner's Title			
Respondent's Name			
Relationship to Sub	ject		
Normative Tables U	sed:	MR	Non-MR

			Normative '	Tables Used:	MR Non-MR
Section	on II. Re	cord of AE	3S-S:2 D	omain Scores	
Part One Domain Scores	Raw Score	Percentile	Standard Score	Age Equiv.	Rating
I. Independent Functioning					
II. Physical Development					
III. Economic Activity					
IV. Language Development					
V. Numbers and Time					
VI. Prevocational/Vocational Activity					
VII. Self-Direction					
VIII. Responsibility					
IX. Socialization					
Part Two Domain Scores					
X. Social Behavior					
XI. Conformity					
XII. Trustworthiness					
XIII. Stereotyped and Hyperactive Behavior					
XIV. Self-Abusive Behavior					
XV. Social Engagement					
XVI. Disturbing Interpersonal Behavior					

ontributing Item or Domain	Factor A Personal Self-Sufficiency	Factor B Community Self-Sufficiency	Factor C Personal-Social Responsibility	Factor D Social Adjustment	Factor E Personal Adjustment
Item 1					
2 —					
3	-				
4	-				
5					
6					
7					
8					
9					
10					
12					
13					
14					
15					
16					
17					
18					
19					
20					
21				28	
22					
23 —		0			
24					
Domain II					
IV —					
V					
Item 50					
51					
52 —					
omain VII					
VIII —					
X —					
XI					
XIII —					_
XIIV —					_
VIA -					

Appendix B 3

A SHORT-FORM OF THE QUETIONNAIRE ON RESOURCES AND STRESS (QRS-F)

This questionnaire asks about feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blanks. Give your honest feeling and opinion. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all the questions.

1.	Other members of the family have to do without things because of	T	F
2.	Our family agrees on important matters	T	F
3.	I worry about what will happen to when I can no longer take care of him/her	T	F
4.	The constant demands for care for limit growth and development of someone else in our family	T	F
5.	I have accepted the fact that might have to live out his/her life in some special setting (eg institution or group home)	T	F
6.	I have given up what I have really wanted to do in order to care for	T	F
7.	is able to fit into the family social group	T	F
8.	Sometimes I avoid taking out in public	T	F
9.	In the future, our family's social life will suffer because of increased responsibilities and financial stress	T	F
10.	It bothers me that will always be this way	T	F
11.	I feel tense whenever I take out in public	T	F
12.	I can go visit with friends whenever I want	T	F
13.	Taking on a vacation spoils pleasure for the whole family	T	F
14.	The family does as many things together now as we ever did	T	F
15.	I get upset with the way my life is going	T	F
16.	Sometimes I feel very embarrassed because of	T	F
17.	doesn't do as much as he/she should be able to do	T	F
18.	There are many places where we can enjoy ourselves as a family when comes along	T	F
19.	is over protected	T	F
20.	has too much time on his/her hands	T	F
21.	I am disappointed that does not lead a normal life	T	F
22.	Time drags for, especially free time	T	F
23.	It is easy for me to relax	T	F
24.	I worry about what will be done with when he/she gets older	T	F
25.	I get almost too tired to enjoy myself	T	F
26.	There is a lot of anger and resentment in our family	Т	F

27.	The constant demands to care for limit my growth and	T	F
	development		
28.	accepts himself/herself as a person	T	F
29.	I feel sad when I think of	T	F
30.	I often worry about what will happen to when I no longer can take care of him/her	T	F
31.	Caring for puts a strain on me	T	F
32.	Members of our family get to do the same kinds of things other families do	T	F
33.	will always be a problem to us	T	F
34.	I rarely feel blue	T	F
35	Lam worried much of the time	Т	F

F-COPES

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES ©

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving, attitudes and behaviors which families develop to respond to problems or difficulties.

Directions

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When t	we face problems or difficulties in our family we d by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1.	Sharing our difficulties with relatives	1	2	3	4	5
2.	Seeking encouragement and support from friends	1	2	3	4	5
3.	Knowing we have the power to solve major problems	1	2	3	4	5
4.	Seeking information and advice from person in other families who have faced the same or similar problems	1	2	3	4	5
5.	Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6.	Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7.	Knowing that we have the strength with our own family to solve our problems	1	2	3	4	5
8.	Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

When we face problems or difficulties in our family we espond by:			Moderatel y Disagree	Neither Agree Nor	Moderatel y Agree	Strongly Agree
9. Seeking informati doctor	on and advice from the family	1	2	3	4	5
10. Asking neighbors	for favors and assistance	1	2	3	4	5
11. Facing the probler solution right awa	ns "head-on" and trying to get y	1	2	3	4	5
12. Watching television	on	1	2	3	4	5
13. Showing that we a	re strong	1	2	3	4	5
14. Attending church	services	1	2	3	4	5
15. Accepting stressfu	l events as a fact of life	1	2	3	4	5
16. Sharing concerns	with close friends	1	2	3	4	5
17. Knowing luck pla able to solve fami	ys a big part in how well we are y problems	1	2	3	4	5
18. Exercising with fr	iends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that dif	ficulties occur unexpectedly	1	2	3	4	5
20. Doing things with etc.)	relatives (get-together, dinners,	1	2	3	4	5
21. Seeking profession difficulties	nal counseling and help for family	1	2	3	4	5
22. Believing we can	handle our own problems	1	2	3	4	5
23. Participating in ch	urch activities	1	2	3	4	5
	y problem in a more positive way become too discouraged	1	2	3	4	5
25. Asking relatives h	ow they feel about problems we	1	2	3	4	5
26. Feeling that no man have difficulty has	atter what we do to prepare, we will adling problems	1	2	3	4	5
27. Seeking advice from	om a minister	1	2	3	4	5
28. Believing if we way	ait long enough, the problem will	1	2	3	4	5
29. Sharing problems	with neighbors	1	2	3	4	5
30. Having faith in Go	od	1	2	3	4	5

Appendix C

List of Culturally Inappropriate Expressions in ABS-S: 2 (Part 1) and their Alternate Culturally Appropriate Expressions

Table AList of Problematic expression identified in Urdu version of SDQ

Items Numbers	Problematic Expressions	
5 and 18	" " (Adult)	
7	". To (Squiring)	
9 and 15	" (bullied)	
10	" 🛄 " (tearful)	

Table A1

List of culturally inappropriate expressions in ABS-S: 2 (Part 1)

Item numbers	Culturally inappropriate Expressions
Item no 1	Chopsticks
Item no 2	Hamburgers or hot dogs, soda fountain
Item no 19	Subway
Item no 22	Pay telephone
Item no 31	One dollar
Item no 32	Bank card
Item no 57	Billiard, Base ball cards

Table A2

List of culturally appropriate expressions for ABS-S: 2 (Part 1)

Item no	Culturally inappropriate Expressions	Alternate Expressions
Item no 1	Chopsticks	Spoon
Item no 2	Hamburgers or hot dogs, at soda fountain	Burger, Canteen
Item no 19	Subway	Bus
Item no 22	Pay telephone	Public call office (PCO)
Item no 31	One dollar	Ten Rupees
Item no 32	Bank card	Automated teller
		machine (ATM) card
Item no 57	Billiard, Base ball cards	Lodo, Stamps

Details of addition of items in the existing Questionnaire on Resources and Stress (QRS-F)

The purpose was to generate items and incorporate in Questionnaire on Resources and Stress (QRS-F). Interviews were conducted to explore some indigenous resources that generated stress in parents of children with autistic disorder.

After initial telephonic interview only 6 parents (3 mothers and 3 fathers) agreed for the interview. Beside parents two experts in the field were also contacted (1 special education teachers and 1 therapist). Total eight individuals were interviewed. Interviews took place at a time and place convenient to the parents and experts, usually in their home and office settings. The question asked from parents and experts was "What problem\Challenges parents faced, while rearing a child with Autism in Pakistan?" Based on the interview following themes emerged.

- Lack of awareness and information regarding ASD in general masses, in parents and in special education staff
- 2. Lack\unavailability of services related to diagnosis, early intervention, schooling, and therapeutic intervention
- 3. Unavailability of separate class room for autism in special schools.
- 4. Sense of insecurity and uncertainty due to unavailability of services
- 5. Finance is one of the major causes of stress for both parents
- 6. Attitude of people towards the child and family (bad omen, bad naseeb, effect of jado)

After identifying the themes item pool was generated and three subscales and its related items were added to QRS-F. The themes identified are "Stress due to lack of awareness", "Stress due to lack of Services" and "Finance stress".

Appendix E

List of Culturally inappropriate Expressions in F-COPES, and their alternate expressions

List of Culturally Inappropriate Expressions and their Alternate Culturally Appropriate Expressions

Table A3

Item no	Culturally inappropriate	Alternate Expressions		
	Expressions			
item 14	attending church services	Offering prayers, worshiping.		
item 23	participating in church activities	religious activities		
item 27	seeking advice from the minister	Head of church, religious and pious person,		

Appendix F

Questionnaires to assess the content validity of translated instruments

Adaptive Behavior scale-School Edition (ABS-S: 2 Part-1)

Strengths and Difficulties Questionnaire (SDQ).

Questionnaire on resources and stress (QRS-F)

The Family Crisis Oriented Personal Evaluation Scale (F-COPES).

To Whom It May Concern

I am a PhD scholar from National Institute of Psychology, Quaid-i-Azam University, and Islamabad. My area of research is related to stress and coping in families of children with autism. As a part of my PhD research work, I am undertaking content validation of the Urdu version of instruments.

In the present study content validity is established in terms clarity and cultural equivalency. The clarity index will be formulated in terms of clarity of instructions, response format, and items. Cultural equivalency is related to cross cultural equivalence between English and Urdu version of instruments.

Based on your expertises in the area you are requested to kindly participate in the study. Your contribution will help in improving the Urdu version of the instruments for the present research work. Moreover, the instruments can further be utilized for screening and diagnoses.

Following instruments are used in the present study

- Adaptive Behavior scale-School Edition ABS-S: 2(Part 1)
- Strengths and Difficulties Questionnaire (SDQ)
- Questionnaire on Resources and Stress (QRS-F)
- The Family Crisis Oriented Personal Evaluation Scales (F-COPES)

Instructions: Please read each of the item statements carefully and mark \(\sqrt{on} \) four point scale parallel to each item. The content validity of items is rated in terms on \(\text{Clarity} \) and \(\text{Cultural equivalence.} \)

Thank you for participating in the research

Nelofar Kiran Rauf

Adaptive Behavior Scale-School Edition ABS-S: 2 (Part 1)

Urdu version of ABS-S: 2 (Part 1) is to assess the adaptive behaviors of children with Autism. It was developed by Lambert, Nihira, and Leland (1993). Part one of the scale was administered in this study. It can be used with school aged children ages 3 to 16 years, who have emotional maladjustments, intellectual impairments, or developmental deficits.

Instructions: Please read each of the item statements carefully and mark \(\sqrt{on} \) four point scale parallel to each item for **item clarity**. The Clarity can be examined in terms of grammar, sentence structure and appropriateness of instructions, items and response format.

Adaptive Behavior Scale-School Edition ABS-S: 2 (Part 1)

Urdu version of ABS-S: 2 (Part 1) is to assess the adaptive behaviors of children with Autism. It was developed by Lambert, Nihira, and Leland (1993). Part one of the scale was administered in this study. It can be used with school aged children ages 3 to 16 years, who have emotional maladjustments, intellectual impairments, or developmental deficits.

Instructions: Please read each of the item statements carefully and mark \(\sqrt{o}\) on four point scale parallel to each item for cross **cultural equivalence**. The Cultural equivalence can be examined in terms of equivalence between Urdu and English versions of instruments for meaning, relevance and cultural appropriateness.

Strengths and Difficulties Questionnaire (SDQ).

It was developed by Goodman, (1997) and translated in Urdu by Samad, Hollis, Prince, and Goodman, (2005). This instrument assesses the children's behavioral and emotional adjustment, completed by primary caregivers. Either parents or teachers of children aged 4 to 16 years can complete the instrument. It consist of 20 items that sum up to generates a "total difficulties" behavior problem score.

Instructions: Please read each of the item statements carefully and mark \sqrt{on} four point scale parallel to each item for **item clarity**. The Clarity can be examined in terms of grammar, sentence structure and appropriateness of instructions, items and response format.

Strengths and Difficulties Questionnaire (SDQ).

It was developed by Goodman, (1997) and translated in Urdu by Samad, Hollis, Prince, and Goodman, (2005). This instrument assesses the children's behavioral and emotional adjustment, completed by primary caregivers. Either parents or teachers of children aged 4 to 16 years can complete the instrument. It consist of 20 items that sum up to generates a "total difficulties" behavior problem score.

Instructions: Please read each of the item statements carefully and mark on four point scale parallel to each item for cross **cultural equivalence**. The Cultural equivalence can be examined in terms of equivalence between Urdu and English versions of instruments for meaning, relevance and cultural appropriateness.

Questionnaire on Resources and Stress (QRS-F)

It was developed in 1983 from Holroyd's much longer Questionnaire on resources and stress (Holroyd, 1974). It is used to assess the positive and negative dimension of parental stress.

To establish the clarity index of maternal and paternal versions of QRS-F, full instruments is used. That constitute of 52 items and five subscales. Along with two already existing subscales that are "Parent and family problem" and "pessimism", three more subscales were added after pre testing of instrument.

Instructions: Please read each of the item statements carefully and mark on four point scale parallel to each item for **item clarity**. The Clarity can be examined in terms of grammar, sentence structure and appropriateness of instructions, items and response format.

Questionnaire on Resources and Stress (QRS-F)

It was developed in 1983 from Holroyd's much longer Questionnaire on resources and stress (Holroyd, 1974). It is used to assess the positive and negative dimension of parental stress.

To establish the **cross cultural equivalence** of maternal and paternal versions of QRS-F, only translated items are included. That constitute of 36 items and two subscales that are "Parent and family problem" and "pessimism".

Instructions: Please read each of the item statements carefully and mark on four point scale parallel to each item for cross **cultural equivalence**. The Cultural equivalence can be examined in terms of equivalence between Urdu and English versions of instruments for meaning, relevance and cultural appropriateness.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES)

It was developed by Hamilton McCubbin, David Olson, and Andrea Larsen (1991). It is used to measure the problem-solving attitudes and behaviors that parents develop in response to problems or difficulties. It contains 31 (one item was removed because of social desirability and two more items were added) items that been divided into five coping patterns i.e., acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal.

Instructions: Please read each of the item statements carefully and mark \(\sqrt{o}\) on four point scale parallel to each item for **item clarity**. The Clarity can be examined in terms of grammar, sentence structure and appropriateness of instructions, items and response format.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES)

It was developed by Hamilton McCubbin, David Olson, and Andrea Larsen (1991). It is used to measure the problem-solving attitudes and behaviors that parents develop in response to problems or difficulties. It contains 29 items (one item was removed because of social desirability) that been divided into five coping patterns i.e., acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal.

Instructions: Please read each of the item statements carefully and mark \(\sqrt{o}\) on four point scale parallel to each item for cross **cultural equivalence**. The Cultural equivalence can be examined in terms of equivalence between Urdu and English versions of instruments for meaning, relevance and cultural appropriateness.

Appendix G

TABLES FOR CONTENT VALIDITY INDEX OF THE ADAPTED VERSIONS OF INSTRUMENTS

Table A4 *Item-level content Validity Index (I-CVI) of ABS-S: 2 (part 1) Instructions, response format, and items for the Clarity Indices*

	Expert	Expert	Expert	Expert	No of	Clarity index
	1	2	3	4	valid	I-CVI
					rating /no	
					of ratings	
Domain I						•
ABS-S: 2 scale						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item1	4	3	3	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
Item 3	4	4	4	3	4/4	1.0
Item4	4	2	4	2	2/4	0.5
Item 5	4	4	4	3	4/4	1.0
Item 6	4	4	4	3	4/4	1.0
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	3	4/4	1.0
Item 10	4	4	4	4	4/4	1.0
Item 11	4	4	4	3	4/4	1.0
Item 12	4	2	4	2	2/4	0.5
Item 13	4	3	3	4	4/4	1.0
Item 14	4	4	3	4	4/4	1.0
Item 15	4	3	4	4	4/4	1.0
Item 16	4	4	3	4	4/4	1.0
Item 17	4	3	3	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	4	3	4	4	4/4	1.0
Item 20	4	4	3	4	4/4	1.0
Item 21	4	4	4	4	4/4	1.0
Item 22	4	3	3	4	4/4	1.0
Item 23	4	4	4	4	4/4	1.0

Item 24	4	4	4	4	4/4	1.0
Domain II						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 25	4	4	4	4	4/4	1.0
Item 26	4	4	4	4	4/4	1.0
Item 27	4	4	4	4	4/4	1.0
Item 28	4	4	4	3	4/4	1.0
Item 29	4	4	4	4	4/4	1.0
Item 30	4	4	4	4	4/4	1.0
Domain III						
Instructions	4	3	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 31	4	3	4	4	4/4	1.0
Item 32	4	4	4	3	4/4	1.0
Item 33	4	4	4	3	4/4	1.0
Item 34	4	4	4	3	4/4	1.0
Item 36	4	3	4	4	4/4	1.0
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Domain IV						
Instructions	4	3	3	4	4/4	1.0
Response format	4	3	4	4	4/4	1.0
Item 37	3	4	3	4	4/4	1.0
Item 38	4	4	4	4	4/4	1.0
Item 39	3	4	4	4	4/4	1.0
Item 40	3	3	3	3	4/4	1.0
Item 41	4	4	4	3	4/4	1.0
Item 42	4	4	3	4	4/4	1.0
Item 43	3	3	4	4	4/4	1.0
Item 44	4	3	4	4	4/4	1.0
Item 45	4	3	3	4	4/4	1.0
Item 46	4	3	4	4	4/4	1.0
Domain V						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 47	4	3	4	4	4/4	1.0
Item 48	4	4	4	3	4/4	1.0
Item 49	4	4	4	3	4/4	1.0

		ı	ı	1	T	T
Domain VI						
Instructions	4	3	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 50	4	3	4	3	4/4	1.0
Item 51	3	4	4	4	4/4	1.0
Item 52	3	3	3	3	4/4	1.0
Domain VII						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 53	4	4	4	4	4/4	1.0
Item 54	3	4	4	4	4/4	1.0
Item 55	4	4	4	4	4/4	1.0
Item 56	4	4	4	4	4/4	1.0
Item 57	4	4	4	3	4/4	1.0
Domain VIII						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 58	3	4	3	3	4/4	1.0
Item 59	4	3	4	4	4/4	1.0
Item 60	4	3	3	3	4/4	1.0
Domain IX						
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Item 61	3	4	4	4	4/4	1.0
Item 62	4	4	3	4	4/4	1.0
Item 63	3	3	3	3	4/4	1.0
Item 64	3	3	3	4	4/4	1.0
Item 65	4	4	4	3	4/4	1.0
Item 66	4	4	3	4	4/4	1.0
Item 67	4	4	3	4	4/4	1.0

Table A5Item-level content Validity Index (I-CVI) of ABS-S: 2 (part 1) items for the cultural equivalency Indices.

	Expert	Expert	Expert	Expert	No of	Cultural
	1	2	3	4	valid	equivalence
					rating /no	index for
					of ratings	items
						I-CVI
Domain I				II.	1	1
ABS-S: 2 scale						
Item1	4	3	3	4	4/4	1.0
Item 2	3	3	3	4	4/4	1.0
Item 3	4	4	4	3	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	3	4	4	4	4/4	1.0
Item 6	4	3	3	4	4/4	1.0
Item7	3	4	3	4	4/4	1.0
Item 8	4	3	3	4	4/4	1.0
Item 9	3	3	4	4	4/4	1.0
Item 10	4	4	3	4	4/4	1.0
Item 11	4	4	4	3	4/4	1.0
Item 12	4	3	4	4	4/4	1.0
Item 13	4	4	4	3	4/4	1.0
Item 14	4	4	4	4	4/4	1.0
Item 15	3	4	3	4	4/4	1.0
Item 16	4	4	4	4	4/4	1.0
Item 17	3	4	3	4	4/4	1.0
Item 18	4	3	3	3	4/4	1.0
Item 19	3	4	4	4	4/4	1.0
Item 20	4	3	3	4	4/4	1.0
Item 21	3	4	4	4	4/4	1.0
Item 22	4	4	4	4	4/4	1.0
Item 23	3	4	3	3	4/4	1.0
Item 24	4	4	4	4	4/4	1.0
Item 25	4	3	4	4	4/4	1.0
Item 26	4	4	4	3	4/4	1.0
Item 27	3	3	3	4	4/4	1.0
Item 28	4	4	4	3	4/4	1.0

Item 29	4	4	3	1	1/1	1.0
				4	4/4	1.0
Item 30	4	3	3	3	4/4	1.0
Item 31	4	4	4	2	3/4	0.75
Item 32	3	4	3	3	4/4	1.0
Item 33	4	4	4	3	4/4	1.0
Item 34	4	4	4	2	3/4	0.75
Item 36	4	3	3	3	4/4	1.0
Item 37	4	3	3	3	4/4	1.0
Item 38	3	4	3	4	4/4	1.0
Item 39	4	4	4	4	4/4	1.0
Item 40	3	4	3	3	4/4	1.0
Item 41	4	3	3	4	4/4	1.0
Item 42	3	3	4	4	4/4	1.0
Item 43	4	3	3	4	4/4	1.0
Item 44	3	4	4	3	4/4	1.0
Item 45	3	3	3	3	4/4	1.0
Item 46	3	3	4	3	4/4	1.0
Item 47	4	3	4	4	4/4	1.0
Item 48	3	3	3	3	4/4	1.0
Item 49	4	3	4	4	4/4	1.0
Item 50	4	3	4	4	4/4	1.0
Item 51	4	4	4	4	4/4	1.0
Item 52	3	4	3	4	4/4	1.0
Item 53	4	3	4	3	4/4	1.0
Item 54	4	4	3	4	4/4	1.0
Item 55	4	3	4	3	4/4	1.0
Item 56	4	3	3	3	4/4	1.0
Item 57	4	3	3	4	4/4	1.0
Item 58	4	4	4	4	4/4	1.0
Item 59	3	4	3	4	4/4	1.0
Item 60	4	3	4	4	4/4	1.0
Item 61	4	4	4	4	4/4	1.0
Item 62	3	3	3	3	4/4	1.0
Item 63	4	3	4	4	4/4	1.0
Item 64	4	3	4	3	4/4	1.0
Item 65	3	3	3	4	4/4	1.0
Item 66	4	3	4	3	4/4	1.0
Item 67	4	4	4	4	4/4	1.0
Equivalance Index S				1 -		1

Equivalence Index S-CVI = 0.99

Table A6Item-level content Validity Index (I-CVI) of SDQ Instructions, response format, and items for the Clarity Indices

	Expert	Expert	Expert	Expert	No of	Clarity
	1	2	3	4	valid	index
					rating /no	I-CVIof
					of ratings	items
Instructions	4	3	2	4	3/4	0.75
Response	4	3	2	4	3/4	0.75
format						
Items of Urdu						
scale SDQ						
Item1	4	4	4	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
Item 3	4	4	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	4	4	4	4	4/4	1.0
Item 6	4	4	3	4	4/4	1.0
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	4	4/4	1.0
Item10	4	4	4	4	4/4	1.0
Item11	4	4	4	4	4/4	1.0
Item 12	4	3	4	3	4/4	1.0
Item 13	4	4	4	4	4/4	1.0
Item 14	4	4	4	4	4/4	1.0
Item 15	4	4	4	4	4/4	1.0
Item 16	4	4	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	4	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0

Table A7Item-level content Validity Index (I-CVI) of SDQ items for the cultural equivalency Indices.

Items of Urdu	Expert 1	Expert	Expert	Expert	No of valid	Cultural
scale SDQ	Lapert	2	3	4	rating /no of	equivalence
scale SDQ		2	3	+	ratings	index for
					radings	items
						I-CVI
Item1	4	4	4	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
					·	
Item 3	3	3	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	4	3	4	4	4/4	1.0
Item 6	4	3	4	4	4/4	1.0
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	4	4/4	1.0
Item10	4	4	4	4	4/4	1.0
Item11	4	4	4	4	4/4	1.0
Item 12	4	4	4	4	4/4	1.0
Item 13	4	4	4	4	4/4	1.0
Item 14	4	3	4	4	4/4	1.0
Item 15	4	4	4	4	4/4	1.0
Item 16	4	3	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	4	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0

Equivalence Index S-CVI = 1.0

Table A8Item-level content Validity Index (I-CVI) of QRS-F (maternal and paternal versions)
Instructions, response format, and items for the Clarity Indices

	Expert	Expert	Expert	Expert	No of	Clarity
	1	2	3	4	valid	index
					rating /no	I-CVI
					of ratings	
Instructions	4	4	4	4	4/4	1.0
Response format	4	4	4	4	4/4	1.0
Items of Urdu						
scale QRS-F						
Item1	3	4	4	4	4/4	1.0
Item 2	4	4	3	4	4/4	1.0
Item 3	3	4	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	4	4	3	4	4/4	1.0
Item 6	4	4	3	4	4/4	1.0
Item7	4	4	3	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	4	4/4	1.0
Item10	4	4	4	4	4/4	1.0
Item11	4	4	4	4	4/4	1.0
Item 12	4	3	4	4	4/4	1.0
Item 13	4	4	4	4	4/4	1.0
Item 14	4	4	4	4	4/4	1.0
Item 15	4	4	4	4	4/4	1.0
Item 16	4	4	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	3	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0
Item 21	4	4	4	4	4/4	1.0
Item 22	4	4	4	4	4/4	1.0
Item 23	4	4	4	4	4/4	1.0
Item 24	4	4	4	4	4/4	1.0
Item 25	3	4	4	4	4/4	1.0
Item 26	4	4	4	4	4/4	1.0
Item 27	3	3	4	4	4/4	1.0
Item 28	4	4	4	4	4/4	1.0

Item 29	4	4	4	4	4/4	1.0
Item 30	4	4	4	4	4/4	1.0
Item 31	4	4	4	4	4/4	1.0
Item 32	4	4	4	4	4/4	1.0
Item 33	4	4	4	4	4/4	1.0
Item 34	4	4	4	4	4/4	1.0
Item 35	4	4	4	4	4/4	1.0
Item 36	4	4	4	4	4/4	1.0
Item 37	4	4	4	4	4/4	1.0
Item 38	4	4	4	4	4/4	1.0
Item 39	4	2	4	4	3/4	0.75
Item 40	4	4	4	4	4/4	1.0
Item 41	3	3	3	4	4/4	1.0
Item 42	4	4	3	4	4/4	1.0
Item 42	4	4	4	4	4/4	1.0
Item 43	4	4	4	4	4/4	1.0
Item 44	4	4	4	4	4/4	1.0
Item 45	4	4	4	4	4/4	1.0
Item 46	4	4	4	4	4/4	1.0
Item 47	4	4	4	4	4/4	1.0
Item 48	4	4	4	4	4/4	1.0
Item 49	4	4	4	4	4/4	1.0
Item 50	4	4	3	4	4/4	1.0
Item 51	2	4	4	4	3/4	0.75

Table A9 *Item-level content Validity Index (I-CVI) of QRS-F (maternal and paternal versions) for the cultural equivalency Indices.*

Items of Urdu	Expert	Expert	Expert		No of	Cultural
scale F-QRS-F	1	2	3		valid	equivalence
2-12-2		_			rating /no	index for
					of ratings	items
					8	I-CVI
Item1	4	4	4	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
Item 3	3	3	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	2	3	4	4	3/4	0.75
Item 6	4	3	4	4	4/4	1.0
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	4	4/4	1.0
Item10	4	4	4	4	4/4	1.0
Item11	4	2	4	4	3/4	0.75
Item 12	4	4	4	4	4/4	1.0
Item 13	4	4	4	4	4/4	1.0
Item 14	4	3	4	4	4/4	1.0
Item 15	4	4	4	4	4/4	1.0
Item 16	4	3	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	4	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0
Item 21	4	4	4	4	4/4	1.0
Item 22	4	4	4	4	4/4	1.0
Item 23	2	3	4	4	3/4	0.75
Item 24	4	4	4	4	4/4	1.0
Item 25	4	3	3	4	4/4	1.0
Item 26	4	4	4	4	4/4	1.0
Item 27	4	4	4	4	4/4	1.0
Item 28	3	4	4	4	4/4	1.0
Item 29	3	4	4	4	4/4	1.0
Item 30	4	4	4	4	4/4	1.0
Item 31	4	4	4	4	4/4	1.0
Item 32	4	4	4	4	4/4	1.0
Item 33	4	4	4	4	4/4	1.0
Item 34	4	4	4	4	4/4	1.0
Item 35	3	4	4	4	4/4	1.0

Equivalence Index S-CVI = 0.97

Table A10 *Item-level content Validity Index (I-CVI) of F-COPES Instructions, response format, and items for the Clarity Indices*

and tiems for the			E	D-22 - 124	No of1! 1	Clarity !: 1
	Expert	_	Expert	Expert	No of valid	Clarity index
	1	2	3	4	rating /no of	I-CVI
I	4	4	4	4	ratings 4/4	1.0
Instructions	4	4	4	4		1.0
Response	4	4	4	4	4/4	1.0
format	4	4	4	4	4/4	1.0
Item1	4	4	4	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
Item 3	4	4	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	4	4	4	4	4/4	1.0
Item 6	4	4	2	4	3/4	0.75
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	2	4	3/4	0.75
Item10	4	4	4	4	4/4	1.0
Item11	4	4	4	4	4/4	1.0
Item 12	4	4	4	4	4/4	1.0
Item 13	4	4	4	4	4/4	1.0
Item 14	4	4	4	4	4/4	1.0
Item 15	4	4	4	4	4/4	1.0
Item 16	4	4	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	3	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0
Item 21	4	4	4	4	4/4	1.0
Item 22	4	4	4	4	4/4	1.0
Item 23	4	4	4	4	4/4	1.0
Item 24	4	4	4	4	4/4	1.0
Item 25	4	4	4	4	4/4	1.0
Item 26	4	4	4	4	4/4	1.0
Item 27	4	4	4	4	4/4	1.0
Item 28	4	4	4	4	4/4	1.0
Item 29	4	4	4	4	4/4	1.0
Item 30	4	4	4	4	4/4	1.0
Item 31	4	4	4	4	4/4	1.0
Clarity Inday S C			<u>'</u>	"	17 1	1.0

Table A11

Item-level content Validity Index (I-CVI) of F-COPES items for the cultural equivalency Indices.

Items of	Expert	Expert	Expert	Expert	No of valid rating	Cultural
Urdu scale	1	2	3	4	/ no of ratings	equivalence
F-COPE	-	_			, no or runngs	index for
1 0012						items
						I-CVI
Item1	4	4	4	4	4/4	1.0
Item 2	4	4	4	4	4/4	1.0
Item 3	4	4	4	4	4/4	1.0
Item4	4	4	4	4	4/4	1.0
Item 5	4	4	4	4	4/4	1.0
Item 6	4	4	4	4	4/4	1.0
Item7	4	4	4	4	4/4	1.0
Item 8	4	4	4	4	4/4	1.0
Item 9	4	4	4	4	4/4	1.0
Item10	4	4	4	4	4/4	1.0
Item11	4	4	4	4	4/4	1.0
Item 12	4	4	4	4	4/4	1.0
Item 13	3	4	4	4	4/4	1.0
Item 14	4	4	2	4	3/4	0.75
Item 15	4	4	4	4	4/4	1.0
Item 16	4	4	4	4	4/4	1.0
Item 17	4	4	4	4	4/4	1.0
Item 18	4	4	4	4	4/4	1.0
Item 19	3	4	4	4	4/4	1.0
Item 20	4	4	4	4	4/4	1.0
Item 21	4	4	4	4	4/4	1.0
Item 22	4	4	4	4	4/4	1.0
Item 23	4	4	4	4	4/4	1.0
Item 24	4	4	4	4	4/4	1.0
Item 25	3	4	4	4	4/4	1.0
Item 26	4	4	4	4	4/4	1.0
Item 27	4	4	4	4	4/4	1.0
Item 28	4	4	4	4	4/4	1.0
Item 29	4	4	4	4	4/4	1.0
Item 30	4	4	4	4	4/4	1.0
Item 31	4	4	4	4	4/4	1.0

Equivalence Index S-CVI = 0.99

Appendix H

Details of items in Subscales of the Instruments

Below is the information regarding the subscales of instruments along with the scoring detail.

Childhood Autism Rating Scale-2 (CARS-2)

Two dimension of the instrument are given below

Core symptoms: 1, 2, 5, 6, 11, 12

Associated symptoms: 3, 4,7,8,9,10,13,14

Urdu versions of Adaptive Behavior scale-School Edition ABS: 2S, (Part 1):

Personal self-sufficiency: Item number 1,3,4,5,6,7,8,10,11,15, 16, 17 and

Domain II: Physical development (item 25-30).

Community self-sufficiency: 2, 9, 12, 13, 14, 18, 19, 20, 21, 22, 23, 24, 50

and Domain III: Economic Activity (item 31-36), Domain IV: Language

development (item 37-46) and Domain V: Number and Time (item 47 -49).

Personal social Responsibility: 51, 52 and Domain VII: Self Direction (item 53-57), Domain VIII: Responsibility (item 58-60), Domain IX: Socialization

(item 61-67)

Urdu version of The Strengths and Difficulties Questionnaire SDQ:

Subscales of the SDQ are as given below

Emotional Symptom Scale: 2, 6, 10, 13, 19

Conduct Problem Scale: 3,5,9,14,17

Hyperactivity Scale: 1,7,12, 16, 20

Peer Problem Scale: 4, 8, 11, 15, 18

Reverse scored items in the questionnaire are 5, 16, 20, 8, and 11

Urdu version of Questionnaire on resources and Stress (QRS-F)

Parent and family problem: 1, 2, 4, 6, 7, 8, 9, 11, 12, 13, 14, 15, 16, 18, 23,

25, 26, 27, 28, 29, 31, 32, 34, 35.

Pessimism: 3, 5, 10, 17, 19, 20, 21, 22, 24, 30, 33

Financial stress: 36, 37, 38, 39

Stress due to lack of Services: 40, 41, 42, 43, 44, 45, and 46

Stress due to lack of awareness: 47, 48, 49, 50, 51

Reversed scored items in the subscale are 2, 7, 12, 14, 18, 23, 32, and 34.

Urdu version of The Family Crisis Oriented Personal Evaluation Scales (F-COPES).

Acquiring Social Support: 1, 2, 5, 8, 10, 16, 20, 25, 29

Reframing: 3, 7, 11, 13, 15, 19, 22, 24

Seeking Spiritual Support: 14, 23, 27, 31

Mobilizing Family Support: 4, 6, 9, 21

Passive Appraisal: 12, 17, 26, 28, 30 (all items are reversed scored)

*Item 18 in the instrument is not included in the scoring.

Appendix I

Table A12 $Sample\ demographic\ description\ for\ Phase\ III\ of\ study\ 1\ (N=35)$

Demographic Variables	Frequency	%
Paternal age		
32 to 42 years	16	72.73%
43 to 52 years	06	27.27%
Maternal age		
26 to 35	19	65.5%
36 to 45	10	34.5%
Father's Education		
Graduation	5	22.72%
Masters	12	54.54%
Above masters	5	22.72%
Mother's education		
Matric	1	3.4%
Intermediate	1	3.4%
Graduation	13	44.8%
Masters	13	44.8%
Above masters	1	3.4%
Mother's work status		
Working	10	37.93%
Non working	19	65.51%
Family system		
Nuclear	19	65.5%
Joint	10	34.5%
Age of the child		
3years – 6 years	16	45.71
7 years – 10 years	11	31.42
11 years- 14 years	08	22.85
Gender		
Male	29	82.85%
Female	06	17.14%

Appendix J

TABLES FOR PSYCHOMETRIC PROPERTIES OF INSTRUMENTS PHASE III STUDY I

Table A13Item Total and Corrected Item Total Correlation for Childhood Autism Rating scale - 2 (N=35)

.69 .75 .63 .57
.75 .63 .57
.63 .57
.57
.71
.65
.71
.53
.53
.50
.73
.61
.63
.60
.40

^{**}p<.01

Table A14Item Total and Corrected Item Total Correlation for Childhood Autism Rating scale - 2 (core dimensions) CARS-2C (N=35)

r	Corrected item total
	correlation
.79**	.65
.74**	.76
.76**	.61
.79**	.63
.77**	.74
.67**	.59
	.79** .74** .76** .79** .77**

^{**}p<.01

Table A15Item Total and Corrected Item Total Correlation for Childhood Autism Rating scale - 2 (Associated symptoms) CARS-20 (N=35)

Item No.	r	Corrected item total
		correlation
3	.75**	.61
4	.67**	.53
7	.81**	.70
8	.65**	.54
9	.56**	.50
10	.56**	.42
13	.71**	.60
14	.52**	.47
		/

^{**}p<.01

Table A16Item Total and Corrected Item Total Correlation for sub factor personal self-sufficiency of Urdu version of Adaptive Behavior Scale-School Edition ABS: 2S (part 1) (N=35)

Item No.	r	Corrected item total correlation
Item 1 =Use of table utensils	.74**	.70
Item 3=Drinking	.74**	.71
Item 4 = Table Manners	.41**	.30
Item 5 = Toilet training	.61**	.52
Item 6 = Self care at Toilet	.85**	.80
Item 7= Washing hands and face	.70**	.64
Item 8 = Bathing	.71**	.66
Item 10 = Tooth brushing	.59**	.52
Item 11 = Posture	.21	.09
Item 15 =Dressing	.81**	.78
Item 16= Undressing at Appropriate time	.79**	.73
Item 17= Shoes	.69**	.64
Domain II= Physical development	.77**	.69

^{**}p<.01

Table A17Item Total and Corrected Item Total Correlation for sub factor Community self-sufficiency of Urdu version Adaptive Behavior Scale-School Edition ABS: 2S (part 1) (N=35)

Item No.	r	Corrected item total correlation
Item 2= Eating in public	.48**	.46
Item 9= Personal Hygiene	.66**	.61
Item 12= Clothing	.17	.05
Item 13= Care of clothing	.54**	.48
Item 14= Laundry	.33*	.30
Item 18 = Sense of Direction	.64**	.59
Item 19 = Transport	.35*	.30
Item 20 = Mobility	.36*	.30
Item21 = Safety on street or school ground	.09	.04
Item22 = Telephone	.33*	.32
Item23 = Miscellaneous Independent Functioning	.53**	.48
Item 24= Safety at Residential Facility or Home	.16	.11
Item 50 = Job Complexity	.69**	.68
Domain III= Economic Activity	.57**	.49
Domain IV= Language development	.95**	.82
Domain V= Number and Time	.88**	.83

^{*}*p* < 0.05, ***p* < 0.01

Table A18Item Total and Corrected Item Total Correlation for Personal social Responsibility of Urdu version of Adaptive Behavior Scale-School Edition ABS: 2S (part 1) (N=35)

		=
Item No.	r	Corrected item total
		correlation
Item 51= Work/school Job performance	.36*	.30
Item 52= Work/School Habits	.61*	.51
Domain VII= Self Direction	.90**	.73
Domain VIII= Responsibility	.62**	.46
Domain IX= Socialization	.88**	.72

^{*}*p* < 0.05, ***p* < 0.01

Table A19Item Total and Corrected Item Total Correlation for Emotional Symptom Scale of (Urdu Version) Strengths and Difficulties Questionnaire (SDQ) (N=29)

r	Corrected item total correlation
.43*	.30
.71**	.53
.80**	.63
.74**	.47
.50**	.30
	.43* .71** .80** .74**

^{**}p < 0.01

Table A20Item Total and Corrected Item Total Correlation for Conduct Problem Scale of (Urdu Version) Strengths and Difficulties Questionnaire (SDQ) (N=29)

Item No.	r	Corrected item total correlation
3	.82**	.65
5	.77**	.35
9	.72**	.48
14	.28	.16
17	.15	.02

^{**}p < 0.01

Table A21Item Total and Corrected Item Total Correlation for hyperactivity Scale of (Urdu Version) Strengths and Difficulties Questionnaire (SDQ) (N=29)

	correlation
.73**	.44
.62**	.39
.54**	.32
.57**	.32
.63**	.38
	.62** .54** .57**

^{**}p < 0.01

Table A22Item Total and Corrected Item Total Correlation for Peer Problem Scale of (Urdu Version) Strengths and Difficulties Questionnaire (SDQ) (N=29)

Item No.	R	Corrected item total
		correlation
4	.66**	.41
8	.19	08
11	.84**	.70
15	.78**	.63
18	.78**	.59

^{**}p < 0.01

Table A23Item Total and Corrected Item Total Correlation for subscale of Parent and family problems of questionnaire on resources and stress "Short form" (QRS-F) (Urdu Version) (N=29)

	QRS-F	(Mother version)	QRS-F (I	Father version)
Item No.	R	Corrected item total correlation	r	Corrected item total correlation
1	.59**	.49	.36*	.30
2	.15	.06	.24	.16
4	.67**	.61	.38*	.30
6	.54**	.48	.31*	.30
7	.48*	.38	.33*	.31
8	.35*	.30	.42*	.34
9	.58**	.51	.53*	.45
11	.66**	.61	.76**	.71
12	.51**	.41	.34*	.30
13	.39*	.30	.54**	.47
14	.33*	.30	.48*	.42
15	.67**	.58	.62**	.55
16	.73**	.69	.35	.30
18	.56**	.49	.61**	.55
23	.53**	.46	.40**	.31
25	.56**	.49	.64**	.58
26	.66**	.60	.68**	.62
27	.63**	.57	.35*	.30
28	.35*	.31	.58**	.50
29	.59**	.54	.71**	.65
31	.61**	.55	.68**	.61
32	.35*	.31	.76**	.71
34	.69**	.64	.35*	.30
35	.76**	.72	.64**	.56

^{*}*p* < .05, ***p* < 0.01

Table A24Item Total and Corrected Item Total Correlation for subscale of Pessimism of questionnaire on resources and stress "Short form" (QRS-F) (Urdu Version) (N=29)

	QRS-F (Mother version)		QRS-F (Father version)	
Item No.	r	Corrected item	r	Corrected item
		total correlation		total correlation
3	.61**	.46	.61**	.49
5	.35*	.30	.52*	.35
10	.80**	.71	.71**	.59
17	.36*	.30	.38*	.30
19	.28	.18	.25	.04
20	.45*	.31	.43*	.30
21	.78**	.70	.88**	.84
22	.20	.02	.09	.03
24	.60**	.47	.74**	.65
30	.64**	.53	.84**	.78
33	.73**	.62	.68**	.56

^{*}*p* < 0.05, ***p* < 0.01

Table A25Item Total and Corrected Item Total Correlation for subscale of Financial stress of questionnaire on resources and stress "Short form" (QRS-F) (Urdu Version) (N=29)

Item No.	QRS-F (Mother version)		QRS-F (Father version)	
	R	Corrected item total correlation	R	Corrected item total correlation
36	.95**	.92	.81**	.69
37	.97**	.94	.93**	.87
38	.97**	.95	.96**	.93
39	.93**	.88	.92**	.85

^{*}*p* < .05, ***p* < 0.01

Table A26Item Total and Corrected Item Total Correlation for subscale of stress due to lack of Services of questionnaire on resources and stress "Short form" (QRS-F) (Urdu Version) (N=29)

	QRS-F (Mother version)		QRS-F (Father version)	
Item No.	r	Corrected item	r	Corrected item
		total correlation		total correlation
40	.62**	.47	.76**	.65
41	.60**	.43	.67**	.54
42	.63**	.47	.76**	.65
43	.81**	.73	.74**	.62
44	.84**	.76	.65**	.50
45	.65**	.53	.57**	.40
46	.86**	.79	.69**	.55

^{*}*p* < .05, ***p* < 0.01

Table A27

Item Total and Corrected Item Total Correlation for subscale of stress due to lack of Awareness of questionnaire on resources and stress "Short form" (QRS-F) (Urdu Version) (N=29)

QRS-F (Maternal version)		QRS-F (Paternal version)	
r	Corrected item total correlation	r	Corrected item total correlation
.06	05	.06	.00
.62**	.32	.64**	.32
.73**	.39	.84**	.65
.74**	.46	.54**	.30
.47**	.32	.58**	.30
	.06 .62** .73** .74**	r Corrected item total correlation .0605 .62** .32 .73** .39 .74** .46	r Corrected item total correlation r .06 05 .06 .62** .32 .64** .73** .39 .84** .74** .46 .54**

^{*}*p* < .05, ***p* < 0.01

Table A28

Item Total and Corrected Item Total Correlation for Acquiring Social Support subscale of The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (Urdu Version) (N=29)

Item No.	r	Corrected item total
		correlation
1	.60**	.48
2	.51**	.39
5	.88**	.83
8	.86**	.81
10	.79**	.71
16	.53**	.41
20	.37*	.31
25	.81**	.74
29	.88**	.83

^{*}*p* < 0.05, ***p* < 0.01

Table A29Item Total and Corrected Item Total Correlation for Reframing sub Scale of The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (Urdu Version) (N=29)

Item No.	r	Corrected item total
		correlation
3	.76**	.67
7	.77**	.67
11	.85**	.79
13	.54**	.40
15	.89**	.86
19	.77**	.70
22	.87**	.82
24	.78**	.71

^{**}p < 0.01

Table A30

Item Total and Corrected Item Total Correlation for Seeking spiritual support sub Scale of The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (Urdu Version) (N=29)

Item No.	r	Corrected item total
		correlation
14	.49**	.30
23	.64**	.35
27	.61**	.32
31	.55**	.31

^{**}p < 0.01

Table A31Item Total and Corrected Item Total Correlation for Mobilizing Family to Acquire and Accept help sub Scale of The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (Urdu Version) (N=29)

Item No.	r	Corrected item total
		correlation
4	.70**	.43
6	.73**	.36
9	.61**	.30
21	.47*	.30

^{*}*p* < 0.05, ***p* < 0.01

Table A32

Item Total and Corrected Item Total Correlation for Passive Appraisal sub Scale of The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (Urdu Version) (N=29)

Item No.	r	Corrected item total correlation
12	.71**	.48
17	.42**	.30
26	.56**	.32
28	.58**	.31
30	.70**	.46

^{*}p < 0.05, **p < 0.01

Appendix K

 Table A33

 Sample demographic Description for the Main Study (study II)

Demographic Variables	Frequency	%
Parent's Characteristic ($n = 186$)		
Paternal age		
32 to 42 years	50	60.2%
43 to 52 years	30	36.1%
53 to 62 years	03	3.61%
Maternal age		
25 to 35 years	70	68%
36 to 45 years	31	30%
46 to 55 years	02	1.9%
Maternal work status		
Full time employed	36	35%
Not employed	67	65%
Marital status of parents		
Married	106	96.4%
Divorced \Separated	4	3.6%
Relationship between parents		
First cousins (blood relation)	31	28.2%
Second cousins	17	15.5%
Out of family	62	56.4%
Family characteristics		
Family system		
Nuclear	68	61.8%
Joint	42	38.2%
Family Income		
5,000-30,000	61	60.4%
31,000-60,000	30	29.7%
61,000-90,000	10	9.9%
Total number of children		
1-3 children	84	76.4%
4-6 children	25	22.7%
6-8 children	1	.9%
Child Characteristics $(n = 110)$		
Age of the child		
3years – 6 years	38	34.5%
7 years – 10 years	40	36.4%
11 years- 14 years	32	29.1%
Gender		
Male	89	80.9%
Female	21	19.1%

Appendix L

Final Adapted version of instruments used in the study II (Main study)